

Isabelle Vullings

Evaluating ageing-in-place reforms

Developing policy assessment tools and understanding care preferences of older adults and informal caregivers in the Netherlands

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Colofon

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Evaluating ageing-in-place reforms

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Chapter 1

General Introduction

The world population is ageing rapidly. In 2019, approximately 703 million people worldwide were aged 65 years or older [1]. This number is expected to increase to around 1.5 billion by the year 2050 [1]. By that time, one in six people worldwide will be aged 65 years or older [1]. As the proportion of older adults rises, physical, functional, and cognitive limitations become more prevalent, resulting in an increased demand for long-term care (LTC) [2]. LTC is labour-intensive and relies heavily on informal care, yet many countries are facing shrinking workforces and fiscal pressures, creating significant challenges for the organisation, accessibility, and sustainability of LTC services [3]. Ageing in place is commonly advocated as a policy strategy to address these challenges, perceived as a potential cost saving alternative to institutionalised care, yet evidence is mixed and there are no standardised evaluation frameworks [4]. This thesis develops an analytical approach for evaluating ageing-in-place (AIP) reform policies that bridges system-level and individual-level perspectives. It combines indicators used at the system level with qualitative and mixed-methods studies that capture the lived experiences and preferences of individuals ageing in place. Special attention is given to groups that are underrepresented or disproportionately affected by AIP policies, including persons with a migration background and persons with dementia [5, 6]. By incorporating these perspectives, the approach aims to help policy makers evaluate ageing in place and give older adults and informal caregivers a voice in policy evaluation, identifying outcomes that are both systemically relevant and meaningful to those directly affected.

Ageing-in-place reform policies

Ageing in place is defined by the World Health Organization as "the ability of older people to live in their own home and community safely, independently, and comfortably, regardless of age, income, or level of intrinsic capacity" [7]. Many Organisation for Economic Co-operation and Development (OECD) countries have reformed their health care systems to promote ageing in place as a cost-saving alternative to institutionalised care [4]. AIP reform policies commonly share four main objectives: 1) making a shift from institutional care towards home- and community based care, encouraging older adults to live at home for as long as possible; 2) increasing responsibilities of informal caregivers, by promoting a more social approach to LTC; 3) ensuring financial sustainability of the LTC system by implementing austerity measures; 4) improving the access and provision of LTC services [4]. Whilst reform policies often share similar principles, there is considerable variation between countries in both the organization of LTC services and the implementation of AIP reform policies.

The Dutch long-term care reform

The Dutch LTC system is mostly publicly funded, requiring minimal co-payments [8]. In 2023, the Netherlands spent 4.1% of their Gross Domestic Product (GDP) on LTC, making it the highest spender amongst the OECD countries [9]. The Dutch government started to reform its LTC system in 2015 (Hervorming Langdurige Zorg (HLZ)) to ensure financial sustainability, improve care quality, and increase personal and societal responsibility [10, 11]. The reform encouraged older adults to age in place, whilst emphasizing a greater involvement of informal care [11, 12]. The new Long-Term Care Act (Wet Langdurige Zorg (WLZ)) was introduced, which restricted residential care to individuals requiring 24-hour care or supervision [10]. A stronger emphasis on community nursing and intermediate care (short term residential care (eerstelijnsverblijf) and geriatric rehabilitation) was reflected in a revision of the Mandatory Health Insurance Act (Zorgverzekeringswet (ZVW)) [10]. In addition, the decentralization of non-residential services under the Social Support Act (Wet Maatschappelijke Ondersteuning 2015 (WMO)) increased municipal responsibilities for community-based care and support [10]. The recent outline agreement on elderly care 2025-2028 builds upon the 2015 vision, outlining challenges of workforce shortages, ageing demographics, and increasing complexity of care needs which require further policy changes [13]. Whilst continuing to emphasize ageing in place, the 2025-2028 policy also aims to strengthen informal caregiving networks, simplify access to in-home care, and ensure institutional care remains available for those who truly need it [13]. It also sets out broader goals: enhancing quality of life, reducing the burden on overextended caregivers, making better use of technology, and integrating care across the different systems (WMO, ZVW, WLZ).

Whilst LTC spending as share of the GDP declined from 4.8% in 2012 to 4.5% in 2017 and 4.1% in 2023, the Netherlands continues to be a high spender on LTC in international comparison [9, 11]. The majority of these LTC costs are allocated to nursing home care (78%), with smaller proportions going to hospital care (8%) or home care (3%) [9]. Considering the strong policy focus on home- and community-based care services, it is notable that only a small percentage of LTC costs is allocated to this type of care. At the same time, in 2023 approximately 13% of adults aged 16 and older provided informal care, spending on average 13 hours per week, an increase in intensity compared with previous years [14]. In addition, 49% of persons living at home with some limitation in activities of daily living reported to have unmet LTC needs [9].

Evaluating ageing-in-place reform policies

Ageing in place is commonly presented as a win-win solution, cost-saving and aligned with patients' preferences, as many wish to continue living at home [15, 16]. However, considering the substantial investments in AIP reform policies and the potential societal implications, it is crucial to assess whether ageing in place is fulfilling this policy ideal. From a societal perspective, it is important to evaluate if the goals of AIP reform policies are met, including whether these reforms are truly cost-saving, or if they, for example, simply shift costs to other care domains. Evidence from the Netherlands found that after decentralisation of non-residential care as part of the 2015 reform, financial incentives at the municipal level led to strategic cost-shifting, as municipalities with tighter budgets increased admissions to publicly insured LTC facilities [17]. In addition, the societal costs of informal caregiving should be considered. A recent study estimated the direct (informal caregiving time and out-of-pocket payments) and indirect (productivity loss) costs of informal care in the Netherlands to range between 17.5 billion euros and 30.1 billion euros in 2019 (depending on valuation approach), corresponding to 2.15% and 3.71% of the Dutch GDP [18].

From an individual perspective, it is important to assess the impact of AIP reform policies on the wellbeing of older adults and informal caregivers. Even though older adults wish to age in place, it is not guaranteed that they can do so successfully. Declining physical health, cognitive impairment, and a diminishing social network can limit the ability to live independently at home and increase the need for care and assistance [19, 20]. Consequently, when appropriate home care is not provided, this can create risks such as loneliness, or the occurrence of falls [21, 22]. In addition, it is important to assess the needs and desires of informal caregivers, as they are often responsible for the daily caregiving of persons ageing in place [23]. Informal caregiving can provide feelings of fulfilment, but it can also negatively impact a person's well-being, increase anxiety, loneliness, and emotional strain [24]. For the evaluation of AIP reform policies, it is essential to incorporate both these individual-level perspectives and system-level perspectives.

Evaluating ageing-in-place reform policies from a system-level perspective

Performance assessment of healthcare systems to evaluate the effects of ageing in place is challenging, due to both conceptual complexity and methodological difficulties in defining measurable outcomes [25]. Health system performance assessment (HSPA) provides a structured approach to examine how effectively health care systems achieve their stated goals and objectives [26]. Several HSPA frameworks have been developed, including the renewed framework proposed by the OECD [27]. This framework presents health systems as operating within a wider socio-economic, demographic, and environmental context that influences and is influenced by the performance of the healthcare system [27]. At its core are health system outcomes, centred on improving pop-

ulation health and well-being while responding to people's needs and preferences [27]. These outcomes are supported by key building blocks, including system resources such as financing and workforce, alongside healthcare services and public health interventions covering prevention, LTC, and treatment [27]. Access, coverage, and quality of care cut across all services to ensure fairness and effectiveness, while efficiency, equity, resilience, and sustainability act as cross-cutting principles guiding how the system functions and evolves [27]. While this framework incorporates key objectives such as people-centredness and population health, its broader scope limits its usability for assessing the specific effects of AIP reform policies [27].

Existing empirical studies on AIP policies remain fragmented, focusing on isolated outcomes such as hospital utilisation [28, 29], place of death [30, 31], or cost-shifting between care sectors [17]. Even though some indicators overlap with broader health system performance assessments (HSPA) frameworks, others are specific to ageing in place, such as shifts between institutionalized care and home- and community-based services or the effects on facility closures [32, 33]. In addition, the increasing diversity among older populations and workforce shortages underscore the need for indicators that address health equity in the context of ageing in place [6, 34]. To adequately evaluate AIP reforms, a more comprehensive assessment approach is needed, one that aligns with the underlying policy objectives and incorporates a broad set of performance indicators across different domains, including costs, quality of care, well-being of older adults, and the role of informal caregivers.

Evaluating ageing-in-place reform policies from an individual-level perspective

In the evaluation of AIP reform policies, it is crucial to integrate the voice of older adults and informal caregivers as they are impacted most by these reforms. Including patients in their own care trajectories and giving them a central role within the healthcare system has become a priority in the recent decades [35]. This is reflected by the OECD HSPA framework, that puts people's needs and preferences at the centre of the healthcare system [27]. In doing so, people-centredness is not only a policy objective, but also instrumental to achieve other policy goals [27]. According to the OECD, a people-centred health system entails: "placing people, their families, and communities at the heart of health systems, empowering them, building care around the needs and expectations of the individual, and delivering health in a way that makes the best use of the resources available" [35]. There are some indicators and policy benchmarks developed to help countries assess how people-centred their systems are, for example the extent to which patients participate in decision-making bodies or are able to choose their healthcare provider [35].

However, the ability of a healthcare system to serve patients' preferences depends on the prior identification and understanding of those preferences. This process is complicated by the intrinsic heterogeneity of individual values and care expectations, as care services considered valuable by some may be less suited for others [36]. This highlights the importance of including a diverse group of older adults and informal caregivers in preference research, including groups that are often underrepresented and might have distinct care needs, such as persons with a migration background and persons with dementia [5, 6]. In addition, needs and preferences are dynamic and may shift over time in response to changes in health status or personal circumstances [37]. At the same time, conceptualisations of people-centred care have broadened, moving beyond a sole focus on patients to recognise the wider social context of care, including family members and informal caregivers [38]. Consequently, there is a need for methodological approaches that can reliably capture the diverse and evolving preferences of individuals and informal caregivers ageing in place, to inform the design and evaluation of AIP reform policies.

Identifying ageing-in-place preferences through discrete choice experiments

Discrete choice experiments (DCEs) are a method commonly used to identify patient preferences in healthcare [39, 40]. In a DCE, participants are presented with a series of hypothetical choice scenarios and are repeatedly asked to select their preferred option from a set of alternatives (e.g. care packages) [40]. The choice options are characterized by attributes (e.g. types of care) and attribute levels (e.g. frequency of care delivery or type of care service involved) [39, 40]. Participants are assumed to make trade-offs based on the relative attractiveness of the attributes and corresponding attribute levels, selecting the option (e.g. care package) that provides the highest overall utility [39, 40]. DCEs offer a powerful approach for identifying the preferences of individuals ageing in place and their informal caregivers, providing evidence to design person-centred care packages and evaluate AIP reform policies in a way that reflects the priorities of those receiving and providing care.

Including underrepresented groups in ageing-in-place preference studies

Whilst identifying AIP preferences, special attention should be given to underserved or under-represented groups, such as persons with dementia or persons with a migration background. Persons with dementia are known to have complex and progressive care needs [5]. In the years following the Dutch LTC-reform, preliminary findings indicated an increased need for crisis-driven support, including unplanned hospitalisations, acute nursing home admissions, and hospital deaths [31, 41]. Such crisis situations are not only costly, but potentially compromise the safety and well-being of persons with dementia ageing in place. Despite the clear need for evidence-based policy to ensure appropriate and timely healthcare services, people with dementia and their informal caregivers are frequently excluded from policy development, resulting in services that do not align with their

needs [5, 42]. Therefore, the inclusion of persons with dementia and their informal caregivers is essential to identify their AIP preferences and provide recommendations for appropriate care services.

In addition, efforts should be made to include persons with a migration background to identify their AIP preferences. Persons with a migration background are often described as hard-to-reach and, as a result, are underrepresented in research and policy development, despite the importance of their experiences for informing inclusive knowledge and policies [43]. Persons with a migration background are less likely to use home- and community-based services, despite having higher rates of functional limitations and chronic conditions [44, 45]. This lower use is associated with a lack of linguistically and culturally appropriate care services, as well as difficulties in navigating the care system [45]. Furthermore, persons with a non-western migration background have a higher risk of developing dementia, due to cardiovascular risk and other contributing factors [46, 47]. It is essential to include these underrepresented groups in our studies to develop inclusive DCEs that generate preference data truly representative of the diverse AIP needs and suitable for informing service planning and policy evaluation.

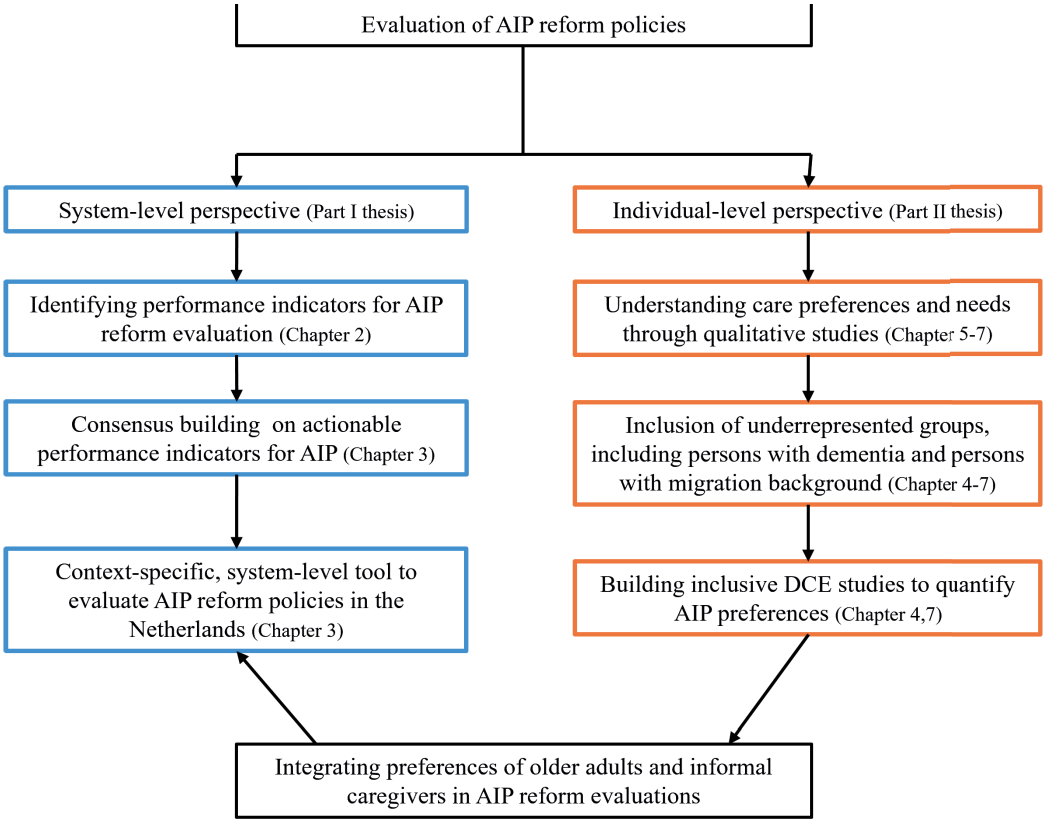
Aim and content of this thesis

The overall aim of this thesis is to develop an analytical approach for evaluating AIP reform policies from a system-level perspective, while incorporating the voices of those ageing in place. In Part I of this thesis, we look at the AIP reform policies from a system-level perspective, building assessment frameworks with relevant performance indicators. In Chapter 2, a first step is made towards building a HSPA framework for evaluating the effects of AIP reform policies by identifying which performance indicators are currently used to evaluate AIP reform policies within the international literature. A comprehensive overview of the identified indicators is provided within an evidence map. Chapter 3 builds on this work, by integrating international evidence with Dutch stakeholder perspectives. With a Delphi study, we address gaps within the current set of performance indicators and assess the relevance and usability of the indicators within the Dutch context. This provides a context-specific, system-level tool to evaluate AIP reform policies in the Netherlands.

Part II of this thesis provides evidence from an individual-level perspective, identifying the care preferences of older adults and informal caregivers ageing in place. Chapter 4 provides a clear guide on the development of a national DCE study to identify the AIP preferences of persons with dementia and informal caregivers in the Netherlands. Methodological choices and strategies to include underrepresented groups are shared, encouraging the development of inclusive DCEs. In Chapter 5 more in-depth information is provided about the experiences and needs of Dutch

persons with dementia and informal caregivers ageing in place using a qualitative interview study. Chapter 6 describes a similar interview study with persons with dementia and informal caregivers with a migration background. This study provides in-depth knowledge about the AIP preferences and barriers experienced by persons with a migration background within the Dutch healthcare setting. In Chapter 7, we identify AIP attributes and attribute levels relevant to older adults and informal caregivers in the Netherlands through a mixed-methods approach, informing the development of a future DCE. Chapter 8 is a general discussion of this thesis, which highlights the main findings and places them in a broader perspective. Methodological limitations are reported and implications for policy, practice and research are provided.

Figure 1. Overview of thesis project



Visual overview of the content of this thesis project. AIP: ageing-in-place, DCE: discrete-choice experiment

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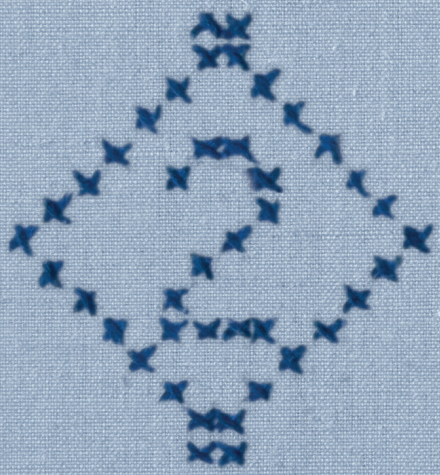
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Part I

Policy-Level Evidence: Indicators and Assessment Frameworks for the evaluation of Ageing-in-Place Reform policies



Chapter 2

Performance Indicators for the Assessment of Aging-In-Place Reform Policies: A Scoping Review and Evidence Map

Joost D. Wammes, Isabelle Vullings*, Dionne S. Kringos, Bram Wouterse, Joost G. Daams, Miranda Langendam*, Janet L. MacNeil Vroomen**
**contributed equally to this work*

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Abstract

Objectives

Many countries have reformed their long-term care system to promote aging-in-place. Currently, there is no framework for evaluating these reforms. This review aimed to identify performance indicators used for aging-in-place reform evaluation.

Design

A scoping review and evidence map of literature following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews checklist.

Setting and participants

Long-term care reforms aimed at aging-in-place.

Methods

The databases Medline, Embase, and Academic Search Premier were searched. Three independent reviewers screened the articles. Pairs of data collectors extracted the data, with conflicts determined by agreement or by a third reviewer. Performance indicators were classified into the Donabedian framework as structure, process, or outcome.

Results

We retained 58 articles. From the included articles, 28 discussed structure indicators, comprising of 71 indicators in the domains expenditures, care availability, and workforce; 36 articles included process indicators comprising 80 indicators about care utilization, service quality, and service satisfaction; and 20 articles reported on outcome indicators comprising 34 indicators about health status and informal caregiving.

Conclusions and Implications

Most articles focused on the performance domains care expenditures and care utilization, whereas measuring effects on older adults and society was less common. A framework assessing system and services delivery indicators and the effects on those aging-in-place with actionable performance indicators is recommended.

Introduction

Aging-in-place, defined by the World Health Organization as "the ability of older people to live in their own home and community safely, independently, and comfortably, regardless of age, income or level of intrinsic capacity," has grown over the last years to be a multifaceted policy ideal.[1] There is consensus that older adults prefer living at home for as long as possible.[2, 3, 4, 5] Most countries have reformed their health care system focusing on aging-in-place as it also perceived to be cost-saving compared with institutional care and a possible solution to cope with the increasing prevalence of older adults and the corresponding increasing costs of care.[6,7] Reviewing national aging-in-place reform policies reveals 4 main objectives: (1) a shift from institutional care to aging-in-place by prioritizing community-based care; (2) a more social approach with regard to care by increasing the responsibilities of informal caregivers; (3) addressing fiscal sustainability by austerity measures; and (4) the improvement of access and provision of care services.[7] However, aging-in-place is not a standardized concept. Although principles of reform policies overlap, there is heterogeneity across countries in how care for older adults is structured and how aging-in-place policies are implemented. Although aging-in-place is often perceived as a win-win for patients' well-being and costs, when adequate care at home is not provided it can pose several threats for older adults like loneliness or occurrence of falls.[8,9]

Considering the billions of euros invested and the implications for society, there is a critical need to evaluate the effect of aging-in-place policies, assessing how arrangements can be optimized for both quality and cost.[10, 11, 12] Performance assessment of health care systems to evaluate the effects of aging-in-place is complex, both in its conceptualization and methodology of how performance can be measured with verifiable standards.[13] In the last decades, health system performance assessment (HSPA) has received significant attention,[14, 15, 16] as it is an important tool to evaluate and measure the extent to which health care systems achieve their goals and objectives.[17] There are several existing HSPA frameworks such as that of the European Observatory on Health Systems and Policies.[18] This framework includes goals such as people-centeredness and health improvement, but is too generic to evaluate specific effects of aging-in-place.[18] Previous research evaluating effects of aging-in-place reform policies have been fragmented, assessing indicators such as hospital use,[19,20] location of death,[21,22] and cost shifting.[23,24] Previous aging-in-place reviews focus on specific dimensions like quality of life for older adults,[25] or the cost-effectiveness of assisted living technologies.[26] However, a comprehensive approach is required that aligns with the purposes of the reforms and includes important performance indicators across all domains of aging-in-place, ranging from costs, quality of life, and informal caregiving.[27,28]

International adoption of consensus-based performance indicators as part of a comprehensive HSPA framework is necessary to allow for exchange of good practices, lessons learned, and innovations, which can improve the effectiveness and efficiency of aging-in-place reforms across countries.[17] A universal HSPA framework for evaluating the effects of aging-in-place reform policies could also help conceptualize and standardize measurements, quantify changes, and set benchmarks. This study attempts to provide the first step toward building this HSPA framework, by conducting a scoping review to identify from the existing literature what performance indicators are used for aging-in-place reform evaluation. An evidence map will be created to provide a comprehensive overview of the identified performance indicators.

Methods

Study Context and Design

This study focuses on aging-in-place reform policies implemented at the national or subnational level (eg, prefecture, state, or province). This can be large-scale reforms that rigorously change the regulatory framework of a care system, but also smaller scale reform policies that promote aging-in-place (eg, increase of home care reimbursements, stricter long-term care (LTC) facility admission criteria, or informal caregiver allowances) fall within context of this study. Performance indicators refer to the operationalization of specific metrics with a clear description of the numerator and denominator [eg, national annual LTC expenditures as percentage of the gross domestic product (GDP)].[13] In this study, performance indicators were grouped into performance domains, which refer to key constructs used for providing information about a specific area of interest to evaluate the functions of LTC systems (eg, health expenditures or care utilization).[13] The scoping review protocol was conducted by J.D.W. and I.V., after 2 rounds of feedback from J.L.M.V. and M.L., the protocol was registered at the Centre for Open Science (D6Q73).[25] The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) extension for Scoping Reviews checklist was used to structure the search and reporting of the results (see Supplementary Table 3).[26]

Search Strategy

The search strategy (Supplementary Table 1) was developed by the research team with the guidance of an experienced information specialist (J.G.D.). The search strategy included 4 key concepts: (1) aging-in-place, (2) evaluation, (3) governmental policy reform, and (4) Organisation for Economic Co-operation and Development countries. The search was restricted to studies written in Dutch or English. On June 21, 2023, J.G.D. conducted an electronic search of the databases Medline, Embase, and Academic Search Premier for scientific papers. The software tool VOSviewer was used to construct a bibliometric network of keywords (including keywords that minimally appeared 6 times in titles or abstracts) from all identified articles (Supplementary Figure 1).27 Because of the considerable number of initial search results, J.G.D., J.D.W., and J.L.M.V. used the NOTing out principle to select irrelevant keywords (eg, infection, risk factor) from the bibliometric network and subsequently deleted corresponding articles from the search results.28 By NOTing out unique terms in off-target records are excluded from the search using the Boolean NOT operator, with the objective to improve precision.[29]

Study Selection

After deleting the duplicates, 3 reviewers (J.D.W., I.V., and J.M.V.) independently screened titles and abstracts for relevance in the web-based screening platform Rayyan.[30] If at least one of the reviewers thought the article was potentially relevant, the full text of the publication was obtained. Full-text articles were screened on predetermined inclusion and exclusion criteria (Supplementary Material) by 3 reviewers J.D.W., I.V., and J.M.V. Aging-in-place reform policies that were implemented at the local or organizational level were excluded as this was outside of the scope of this study's research question. In addition, interventions that targeted a specific population or disease were excluded, as this was also beyond the scope of the research. Available published evidence without restrictions to publication year were considered. Articles were not excluded based on research design (eg, observational studies, randomized controlled trials). Disagreements on in- and exclusion were reconciled through discussion with the research team.

Data Abstraction and Synthesis

For all included articles, the following data were abstracted: country of the reform policy, reform policy name, reform implementation year, a description of the study population, data source, study method, performance domain, performance indicators, health care setting, and care level. Data were abstracted by 2 researchers J.D.W. and I.V., using a standardized form that was created by the research group. The Donabedian model was used to structure the data synthesis of the performance indicators identified.[31] In the context of this study, the 3 organizational concepts of the

framework are defined as: (1) structure indicators reflect the input of the health system in which care is delivered; (2) process indicators relate to what care is delivered; and (3) outcome indicators demonstrate the impact on patients and society.[31] In addition, performance indicators were categorized into a performance domain and by the level of care on which the indicators were measured (ie, total LTC, LTC facility, home and community-based care, hospital care, primary care, informal care, and indicators related to older adults).

Evidence Map

An evidence map was created to provide an overview of all the available information. A Sankey diagram was used to visualize the connection between (1) the Donabedian framework concepts structure, process, and outcome[31]; (2) performance domain; (3) and the level of care on which performance indicators were measured. The evidence map was created with the online tool Sankeymatic.[32]

Results

Characteristics of Included Publications

The search from the 3 databases identified 8107 unique records. A total of 58 publications that described 1 or more performance indicators met the final inclusion criteria and were included in this review (Figure 1 and Table 1). All research originated from high- and middle-income countries of which mostly came from the United States (n = 16), followed by the Netherlands (n = 10), and Japan (n = 7). The included literature comprised observational studies (n = 31), quasi-experimental studies (n = 12), narrative reviews or policy document analysis (n = 8), cohort studies (n = 6), and a qualitative study (n = 1). Studies were frequently descriptive (n = 37), describing general trends of performance indicators before and after aging-in-place reform implementation. However, also more advanced analyses were conducted such as difference-in-difference (n = 9) and interrupted time series analyses (n = 5) to research associations between performance indicators and aging-in-place reform policies. A detailed description on individual study design, data, and outcomes is presented in Table 1.

Fig. 1. PRISMA flowchart

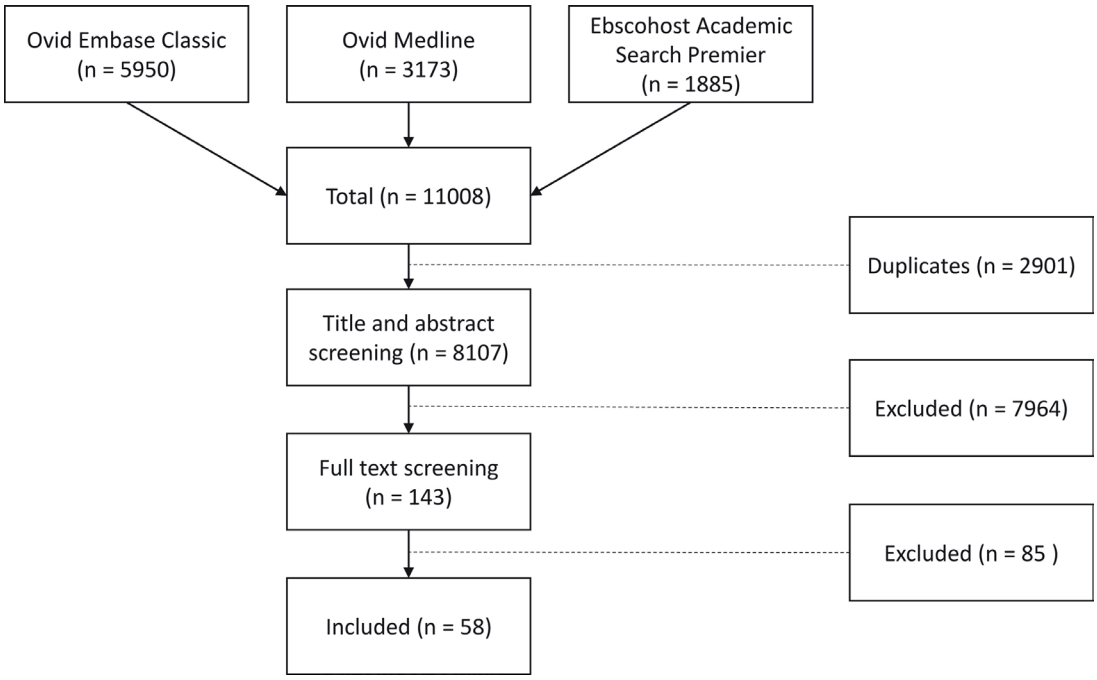


Table 1. Description of included studies

Author	Country	Reform	Data	Article type	Analysis type	Performance domain	Performance indicator
Van der Aa et al. (2019)[50]	NED	National Dutch LTC reforms of 2006, 2007 and 2015	Annual (2010-2018) national budget estimate data from the Dutch Ministry of Health	Narrative review/policy document analysis	Descriptive analysis	Older adult expenditures	Annual co-payments as percentage of the total national health care expenditure
						Older adult expenditures	Annual co-payments as percentage of the total national LTC expenditure
Abbing et al. (2023)[33]	NED	National Dutch LTC reforms of 2001, 2003 and 2015	Longitudinal Aging Study Amsterdam, wave 1998, 2008 and 2009/ 55-84 year-old adults (n = 1,560)	Cohort study	Descriptive analysis	Community-based care utilisation	Percentage of cohort using community-based care (personal care, home nursing care domestic help),
						Informal care utilisation	Percentage of cohort using Informal care
						Older adult expenditures	Percentage of cohort using Private paid care
Abbing et al. (2022)[79]	NED	National Dutch LTC reforms of 2003, 2007 and 2015	Longitudinal Aging Study Amsterdam, wave 1998, 2008 and 2009/ 55-84 year-old adults (n = 1456)	Cohort study	Descriptive analysis	Older adult health status	Psychological wellbeing measured by the Centre for Epidemiology Studies Depression Scale
						Older adult health status	Cognitive functioning measured by the Mini Mental State Examination
						Older adult health status	Physical functioning measured by the Katz ADL index
Abrahamsen et al. (2022)[60]	NOR	The action plan for eldercare of 1998	Individual-level register data of Statistics Norway (SSB)	Quasi experimental study	Difference-in-difference analysis	Community-based care utilisation	Percentage of people 80 years and older using home-based care
						Informal caregiver burden	Probability of a Sickness absence for daughters with no siblings and with only one living parent at least 80 years old
						Informal caregiver burden	Probability of a primary care consultation for daughters with no siblings and with only one living parent at least 80 years old
Alders et al. (2022)[23]	NED	National Dutch LTC reform of 2015	Annual (2015-18) municipality data from 327 of the 355 Dutch municipalities, national LTC data, and national data from the Dutch ministry of Interior,	Observational study	Descriptive analysis	LTC facility utilisation	Annual number of people admitted to nursing home care covered by public LTC insurance per 10,000 people over 65
						Community-based care utilisation	Annual number of people admitted to home care covered by public LTC insurance per 10,000 people over 65
						Costs-shifting	Costs-shifting from home care covered by municipalities towards LTC services covered by the national public LTC insurance (comparison between municipalities with a low versus high solvency rate)

Table 1. Description of included studies (continued)

Author	Country	Reform	Data	Article type	Analysis type	Performance domain	Performance indicator
Allan et al. (2022)[52]	ENG	National Care Act 2014	National Care Quality Commission data (2014-2016), Panel of all care homes for older people in England	Observational study	Descriptive analysis	LTC facility availability	Percentage change in total national number of nursing home beds
						LTC facility availability	Percentage change in total national number of nursing homes
						LTC facility availability	Total national number of nursing home closures
						LTC facility availability	Total national number of nursing home openings
						LTC facility availability	Effect of home care supply on nursing home closures
Anastos-Wallen et al. (2020)[59]	USA	Affordable Care Act Balancing Incentive Program of 2010	American Time Use Survey (2011-2018), informal caregivers	Cohort study	Descriptive analysis	Informal caregiver workforce	Prevalence of informal caregivers in survey panel
						Informal caregiver burden	Prevalence of informal caregivers providing daily care
						Informal caregiver burden	Time slept in minutes of informal caregivers.
Angunawela et al. (2000)[77]	ENG	National Health Service and Community Act 1993	Admissions Forston Clinic in Dorchester during a 3-month period in 1992, 1993 and 1996 (n = 97)	Cohort study		Hospital Care utilisation	Annual proportion of discharges to home, and nursing home/residential care
						Hospital Care utilisation	Average length of hospital stay of patients discharged to home, and nursing home/residential care
						Hospital Care utilisation	Bed blocking; delay in placement to home, and nursing home/residential care
Asiskovitch (2013)[34]	ISR	Long-Term Care Insurance Program introduced in 1998	National Insurance Institute data (1998-2010), adults 60 year and over	Observational study	Descriptive analysis	Total LTC expenditures	Annual LTC Insurance Program expenditure as percentage of the total National Insurance Expenditure
						Total LTC care utilisation	Monthly average of beneficiaries under the LTC Insurance Program
						Total LTC care utilisation	Beneficiaries as percentage of the older adult population
Bruvik et al. (2017)[73]	NOR	Norwegian Coordination reform in 2012	Data from two hospitals in the city of Bergen (2009-2014), discharged adults 70 year and over (n = 365)	Observational study	Descriptive analysis	Care utilisation	Proportions of discharges from short stay nursing home to home and nursing home
						Older adult health status	Mortality rate 6 and 12 months after hospital discharge
						Hospital care utilisation	Hospital readmission rate after short stay nursing home
						Hospital care utilisation	Average length of hospital stay in days

Table 1. Description of included studies (continued)

Author	Country	Reform	Data	Article type	Analysis type	Performance domain	Performance indicator
Carmichael et al. (1998)[64]	ENG	NHS Community Care Act in 1990	1985 General Household Survey by the British Office of Population Censuses and Surveys	Observational study	Descriptive analysis	Informal caregiver burden	Weekly hours of informal care
						Informal caregiver burden	Weekly hours of labour participation
						Informal caregiver burden	Effect of informal caregiving on labour supply of woman.
Coe et al. (2019)[35]	USA	Cash and Counselling Demonstration and Evaluation program in 1998	1998–2003 Medicaid claims data from the states from adults 65 and over: Arkansas, New Jersey, and Florida (n = 4,888)	Observational study	Descriptive analysis	Hospital care utilisation	Number of emergency room visits for adults receiving paid or unpaid informal care
						Hospital care utilisation	Any in hospital days for adults receiving paid or unpaid informal care
						Hospital care utilisation	Length of hospital stay in days for adults receiving paid or unpaid informal care
						Hospital care expenditures	Medicaid inpatient expenditures for adults receiving paid or unpaid informal care
						Older adult health status	Health outcomes (current health status, urinary tract infection, respiratory infection, bedsores, contractures, and shortness of breath) for adults receiving paid or unpaid informal care
Costa-Font et al. (2017)[51]	ESP	Sistema para la Autonomia y Atencion a la Dependencia, SAAD in 2007	Wave 2004, 2006, 2007, 2011 and 2013 of the Survey of Health, Ageing and Retirement in Europe, adults 55 years and over (n = 11,500)	Quasi experimental study	Difference-in-difference analysis	Older adult expenditures	Pre and post-reform savings in monthly terms defined as the sum of three components: (i) bank accounts; (ii) bond, stock and mutual funds; and (iii) savings for long-term investments, minus financial liabilities.
Costa-Font et al. (2018)[74]	ESP	Sistema para la Autonomia y Atencion a la Dependencia, SAAD in 2007	Wave 2004, 2006, 2007, 2011 and 2013 of the Survey of Health, Ageing and Retirement in Europe, adults 65 years and over (n = 14,766)	Quasi experimental study	Difference-in-difference analysis	Hospital care utilisation	Any hospital admission in past 12-months
						Hospital care utilisation	Number of hospital visits in past 12-months
						Hospital care utilisation	Hospital length of stay in days in past 12-months
Dijkhof (2014)[78]	NED	Dutch Social Support Act of 2007	Survey data SGBO Benchmarking Dutch municipalities (2008-2010)	Narrative review/policy document analysis	Descriptive analysis	Community-based care service satisfaction	Client satisfaction (mark out of 10) on domestic help, collective transport system, home adaptations/ appliances (e.g. wheelchairs)

Table 1. Description of included studies (continued)

Author	Country	Reform	Data	Article type	Analysis type	Performance domain	Performance indicator
D'Souza et al. (2009)[61]	USA	Policy and budget restrictions in Medicaid Home- and Community-Based Services Programs between 2002 and 2005	Annual data (2002-2005) Minimum Data Set for Home Care assessment (n = 112,182) records Michigan Institute of Gerontology	Observational study	Descriptive analysis	Hospital care utilisation	Percentage of emergency room use in past 90 days
						Hospital care utilisation	Percentage of hospitalizations in past 90 days
						LTC facility utilisation	Percentage of nursing home facility use past 90 days
						LTC facility utilisation	Percentage of long-term nursing home facility placement
						Older adult health status	Mortality rate
						Older adult health status	Activities of daily living measured by Fries' ADL index
						Older adult health status	Cognitive function measured by Morris' Cognitive Performance Scale
						Informal caregiver burden	Caregiver burden measured by caregiver distress scale.
Goldbergstein et al. (2009)[62]	USA	Medicare Balance Budget Act, Interim Payment System 1997	Waves 1993, 1995, 1998 and 2000 of the Asset and Health Dynamics among the Oldest-Old Survey and data from the 1996, 1998, and 2000 waves of the Health and Retirement Study, 50 years and over adults with at least ADL or IADL limitation	Observational study	Descriptive analysis	Informal care utilisation	Any informal care use in past 30-days
						Informal caregiver burden	Average of weekly informal caregiver hours
						Informal caregiver burden	The effect of a decrease in home care payments on informal caregiving
Gonsalves et al. (2016)[63]	CHE	Introduction of patient cost sharing for home care in cantons in 2011	Waves 1997, 2002, 2007 and 2012 of the Swiss Health Survey	Observational study	Descriptive analysis	Community-based care utilisation	Annual home care hours per capita
						Hospital care utilisation	Annual proportion of older adults with any hospitalizations
						Hospital care utilisation	Annual average length of hospital stay in days
						Hospital care utilisation	Annual proportion of older adults with doctor visits
						Hospital care utilisation	Annual average number of doctor visits per capita
						Primary care utilisation	Annual proportion of older adults with general practitioner visits
						Primary care utilisation	Annual average number of general practitioner visits per capita
						Hospital care utilisation	Annual proportion of older adults with any specialist visits
						Hospital care utilisation	Annual average number of specialist visits per capita

Table 1. Description of included studies (continued)

Author	Country	Reform	Data	Article type	Analysis type	Performance domain	Performance indicator
Harrington et al. (2011)[36]	USA	The Medicaid 1915c waiver program	Data from 49 state Medicaid waiver programs	Cohort study	Descriptive analysis	LTC facility expenditures	Annual total expenditures on nursing home facilities
						Community-based care expenditures	Annual total expenditures on personal care services
						Community-based care expenditures	Annual total Medicaid waiver expenditures on home and community-based care
						Costs-shifting	Total costs of Medicaid Home and community-based care 1915c waiver programs, compared with the costs of alternative institutional care
Hyun et al. (2014)[75]	KOR	Introduction of the social insurance scheme for long-term care in 2008	Annual data (2007-2010) from the Korean National Health Insurance Service, 65 years and over adults (n = 3,903,448)	Quasi experimental study	Difference-in-difference analysis	Hospital care utilisation	Average hospital length of stay in days
Jung et al. (2010)[65]	USA	Home Health Compare introduced in late 1990s	Home Health Compare data set	Observational study	Descriptive analysis	Hospital care utilisation	Percentage of hospitalizations among home care recipients
						Older adult health status	ADL activity scores (bathing, getting in and out of bed, and taking oral medicines)
						Older adult health status	Percentage of home care recipients who have less pain when moving around
Kaye et al. (2009)[24]	USA	Expansion of home and community-based care waivers under Medicaid since 2000	spending for fiscal years 1995–2005 from the Centers for Medicare and Medicaid Services	Observational study	Descriptive analysis	Costs-shifting	The impact of increased home and community-based care programs on total Medicaid spending (institutional and home and community-based care)

Table 1. Description of included studies (continued)

Author	Country	Reform	Data	Article type	Analysis type	Performance domain	Performance indicator
Kim et al. (2021)[37]	KOR	Introduction of the social insurance scheme for long-term care in 2008	National population level data from the National Health Insurance Service (2008, 2009, 2010, 2012, 2014, 2016 and 2018), 65 years and over adults (n = 42,758,418)	Narrative review/policy document analysis	Descriptive analysis	LTC facility availability	Annual number of LTC facilities (aged care facilities, and senior congregate housing)
						Community-based care availability	Annual number of home and community-based care service providers
						Community-based care workforce	Annual number of long-term care workforce (social care workers, registered home care nurses, nurse aide, and care helpers)
						Total LTC Care utilisation	Annual number of LTC benefit recipients
						Total LTC expenditures	Annual LTC expenditure per capita
						Total LTC expenditures	Annual LTC expenditure as % of GDP
						Total LTC expenditures	Annual sum of Total LTC expenditures
Kitchener et al. (2005)[38]	USA	The 1999 Olmstead Supreme Court decision requirement that states need op expand alternative home and community-based service programs	The Centers for Medicaid and Medicare Service waiver data, and national survey data of personal care services and home health programs (1999, 2000, and 2001)	Observational study	Descriptive analysis	Community-based care availability	Annual number of home care programs
						Community-based care utilisation	Annual number of home care participant and Participation per 1000 population
						Community-based care expenditures	Annual average spending per participant on home health programs
						Community-based care utilisation	Annual total participants per 1000 population in Medicaid home and community based care programs
						Community-based care expenditures	Annual total spending and spending per participant on Medicaid home and community-based care
Kitchener et al. (2006)[49]	USA	Medicaid 1915c HCBS waiver program	The Centers for Medicaid and Medicare Service waiver data	Observational study	Descriptive analysis	Costs-shifting	Annual Medicaid home-based care waiver "program expenditures" compared with estimates of institutional care expenditures for nursing facilities, intermediate care, and acute care hospitals
						Costs-shifting	Annual per participant home-based care Medicaid waiver expenditures compared with institutional care expenditures
						Costs-shifting	Annual total public expenditures on home-based care Medicaid waiver programs compared with total public expenditures on institutional care

Table 1. Description of included studies (continued)

Author	Country	Reform	Data	Article type	Analysis type	Performance domain	Performance indicator
Krabbe-Alkemade et al. (2020)[39]	NED	National Dutch Long-term Care reform of 2015	National insurance claims on curative and long-term care, and assistive care claims by the Dutch Central Administration office (2012-2016, adults 65 years and over	Observational study	Descriptive analysis	LTC facility expenditures	Annual per capita health expenditure on institutional care
						Community-based care expenditures	Annual per capita health expenditure on assistive and district nursing
						Hospital care expenditures	Annual per capita health expenditure on specialist care
						Primary care expenditures	Annual per capita health expenditure on General practitioner care
						Costs-shifting	Annual decomposition of cost-shifting between primary, specialist, assistive, district nursing and institutional care after reform implementation
Kristinsdottir et al. (2021)[64]	BEL, FIN, ICE, ITA, NED	Aging in place reforms of five European countries between 2001 and 2014	European research projects (2001-2014), Aged in Home Care and Identifying best practices for care-dependent elderly by Benchmarking Costs and outcomes of Community Care, InterRAI – home care data, adults 65 years and over (n = 7051)	Observational study	Descriptive analysis	Community-based care utilisation	Annual average hours of formal care (home care nursing and social services provided within a week before evaluation date)
						Older adult health status	Annual average functional abilities score of home care clients measured by the Activities of Daily Living Hierarchy scale
						Older adult health status	Annual average cognitive abilities score of home care clients measured by the Cognitive Performance Scale.
Kubalčíková et al. (2016)[53]	CZE	The 2006 Czech Social Care Act	National statistics from the Ministry of Labour and Social Affairs in the Czech Republic and the Czech Statistical Office (2008-2012), adults 65 years and over	Narrative review/policy document analysis	Descriptive analysis	Community-based care utilisation	Annual number and national coverage rate of domiciliary services; number of users
						LTC facility availability	Annual number of residential care and nursing homes
						LTC facility utilisation	Annual number of residential care number of users, and utilisation rate per adults 65 years and over
						LTC facility utilisation	Annual number of nursing home care users, utilisation rate per adults 65 years and over
						Community-based care utilisation	Annual number of home care users and utilisation rate per adults 65 years and over

Table 1. Description of included studies (continued)

Author	Country	Reform	Data	Article type	Analysis type	Performance domain	Performance indicator
Lin et al. (2020)[40]	JAP	Coinsurance measure under the National Long-term Care Insurance in 2015	Long-term care claim data from one Japanese prefecture, adults 65 years and over (n= 23,879)	Quasi experimental study	Difference-in-difference analysis	National LTC expenditure	Annual average monthly total Long-term care expenditures
						Hospital care expenditures	Annual average monthly total hospital care expenditures
						Older adult expenditures	Annual average monthly LTC payments per capita
						Community-based care utilisation	Annual average monthly home care service use in minutes
						LTC facility utilisation	Annual average monthly LTC facility service use in days
						Hospital care utilisation	Annual average monthly hospital length of stay in days
						Community-based care utilisation	Annual average monthly use of ambulatory nursing care
MacNeil Vroomen et al. (2020)[81]	NOR	Norwegian Coordination reform in 2012	Mortality data from the Norwegian Cause of Death Registry hosted by the Norwegian Institute of Public Health, adults 65 years and over (n = 417,862)	Quasi experimental study	Interrupted time series analysis	Older adult health status	Quarterly probability location of death (hospital, nursing home facility, home, or other)
MacNeil Vroomen et al. (2021)[22]	NED	National Dutch Long-term Care reform of 2015	National death certificate data by Statistics Netherlands (2012-2017), adults 65 years and over (n = 727,519)	Quasi experimental study	Interrupted time series analysis	Older adult health status	Quarterly probability location of death (hospital, nursing home facility, home, or other)
McAuley et al. (2008)[56]	USA	Balance Budget Act 1997	Medicare Provider of Service files and the Area Resource File, data from 3,126 counties in the United States	Observational study	Descriptive analysis	Community-based care Workforce	Yearly number of home Health Agency Registered Nurses per 10,000 population adults 65 years and over
						Community-based care Workforce	Yearly number of vocational Nurses per 10,000 population adults 65 years and over
						Community-based care Workforce	Yearly home Help Aides per 10,000 population adults 65 years and over
						Primary care workforce	Yearly number of social Workers per 10,000 population adults 65 years and over
						Primary care workforce	Yearly number of physical therapists per 10,000 population adults 65 years and over

Table 1. Description of included studies (continued)

Author	Country	Reform	Data	Article type	Analysis type	Performance domain	Performance indicator
McGarry et al. (2023)[41]	USA	Expansion of Medicaid home and community based services between 199 and 2017	1999–2017 Centers for Medicare and Medicaid Services Quarterly Medicaid Statement of Expenditures for the Medical Assistance Program, and Medicaid spending on waiver programs from the 2009–2017 Annual Report on Home and Community Based Services Waivers, adults 65 years and over	Quasi experimental study	Difference-in-difference analysis	Total LTC care utilisation	Yearly number of individuals aged 65 and older who are dually enrolled in Medicaid and Medicare for at least one month per state
						Community-based care utilisation	Yearly number of individuals enrolled in home and community based waiver per state
						LTC facility utilisation	Size of the nursing home population within states per year
						LTC facility expenditures	Yearly total spending on nursing home care per state
						National LTC expenditures	Sum of total spending on home and community based care and institutional care per state per year
Miller et al. (2002)[42]	USA	Different policy measures introduced in the late 1990s such as the Certificate of Needs program, the expansion of community-based care, and Medicare maximization	Long-Term Care Program and Market Characteristics data compiled by the University of California, San Francisco, and Wichita state university between 1983 and 1998	Observational study	Descriptive analysis	National LTC expenditures	Yearly total national long-term care expenditures
						LTC facility expenditures	Yearly total national nursing facility care expenditures
						Community-based care expenditures	Yearly total national community-based care expenditures
						Community-based care expenditures	Yearly share of long-term care dollars supporting community-based care
Monkerud et al. (2016)[43]	NOR	Norwegian Coordination reform in 2012	Norwegian Patient Register and from Statistics Norway/ KOSTR (2010-2013), adults 67 years and over	Observational study	Descriptive analysis	Hospital care expenditures	Annual costs of specialist rehabilitation per capita
						Older adult expenditures	Annual private rehabilitation services co-payments per capita
						Primary care utilisation	Annual municipal sum of man-hours worked by physio- and occupational therapists per capita
Monro et al. (2021)[57]	AUS	Living Longer Living Better aged care reform package of 2012	qualitative interview data with employees of residential care facilities	Qualitative study	Thematic analysis	LTC facility workforce	LTC facility staffing numbers
						LTC facility workforce	Staff casualization and turnover
						Hospital care utilisation	Rate of resident hospital admission
Moura (2022)[76]	PRT	Introduction national Network of publicly subsidized nursing homes and home care teams in 2006	National hospital data from the Administração Central do Sistema de Saúde (2000-15)	Observational study	Difference-in-difference analysis	Hospital care utilisation	Annual national share of bed blockers on total emergency admissions

Table 1. Description of included studies (continued)

Author	Country	Reform	Data	Article type	Analysis type	Performance domain	Performance indicator
Ng et al. (2012)[44]	USA	Introduction of new funding options and policy measures to increase home and community based services for Medicaid programs	Data on Medicaid waivers from the Centers for Medicare & Medicaid Services (CMS) State surveys of personal care and home health programs for the Kaiser Commission on Medicaid and the Uninsured	Observational study	Descriptive analysis	Community-based care utilisation	Yearly number of participants in Medicaid HCBS waivers
						Community-based care expenditures	Yearly Medicaid Expenditures on Home- and Community Based Services
						Community-based care expenditures	Medicaid HCBS Participants and Expenditures as a percentage of Total Medicaid Long-Term Care for Elders and disabled per year
						Community-based care availability	Yearly number of Persons on Medicaid HCBS Elderly and Disabled Waivers Wait Lists
Orsini (2019)[82]	USA	Medicare Balance Budget Act, Interim Payment System 1997	Population estimates produced by The Survey of Epidemiology and End Results, and Multiple Causes of Death files (1993-2000), adults 65 years and over (n = 13,804,156)	Quasi experimental study	Difference-in-Difference analysis	Older adult health status	Annual mortality rate for states with restrictive home care measures and for non-restrictive states.
Penning et al. (2006)[66]	CAN	British Columbia Closer to Home policy 1993 and restructuring through regionalization of home and community based care in 1997	Annual (1990-2000) Home care and hospital utilisation data from the British Columbia Linked Health Data, adults 65 years and over	Observational study	Change-point analysis	Community-based care utilisation	Yearly number of unique claims of home support service and as percentage of total population.
						LTC facility utilisation	Yearly number of unique claims of home nursing care and as percentage of total population
						Community-based care utilisation	Yearly total hours home support and hours per claim of home support
						Hospital care utilisation	Yearly hospitalization rates among home support users
						LTC facility utilisation	Yearly total home nursing visits and visits per claim of home nursing.
						Hospital care utilisation	Yearly hospitalizations rates among home nursing users
Plasier et al. (2017)[67]	NED	The introduction of the Dutch 'usual care protocol' in 2005 and the social support act of 2007	Annual data (2004-2011) by the Central Administration Office (CAK) linked to survey data from annual cross-sectional population studies on health and care and data on income by the Dutch tax authorities, adults 18 years and over (n = 49,189)	Observational study	Descriptive analysis	Community-based care utilisation	Annual total number of persons using of community-based care in the form of nursing, personal care and household help, provided in kind by a home care Organisation to the independent community-dwelling population.

Table 1. Description of included studies (continued)

Author	Country	Reform	Data	Article type	Analysis type	Performance domain	Performance indicator
Ricker-Smit et al. (1978)[68]	USA	Enactment of Medicare and Medicaid in 1965, and the Medicare Home Health Agency revision in 1967	Annual (1696-1973) Medicare and Medicare data of home health agencies from the state of California	Observational study	Descriptive analysis	Community-based care utilisation	Yearly number of clients of home and community based care
						Community-based care utilisation	Yearly total visits of home and community based care
						Community-based care utilisation	Average number of visits per client per year
Sano et al. (2022)[45]	JAP	Coinsurance measure under the National Long-term Care Insurance in 2015	Data covering 93.4% of all Japanese municipalities from the Survey of Long-term Care Benefit Expenditures (2015-2016), adults 65 years and over (n = 1,983,163)	Observational study	Difference-in-difference analysis	Community-based care utilisation	Service utilisation in percentages among beneficiaries of in- home services, adult day services, short-stay services, and renting welfare equipment
						Community-based care expenditures	Expenditure per person per month of in- home services, adult day services, short-stay services, and renting welfare equipment
Sato et al. (2006)[46]	JAP	Public Long-term Care Insurance Program Rural Japan in 2006	Long-term care insurance claim records from five municipal insurers in Kimotsuki County, Kagoshima (2001), adults 65 years and over (n = 1870)	Observational study	Descriptive analysis	Community-based care expenditures	3-month individual average costs of home help among beneficiaries
						Community-based care expenditures	3-month individual average costs of visiting care services among beneficiaries
						Community-based care expenditures	3-month individual average costs of adult daycare services among beneficiaries
						Older adult expenditures	Average monthly amount of total co-payments among beneficiaries
Shapiro (2000)[47]	CAN	Combine assessment of needs for facility and home care in 1980 to limit facility care access, and downsizing of the hospital sector between 1990 and 1998 to increase discharges to the community.	Manitoba Province Health data (1981-82, 1988-89, 1991-92, 1995-96), adults aged 75 years and over	Observational study	Descriptive analysis	LTC facility availability	Yearly number of long-term care beds of the Manitoba province, stratified by care level (light, medium & high)
						LTC facility availability	Yearly number of long-term care beds per 1000 adults 75 years and over
						LTC facility expenditures	Yearly net cost per long-term care bed

Table 1. Description of included studies (continued)

Author	Country	Reform	Data	Article type	Analysis type	Performance domain	Performance indicator
Skopec (2020)[69]	USA	Introduction of Medicare Advantage	2016 Home Health Outcome and Assessment Information Set (OASIS) and Medicare Master Beneficiary Summary File	Observational study	Linear regression analysis	Community-based care utilisation	Annual percentage home care utilisation among beneficiaries
						Total LTC utilisation	Annual total number of Medicare beneficiaries
						Community-based care utilisation	Annual average number of days of home care utilisation per care spell
						Hospital utilisation	Annual hospitalization rate among home care users
						Community-based care service quality	Home health compare star rating
Stabile et al. (2006)[48]	CAN	Introduction of province home health programs under the Canadian Health Act in 1992	The National Population Health Survey (1994-1995, 1996-1997, and 1998-1999); General Social Survey (GSS) for 1992, 1994, and 1996, adults 65 years and over	Observational study	Descriptive analysis	Community-based care expenditures	Yearly provincial public home care spending per individual 65 years and over
						Community-based care expenditures	Yearly fraction of provincial health care budget devoted to home care in percentages
						Community-based care utilisation	Yearly percentage of people in need for provincial home care
						Community-based care utilisation	Yearly provincial home care utilisation in percentages
Strandell et al. (2018)[58]	SWE	Changes in home care policies since 2005 including a decline in residential care, demands to increase efficiency, cost-containment and extensive re-organisation such as New Public Management	The Nordcare study, a postal survey to care workers in Sweden of (2005 and 2015), home care workers (n = 371)	Observational study	Descriptive analysis	Community-based care workforce	Daily number of clients for home-care workers in 2015 compared to 2005
						Community-based care workforce	Working conditions (e.g., workload, job autonomy, emotional impact and supervision support) for home-care workers in 2015 compared to 2005
						Community-based care workforce	Job tasks household, admin, social support, personal care, medical care) for home-care workers in 2015 compared to 2005
Stuart et al. (2001)[70]	DEN	Skævinge policy increasing community health services in 1984	National hospital data, per county and Skaevinge area, adults 60 years and over	Narrative review/policy document analysis	Descriptive analysis	Hospital care utilisation	Hospital admission per capita of the municipality in the years 1984 and 1997
						Hospital care utilisation	Length of stay in days per admission compared to the country average 1984, 1990 and 1994
						Older adult health status	The proportion of individuals reporting a "better than average" health status in the years 1985 and 1997

Table 1. Description of included studies (continued)

Author	Country	Reform	Data	Article type	Analysis type	Performance domain	Performance indicator
Sun et al. (2023)[71]	JAP	The introduction of conventional home care support clinics (HCSCs) and the introduction of enhanced HCSCs	National database of Health Insurance Claims and Specific Health Check-ups	Cohort study	Descriptive statistics	Hospital care utilisation	Odds ratio for emergency house call, general clinic compared to HSCSs and enhanced HSCSs
					Univariable and multivariable logistic regression analyses	Hospital care utilisation	Odds ratio for hospitalization (at least once) during follow-up, general clinic compared to HSCSs and enhanced HSCSs
						Older adult health status	Location of death (hospital, home, unknown) in proportions
Szebehely et al. (2012)[54]	SWE	Health care reforms between 1990 to 2005 including decline in home care coverage and marketization of home care in 1990	Statistics Sweden's Business Register (1993-2010); Statistics Sweden's Surveys of Living Conditions (1988-1989 and 2004-2005), adults 65 years and over (n = 821)	Narrative review/policy document analysis	Descriptive analysis	Community-based care availability	Marketization of home care services measured by the ratio of personnel working for a for-profit and non-profit home care provider
						Community-based care utilisation	Proportions of adults receiving home care services both publicly and privately funded
						Community-based care utilisation	Proportions of adults receiving care by informal caregivers that are non-home residing friends
Tonks (1994)[72]	IRL	1990 Irish community-based care act	National data by the Department of Health and Social services (1983, 1988, 1990 and 1992), adults 75 years and over	Narrative review/policy document analysis	Descriptive analysis	LTC facility utilisation	Annual number of people in residential homes.
						LTC facility utilisation	Annual number of people in nursing homes
						Hospital care utilisation	Annual number of people in geriatric hospitals
Tran et al. (2021)[80]	AUS	Implementation of new home care packages in 2013 including free choice personal budgets for home care users	Waves (2007–2017) of the Household, Income and Labour Dynamics in Australia, adults 65 years and over (n = 1780)	Observational study	Before-After analysis	Older adult health status	Mental health before and after reform, measured by the five-item MHI-5 scale, which is a sub-scale of the SF-36 general health survey
Wammes et al. (2021)[21]	JAP	The Revised Medical Care Act in 2006	National Death certificate data covering the total Japanese population (1996-2016), adults 65 years and over (n = 19,307,104)	Quasi experimental study	Interrupted time series analysis	Older adult health status	Quarterly probability in location of death (hospital, nursing home facility, home, or other)
Wammes et al. (2022)[83]	JAP	Japanese Orange Plan Reform in 2013	National Death certificate data covering the total Japanese population (2006-2016), adults 65 years and over (n = 149,638)	Quasi experimental study	Interrupted time series analysis	Older adult health status	Quarterly probability in location of death (hospital, nursing home facility, home, or other)

Table 1. Description of included studies (continued)

Author	Country	Reform	Data	Article type	Analysis type	Performance domain	Performance indicator
Wammes et al. (2023)[20]	NED	National Dutch Long-term Care reform of 2015	Compulsory municipal resident register and Dutch hospital data covering the total Dutch population (2009-2018), adults 65 years and over (N = 3,777,096)	Quasi experimental study	Interrupted time series analysis	Hospital care utilisation	National monthly acute hospitalization rate per 10,000 adults 65 years and over
						Hospital care utilisation	National average monthly length of hospital stay in days
Yong et al. (2012)[55]	JAP	National Long-Term Care Insurance Policy in Japan (Kaigo Hoken Ho) in 2000	National data from the Ministry of Health, Labour; Survey long-term care insurance in Japan, adults 65 years and over (n = 11,181),	Narrative review/policy document analysis	Descriptive analysis	Community-based care availability	Annual number of home-based care service providers
						LTC availability	Annual number of long-term care facility service providers
						Total LTC utilisation	Annual number of long-term care users
						Community-based care utilisation	Annual number of home care users
						LTC facility utilisation	Annual number of long-term care facility service users
						Total LTC service satisfaction	Percentage of respondents satisfied with long-term care services and service level fees
						Informal caregiver burden	Percentage of respondents reporting a caregiver distress reduction
Zhang et al. (2021)[85]	ENG	The 2014 Care Act	The British Household Panel Survey (2004–2007) and the UK Household Longitudinal Study (2009–2018) (n = 29,174)	Observational study	Multivariate regression analysis	Informal caregiver burden	The effect of local authorities spending on adult social services on the subjective well-being of unpaid informal caregivers measured by the General Health Questionnaire 12-item

AUS, Australia; BEL, Belgium; CAN, Canada; CHE, Switzerland; CZE, The Czech Republic; DEN, Denmark; ENG, England; ESP, Spain; FIN, Finland; HSCS, home care support clinics; ICE, Iceland; IRL, Ireland; ISR, Israel; ITA, Italy; JAP, Japan; KOR, South Korea; NED, The Netherlands; NOR, Norway; PRT, Portugal; SWE, Sweden; USA, United States of America.

Structure Performance Indicators

From all the included articles, 28 (48.3%) discussed one or more structure performance indicators, in total comprising 71 nonunique indicators within the performance domains of expenditures, care availability, or workforce. Supplementary Table 2 shows a comprehensive presentation of all the identified performance indicators per performance domain, categorized by care level.

Expenditures

A total of 21 articles described performance indicators within the performance domain of expenditures. Most of these metrics encompassed the assessment of annual gross costs at a specific care level.[33, 34, 35, 36, 37, 38, 39, 40, 41, 42, 43, 44, 45, 46, 47, 48] For example, indicators used at the LTC facility level comprised the annual aggregated LTC facility costs or the mean LTC facility bed costs. Five articles underscored cost-shifting dynamics across care levels as a salient performance indicator.[23,24,36,39,49] This primarily involved the redirection of expenditures from LTC facility care to home and community-based care. In addition, 6 articles considered costs paid for by older adults themselves.[33,40,43,46,50,51] These articles incorporated performance indicators such as the average LTC co-payments per capita, the proportion of individuals self-funding private care, but also presented the total annual family savings as a performance indicator.

Care availability

A total of 8 articles discussed performance indicators in the care availability performance domain, which were assessed at the LTC facility level and the home and community-based care level. Across both care levels, most of performance indicators were associated with the overall national supply of services.[37,38,47,52, 53, 54, 55] This included metrics like the count of home care service providers or the capacity of LTC facility beds. One article used increased home care delivery vs the closure of LTC facilities as an indicator.[52] In addition, performance indicators indirectly measuring care availability were identified, such as the number of individuals on waiting lists for home care.[44]

Workforce

Five studies described various performance indicators within the workforce domain. A predominant focus has been on quantifying the workforce composition across different care levels, encompassing metrics such as the count of LTC facility nurses, home care aides, or physical therapists.[37,56, 57, 58] In addition, 1 article delved into working conditions, examining factors such as the daily client load as a performance indicator.[58] The significance of informal caregiver workforce was addressed in another article, reporting the prevalence of individuals providing informal care.[59]

Process Performance Indicators

From all the included articles, 36 (62.1%) reported on process performance indicators, in total comprising 80 indicators within the performance domains of care utilization, care service quality, or care satisfaction.

Care utilization

Utilization performance indicators were identified in 35 articles. These indicators mostly quantified the number of users per care level,[20,23,33,34,37,38,40,41,44,45,48,53, 54, 55,57,60, 61, 62, 63, 64, 65, 66, 67, 68, 69, 70, 71, 72] exemplified by metrics like the count of beneficiaries in LTC programs or the census of LTC facility residents. Other indicators gauged care utilization by assessing the overall volume of services provided,[35,37,40,43,61,63,64,68,71,73,74] encompassing variables such as aggregate hours of home care provided or the number of general practitioner visits. The evaluation of care utilization also included performance indicators measuring length of stay,[20,35,40,63,70,73,75, 76, 77] such as average length of hospitalization stay in days. Multiple articles also examined the proportions of older adults receiving informal care.[33,54,62]

Care service quality

One article examined the quality of home and community-based care as a performance indicator. It used the Home Health Compare star rating as a performance indicator. This rating reflects how home health agencies' scores compare with each other based on measurements of their quality of patient care, as assessed by the Centers for Medicare and Medicaid Services.[69]

Care satisfaction

Two studies described performance indicators within the care satisfaction domain. In 1 study, performance was assessed using Likert scales to capture client satisfaction regarding the overall quality of LTC services received.[55] The second article used a 0 to 10 rating system for home and community-based care as a performance indicator.[78]

Outcome Performance Indicators

From all the included articles, 20 (34.5%) discussed outcome indicators, in total comprising 34 indicators within the performance domains of health status and informal caregiver burden.

Health status

A total of 14 studies described various performance indicators within the health status domain. Metrics objectified well-being by measuring quality of life and mental health.[35,70,79,80] Also, functional abilities such as activities of daily living (ADL) scores and cognitive function measured by Mini Mental State Exam were considered.[61,64,65,79] Many articles also used mortality or location of death as a performance indicator.[21,22,61,71,73,81, 82, 83]

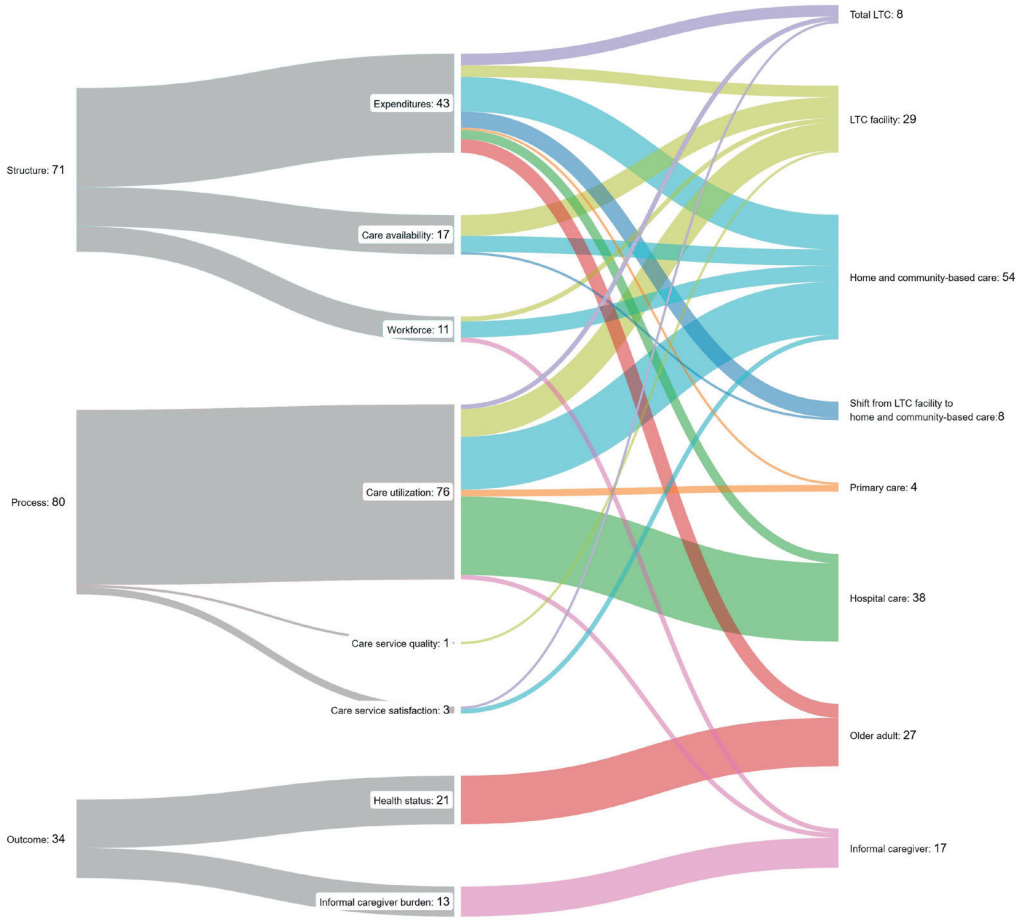
Informal caregiver burden

Seven articles discussed multiple performance indicators within the informal caregiver burden domain. These indicators included measures assessing subjective caregiver burden or their likelihood of experiencing illness.[55,59,61,62,84,85] The impact of informal caregiving on home care payments and labor participation was also mentioned.[60,84]

Evidence Map of Performance Indicators for Aging-In-Place Evaluation

The evidence map in Figure 2 illustrates the interrelation among the 3 organizational concepts of the Donabedian framework,[31] the performance domains, and the care levels on which these indicators are measured. A higher frequency of "nonunique" structure (38.4%) and process (43.2%) performance indicators were identified compared with outcome performance indicators (18.4%). Performance indicators within the performance domains care utilization (41.1%) and expenditures (23.2%) were most frequently reported in the literature. Most indicators were measured on the care level home and community-based care (29.2%), followed by hospital care (20.5%), LTC facility (15.7%), assessments related to older adults (14.6%), informal care (9.2%), total LTC (4.3%), shift from LTC facility to home and community-based care (4.3%), and primary care (2.2%).

Fig. 2. Evidence map



Evidence map reporting on the frequency of performance indicators identified and their categorization into the Donabedian framework concepts,[31] performance domains, and the level of care on which performance indicators were measured.

Discussion

This review provides a comprehensive summary of the current performance indicators used in scientific literature to assess aging-in-place reform policies. The results of the scoping review and evidence map showed that more articles discussed structure and process performance indicators compared with outcome performance indicators. From the identified structure and process performance indicators, most focused on the performance domains care expenditures and care utilization. Outcome performance indicators that assessed the performance domains of health status and informal caregiver burden were less reported. Most performance indicators were measured on the level of home and community-based care, followed by hospital care, assessments related to older adults, LTC facility, informal care, total LTC, shift from LTC facility to home and community-based care, and primary care.

The strength of an HSPA framework is determined by many factors such as the selection of performance indicators, its alignment to policy objectives, measurements techniques, and the availability and quality of data.[17] With the appropriate indicators, countries can evaluate their policy goals and objectives while also supporting future evidence-based decision making. There is general alignment between the performance indicators found in this scoping review and the 4 main reform policy objectives of aging-in-place.[7] This is imperative for indicators to be actionable, as performance indicators should have a distinct evaluation purpose for an intended decision-making function.[86] The first objective, a shift from institutional care toward aging-in-place, could be gauged by performance indicators like the utilization of LTC facilities or home and community-based care, quantified by metrics such as the absolute numbers of users or service volume. However, only one study specifically measured the shift of care by measuring the association of increased home care supply on LTC facility closures.[52] The second objective, increasing the responsibilities of informal caregivers, aligns with metrics like the prevalence of informal caregivers and measurements of informal caregiver burden.[53,59] However, performance indicators related to the informal caregiver were less described than indicators on other care levels. Performance indicators associated with the third objective, addressing fiscal sustainability, were frequently identified in the literature. They mostly encompass metrics related to national expenditures across various care levels. More interestingly, performance indicators were identified that measured cost shifting from LTC facility expenditures towards home and community-based care.[23,24,34,39,49] The fourth objective, improvement of access and provision of care services, corroborates with identified performance indicators such as the number of LTC facility beds and the number of people on waiting lists for home care.[44,47]

Although some policy domains and associated performance indicators (eg, expenditures and national LTC costs) identified in this scoping review bear resemblance to those of more generic HSPA frameworks,[18] this review pinpointed additional indicators specifically tailored for the assessment of aging-in-place. For example, these include the shift in costs from LTC facility expenditures to those related to home and community-based care,[23,24,34,39,49] as well as the effects of increased availability of home care on the closure of LTC facilities.[52] Furthermore, performance indicators describing potential adverse effects of aging-in-place on society, such as decreased health status of older adults and increased caregiver burden were also found.[35,55,59,61,70]

However, outcome performance indicators related to the older adult and informal caregivers such their well-being were less discussed in literature compared with process and structure indicators. This is consistent with a review conducted by Vanleerberghe et al. who concluded that although assessing quality-of-life outcomes in people who are aging-in-place is important, the literature reveals this is seldom performed in a structural way.[87] In addition, it is important to acknowledge that the performance indicators identified in this scoping review are not all encompassing. A study by Pani-Harreman et al. outlined 5 crucial themes for successful aging-in-place: (1) place, (2) social network, (3) support, (4) technology, and (5) personal characteristics of older individuals.[88] These themes were underrepresented in the current evaluations of aging-in-place reforms. For instance, to prolong the duration of people living at home, also factors such as adequate housing and a strong social network should be measured. It is imperative to determine how these concepts can be assessed through actionable performance indicators in future research and policy. Furthermore, overarching developments such as the diversification of our aging population and scarcity in the health care workforce ask for performance indicators that address health equity and social determinants of health.[89,90]

While the primary objective of this scoping review did not revolve around the methodological considerations of the included articles, this review provided a general description of study characteristics. This can offer some insights into the actionability of the studied performance indicators, in particular how fit indicators are for the intended use.[86] The approach in most of the included studies involved the utilization of annual data, primarily using descriptive analyses, which only facilitated the description of larger trends of performance indicators. In contrast, the included quasi-experimental studies, using more complex methods such as difference-in-difference analysis, were able to discern specific changes in performance of indicators by comparing pre- to post-implementation of aging-in-place policies. Although the latter might be preferred, the selection of quality indicators and measurement methods are often determined by considerations of data availability and quality.[13] For some performance domains such as health care expenditures, data might

be more accessible compared with health status of older adults. This might provide an explanation why most quasi-experimental articles included performance indicators within the performance domains of expenditures and care utilization.

Furthermore, the performance indicators identified in this study that targeted similar performance domains or performance indicators showed heterogeneity within and across countries. For example, some studies used the total number of LTC facility users as a percentage of the population of those ≥65 years old as an indicator to evaluate LTC facility utilization,[23,53] whereas studies from other countries measured the annual number of new LTC facility placements.[61,66] To enable international collaborations, an agreed set of performance indicators as part of a comprehensive HSPA framework is necessary to allow for exchange of knowledge and international comparisons.[17]

This study has some limitations. First, the search was limited to studies written in Dutch or English. Second, the omission of gray literature from the search strategy may exclude evaluations conducted by governments and national health services, which are often disseminated through non-scientific reports. However, because of the vast volume of policy reports and linguistic constraints, this was deemed beyond the scope of this research. Finally, the broad focus of the key search themes may have led to the oversight of specific performance domains (eg, housing quality, technology use) important for assessing effects of aging-in-place.

This study provides evidence toward building an HSPA framework for evaluating the effects of aging-in-place policies by providing an overview of performance indicators currently used in literature. The general aim of performance indicators is to provide an evidence base for policy decision making. For aging-in-place performance indicators to be actionable for policy use, they should facilitate a designated decision-making purpose.[86] Most of the research focused on performance indicators within the performance domains of expenditures and care utilization, whereas other performance indicators measuring effects on older adults and society were less common. Further research is recommended to establish a comprehensive framework to assess effects of aging-in-place policies with actionable performance indicators.

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Appendix 1.

Search strategy in MEDLINE, Embase, and Ebscohost Academic Search Premier

Ovid MEDLINE(R) ALL <1946 to June 19, 2023> Search date: 21 June 2023		
#	**Searches**	**Results**
1	community health services/ or independent living/ or home environment/ or home care agencies/ or home care services/ or personal autonomy/	98323
2	(ag?ing adj2 place).ab,kf,ti.	1222
3	((living adj2 independent*) or self reliance).ab,kf,ti.	6759
4	((decentral* adj5 (healthcare system or care system)) or home care team? or (home care adj3 service?) or (ag?ing adj3 community) or ((home or community) adj5 service?) or community based or community dwelling or community care or household).ab,kf,ti.	225418
5	((("own home" or "at home") adj3 (ag?ing or death or mortal* or dying)) or (("own home" or "at home") adj15 (mortal* or death?)) or home death? or "location of death" or "place of death").ab,kf,ti.	4756
6	(caregiv* adj2 (allowance or percentage)).ab,kf,ti.	72
7	personal autonomy.ab,kf,ti.	798
8	or/1-7	309239
9	(adolescen* or youth? or juvenile or pe?diatric* or youngster? or young adult?).ab,kf,ti.	935851
10	8 not 9 [Aging in Place]	287752
11	exp hospitalization/ or hospital mortality/ or geriatric assessment/	352360
12	((evaluat* or assess*) adj3 (place or location)).ab,kf,ti.	6798
13	(length adj2 stay).ab,kf,ti.	79431
14	(hospitali?ation or institutionalisation or patient admission or ((admission or utili?ation) adj3 hospital?)).ab,kf,ti.	231397
15	(health expenditure? or cost? or "out of pocket" or subsid* or fund*).ab,kf,ti.	1170754
16	(hospital adj3 (ag?ing or death or mortal* or dying)).ab,kf,ti.	69224
17	(((geriatric* or elderly or older adult? or senior citizen?) adj3 survey?) or national health survey? or geriatric assessment).ab,kf,ti.	9885
18	or/11-17 [Evaluation]	1676922
19	exp national health programs/ or health policy/ or health care reform/	187387
20	((Australia or Austria or Belgium or Canada or Chile or Colombia or Costa Rica or Czech Republic or Denmark or Estonia or Finland or France or Germany or Greece or Hungary or Iceland or Ireland or Israel or Italy or Japan or Korea or Latvia or Lithuania or Luxembourg or Mexico or Netherlands or New Zealand or Norway or Poland or Portugal or Slovak Republic or Slovenia or Spain or Sweden or Switzerland or Turkey or United Kingdom or United States) adj3 evidence).ab,kf,ti.	4376
21	(care* adj10 reform?).ab.	8366
22	reform?.ab. /freq=2	8878
23	((care* or health) adj3 (reform? or policy or act or program? or programme?)).ab,kf,in,ti.	306411
24	policy intervention?.ab,kf,ti.	3047
25	(plan and (Australia or Austria or Belgium or Canada or Chile or Colombia or Costa Rica or Czech Republic or Denmark or Estonia or Finland or France or Germany or Greece or Hungary or Iceland or Ireland or Israel or Italy or Japan or Korea or Latvia or Lithuania or Luxembourg or Mexico or Netherlands or New Zealand or Norway or Poland or Portugal or Slovak Republic or Slovenia or Spain or Sweden or Switzerland or Turkey or United Kingdom or United States)).ab,kf,ti.	16786
26	(national adj5 (reform? or policy or act or program? or programme?)).ab,kf,ti.	60829
27	health policy.in.	69445

Ovid MEDLINE(R) ALL <1946 to June 19, 2023> Search date: 21 June 2023		
28	or/19-27 [governmental policy reform]	527998
29	(Australia or Austria or Belgium or Canada or Chile or Colombia or Costa Rica or Czech Republic or Denmark or England or Estonia or Finland or France or Germany or Greece or Hungary or Iceland or Ireland or Israel or Italy or Japan or Korea or Latvia or Lithuania or Luxembourg or Mexico or Netherlands or New Zealand or Norway or Poland or Portugal or Slovak Republic or Slovenia or Spain or Scotland or Sweden or Switzerland or Turkey or United Kingdom or United States or USA or Wales).in. [OECD countries]	15675677
30	and/10,18,28-29	5570
31	(concentration index or lmics or tuberculosis care or rural Tanzaenia or rural india or benefit incidence analysis or disease management or colorectal cancer or robert wood johnson foundation).ab,ti. [VOS blue]	160198
32	(tuberculosis patient or financial toxicity or paper analyze or prescription drug coverage or ((prescri* adj3 drug?) not prescription)).ab,ti. [VOS light blue]	17359
33	(non communicable disease or household food insecurity or food insecurity or cardiovascular disease or diabete or diet or hypertension or blood pressure or physical inactivity).ab,ti. [VOS purple]	1153839
34	(heart disease or migrant? or politician? or pharmac* or psychiatry or pharmacy or schizophreni* or psychos* or mental health policy or faculty or disease management or community partner or community partnership or cancer screening or weight loss or academic institution or smoking or student? or participatory research or health disparity or “tobacco use” or community leader or childhood obesity).ab,ti. [VOS red]	2196817
35	(cancer patient? or congestive heart failure or diabetes mellitus or randomized trial or randomized controlled trial or clinical trial or exercise program* or recruitment strateg* or fatigue or anxiety or cognitive behavio?ral therapy or cbt).ab,ti. [VOS green]	1186966
36	(HIV or infection or vaccination or “hepatitis c” or hiv prevention or art? or sars cov or breastfeeding or treatment program or blood or cervical cancer screening or hiv testing or antiretroviral therapy or infectious disease or mother or birth or vaccine? or maternal or child health or newborn? or family planning or childhood illness or neonatal mortalit* or sanitation or acute malnutrition or malaria or insecticide or tb diagnosis or tb care or child mortality).ab,ti. [VOS gold]	4732604
37	or/31-36	7990070
38	30 not 37	3172
39	System for Promotion of Personal Autonomy and Assistance for Persons in a Situation of Dependency (SAAD).mp.	1
40	38 or 39	3173

Ovid Embase Classic+Embase <1947 to 2023 June 19> Search date: 21 June 2023

#	Searches	Results
1	community care/ or community program/ or community support/ or independent living/ or home environment/ or exp home care/ or personal autonomy/	184264
2	(ag?ing adj2 place).ab,kw,ti.	1108
3	((living adj2 independent*) or self reliance).ab,kw,ti.	8655
4	((decentral* adj5 (healthcare system or care system)) or home care team? or (home care adj3 service?) or (ag?ing adj3 community) or ((home or community) adj5 service?) or community based or community dwelling or community care or household).ab,kw,ti.	279069
5	((("own home" or "at home") adj3 (ag?ing or death or mortal* or dying)) or (("own home" or "at home") adj15 (mortal* or death?)) or home death? or "location of death" or "place of death").ab,kw,ti.	7383
6	(caregiv* adj2 (allowance or percentage)).ab,kw,ti.	123
7	personal autonomy.ab,kw,ti.	1041
8	or/1-7	439423
9	(adolescen* or youth? or juvenile or pe?diatric* or youngster? or young adult?).ab,kw,ti.	1322401
10	8 not 9 [Aging in Place]	408738
11	hospitalization/ or exp hospital mortality/ or geriatric assessment/ or "length of stay"/	796241
12	((evaluat* or assess*) adj3 (place or location)).ab,kw,ti.	10178
13	(length adj2 stay).ab,kw,ti.	151706
14	(hospitali?ation or institutionalisation or patient admission or ((admission or utili?ation) adj3 hospital?)).ab,kw,ti.	403572
15	(health expenditure? or cost? or "out of pocket" or subsid* or fund*).ab,kw,ti.	1583439
16	(hospital adj3 (ag?ing or death or mortal* or dying)).ab,kw,ti.	117350
17	(((geriatric* or elderly or older adult? or senior citizen?) adj3 survey?) or national health survey? or geriatric assessment).ab,kw,ti.	15539
18	or/11-17 [Evaluation]	2473602
19	health care policy/	220743
20	((Australia or Austria or Belgium or Canada or Chile or Colombia or Costa Rica or Czech Republic or Denmark or Estonia or Finland or France or Germany or Greece or Hungary or Iceland or Ireland or Israel or Italy or Japan or Korea or Latvia or Lithuania or Luxembourg or Mexico or Netherlands or New Zealand or Norway or Poland or Portugal or Slovak Republic or Slovenia or Spain or Sweden or Switzerland or Turkey or United Kingdom or United States) adj3 evidence).ab,kw,ti.	5392
21	(care* adj10 reform?).ab.	9740
22	reform?.ab. /freq=2	9935
23	((care* or health) adj3 (reform? or policy or act or program? or programme?)).ab,kw,in,ti.	382545
24	policy intervention?.ab,kw,ti.	3441
25	(plan and (Australia or Austria or Belgium or Canada or Chile or Colombia or Costa Rica or Czech Republic or Denmark or Estonia or Finland or France or Germany or Greece or Hungary or Iceland or Ireland or Israel or Italy or Japan or Korea or Latvia or Lithuania or Luxembourg or Mexico or Netherlands or New Zealand or Norway or Poland or Portugal or Slovak Republic or Slovenia or Spain or Sweden or Switzerland or Turkey or United Kingdom or United States)).ab,kw,ti.	27143
26	(national adj5 (reform? or policy or act or program? or programme?)).ab,kw,ti.	81721
27	health policy.in.	91684
28	or/19-27 [governmental policy reform]	651649
29	(Australia or Austria or Belgium or Canada or Chile or Colombia or Costa Rica or Czech Republic or Denmark or England or Estonia or Finland or France or Germany or Greece or Hungary or Iceland or Ireland or Israel or Italy or Japan or Korea or Latvia or Lithuania or Luxembourg or Mexico or Netherlands or New Zealand or Norway or Poland or Portugal or Slovak Republic or Slovenia or Spain or Scotland or Sweden or Switzerland or Turkey or United Kingdom or United States or USA or Wales).in. [OECD countries]	28311483

30	and/10,18,28-29	10434
31	(concentration index or lmics or tuberculosis care or rural Tanzaenia or rural india or benefit incidence analysis or disease management or colorectal cancer or robert wood johnson foundation).ab,ti. [VOS blue]	239789
32	(tuberculosis patient or financial toxicity or paper analyze or prescription drug coverage or ((prescri* adj3 drug?) not prescription)).ab,ti. [VOS light blue]	28363
33	(non communicable disease or household food insecurity or food insecurity or cardiovascular disease or diabete or diet or hypertension or blood pressure or physical inactivity).ab,ti. [VOS purple]	1766709
34	(heart disease or migrant? or politician? or pharmac* or psychiatry or pharmacy or schizophreni* or psychos* or mental health policy or faculty or disease management or community partner or community partnership or cancer screening or weight loss or academic institution or smoking or student? or participatory research or health disparity or "tobacco use" or community leader or childhood obesity).ab,ti. [VOS red]	3268385
35	(cancer patient? or congestive heart failure or diabetes mellitus or randomized trial or randomized controlled trial or clinical trial or exercise program* or recruitment strateg* or fatigue or anxiety or cognitive behavio?ral therapy or cbt).ab,ti. [VOS green]	1823738
36	(HIV or infection or vaccination or "hepatitis c" or hiv prevention or art? or sars cov or breastfeeding or treatment program or blood or cervical cancer screening or hiv testing or antiretroviral therapy or infectious disease or mother or birth or vaccine? or maternal or child health or newborn? or family planning or childhood illness or neonatal mortalit* or sanitation or acute malnutrition or malaria or insecticide or tb diagnosis or tb care or child mortality).ab,ti. [VOS gold]	6684841
37	or/31-36	11441879
38	30 not 37	5949
39	System for Promotion of Personal Autonomy and Assistance for Persons in a Situation of Dependency (SAAD).mp.	1
40	38 or 39	5950

Ebscohost Academic Search Premier Search date: 21 June 2023

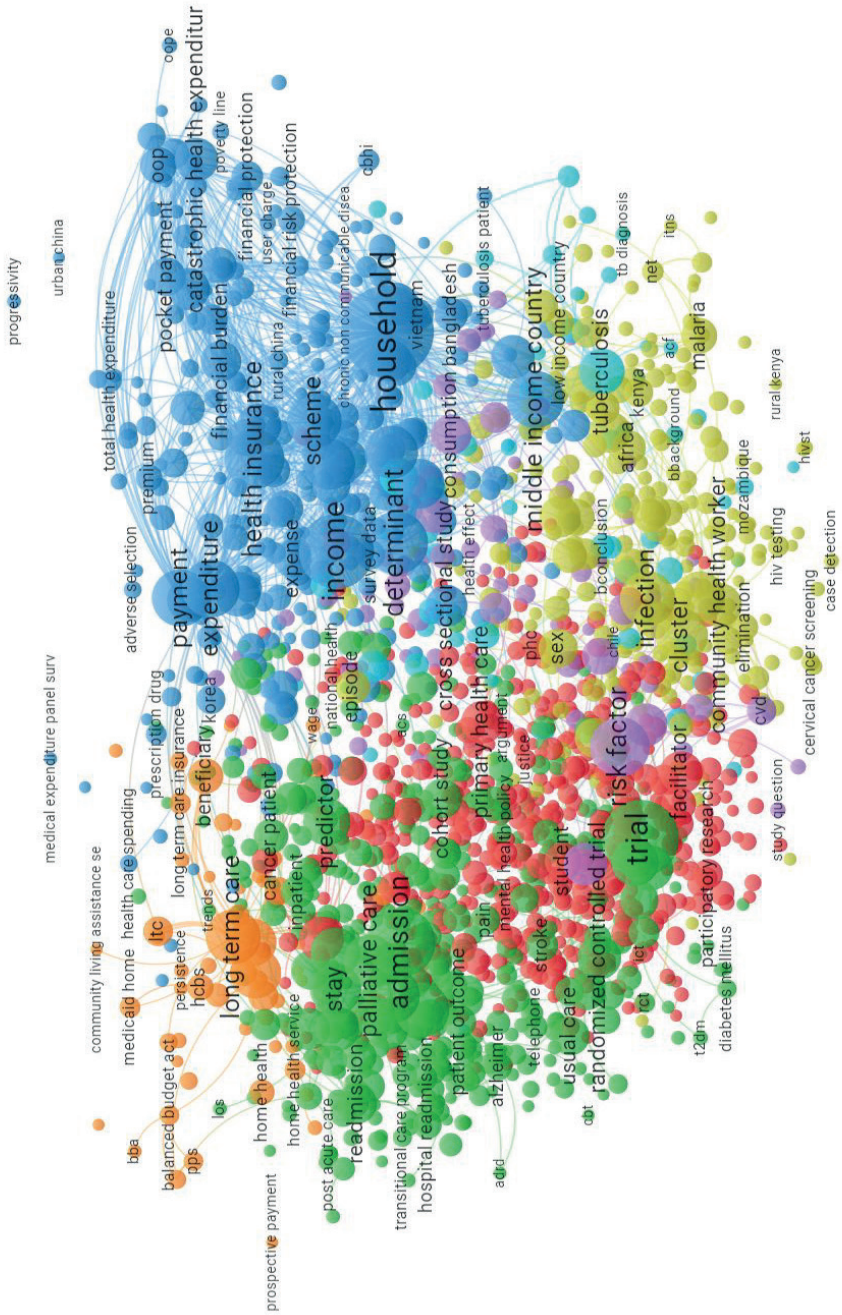
#	Searches	Results
1	AB (ag#ing N2 place) OR TI (ag#ing N2 place) OR KW (ag#ing N2 place) OR SU (ag#ing N2 place)	1362
2	AB ((living N1 independent*) or self reliance) OR TI ((living N1 independent*) or self reliance) OR KW ((living N1 independent*) or self reliance) OR SU ((living N1 independent*) or self reliance)	15918
3	AB ((decentral* N4 (healthcare system or care system)) or home care team# or (home care N2 service#) or (ag#ing N2 community) or ((home or community) N4 service#) or community based or community dwelling or community care or household) OR TI ((decentral* N4 (healthcare system or care system)) or home care team# or (home care N2 service#) or (ag#ing N2 community) or ((home or community) N4 service#) or community based or community dwelling or community care or household) OR KW ((decentral* N4 (healthcare system or care system)) or home care team# or (home care N4 service#) or (ag#ing N4 community) or ((home or community) N4 service#) or community based or community dwelling or community care or household) OR SU ((decentral* N4 (healthcare system or care system)) or home care team# or (home care N4 service#) or (ag#ing N4 community) or ((home or community) N4 service#) or community based or community dwelling or community care or household)	337385
4	AB ((("own home" or "at home") N4 (ag#ing or death or mortal* or dying)) or (("own home" or "at home") N14 (mortal* or death#)) or home death# or "location of death" or "place of death") OR TI ((("own home" or "at home") N4 (ag#ing or death or mortal* or dying)) or (("own home" or "at home") N14 (mortal* or death#)) or home death# or "location of death" or "place of death") OR KW ((("own home" or "at home") N4 (ag#ing or death or mortal* or dying)) or (("own home" or "at home") N14 (mortal* or death#)) or home death# or "location of death" or "place of death") OR SU ((("own home" or "at home") N4 (ag#ing or death or mortal* or dying)) or (("own home" or "at home") N14 (mortal* or death#)) or home death# or "location of death" or "place of death")	10772
5	AB (caregiv* N1 (allowance or percentage)) OR TI (caregiv* N1 (allowance or percentage)) OR KW (caregiv* N1 (allowance or percentage)) OR SU (caregiv* N1 (allowance or percentage))	196
6	AB personal autonomy OR TI personal autonomy OR KW personal autonomy OR SU personal autonomy	1763
7	S1 OR S2 OR S3 OR S4 OR S5 OR S6	358611

8	AB (adolescen* or youth# or juvenile or pe#diatric* or youngster# or young adult#) OR TI (adolescen* or youth# or juvenile or pe#diatric* or youngster# or young adult#) OR KW (adolescen* or youth# or juvenile or pe#diatric* or youngster# or young adult#) OR SU (adolescen* or youth# or juvenile or pe#diatric* or youngster# or young adult#)	879203
9	S7 NOT S8	333863
10	AB ((evaluat* or assess*) N2 (place or location)) OR TI ((evaluat* or assess*) N2 (place or location)) OR KW ((evaluat* or assess*) N2 (place or location)) OR SU ((evaluat* or assess*) N2 (place or location))	7599
11	AB (length N1 stay) OR TI (length N1 stay) OR KW (length N1 stay) OR SU (length N1 stay)	50469
12	AB (hospitali#ation or institutionalisation or patient admission or ((admission or utili#ation) N2 hospital#)) OR TI (hospitali#ation or institutionalisation or patient admission or ((admission or utili#ation) N2 hospital#)) OR KW (hospitali#ation or institutionalisation or patient admission or ((admission or utili#ation) N2 hospital#)) OR SU (hospitali#ation or institutionalisation or patient admission or ((admission or utili#ation) N2 hospital#))	190126
13	AB (health expenditure# or cost# or "out of pocket" or subsid* or fund*) OR TI (health expenditure# or cost# or "out of pocket" or subsid* or fund*) OR KW (health expenditure# or cost# or "out of pocket" or subsid* or fund*) OR SU (health expenditure# or cost# or "out of pocket" or subsid* or fund*)	2258585
14	AB (hospital N2 (ag#ing or death or mortal* or dying)) OR TI (hospital N2 (ag#ing or death or mortal* or dying)) OR KW (hospital N2 (ag#ing or death or mortal* or dying)) OR SU (hospital N2 (ag#ing or death or mortal* or dying))	35076
15	AB (((geriatric* or elderly or older adult# or senior citizen#) N2 survey#) or national health survey# or geriatric assessment) OR TI (((geriatric* or elderly or older adult# or senior citizen#) N2 survey#) or national health survey# or geriatric assessment) OR KW (((geriatric* or elderly or older adult# or senior citizen#) N2 survey#) or national health survey# or geriatric assessment) OR SU (((geriatric* or elderly or older adult# or senior citizen#) N2 survey#) or national health survey# or geriatric assessment)	34520
16	S10 OR S11 OR S12 OR S13 OR S14 OR S15	2506596
17	AB ((Australia or Austria or Belgium or Canada or Chile or Colombia or Costa Rica or Czech Republic or Denmark or Estonia or Finland or France or Germany or Greece or Hungary or Iceland or Ireland or Israel or Italy or Japan or Korea or Latvia or Lithuania or Luxembourg or Mexico or Netherlands or New Zealand or Norway or Poland or Portugal or Slovak Republic or Slovenia or Spain or Sweden or Switzerland or Turkey or United Kingdom or United States) N2 evidence) OR TI ((Australia or Austria or Belgium or Canada or Chile or Colombia or Costa Rica or Czech Republic or Denmark or Estonia or Finland or France or Germany or Greece or Hungary or Iceland or Ireland or Israel or Italy or Japan or Korea or Latvia or Lithuania or Luxembourg or Mexico or Netherlands or New Zealand or Norway or Poland or Portugal or Slovak Republic or Slovenia or Spain or Sweden or Switzerland or Turkey or United Kingdom or United States) N2 evidence) OR KW ((Australia or Austria or Belgium or Canada or Chile or Colombia or Costa Rica or Czech Republic or Denmark or Estonia or Finland or France or Germany or Greece or Hungary or Iceland or Ireland or Israel or Italy or Japan or Korea or Latvia or Lithuania or Luxembourg or Mexico or Netherlands or New Zealand or Norway or Poland or Portugal or Slovak Republic or Slovenia or Spain or Sweden or Switzerland or Turkey or United Kingdom or United States) N2 evidence) OR SU ((Australia or Austria or Belgium or Canada or Chile or Colombia or Costa Rica or Czech Republic or Denmark or Estonia or Finland or France or Germany or Greece or Hungary or Iceland or Ireland or Israel or Italy or Japan or Korea or Latvia or Lithuania or Luxembourg or Mexico or Netherlands or New Zealand or Norway or Poland or Portugal or Slovak Republic or Slovenia or Spain or Sweden or Switzerland or Turkey or United Kingdom or United States) N2 evidence)	10686
18	AB (care* N9 reform#)	16149
19	AB ((care* or health) N2 (reform# or policy or act or program# or programme#)) OR TI ((care* or health) N2 (reform# or policy or act or program# or programme#)) OR KW ((care* or health) N2 (reform# or policy or act or program# or programme#)) OR SU ((care* or health) N2 (reform# or policy or act or program# or programme#))	207460
20	AB policy intervention# OR TI policy intervention# OR KW policy intervention# OR SU policy intervention#	13808

21	AB (plan and (Australia or Austria or Belgium or Canada or Chile or Colombia or Costa Rica or Czech Republic or Denmark or Estonia or Finland or France or Germany or Greece or Hungary or Iceland or Ireland or Israel or Italy or Japan or Korea or Latvia or Lithuania or Luxembourg or Mexico or Netherlands or New Zealand or Norway or Poland or Portugal or Slovak Republic or Slovenia or Spain or Sweden or Switzerland or Turkey or United Kingdom or United States)) OR TI (plan and (Australia or Austria or Belgium or Canada or Chile or Colombia or Costa Rica or Czech Republic or Denmark or Estonia or Finland or France or Germany or Greece or Hungary or Iceland or Ireland or Israel or Italy or Japan or Korea or Latvia or Lithuania or Luxembourg or Mexico or Netherlands or New Zealand or Norway or Poland or Portugal or Slovak Republic or Slovenia or Spain or Sweden or Switzerland or Turkey or United Kingdom or United States)) OR KW (plan and (Australia or Austria or Belgium or Canada or Chile or Colombia or Costa Rica or Czech Republic or Denmark or Estonia or Finland or France or Germany or Greece or Hungary or Iceland or Ireland or Israel or Italy or Japan or Korea or Latvia or Lithuania or Luxembourg or Mexico or Netherlands or New Zealand or Norway or Poland or Portugal or Slovak Republic or Slovenia or Spain or Sweden or Switzerland or Turkey or United Kingdom or United States)) OR SU (plan and (Australia or Austria or Belgium or Canada or Chile or Colombia or Costa Rica or Czech Republic or Denmark or Estonia or Finland or France or Germany or Greece or Hungary or Iceland or Ireland or Israel or Italy or Japan or Korea or Latvia or Lithuania or Luxembourg or Mexico or Netherlands or New Zealand or Norway or Poland or Portugal or Slovak Republic or Slovenia or Spain or Sweden or Switzerland or Turkey or United Kingdom or United States))	216481
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23	AB health policy OR TI health policy OR KW health policy OR SU health policy	99076
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29	S27 NOT S28	1885

Appendix 2.

Bibliometric network of keywords



Appendix 3. Definitions and Inclusion and Exclusion criteria

1.1 Definitions

Ageing-in-place: Meeting the desire and ability of people, through the provision of appropriate services and assistance, to remain living relatively independently in the community in his or her current home or an appropriate level of housing. Ageing in place is designed to prevent or delay more traumatic moves to a dependent facility, such as a nursing home.[1]

Ageing-in-place reform policies: Change in policy at the national level (or country specific region e.g., prefecture, state,) targeting older adults at the population level. For this scoping review we will only consider reforms that are targeted at or influence aging-in-place for older adults. We do not include reforms that are only target at one specific patient group. Policy changes could, for example, be targeted at the financial level (budget cuts, changes in allowances and coverage levels), legislative level (introduction of new care acts), political level (decentralization, shifting of responsibilities to municipal level, more emphasize on informal care.

Older adults: in this study we define older adults to have the arbitrary age of 60 years or older.

1.2 Eligibility criteria

Inclusion criteria:

1. Evaluation of a reform policy that was targeted at or had an influence on ageing in place.
2. Reform policies that are implemented at the national (or country specific region e.g., prefecture, state,) level.
3. Indicators used are measurable (over time).

Exclusion criteria:

1. Reform policies that are targeted at specific diseases or populations.
2. Reform policies that are implemented at the organizational or city level.
3. Reform policies/indicators that do not influence ageing in place for older adults.
4. Reforms policies that are implemented in low-income countries.

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Appendix 4. Comprehensive presentation of all the identified performance indicators per performance domain, categorized by care level.

Structure performance indicators		
Performance domain	**Care level**	**Performance indicator**
Expenditures	Total long term care (LTC)	- Annual national LTC expenditures [1-4] - Annual LTC expenditures as percentage of the gross domestic product [1] - Annual LTC expenditures as percentage of the total health care budget [5] - Annual LTC expenditures per capita [1]
	LTC facility	- Annual sum of LTC facility expenditures [3,4,6] - Annual average expenditures per LTC facility bed [7] - Annual per capita expenditures on LTC facility care [8]
	Home and community-based care	- Annual expenditures of home and community-based care Programs [4,6,9-11]. - Annual home and community-based care expenditures as percentage of total LTC costs [4,10,11] - Annual home and community-based care expenditures on the provincial level [12] - Annual average per capita expenditures of home and community-based care [6,10,13,14]
	Cost-shifting between LTC facility and home and community-based care	- Cost-shifting between LTC facility and home and community-based care on the national level [8,15] - Cost-shifting between LTC facility and home and community-based care on program level (Medicare/Medicaid) [6,10,16]
	Primary care	- Annual municipal sum of primary care rehabilitation service expenditures [17] - Annual per capita expenditures on general practitioner care [8]
	Hospital care	- Total annual hospital expenditures [2,18] - Annual per capita expenditures on specialist care [8] - Annual per capita expenditures of specialist rehabilitation [17]
	Older adult	- Annual co-payments as a percentage of the total national LTC expenditures [19] - Total annual family savings [20] - Proportion of people paying out of pocket for private care [17,21] - Average per capita LTC co-payments [2,14]
Care availability	LTC facility	- Total number of LTC facilities [1,22,23] - Number of LTC facility service providers [24] - Number of LTC facility opening and closures [22] - Total amount of LTC facility beds [7,22]
	Home and community-based care	- Number of different national home care programs [9] - Number of home care service providers [1,24] - Marketization rate of home care service providers [25] - Number of people on the waiting list of the national home care programs [11]
Workforce	LTC facility	- Annual number of LTC facility nurses [1,26] - LTC staff casualization and turnover [26]
	Home and community-based care	- Annual number of registered home care nurses and home help aides [1,27] - Working conditions of home care workers: clients per day, job tasks, job autonomy, supervision support [28]
	Primary care	- Annual number of social workers [27] - Annual number of physical therapists [27]
	Informal caregiver	- Prevalence of informal caregivers [29]

Process performance indicators		
Performance domain	**Care level**	**Performance indicator**
Care utilization	National LTC	- Annual number of LTC beneficiaries under the public LTC Insurance [1,24,30] - LTC beneficiaries under the public LTC insurance as a percentage of the population ≥65 year old [23] - Number of enrolments in specific LTC programs [3,5] - Percentage of public formal LTC utilization [21]
	LTC facility	- Number of LTC facility users [3,24,31,32] - Number of LTC facility users as a percentage of the population ≥65 year old [15,23] - Number of new placements in LTC facility [31,33] - Total LTC facility days [33 2]
	Home and community-based care	- Annual total number of home care users [11,12,24,34,35] - Number of home care users as a percentage of the cohort/population (≥65 year old) [9,15,23,30,36] - Total amount of home care visits [35] - Annual average number of days of home care utilization per claim [30] - Annual average number of visits per client [35] - Annual number of unique claims of home support services as a percentage of the population ≥65 year old [31] - Service utilization specified in service type (in-home, day care, or domiciliary care) [23 13] - Total amount of minutes or hours of home care provide [2,31,37] - Annual home care hours per capita [38]
	Primary care	- Annual number of general practitioner visits [38] - Average per person number of visits [38] - Sum of person-hours worked by physio- and occupational therapists per capita [17]
	Hospital care	- Annual number of hospital visits of the older adult population [18 38,39 40] - Hospitalizations as a rate of the older adult population [38,41,42] - Number of hospitalizations amongst LTC facility residents [26,31] - Annual number of hospitalizations amongst home care users [31,39,43 30] - Annual number of emergency department visits [18,33] - Annual number of geriatric hospital visits [32] - Annual number of specialists care visits [38] - National rate of acute hospitalizations per month [42] - Hospital readmission rate [44] - Length of hospital stay [2,18,38,39,41,42,44-46] - Number of bed blockers [46,47] - Discharge destination i.e., home or LTC facility [44,46]
	Informal care	- Proportions of older adults receiving informal care (per week/month) [21,25,48]
Care quality	Home and community-based care	- The Home Health Compare star rating (Medicare/Medicaid) [30]
Care satisfaction	Total LTC	- Client satisfaction regarding the received LTC services measured by Likert scales [24]
	Home and community-based care	- Mark out of 10 on domestic help, the collective transport system, and home adaptations [49]
Outcome performance indicators		
Performance domain	**Care level**	**Performance indicator**
Health status	Older adult	- Wellbeing of older adults measured by quality of life scales [18,41] - Mental health status of older adults [50,51] - Functional abilities of older adults such as activities of daily life scores, and care dependency [33,37,43,50] - Cognitive function [33,37,50] - Disease related factors such as urinary tract infections, respiratory diseases, bedsores, contractions and pain [18,43] - Mortality rates [33,44,52] - Location of death i.e., hospital, nursing home facility, home, or Other [40,53-56]

Caregiver burden	Informal caregiver	- Frequency of daily caregiving and the average weekly hours of caregiving activities [29,48,57] - Informal caregiver distress [24,29,33] - General health of the informal caregiver [58] - Probability of sickness of informal caregivers [36] - Effect of changes in home care payments on informal caregiving Hours [48] - Effect of informal caregiving on labour supply and weekly hours of labour participation [57]

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Appendix 5. Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
TITLE			
Title	1	Identify the report as a scoping review.	1
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	3-4
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	4
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	5
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	6 & appendix 3
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	5-6
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	Appendix 1
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	6
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	6-7
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	6-7
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	N.A.
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	6-7
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	8 & Figure 1
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	Table 1
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	Click here to enter text.
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	Table 1
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	8 - 12

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	35
Limitations	20	Discuss the limitations of the scoping review process.	38
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	38
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	1

JBI = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.

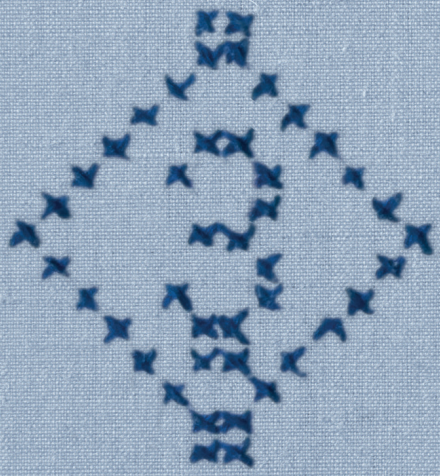
* Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.

† A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).

‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.

§ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document).

From: Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMAScR): Checklist and Explanation. Ann Intern Med. 2018;169:467–473. doi: 10.7326/M18-0850.



Chapter 3

Actionable performance indicators for evaluating ageing-in-place reforms in the Netherlands: a three-round Delphi consensus study

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Submitted

Abstract

Background

Population ageing, rising care complexity, and workforce shortages challenge long-term care. Reforms emphasise ageing in place (AIP), but no validated set of indicators currently exists for evaluating these reforms. We aimed to develop a standardised set of actionable indicators to evaluate Dutch AIP reforms.

Methods

A three-round online Delphi study was conducted with policymakers, researchers, healthcare professionals, and representatives of older adults and informal caregivers. Indicators were rated on fit-for-purpose (relevance to policy goals) and fit-for-use (usability for decision-making) using 5-point Likert scales. For round 1 consensus used mean scores (≥4) and standard deviation (≤0.69), later rounds used ≥75% agreement. Round 3 used weighted scoring to rank indicators within domains.

Findings

81 out of 92 invited experts completed round 1 (88%); 66 (82%) completed round 2 and 64 (79%) completed round 3. 53 actionable indicators reached consensus across 10 domains: older adult health status, informal caregiver burden, health inequalities, care satisfaction, person-centred care, care availability, coverage of care, care utilisation, workforce, and expenditures. Outcome domains formed a substantial share of the final set. No quality indicators reached consensus, as panellists noted trade-offs between risk prevention and autonomy.

Interpretation

This stakeholder-informed framework shifts AIP performance measurement beyond utilisation and expenditure towards outcomes such as wellbeing, caregiver burden, and equity. The absence of consensus on quality-of-care indicators suggests that quality may be embedded across multiple domains rather than a standalone concept. The methodology is transferable to other countries evaluating similar reforms.

Funding

The Netherlands Organisation for Health Research and Development (ZonMw).

Introduction

The Netherlands sits at the leading edge of long-term care (LTC) challenges facing many high-income countries. In 2023, the Netherlands allocated 4.2% of its gross domestic product to LTC, the highest share among Organisation for Economic Co-operation and Development (OECD) countries[1], yet the number of older people continues to rise faster than the available workforce.[2] To contain costs and promote autonomy under this pressure, Dutch LTC policy shifted towards ageing in place (AIP). In 2015, the Netherlands enacted a major restructuring of its long-term care system, known as the Long-Term Care Reform (*Hervorming Langdurige Zorg*).[3] The previous Exceptional Medical Expenses Act (*Algemene Wet Bijzondere Ziektekosten, AWBZ)* was replaced by three statutory schemes covering distinct parts of the care continuum: the Long-Term Care Act (*Wet langdurige zorg, Wlz)* for people requiring 24-hour supervision; the Health Insurance Act (*Zorgverzekeringswet, Zvw)*, which absorbed district nursing; and the Social Support Act (*Wet maatschappelijke Ondersteuning, Wmo)*, under which municipalities became responsible for domestic help, day activities, and assistive devices.[3,4] The reform was designed to enable older adults to live at home longer and thereby contain costs.[3,4] More than a decade after these changes were introduced, however, evidence remains fragmented on whether these reforms are achieving their intended goals: enabling older adults to remain at home longer, maintaining wellbeing and autonomy, containing institutional long-term care costs, and shifting care towards home- and community-based settings.[5] This lack of insight is not unique to the Netherlands, but seems common among countries that have engaged in AIP reforms.

Generating such evidence requires actionable performance indicators that are both relevant to policy objectives (fit-for-purpose) and usable for decision-making (fit-for-use).[6] Health System Performance Assessment (HSPA) frameworks organise such indicators around system structures, processes, and outcomes.[7] Evaluating health system performance in the context of AIP is however, conceptually and methodologically challenging, particularly in defining and measuring outcomes with verifiable standards in a multidimensional cross-sectoral setting.[8] Three limitations in the current evidence base further prevent existing frameworks from being directly applied to AIP reform. First, generic HSPA frameworks such as the OECD's emphasise broad goals like people-centredness and health improvement, but are too general to capture the specific outcomes of AIP reform.[9] Second, our review of the international literature showed that reported indicators cluster around structures and processes (for example, expenditures, and utilisation) while outcome indicators such as effects on older adults' health and caregiver burden are markedly underrepresented, and equality indicators are largely absent despite a more diverse ageing population and persistent workforce

shortages.[10-12] Third, even when indicators have been described in the literature, their actionability in a specific national context, including the Dutch setting, has not been systematically assessed with the stakeholders who would use them. As a result, no validated, context-specific indicator set currently exists for evaluating AIP reform policies in countries such as the Netherlands.

To address these gaps, this study aims to develop a stakeholder-validated set of actionable performance indicators for evaluating AIP reform in the Netherlands. Building on our prior review of the international literature[12], the OECD HSPA framework[9], and evidence on equality[10], we applied the Delphi technique with a diverse panel of Dutch stakeholders to assess the actionability of candidate indicators. The resulting framework integrates international evidence with Dutch expert perspectives to provide a context-specific, system-level basis for evaluating AIP reforms.

Methods

Design

The Delphi was administered through three online survey rounds. This method was chosen to systematically synthesise expert opinion on a complex policy issue through iterative anonymous feedback rounds.[13] The Guidance on Conducting and Reporting Delphi Studies (CREDES) was used for the reporting of this study (see supplementary section).[14] The Medical Research Ethics Committee of the Amsterdam University Medical Centre waived the obligation for the study to undergo formal ethical approval as described under Dutch law in the Medical Research in Humans Act (ref. no. 2025.0814). Panellists received study information and provided written informed consent before participation.

Initial indicator development:

In a previous scoping review we identified 78 performance indicators used for AIP reform evaluation, covering domains of health system structures, processes and outcomes.[12] These indicators were refined through feedback from an advisory panel of four experts representing policy, research, caregiver, and care recipient perspectives. Based on this feedback, the indicators were anchored within the OECD HSPA framework, to align the study with the policy perspective.[9]

Finally, some domains relevant to AIP, such as health inequalities, had no or limited coverage. Therefore, the initial list of indicators was supplemented with suggestions from the advisory panel, indicators proposed by the OECD[9], or insights from relevant AIP literature[10,11], creating a more comprehensive set of 93 performance indicators across 11 domains (older adult health status, informal caregiver burden, health inequalities, care satisfaction, person-centred care, quality of care,

care availability, care coverage, care utilisation, workforce, expenditures and financing). The full list of initial indicators mapped to the OECD HSPA framework is available in the supplementary material.

Panel composition and recruitment

Purposive sampling was used to recruit a diverse panel of AIP experts, consisting of policymakers or advisors (e.g. ministries, insurers, municipalities, and sector organisations), researchers (academia, national research institutes) healthcare professionals (e.g. nurses, geriatricians, general practitioners), older adult representatives (older adult panels, patient advocacy groups), and informal caregiver representatives (informal caregiver panels, advocacy groups). The experts were identified through AIP literature and policy reports, professional networks of co-authors, contacting governmental and non-governmental organisations, and snowball sampling. To ensure diversity within the panel, some participants were recruited through organisations representing older adults with a migration background. Furthermore, policy advisors and researchers with expertise in health inequalities were invited.

Inclusion criteria included: 1) demonstrated expertise or lived experience relevant to ageing-in-place, either through professional role, research activities, or personal caregiving experience; 2) ability to communicate in Dutch; 3) being ≥18 years; 4) willingness to participate in all three rounds. For policymakers and professionals, expertise was defined as at least two years of experience. For older adults and informal caregivers, direct experience with AIP was required. Persons were excluded if they did not meet these requirements, and if they were unable to complete the online questionnaires due to limited digital access or literacy.

The researchers contacted potential experts or organisations by email, providing a short introduction to the study. Those who expressed interest were provided with an information letter (see supplementary section) detailing study procedures, confidentiality, and data use. The participants provided written informed consent before the first questionnaire. All rounds were administered online, with individualised survey links emailed to participants.

Questionnaire rounds

Each Delphi round was accessible for 21 days; the questionnaire required approximately 40 minutes to complete. Response rates for Rounds two and three were calculated using the number of round 1 completers as the denominator, reflecting attrition among the engaged panel. In round 1, demographic information (occupation, working experience) was collected. At the start of the questionnaire, panellists were invited to select the indicator domains they wished to assess, based on their expertise and familiarity with the topic. Panellists assessed indicator actionability using two criteria: fit-for-purpose (relevance to AIP policy objectives) and fit-for-use (usability for policy and decision-making).[6] For each indicator, panellists completed two five-point Likert scales: one assessing fit-for-purpose and one assessing fit-for-use, ranging from unimportant/not usable to very important/very usable. An additional 'cannot assess' was available in case panellists felt they lacked sufficient expertise to judge the indicator. Panellists could justify their ratings in an open-ended question. After completing each domain, panellists could suggest missing indicators. At the end of the questionnaire, panellists could indicate missing domains.

The second round aimed to reach consensus on indicators that remained uncertain after round 1. Researchers reviewed the quantitative and qualitative findings from round 1 to identify indicators requiring clarification or revision. Based on this feedback, some indicators were rephrased or refined to improve clarity and interpretability. In addition, new indicators and domains proposed by panellist were reviewed by the research team. These newly proposed items were included in round 2 for assessment by the full panel. Panellists were invited to reassess indicators, both revised and newly added, using the same two criteria of fit-for-purpose and fit-for-use, on the previously described five-point Likert scales. Panellists were invited to justify their ratings in open-ended question.

The third round aimed to identify which indicators should be prioritised and was used to reach consensus on some final indicators that were further refined with input from round 2. Panellists reassessed further revised indicators on the previously used five-point Likert scales. Finally, within each selected domain, panellists ranked the indicators according to their perceived importance for evaluating AIP reform policies. The results from this round provided an overview of the relative importance of indicators within domains.

Data analysis

The analysis of round 1 followed a similar approach to previous consensus-based studies.[15,16] For each indicator, the mean and standard deviation (SD) of panellists' ratings were calculated separately for both criteria, providing a continuous measure that allows finer distinction between

indicators, while the SD highlights areas of disagreement within the panel.[13,17] Indicators with a mean score of ≥4 on the five-point Likert scale for fit-for-purpose were considered prime indicators, while those with a mean score of ≥4 on fit-for-use were considered usable indicators. Consistent with previous studies, a SD ≤0.69 was interpreted as high consensus, between 0.70 and 0.79 as moderate consensus, and between 0.80 and 0.89 as low consensus.[16] Indicators with a mean score of ≥4 on both criteria and SD ≤0.69 were considered actionable with high consensus. Indicators with a mean score of <3 on both criteria and SD ≤0.69 were not actionable, with high consensus. Indicators with intermediate mean scores or higher SD values, reflected uncertainty or disagreement among panellists. The open-ended responses in round 1 was analysed through inductive coding, identifying suggestions for clarification, rewording, or modification of indicators. Two researchers (IV & KB) independently coded the responses for each indicator and subsequently met to compare and discuss their coding. Based on the quantitative and qualitative results, indicators were revised and refined before they were revisited in the second round.

For the analysis of round 2, the proportion of panellists rating an indicator with a score of 4 or higher on the five-point Likert scales was calculated. Consensus was defined as ≥75% of panellists rating an indicator as either 4 or 5, consistent with established Delphi threshold.[17] The purpose of this round was to confirm and consolidate agreement on the revised indicators, percentage agreement allowed consensus to be captured more directly than in the exploratory first round.[17,18] Indicators that received rating of 4 or 5 on both criteria from ≥75% of panellists were included in the final set. For these indicators, responses to the open-ended questions were analysed to identify suggestions for wording clarifications. For the indicators that did not meet the ≥75% agreement threshold, the qualitative responses were analysed using inductive coding by two independent researchers (IV and KB). They assessed whether the qualitative feedback supported the quantitative ratings and examined the nature of the comments. Indicators for which feedback emphasised limited relevance or usability, without suggestion for improvement, were discarded. Indicators for which panellists provided further modifications to improve the relevance or usability of the indicator, were revised accordingly. The revised indicators were presented to the panel in Round three for further evaluation.

For the analysis of the final round, the reassessed indicators were included in the final set if they received a rating of 4 or 5 on both criteria from ≥75% of panellists. The prioritisation of indicators was based on each panellists' ranking of the indicators within each domain. A weighted scoring system was applied. For example, in a domain with five indicators, the indicator ranked first received five points, the indicator ranked second received four points, third three points, fourth two points, and fifth one point. The total score for each indicator was calculated by summing the

points across all panellists. Within the domains, indicators were subsequently ranked from highest to lowest total score, with higher scores reflecting greater perceived importance for evaluating AIP reform policies.

Results

Panel composition

The Delphi study took place between November 2025 and April 2026. Initially, 92 participants were invited to complete the first questionnaire. A total of 81 participants completed the first round (88%, 81 of 92). Among these, 77 provided a complete response and 4 provided a partial response. A complete response was defined as completing all domains selected at the start of the questionnaire, a partial response indicated that not all selected domains were completed. The response rate in round 2 was 82% (66 of 81), of which 64 participants provided a complete response and 2 provided a partial response. The response rate in the third round was 79% (64 of 81), with 59 complete responses and 5 partial. All panellists who completed the first round were invited to participate in the subsequent rounds. Table 1 provides an overview of the panel composition.

The domains with the highest response rate were: informal caregiver burden (N=65), care availability (N=61), and the health of older adults (N=58), followed by person-centred care (N=51), quality of care (N=48), care utilisation (N=45), care satisfaction (N=41), and workforce (N=41). Domains with lower response rates were health inequalities (N=38), expenditures and financing (N=38), and care coverage (N=20).

Indicators

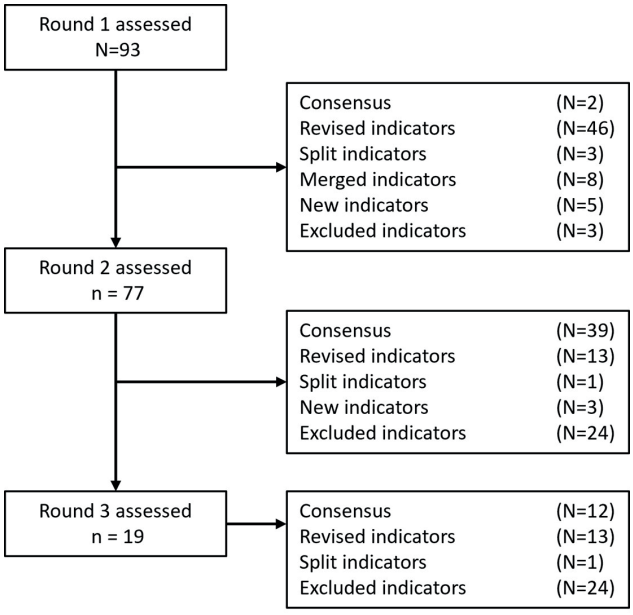
Figure 1 provides an overview of the indicator flow between rounds, illustrating that most indicators reached consensus in the second round. A detailed overview of how each indicator developed throughout the rounds can be found in the supplementary section.

Table 1. Panel composition

Characteristics		Round 1 n (%)	Round 2 n (%)	Round 3 n (%)
Sex	Male	22 (27.2%)	17 (25.8%)	19 (29.7%)
	Female	59 (72.8%)	49 (74.2%)	45 (70.3%)
Expert group *	Policymaker	20 (24.7%)	14 (21.2%)	16 (25%)
	Healthcare professional	25 (30.7%)	18 (27.3%)	16 (25%)
	Older adult (representative)	13 (16%)	12 (18.2%)	13 (20.3%)
	Informal caregiver (representative)	22 (27.2%)	15 (22.7%)	18 (28.1%)
	Researcher	21 (25.9%)	17 (25.8%)	16 (25%)
Years of working experience	less than 5 years	9 (11.1%)	7 (10.6%)	8 (12.5%)
	5 – 10 years	18 (22.2%)	13 (19.7%)	12 (18.7%)
	11 – 20 years	25 (30.9%)	20 (30.3%)	19 (29.7%)
	20 years and over	29 (35.8%)	26 (39.4%)	25 (39.1%)

*This information was collected in round 1 questionnaire, after which panellists were assigned a unique identification number for use in subsequent rounds. Panellists could select multiple answers, as some contributed from a double expert-perspective.

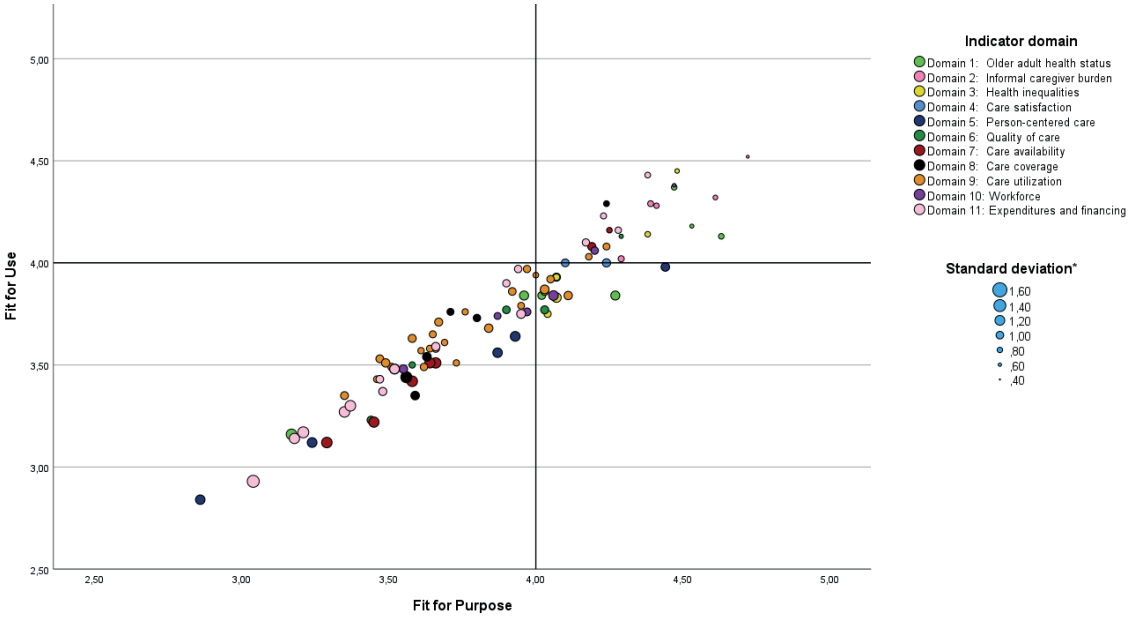
Figure 1. Indicator flowchart



Delphi round 1

In the first round the panellists assessed 93 indicators. Most indicators did not meet the pre-defined consensus criteria. Figure 2 represents this variability in the size of the dots, with larger dots indicating higher standard deviations, while smaller dots indicate more consistent scoring across panellists. Fit-for-purpose and fit-for-use showed a positive association, with higher scores on one criterion generally occurring alongside higher scores on the other. Notably, most indicators are in the lower-left quadrant, illustrating that they were not yet considered fit-for-purpose and fit-for-use. A detailed overview of the mean scores and standard deviations per indicator can be found in the supplementary material.

Figure 2. Scatter plot of mean scores on fit-for-purpose and fit-for-use after round 1.



Scatter plot of mean scores per indicators on fit-for-purpose and fit-for-use assessed in round 1, with a mean score of 4 or higher indicators considered fit-for-purpose and/or fit-for-use. The size of the dots represents the variability, with larger dots indicating a higher standard deviation, so more uncertainty within the panel about the scoring of the indicator. The standard deviations used for the graph is the combined mean standard deviation for the scores on fit-for-purpose and fit-for-use.

Two indicators reached consensus, with a score of 4 or higher for both criteria, illustrating that they were considered fit-for-purpose and fit-for-use within the policy context of AIP. The standard deviations reflected high or moderate consensus. the open-ended responses confirmed that partic-

ipants found the indicators actionable and besides minor wording suggestions, had no substantial comments. Table 2 provides a summary of the results for these two indicators.

Table 2. Indicators with consensus after Delphi round 1.

Indicator	Fit-for-purpose		Fit-for-use	
	Mean	Std. Dev.	Mean	Std. Dev.
Domain: Informal caregiver burden (N=65)				
9. Informal caregiver distress, measured using a standardised questionnaire (e.g. Zarit Burden interview or Caregiver Strain Index)	4.72	0.49	4.52	0.63
Domain: Health inequalities (N=41)				
14. Differences in the use of formal home care between income or migration groups	4.48	0.69	4.45	0.74

Mean and standard deviation of panellists' ratings on five-point Likert scales (1 = unimportant/not usable; 5 = very important/very usable). Round 1 consensus required mean ≥4 and SD ≤0.69 on both fit-for-purpose and fit-for-use. Domain N varied as panellists self-selected which domains to assess based on expertise.

The responses to the open-ended questions generated in-depth insights into indicators' relevance and usability. Panellists frequently reported that indicators were insufficiently specific to the Dutch policy context. In particular, confusion arose around concepts such as "long-term care", which can refer to different forms of care. Panellists indicated that stratification by type of care would improve interpretability and policy relevance. In the Dutch setting, this refers to the three major care acts related to care for older adults: 1) care provided under the 'Long-Term Care Act' (Wlz), including both institutional care (wlz-with residency) and care provided at home (wlz-without residency), 2) district nursing provided under the Zvw, and home care provided under the Wmo.[3]

Furthermore, participants emphasised that several indicators did not directly align with AIP policy objectives or were only meaningful when interpreted in relation to other indicators. Finally, conceptual overlap between indicators was reported. Panellists suggested separating indicators that capture different underlying concepts and combining those that refer to similar constructs. For example, the indicator "the percentage of older adults who postpones care due to costs or distance" was split into two separate indicators, to distinguish between either financial or geographical barriers, as panellists pointed out that these are different concepts with different policy implications. A detailed overview of the open-ended responses per indicator and resulting changes, is provided in the supplementary material.

Finally, five indicators were excluded in the first round due to low scores on both fit-for-purpose and fit-for-use. The qualitative comments indicated that indicators were considered less actionable, without sufficient direction for further refinement. Therefore, these indicators were not carried forward to the next round. In addition, five new indicators were included based on panellists' re-

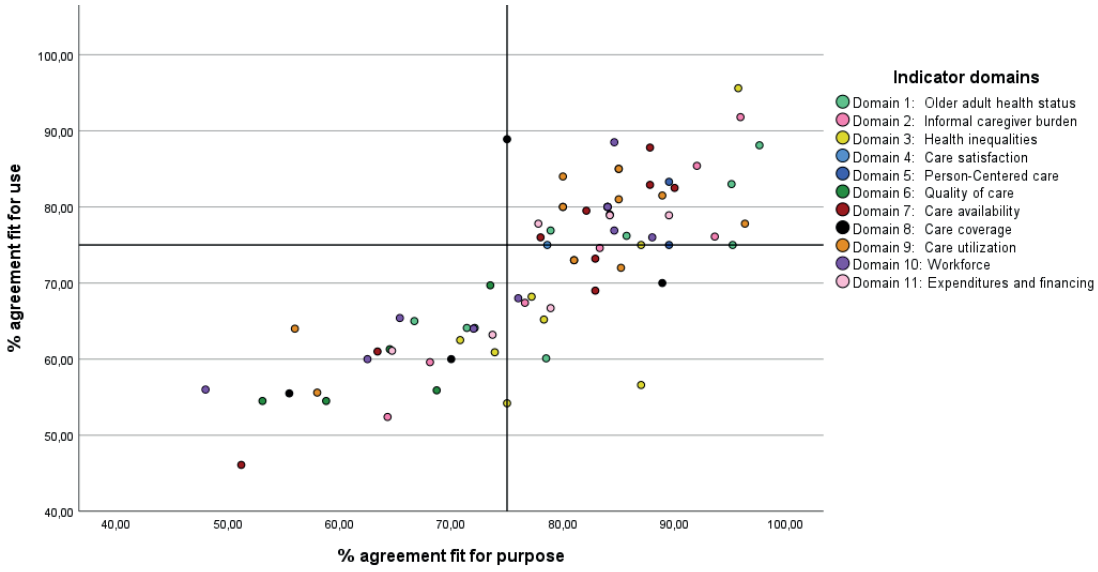
sponses to the questions about missing indicators. No new domains were proposed by the panellists.

Delphi round 2

In the second round the panellists assessed 77 indicators, Figure 3 provides a visual overview of the percentage agreement for the indicators. Consensus was reached on 39 indicators in the upper-right quadrant, illustrating that more than 75% of the panel rated them as fit-for-purpose and fit-for-use (score of 4 or higher on 5-point Likert scale). Table 3 provides an overview of indicators reaching consensus in round 2. Most indicators that did not meet the 75% agreement threshold were in the lower-left quadrant, indicating a lower agreement on both fit-for-purpose and fit-for-use. A smaller subset of indicators fell in the lower-right quadrant, indicating that indicators met the threshold for fit-for-purpose but not for fit-for-use. A detailed overview of the percentage agreement per indicator can be found in the supplementary section.

In the quality-of-care domain, none of the indicators reached the predefined consensus thresholds. Panellists found many of these indicators insufficiently specific to ageing-in-place. Furthermore, some indicators related to avoidable mortality and avoidable hospital admissions, sparked debate about the definition of "avoidable". Panellists highlighted that assessing avoidability in practice involves trade-offs between risk prevention and quality of life. For example, one panellist indicated that incidents such as falls may be considered preventable; however, in the context of ageing-in-place, individuals and care providers may consciously accept a higher level of risk to preserve autonomy and quality of life. Therefore, outcomes classified as negative within a clinical framework do not necessarily reflect poor-quality care in this context.

Figure 3. Scatterplot % agreement on fit-for-purpose and fit-for-use after round 2.



Scatter plot % agreement on fit-for-purpose and fit-for-use for the indicators assessed in Round 2. Consensus was defined as 75% of the panel rating the indicator both fit-for-purpose (score of 4 or higher on five-point Likert scale) and fit-for-use (score of 4 or higher on five-point Likert scale).

Table 3. Indicators with consensus after round 2.

Indicator	Fit-for-purpose % agreement	Fit-for-use % agreement
Domain: Health status of older adults (N=47)		
1. Perceived wellbeing of older adults, measured using a validated multidimensional quality-of-life scale	97.6%	88.1%
2. Mental wellbeing of older adults measured with a short, validated questionnaire (e.g. the Mental Health Inventory-5)	95.2%	75.0%
3. Functional abilities of older adults (Activities of Daily Living scores, care dependency scores) in relation to available care and living situation	95.1%	83.0%
7. Alignment between the preferred and actual location of death among older adults (hospital, nursing home, home, hospice)	78.9%	76.9%
NEW1. Prevalence of (moderate or severe) loneliness among older adults, separated by home-based and institutional settings	85.7%	76.2%
Domain: Informal caregiver burden (N=63)		
8. Informal care for home-dwelling older adults, measured by frequency of daily caregiving and average weekly hours	92.0%	85.4%
10. Wellbeing of informal caregivers, measured with a validated quality-of-life scale that captures both the positive effects and negative effects of caregiving	95.9%	91.8%
11. Sickness absence rate and frequency among working informal caregivers, supplemented with (if available) the proportion of absence episodes where caregiving is recorded as a (partial) cause	93.6%	76.0%
12. The ratio between formal care hours (Zvw*, Wmo†, Wlz‡) to informal care hours provided	83.3%	75.6%
Domain: Health inequalities (N=25)		
16a. Percentage of older adults who delay care due to costs (including deductibles and co-payments)	95.7%	95.6%
17a. Percentage of older adults experiencing a language barrier understanding or accessing care options	87.0%	75.0%
Domain: Care satisfaction (N=34)		
20. Perceived quality of care at the organisational level, among people with care needs in district nursing or long-term care (e.g. measured using the average scores of the Generiek Kompas: a national LTC outcomes instrument from Zorginstituut Nederland)	78.6%	75.0%
Domain: Person-centred care (N=40)		
22. The extent of shared decision-making about care and support options aimed at ageing-in-place, with active involvement of the client and informal caregiver (if relevant) by professionals (e.g. GPs, community nurses)	89.5%	83.3%
25. Percentage of older adults who, during a consultation with a healthcare professional (General practitioner, practice nurse, community nurse), feel that sufficient time is taken for them and that they are understood	89.5%	75.0%
Domain: Care availability (N=44)		
33. Number of persons on the waiting list for institutional long-term care, stratified by Wlz care profile	87.8%	82.9%
35a. Total number of places in institutional care facilities relative to the total number of older adults	78.0%	76.0%
36. Available home care hours per 100 older adults per region per year	82.1%	79.5%
38a. Number of people on the waiting list for home care services, stratified by type of service (Wlz– non-residential MPT§/VPT¶, district nursing Zvw, domestic support Wmo)	90.0%	82.5%
38b. Average waiting time (in days) for each type of home care: Wlz non-residential (MPT/VPT/PGBǁ), district nursing, and domestic support	87.8%	87.8%
Domain: Coverage of care (N=12)		
39. Number of care recipients with a Wlz indication, stratified by institutional care (with residence) and extramural care (VPT, MPT, PGB)	80.0%	80.0%
57. Number (and %) of users of publicly financed domestic support, broken down by income group	75.0%	88.9%

Table 3. Indicators with consensus after round 2.

Indicator	Fit-for-purpose % agreement	Fit-for-use % agreement
Domain: Care utilisation (N=30)		
47. Total number of clients receiving Wlz care with residence (care in an institutional setting)	84.0%	80.0%
48. Number of clients receiving Wlz care with residence as a percentage of the population aged ≥65 years	85.0%	85.0%
49. Median length of stay in Wlz care with residence, stratified by Wlz-care profile	84.0%	80.0%
51. Total number of home care hours provided per year, stratified by type of care (Zvw – district nursing, Wmo – support, Wlz care without residence such as VPT/MPT)	80.0%	80.0%
54. Number of home care clients as a percentage of the population aged ≥65 years, stratified by type of home care (Zvw – district nursing, Wlz care without residence, Wmo – support)	80.0%	84.0%
55. Average number of care interactions per client per day	84.0%	80.0%
59. Number of hospital admissions (per 1,000 inhabitants) for people ≥65 years, stratified by living situation (community-dwelling without care, community-dwelling with care [Wmo, Zvw, Wlz without residence], Wlz care with residence)	85.0%	85.0%
63. Number of acute hospital contacts (ER visits, emergency admissions) per 1,000 inhabitants aged ≥65 years, stratified by living situation (community-dwelling without care, community-dwelling with care [Wmo, Zvw, Wlz without residence], Wlz care with residence)	88.9%	81.5%
67. Percentage of hospital readmissions within 30 days after discharge among residents aged ≥ 65 years	85.0%	81.0%
70. Discharge destination for older adults aged ≥ 65 years (return home, primary care facility, geriatric rehabilitation, Wlz care with residence)	96.3%	77.8%
Domain: Workforce (N=27)		
73. Availability of staff providing home care, expressed as the annual number of active home care employees, stratified by: district nurses (level 4/5/bachelor's), care and support staff, and domestic support workers	88.0%	76.0%
76. Percentage of the population providing informal care to persons ≥65 years	84.6%	88.5%
NEW6. Percentage of care professionals (stratified by district nursing, Wmo home care, Wlz care without residence, Wlz care with residence) reporting high workload	84.6%	76.9%
NEW7. Percentage of care professionals who report that collaboration and information exchange between district nursing, GPs/practice nurses, the social domain, and institutional care functions well	84.0%	80.0%
Domain: Expenditures and financing (N=19)		
77. Total annual national expenditures on long-term care for older adults, stratified by care setting (Wlz care with residence, Wlz home care VPT/MPT/PGB, Zvw home care/district nursing, Wmo support)	77.8%	77.8%
81. Cost shift in total older adult care expenditures, expressed as the percentage of spending allocated to Wlz care with residence versus home care components (Wlz without residence, Zvw, Wmo)	84.2%	79.0%
84. Annual expenditures on elderly care, stratified by type of care (Wlz with residence, Wlz without residence, Zvw home care, Wmo support) per 1,000 inhabitants aged ≥65 years	84.2%	78.9%
91. Annual expenditures on GP care for adults aged ≥65 years	89.5%	78.9%

*% agreement = proportion of panellists who selected the domain and rated the indicator 4 or 5 on a five-point Likert scale. Domain N varied as panellists self-selected which domains to assess based on expertise. Consensus required ≥75% agreement on both fit-for-purpose and fit-for-use. * Zvw = Zorgverzekeringswet (Health Insurance Act); † Wmo = Wet maatschappelijke ondersteuning (Social Support Act); ‡ Wlz = Wet langdurige zorg (Long-Term Care Act); § MPT = Modulair Pakket Thuis (Modular Home Care Package); ¶ VPT = Volledig Pakket Thuis (Full Home Care Package); ‖ PGB = Persoonsgebonden Budget (Personal Care Budget).*

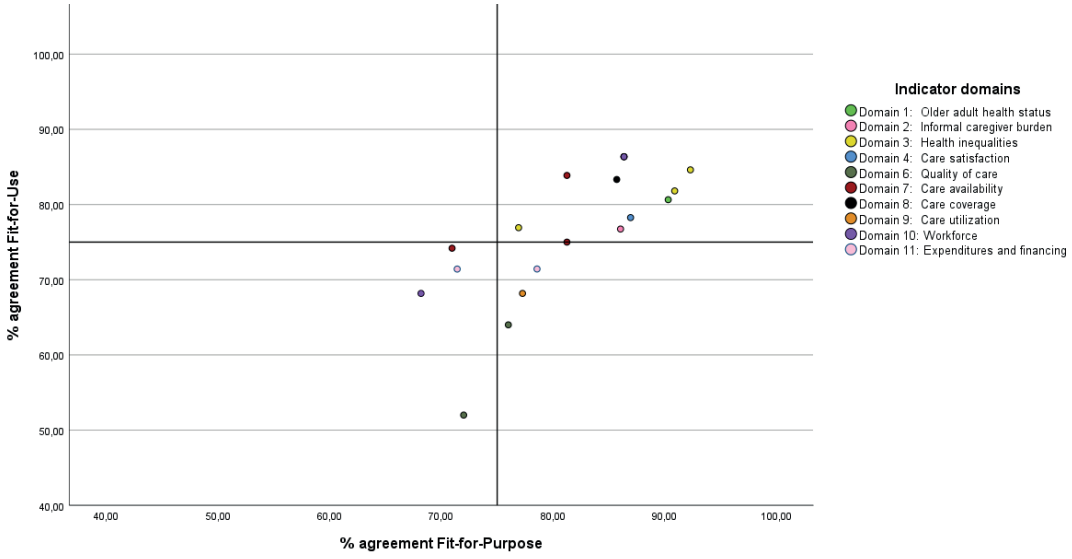
For the indicators that did not reach consensus, qualitative comments were analysed for potential further refinement. Special attention was given to indicators in the lower-right quadrant, which were considered relevant but scored lower on usability. For some indicators, panellists' feedback

provided concrete directions for refinement. For example, the indicator on available crisis places in institutionalised care facilities lacked an indication of the target population (i.e. older adults) and would be more meaningful if related to the size of the older adult population. However, for other indicators the qualitative feedback did not provide a clear argument for improvement. A detailed overview of the open-ended response for indicators that did not meet the % agreement threshold in round 2 can be found in the supplementary section.

Delphi round 3

Figure 4 provides a visual overview of the percentage agreement for the indicators assessed in round three. Panellists assessed 19 indicators, of which 12 reached consensus with more than 75% of the panel rating them as fit-for-purpose and fit-for-use (score of 4 or higher on a 5-point Likert scale). Table 4 provides an overview of indicators reaching consensus. For the indicators that did not reach consensus, about half were considered neither fit-for-purpose, nor fit-for-use, placing them in the lower-left quadrant. The remaining indicators were considered fit -for-purpose but not fit-for-use.

Figure 4. Scatterplot % agreement on fit-for-purpose and fit-for-use after round 3.



Scatter plot % agreement on fit-for-purpose and fit-for-use for the indicators assessed in round 3. Consensus was defined as 75% of the panel rating the indicator both fit-for-purpose (score of 4 or higher on five-point Likert scale) and fit-for-use (score of 4 or higher on five-point Likert scale).

Table 4. Indicators with consensus after round 3.

Indicator	Fit-for-purpose % agreement	Fit-for-use % agreement
Domain: Health status of older adults (N=43)		
6. Fall incidents among older adults, separated by home-based and institutional settings	90.3%	80.6%
Domain: Informal caregiver burden (N=63)		
13b. Percentage of informal caregivers reporting reduced working hours or contract hours due to caregiving duties	86.1%	76.7%
Domain: Health inequalities (N=25)		
15. Perceived accessibility and satisfaction with care (long-term care with residency, long-term care without residency, district nursing, and domestic support)	90.9%	81.8%
16b. Percentage of older adults (≥65 years) who delay care due to limited accessibility of care providers (e.g., distance, reachability, or mobility problems)	92.3%	84.6%
18. Self-reported health and functioning (such as mobility, daily activities, and energy), separated by socioeconomic status among older adults (≥65 years)	76.9%	76.9%
Domain: Care satisfaction (N=32)		
NEW4. Percentage of older adults living at home who report having unmet care needs	86.9%	78.3%
Domain: Care availability (N=44)		
35b. Number of available inpatient crisis beds for older adults, relative to the number of older adults	81.3%	83.9%
NEW5. Average waiting time for Wlz* care with residency (VVT)† for older adults, linked to urgency	81.3%	75.0%
Domain: Coverage of care (N=12)		
41. Percentage of older adults who purchase private (self-paid) care or support due to insufficient availability of public care, separated by income-groups	85.7%	83.3%
Domain: Care utilisation (N=34)		
68. Average length of hospital stay for older adults ≥65 years, separated by living situation (community-dwelling, Wlz care without residence, Wlz care with residence)	86.4%	86.4%
69. Number of older adults (≥65 years) occupying hospital beds unnecessarily ('bed blockers'), broken down by living situation (Wlz with residency, Wlz without residency, living at home with Wmo‡ support, living at home with Zvw§ support, living at home without care)	86.4%	86.4%
Domain: Workforce (N=30)		
NEW8. Collaboration between professional and informal care within district nursing and Wlz care with residency, expressed as the percentage of clients for whom structured coordination with informal caregivers and/or the informal network is documented	86.4%	86.4%

*% agreement = proportion of panellists who selected the domain and rated the indicator 4 or 5 on a five-point Likert scale. Domain N varied as panellists self-selected which domains to assess based on expertise. * Wlz = Wet langdurige zorg (Long-Term Care Act); † VVT = Verpleeg-, Verzorgings- en Thuiszorg (the Dutch nursing-home, residential-care, and home-care sector); ‡ Wmo = Wet maatschappelijke ondersteuning (Social Support Act); § Zvw = Zorgverzekeringswet (Health Insurance Act).*

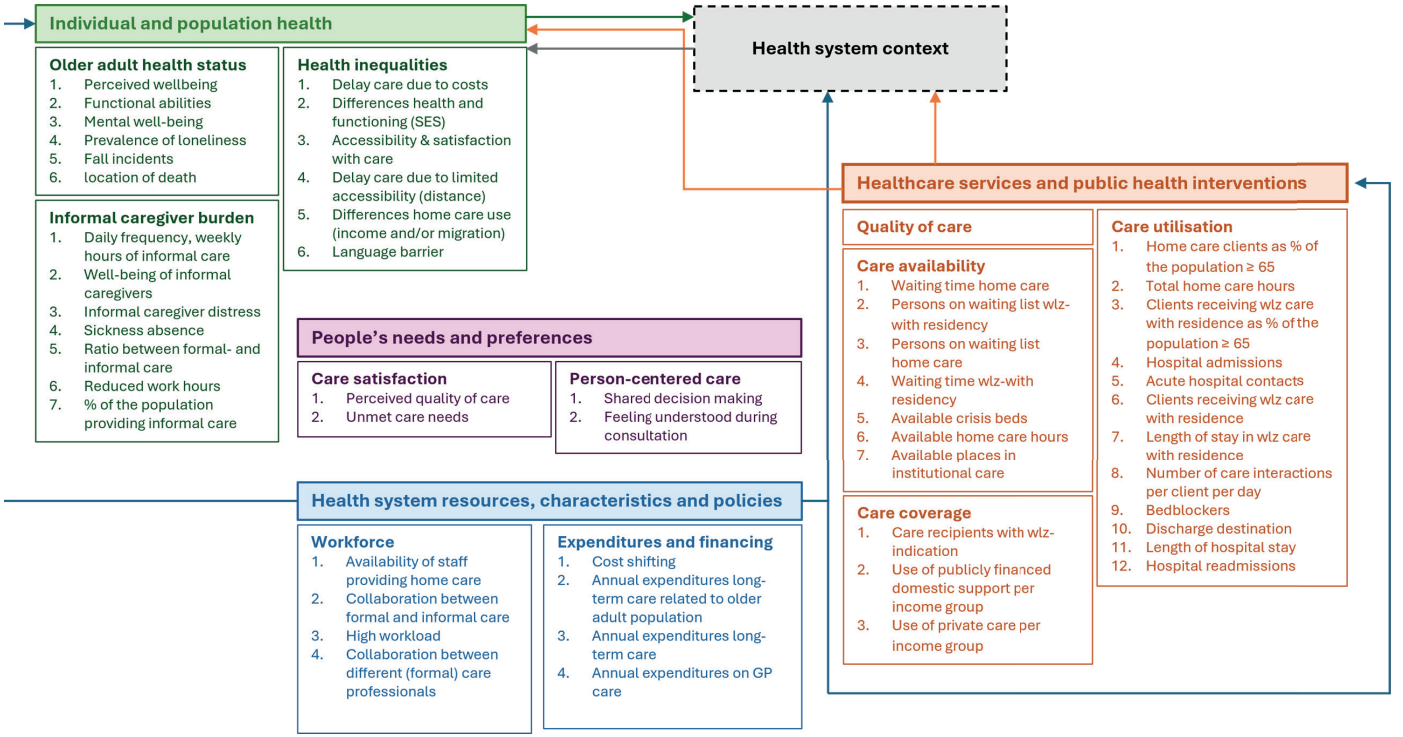
The final set of 53 actionable performance indicators is distributed across 10 domains. The results of the ranking exercise revealed which indicators should be prioritised per domain (See supplementary section for a detailed overview). Figure 5 provides a visual overview of the final framework, with indicators listed in order of importance per domain. The indicators are anchored in the OECD HSPA framework.[9] The framework recognises that the health system operates in a wider socio-economic, demographic, and environmental context, that influences and interacts with the health system.[9] This relationship is circular, as these macro-economic and environmental condi-

tions can facilitate or constrain policy implementation, and the health system in return also affects this wider context through its social and environmental impact.[9]

The framework starts with the outcomes of AIP reform policies, reflecting the consequences of these policies for the health and wellbeing of older adults and informal caregivers. The three outcome-oriented domains make up a large proportion of the indicators, measuring factors such as mental health, loneliness, the intensity of informal caregiving, and impacts on the working lives of caregivers. In addition, the health inequalities domain highlights disparities related to AIP including differences in care use across income groups, language barriers, and the postponement of care due to costs or distance. The framework emphasises that the system should be organised around people's needs and preferences. Whilst there are some indicators reflecting person-centred care and care satisfaction, focusing on unmet care needs and perceived quality of care, it is important to emphasize that indicators capturing people's needs and preferences are limited. The panelists mentioned that this domain might benefit from more in-depth information in addition to measurable performance indicators.

The section on health system resources and characteristics covers the structural element of the healthcare system. The domain of workforce provides information about the availability and working conditions of personnel working in long-term care. The expenditures and financing domain includes indicators related to the expenditure on long-term care and costs shifting between institutionalised care and home and community-based care. Finally, healthcare services and public health interventions reflect the activities that fall under healthcare, including access and coverage, with quality of care treated as a critical objective that cuts across service delivery. The domain of care utilisation contains the largest number of indicators, measuring the use of home and community-based care, and the demand for institutional long-term care and hospital care. This domain also measures how effectively the healthcare system works and how older adults move between different care setting, with indicators looking at discharge destination, bed blockers, length of stay, or hospital readmission. The domain of care availability focuses on the extent to which care services are accessible, including indicators such as waiting times and waiting list, as well as the availability of crisis beds and places in institutional care.

Figure 5. The final framework



Final framework with 53 actionable performance indicators that can be used for the evaluation of AIP reform policies in the Netherlands. The indicators reached consensus in the three-round Delphi study and are anchored in the OECD HSPA framework. *Quality of care domain did not contain any actionable indicators

Discussion

In this Delphi study, a diverse panel of stakeholders including policymakers, researchers, healthcare professionals, older adults and informal caregivers, reached consensus on 53 actionable performance indicators for evaluating AIP reforms in the Netherlands. Outcome-oriented domains (older adult health, caregiver burden, and inequalities) accounted for a large share of the final set, capturing wellbeing, mental health, loneliness, and functional ability; caregiver distress, caregiver wellbeing; and inequalities in care use, language barriers, and care delays. Quality of care was the only domain to yield no consensus. Although two person-centred care indicators reached consensus (shared decision-making and feeling adequately understood by professionals), panellists considered indicators in this domain too generic to capture heterogeneity in preferences across individuals.

Our findings extend existing AIP performance assessment in several ways. A recent review of the international literature found that reported indicators clustered around structural and process domains, such as expenditures and utilisation, with indicators of older adults' health, caregiver burden, and equity markedly underrepresented.[12] Furthermore, generic HSPA frameworks, including the OECD's framework, name people-centredness and equity as system goals but provide few indicators specific to AIP.[9] Quality-of-life outcomes for older adults AIP, although considered important, are rarely measured systematically.[19] Several indicators in our final set begin to close this gap, as outcome-oriented indicators account for a large share. Reductions in caregiver working hours and caregiving-related sickness absence make visible the occupational and health consequences for caregivers.[10] Indicators of formal-informal care collaboration address an emerging priority in integrated care delivery that remains poorly measured.[20,21] The stratified equality indicators, care delays by cost, distance, or language, and differences in formal home care use across income and migration groups, address a gap documented in international AIP research[10,11] but not reflected in comparable indicator sets.[22]

Methodologically, the present study extends prior Delphi-based indicator work in adjacent fields. Consensus frameworks developed for age-friendly communities[15] and for integrated care for older adults[23] have focused on system-level features and community design, rather than on the performance of national policy reform. Comparable indicator sets for home-care quality have similarly concentrated on service delivery and process measures.[22] Our framework differs in its anchoring within a national HSPA structure and its explicit orientation towards reform evaluation, integrating outcome- and equity-focused indicators alongside structural and process measures. Together, these additions reorient AIP performance measurement towards outcomes for older adults and

caregivers and towards the equity dimensions of care access, rather than towards the system inputs and activities that have historically dominated.

Quality of care is conventionally measured through indicators such as preventable mortality and avoidable hospital admissions[9], but these were subject to considerable debate in our panel. Experts highlighted that, in care for older adults, there is often a trade-off between risk prevention and quality of life, where greater risk may be accepted to preserve autonomy and wellbeing.[24] For example, falls may be classified as preventable, but in the context of AIP they do not necessarily reflect poor quality of care if maintaining independence is prioritised. These findings may reflect a broader shift in Dutch long-term care policy and practice, in which quality measurements based on standardised population-level outcomes is increasingly complemented by approaches that account for individual patient preferences, lived experiences, and the care setting.[25] This is consistent with international moves towards person-centred and values-based care.[26] Furthermore, a recent review of home-care quality indicators identified service delivery (e.g. waiting times and type of services), outcomes for older adults (e.g. wellbeing, quality of life), and person-centredness as the most commonly used domains.[22] Each of these is reflected somewhere in our final set, but distributed across multiple domains rather than concentrated within quality of care. This suggests that quality of care in the context of AIP may be best understood as a cross-cutting concept embedded across multiple domains.

Although person-centredness is recognised as a core system objective, panellists considered most existing indicators too generic to capture the diversity and changing nature of preferences in AIP contexts. Qualitative approaches and patient-reported measures may therefore complement quantitative system-level indicators.

Strengths and limitations

This Delphi study had several strengths. The expert panel was diverse and achieved high retention across all three rounds, and the inclusion of older adults and informal caregivers alongside policymakers, researchers, and healthcare professionals brought lived-experience perspectives directly into the consensus process. The combined input of these stakeholders provides structured guidance on indicators considered important across different perspectives.

Several limitations should be noted. First, eligibility required online questionnaire access and Dutch-language proficiency, which may have underrepresented the most digitally excluded older adults, a group particularly relevant to the equity domain included in the evaluation framework. Second, panellists could self-select which domains to assess based on their expertise. This self-selection was deliberate and ensured that each indicator was rated by panellists with relevant knowl-

edge, but it also means that consensus thresholds in lower-response domains rested on smaller subsets of the panel; agreement on care coverage indicators, in particular, reflects a narrower base should be interpreted accordingly. Finally, the resulting indicator set reflects the agreement of the panel that was assembled, a different panel composition could have produced different consensus outcomes.[27] Accordingly, the exclusion of indicators should not be taken as evidence that they are less valid or important, but as a reflection that sufficient agreement could not be achieved among this diverse group of experts.

Implications

This study provides a stakeholder-validated indicator set that can inform several next steps in research and policy. First, pilot data collection is needed for indicators not currently captured in Dutch monitoring, including caregiver working-hour reductions, cost-shifting between long-term care schemes, and formal-informal care collaboration.[21] Second, the indicator set can support pathway analysis by linking system inputs (workforce, expenditures), with service delivery and performance dimensions (access, quality, user experience), and final outcomes (older adult health, informal caregiver wellbeing, equity), an approach central to international HSPA.[28] Third, the growing emphasis on context and person-centredness in long-term care makes it harder to assess quality of care through standardised population-level indicators. Future work should therefore develop mixed-methods evaluation approaches that combine quantitative system-level performance measurement with methods capable of capturing individual preferences and experiences that vary across individuals and change over time.[29,30] Finally, AIP is cross-sectoral and extends beyond healthcare; future evaluation frameworks should incorporate housing, age-friendly environments, transport, and digital inclusion.[31-33]

For Dutch policymakers, our results provide useful input on how to better evaluate and monitor the effects of current and future AIP policies. A first evaluation of the 2015 long-term care reform[34] identified several knowledge gaps, including limited insight into the (health) effects of AIP, trends in the use of care and social support, and unmet care needs. The policy push towards AIP continued, as increased use of care at home is a crucial element in the agreement on care for older people signed by the government and societal partners in 2025.[4] While some indicators related to AIP are being monitored (e.g. long-term care utilisation or costs)[35], current monitoring is largely driven by data availability rather than by a comprehensive evaluation framework. Our overview identifies remaining blind spots, in particular on broader wellbeing of both older adults themselves and their caregivers.

Although the indicator set is specific to the Dutch system, the underlying domains are likely transferable across high-income countries. The structural specifications (e.g. the distribution of expenditures across Wlz, Zvw, and Wmo) are tied to the Dutch institutional context, but the properties they measure namely, cost distribution, the relationship between living arrangements and hospital admissions, are relevant to long-term care evaluation internationally. The consensus-building methodology itself is reproducible: other countries undertaking similar reforms could apply the Delphi approach with stakeholders representing their own institutional structures.

Conclusion

A diverse panel of Dutch AIP experts reached consensus on 53 actionable performance indicators across 10 domains, anchored in the HSPA framework. The set is notable for its emphasis on outcome-oriented indicators of wellbeing, informal caregiver burden, and equality, and for the absence of consensus on conventional quality-of-care metrics. Evaluating AIP reforms requires broader attention to wellbeing, caregiver burden, inequalities, and person-centred outcomes. The consensus-based methodology may support development of context-specific AIP evaluation frameworks in other countries.

Declaration of interests

The author declares that there are no conflicts of interest regarding the publication of this paper.

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Supplementary material 1. CREDES Reporting Checklist

Conducting and REporting of DElphi Studies

Reference: Jünger S, Payne SA, Brine J, Radbruch L, Brearley SG. Guidance on Conducting and REporting DElphi Studies (CREDES) in palliative care: Recommendations based on a methodological systematic review. *Palliative Medicine* 2017;31(8):684–706. doi:10.1177/0269216317690685.

#	Reporting item	Description (verbatim from Jünger et al., 2017)	Page / section in manuscript
Rationale for the choice of the Delphi technique			
1	**Justification**	The choice of the Delphi technique as a method of systematically collating expert consultation and building consensus needs to be well justified. When selecting the method to answer a particular research question, it is important to keep in mind its constructivist nature.	4
Planning and design			
2	**Planning and process**	The Delphi technique is a flexible method and can be adjusted to the respective research aims and purposes. Any modifications should be justified by a rationale and be applied systematically and rigorously.	4--6
3	**Definition of consensus**	Unless not reasonable due to the explorative nature of the study, an a priori criterion for consensus should be defined. This includes a clear and transparent guide for action on (a) how to proceed with certain items or topics in the next survey round, (b) the required threshold to terminate the Delphi process, and (c) procedures to be followed when consensus is (not) reached after one or more iterations.	5-6
Study conduct			
4	**Informational input**	All material provided to the expert panel at the outset of the project and throughout the Delphi process should be carefully reviewed and piloted in advance in order to examine the effect on experts' judgements and to prevent bias.	4-5, supplementary material
5	**Prevention of bias**	Researchers need to take measures to avoid directly or indirectly influencing the experts' judgements. If one or more members of the research team have a conflict of interest, entrusting an independent researcher with the main coordination of the Delphi study is advisable.	4-6
6	**Interpretation and processing of results**	Consensus does not necessarily imply the 'correct' answer or judgement; (non)consensus and stable disagreement provide informative insights and highlight differences in perspectives concerning the topic in question.	5-6
7	**External validation**	It is recommended to have the final draft of the resulting guidance reviewed and approved by an external board or authority before publication and dissemination.	4
Reporting			
8	**Purpose and rationale**	The purpose of the study should be clearly defined and demonstrate the appropriateness of the use of the Delphi technique as a method to achieve the research aim. A rationale for the choice of the Delphi technique as the most suitable method needs to be provided.	4
9	**Expert panel**	Criteria for the selection of experts and transparent information on recruitment of the expert panel, sociodemographic details including information on expertise regarding the topic in question, (non)response, and response rates over the ongoing iterations should be reported.	4, 7

#	Reporting item	Description (verbatim from Jünger et al., 2017)	Page / section in manuscript
10	**Description of the methods**	The methods employed need to be comprehensible; this includes information on preparatory steps (How was available evidence on the topic in question synthesised?), piloting of material and survey instruments, design of the survey instrument(s), the number and design of survey rounds, methods of data analysis, processing and synthesis of experts' responses to inform the subsequent survey round, and methodological decisions taken by the research team throughout the process.	4-5
11	**Procedure**	Flow chart to illustrate the stages of the Delphi process, including a preparatory phase, the actual 'Delphi rounds', interim steps of data processing and analysis, and concluding steps.	7, 8
12	**Definition and attainment of consensus**	It needs to be comprehensible to the reader how consensus was achieved throughout the process, including strategies to deal with non-consensus.	5, 6
13	**Results**	Reporting of results for each round separately is highly advisable in order to make the evolving of consensus over the rounds transparent. This includes figures showing the average group response, changes between rounds, as well as any modifications of the survey instrument such as deletion, addition or modification of survey items based on previous rounds.	7-15, Supplementary material
14	**Discussion of limitations**	Reporting should include a critical reflection of potential limitations and their impact on the resulting guidance.	17
15	**Adequacy of conclusions**	The conclusions should adequately reflect the outcomes of the Delphi study with a view to the scope and applicability of the resulting practice guidance.	18
16	**Publication and dissemination**	The resulting guidance should be clearly identifiable from the publication, including recommendations for transfer into practice and implementation. If the publication does not allow for a detailed presentation of either the resulting practice guidance or the methodological features of the applied Delphi technique, or both, reference to a more detailed presentation elsewhere should be made (e.g. availability of the full guideline from the authors or online; publication of a separate paper reporting on methodological details and particularities of the process, e.g. persistent disagreement and controversy on certain issues). A dissemination plan should include endorsement of the guidance by professional associations and health care authorities to facilitate implementation.	17, 18

Note. The CREDES checklist was developed by Jünger and colleagues (2017) in the context of palliative care research, but its 16 items are widely applied as a general reporting standard for Delphi studies in health-services and clinical research. The full guidance, including the methodological systematic review on which the recommendations are based, is openly available at https://doi.org/10.1177/0269216317690685.

Supplementary material 2. Initial indicators mapped to the OECD HSPA framework

Note: This first list represents the initial pool of indicators identified in the literature review and grouped according to the OECD Health System Performance Assessment (HSPA) framework. These indicators were the input to Round 1 of the Delphi study; many were subsequently revised, merged, split, or excluded across the three rounds (see Supplementary materials 5–10).

Individual and population health
HSPA framework domain

Indicators related to health status of older adults:

1. Wellbeing of older adults, measured in quality-of-life scales
2. Mental health status of older adults (measured in validated questionnaires, e.g. the Mental Health Inventory -5 scale)
3. Functional abilities of older adults (Activities of Daily Living scores, care dependency scores)
4. Cognitive functioning (Mini-Mental State Examination scores)
5. Disease-related factors (e.g. urinary tract infections, respiratory conditions, pressure ulcers, pain)
6. Mortality rates
7. Location of death (hospital, nursing home, home, other)

Indicators related to informal caregiver burden:

8. Frequency of daily caregiving and the average weekly hours of informal care
9. Informal caregiver distress, measured using a standardised questionnaire (e.g. Zarit Burden interview or Caregiver Strain Index)
10. General health of informal caregivers, measured in quality-of-life scales
11. Probability of sickness absence among informal caregivers
12. Effect of changes in home care payments on informal caregiver hours
13. Effect of informal caregiving on labour supply and weekly hours of labour participation

Indicators related to health inequalities:

14. Differences in the use of formal home care between income or migration groups
15. Differences in client satisfaction with long-term care between income or migration groups
16. Percentage of older adults who postpone care due to costs or distance
17. Percentage of older adults experiencing cultural or linguistic barriers in interactions with healthcare providers
18. Differences in self-reported health, disaggregated by socioeconomic status
19. Differences in mortality rates between regions and income groups

People's needs and preferences

HSPA framework domain

Indicators related to care satisfaction:

20. Client satisfaction with received long-term care services, measured on a 0-10 scale (or Likert scale)
21. Client satisfaction with received home care services, measured on a 0-10 scale (or Likert scale)

Indicators related to person-centred care:

22. Extent to which physicians actively involve patients in decisions about care and treatment
23. Percentage of older adults who made an appointment with a healthcare practitioner online
24. Percentage of older adults who sought health-related information online
25. Extent to which patients feel that physicians spend sufficient time with them during consultations
26. Extent to which patients perceive physicians' explanations as clear and easy to understand

Healthcare services and public health interventions: quality

HSPA framework domain

Indicators related to quality of care:

27. Avoidable mortality among the population ≥ 65 years old
28. Avoidable hospital admissions due to chronic diseases (e.g. COPD, diabetes) among the population aged ≥ 65 years
29. Percentage of chronic opioid users among the population aged ≥ 65 years
30. Older patients with prescriptions for benzodiazepines or similar medications
31. Perceptions of healthcare professionals regarding patient safety culture, measured using a standardised questionnaire (e.g. Hospital Survey on Patient Safety Culture)

Healthcare services and public health interventions: access and coverage

HSPA framework domain

Indicators related to care availability:

32. Total number of long-term care (LTC) facilities
33. Total number of LTC facility service providers
34. Total number of LTC facility openings and closures
35. Total number of LTC facility beds
36. Total number of different national home care programs
37. Total number of home care services providers
38. Total number of people on waiting lists of national home care programs

Indicators related to coverage of care:

39. Annual number of LTC beneficiaries under the public LTC insurance
40. LTC beneficiaries under the public LTC insurance as percentage of the population ≥ 65 years old
41. Annual co-payments as percentage of the total national LTC expenditures
42. Number of people paying out-of-pocket contributions for private care
43. Annual per capita LTC co-payments
44. Marketisation rate of home care service providers

Indicators related to care utilisation:

45. Number of enrolments in specific LTC programs
46. Percentage of public formal LTC utilisation
47. Total number of LTC facility users
48. Number of LTC facility users as a percentage of the population ≥ 65 years old
49. Number of new placements in LTC facilities
50. Total number of resident days in LTC facilities
51. Annual total number of home care users
52. Number of home care users as a percentage of the population ≥ 65 years old
53. Total number of home care visits
54. Annual average number of home care visits per client
55. Annual number of unique claims of home support services
56. Service utilisation specified in service type (in-home, day care, outpatient care)
57. Total amount of minutes or hours home care provided
58. Annual home care hours per capita
59. Annual number of hospital visits of the older population ≥ 65 years old
60. Hospitalisations as a percentage of the older population ≥ 65 years old
61. Number of hospitalisations amongst LTC facility residents
62. Annual number of hospitalisations among home care users
63. Annual number of emergency department visits for adults ≥ 65 years old
64. Annual number of geriatric hospital visits
65. Annual number of specialists care visits for adults ≥ 65 years old
66. National rate of acute hospitalisations per month
67. Hospital readmission rates
68. Average length of hospital stay
69. Number of bed blockers
70. Discharge destination after hospital stay (home, long-term care facility, other)

Healthy system resources, characteristics and policies: expenditures and financing

HSPA framework domain

Indicators related to expenditures and financing:

71. Annual national LTC expenditures
72. Annual LTC expenditures as percentage of the GDP
73. Annual LTC expenditures as percentage of the total healthcare budget
74. Annual LTC expenditures per capita
75. Annual sum of LTC facility expenditures
76. Average annual expenditures per LTC facility bed
77. Annual per capita expenditures on LTC facility care
78. Annual expenditures on home and community-based care programs
79. Annual expenditures on home and community-based care as a percentage of the total LTC expenditures
80. Annual home and community-based care expenditures on the provincial level
81. Annual average per capita expenditures on home and community-based care
82. Cost-shifting between LTC facilities and home and community-based care on the national level
83. Annual municipal sum of primary care rehabilitation service expenditures
84. Annual per capita expenditures on general practitioners care
85. Total annual hospital expenditures
86. Annual per capita expenditures on specialist care
87. Annual per capita expenditures on specialist rehabilitation

Healthy system resources, characteristics and policies: workforce

HSPA framework domain

Indicators related to workforce:

88. Annual number of LTC facility nurses
89. LTC staff casualization and turnover
90. Annual number of registered home care nurses and home help aids
91. Annual number of social workers
92. Annual number of physical therapist
93. Prevalence of informal caregivers

Supplementary material 3. Participant information letter

Note: This is the participant information letter (translated from Dutch) provided to members of the expert panel before they were asked to give consent to take part in the Delphi study. The letter was reviewed by the non-WMO research ethics committee of Amsterdam UMC (Wet medisch-wetenschappelijk onderzoek met mensen [WMO], Medical Research Involving Human Subjects Act); the committee determined that the study did not fall within the scope of the WMO.

Dear reader,

With this information letter, we would like to ask whether you would like to take part in a scientific study aimed at improving policy on care for older adults in the Netherlands. In this study, together with experts and stakeholders, we are mapping out which performance indicators are most suitable for measuring the effects of reforms in long-term care for older adults.

Participation is voluntary. This letter explains what kind of study this is and what it would mean for you if you decide to take part.

If you are interested:

Please read this letter carefully.

Feel free to ask questions to the researcher who has provided you with this information.

Whether or not you take part has no consequences for your treatment in the hospital. Would you like to take part? Then please complete the form attached as an appendix.

1. General information

The pressure on long-term care in the Netherlands is increasing as a result of population ageing and staff shortages. To relieve this pressure, government policy is firmly oriented towards enabling people to live independently at home for longer, making greater use of informal care, and reducing the use of institutional care. However, there is still little consensus on how the effects of this policy can best be evaluated. With our research, we therefore aim to contribute to the development of performance indicators that can be used to assess policy aimed at independent living at home for longer.

The study is conducted by Amsterdam UMC.

2. What is the aim of the study?

The aim of this Delphi study is to reach consensus, together with you, as an expert or stakeholder, on which of these indicators are genuinely suitable and applicable within the Dutch context.

3. What happens if you take part in the study?

The study consists of three rounds, in each of which you will receive an online questionnaire. Each round takes approximately 20–30 minutes to complete. You will have three weeks per round to complete the questionnaire at a time that suits you.

Round 1: Assessment of the indicators in terms of relevance and usability. You can also indicate whether you feel any indicators are missing.

Round 2: Reassessment of the indicators based on aggregated feedback from Round 1, with the aim of reaching consensus.

Round 3: Prioritisation of the remaining indicators in terms of importance.

4. What does taking part mean for you?

You will not derive any direct benefit from taking part in this study yourself.

Your participation can, however, contribute to the development of a broadly supported set of performance indicators. These indicators may in future be used by policymakers and government bodies to assess whether the reforms in care for older adults are actually having an effect — both for older adults themselves and for society.

5. If you do not wish to take part, or wish to withdraw

Participation in the study is entirely voluntary. You only sign the consent form if you wish to take part.

You may withdraw your consent at any time. We do ask that you notify the researcher as soon as possible if you do so. You are not required to give a reason for withdrawing your consent.

6. What do we do with your data?

To protect your privacy, we assign your data a code. Only this code will appear on your data. Information that directly identifies you will then no longer be used. The key to the code is kept in a secure location within our organisation. Only the researcher and members of the research team know which code you have. Whenever we process or share your data, we use only this code. In reports and publications about the study, no one will be able to trace the information back to you.

How long do we keep your data? We retain your data for 10 years within our organisation.

Would you like to know more about your privacy? If you would like to know more about your rights regarding the processing of personal data, please consult the website of the Dutch Data Protection Authority.

Do you have questions about your rights? Please contact the person responsible for processing your personal data. For your study, this is the corresponding author of the main manuscript.

If you have any complaints regarding your privacy, we recommend that you first discuss them with the research team. You may also contact the Data Protection Officer of Amsterdam UMC. Alternatively, you may file a complaint with the Dutch Data Protection Authority.

7. Do you have a complaint?

If you have a complaint, please discuss it with the researcher. If you would prefer not to do so, you may contact the staff at Patient Services (*Patiëntenservice Zorgsupport*).

For the AMC location: Patient Services (*Patiëntenservice Zorgsupport*)

Telephone: 020-566 6440

For substantive questions, you can contact the researchers. Thank you for your attention.

Supplementary material 4. Flowchart of indicators per Delphi round

Note: This flowchart summarises the trajectory of every indicator across the three Delphi rounds — whether consensus was reached, whether the indicator was revised, merged with another indicator, split into multiple indicators, or excluded from further consideration. "NEW" indicators are those proposed by panellists during Round 1 or Round 2 and added to subsequent rounds.

Nr.	Indicator	Round 1.	Round 2.	Round 3.
Domain: Health status of older adults				
1.	Well-being older adults	No consensus, revised for next round	Reached consensus	
2.	Mental well-being older adults	No consensus, revised for next round	Reached consensus	
3.	Functional abilities older adults	No consensus, revised for next round	Reached consensus	
4.	Cognitive functioning older adults	No consensus, revised for next round	No consensus, excluded from further rounds	
5.	Prevalence disease-related factors	No consensus, revised for next round	No consensus, excluded from further rounds	
6.	Mortality rates	No consensus, revised, focus on fall-incidents	No consensus, revised for next round	Reached consensus
7.	Location of death	No consensus, revised for next round	Reached consensus	
NEW1.	Control over own life	New indicator proposed in round 1	No consensus, excluded from further rounds	
NEW2.	Loneliness	New indicator proposed in round 1	Reached consensus	
Domain: Informal caregiver burden				
8.	Frequency of informal caregiving	No consensus, revised for next round	Reached consensus	
9.	Informal caregiver distress	Reached consensus		
10.	Well-being informal caregiver	No consensus, revised for next round	Reached consensus	
11.	Sickness absence	No consensus, revised for next round	Reached consensus	
12.	Ratio formal/informal care	No consensus, revised for next round	Reached consensus	
13.	Labour supply and participation	No consensus, split in two indicators	13a. Average weekly working hours: no consensus, excluded from further rounds	
			13b. Reduces working hours: no consensus revised for next round	Reached consensus
NEW3.	Shared informal caregiving	New indicator proposed in round 1	No consensus, excluded from further rounds	
Domain: Health inequalities				
14.	Differences home care use (income and/or migration)	Reached consensus		
15.	Satisfaction with care	No consensus, revised for next round	No consensus, revised for next round	Reached consensus

Nr.	Indicator	Round 1.	Round 2.	Round 3.
16.	Delay care due to costs or distance	No consensus, split in two indicators	16a. Delay care costs: reached consensus	
			16b. Delay care distance: no consensus, revised for next round	Reached consensus
17.	Cultural or language barrier	No consensus, split in two indicators	17a. Language barrier: reached consensus	
			17b. Cultural barrier: No consensus, excluded from further rounds	
18.	Differences health and functioning (Socio-Economic status)	No consensus, revised for next round	No consensus, revised for next round	Reached consensus
19.	Differences Mortality rates (regions/income)	No consensus, revised for next round	No consensus, excluded from further rounds	
Domain: Care satisfaction				
20.	Client satisfaction institutional care	No consensus, indicators merged	20. Client satisfaction organisation level: reached consensus	
21.	Client satisfaction home care			
NEW4.	Unmet care needs		New indicator, proposed in round 2	Reached consensus
Domain: Person-centred care				
22.	Shared decision making	No consensus, revised for next round	Reached consensus	
23.	Online appointment making	No consensus, revised for next round & moved to health inequalities domain	Digital accessibility: No consensus, excluded from further rounds	
24.	Seeking health-related information online	No consensus, excluded from further rounds		
25.	Sufficient time during consultation	No consensus, indicators merged	25. Sufficient time & feeling understood: reached consensus	
26.	Feeling understood during consultation			
Domain: Quality of care				
27.	Avoidable mortality	No consensus, revised for next round	No consensus, excluded from further rounds	
28.	Avoidable hospital admission	No consensus, revised for next round	No consensus, excluded from further rounds	
29.	Chronic opioid users	No consensus, revised for next round	No consensus, excluded from further rounds	
30.	Prescriptions of benzodiazepines and similar medications	No consensus, revised for next round	No consensus, excluded from further rounds	
31.	Perceptions of healthcare professionals regarding patient safety culture	No consensus, revised for next round	No consensus, split in two indicators	31a. Perception home care professionals: no consensus 31b. Perception of professionals institutionalised care: no consensus
Domain: Care availability				
32.	Long-term care (LTC) facilities	No consensus, revised for next round, focus on regional availability	No consensus, revised for next round	

Nr.	Indicator	Round 1.	Round 2.	Round 3.
33.	LTC facility service providers	No consensus, revised for next round, focus on persons on waiting list institutional long-term care	Reached consensus	
34.	LTC facility openings and closures	No consensus, revised for next round, focus on public/ private LTC institutions	No consensus, excluded from further rounds	
35.	LTC facility beds	No consensus, split in two indicators	35a. Places in institutional LTC care relative to older adults: reached consensus	
			35b. available crisis beds in LTC institutions: no consensus	Reached consensus
36.	Different national home care programs	No consensus, revised for next round, focus on available home care hours	Reached consensus	
37.	Home care services providers	No consensus, revised for next round, focus on average travel time	No consensus, excluded from further rounds	
38.	People on waiting lists of national home care programs	No consensus, split in two indicators	38a. people on waiting list: reached consensus 38b. average waiting time: reached consensus	
NEW5	Average waiting time for long-term care under the Wet langdurige zorg (Wlz) with residency (LTC facility placement)		New indicator, proposed in round 2	Reached consensus
Domain: Coverage of care				
39.	LTC beneficiaries under the public LTC insurance	No consensus, indicators merged	39. Care recipients with a LTC *(Wlz)* indication: Reached consensus	
40.	LTC beneficiaries under the public LTC insurance as % population ≥ 65			
41.	Out-of-pocket contributions for private care	No consensus, revised for next round	No consensus, revised for next round	Reached consensus
42.	Co-payments as percentage of the total national LTC expenditures	No consensus, indicators merged	40. Co-payments different types of care: no consensus, excluded from further rounds	
43.	Per capita LTC co-payments			
44.	Marketisation rate of home care service providers	No consensus, revised for next round, focus on collaboration	No consensus, excluded from further rounds	
Domain: Care utilisation				
45.	Enrolments in specific LTC programs	No consensus, excluded from further rounds		
46.	Public formal LTC utilisation	No consensus, revised for next round, focus on ratio of formal/informal care	Overlap with indicator informal caregiver domain, indicator excluded	
47.	LTC facility users	No consensus, revised for next round	Reached consensus	
48.	LTC facility users as a % ≥ 65 years	No consensus, revised for next round	Reached consensus	

Nr.	Indicator	Round 1.	Round 2.	Round 3.
49.	New placements in LTC facilities	No consensus, indicators merged	49. length of stay in Wlz care with residence: reached consensus	
50.	Resident days in LTC facilities			
51.	Number of home care users	No consensus, indicators merged	51. home care hours per type of care: reached consensus	
52.	Home care visits			
53.	Minutes or hours home care provided			
54.	Home care users as a % ≥ 65 years	No consensus, revised for next round	Reached consensus	
55.	Average number of home care visits per client	No consensus, indicators merged	55. Care interactions per client per day: reached consensus	
56.	Home care hours per capita			
57.	Claims of home support services	No consensus, revised for next round & moved to coverage domain	Public domestic support, by income group: reached consensus	
58.	Service utilisation specified in service type	No consensus, revised for next round	No consensus, revised for next round	No consensus
59.	Hospital visits of ≥ 65 years	No consensus, indicators merged	59. hospital admissions for people aged 65 and older: reached consensus	
60.	Hospitalisations as a % ≥ 65 years			
61.	Hospitalisations amongst LTC facility residents			
62.	Hospitalisations among home care users			
64.	Geriatric hospital visits			
63.	Emergency department visits for adults ≥ 65 years	No consensus, indicators merged	63. Number of acute hospital contacts: reached consensus	
65.	Acute hospitalisations per month			
66.	Specialists care visits for adults ≥ 65 years old	No consensus, revised for next round	No consensus, excluded from further rounds	
67.	Hospital readmission rates	No consensus, revised for next round	Reached consensus	
68.	Average length of hospital stay	No consensus, revised for next round	No consensus, revised for next round	Reached consensus
69.	Number of bed blockers	No consensus, revised for next round	No consensus, revised for next round	Reached consensus
70.	Discharge destination after hospital	No consensus, revised for next round	Reached consensus	
Domain: Workforce				
71.	LTC facility nurses	No consensus, revised for next round	No consensus, revised for next round	No consensus
72.	LTC staff casualization and turnover	No consensus, split in two indicators	72a. Staff turnover: no consensus, excluded from further rounds 72b. flexible staffing: no consensus, excluded from further rounds	
73.	Home care nurses and home help aids	No consensus, revised for next round	Reached consensus	

Nr.	Indicator	Round 1.	Round 2.	Round 3.
74.	Social workers	No consensus, revised for next round	No consensus, excluded from further rounds	
75.	Physical therapist	No consensus, revised for next round	No consensus, excluded from further rounds	
76.	Prevalence of informal caregivers	No consensus, revised for next round	Reached consensus	
NEW6	High workload	New indicator proposed in round 1	Reached consensus	
NEW7	Collaboration between different care professionals	New indicator proposed in round 1	Reached consensus	
NEW8	Collaboration between formal and informal care		New indicator proposed in round 2	Reached consensus
Domain: Expenditures and financing				
77.	National LTC expenditures	No consensus, indicators merged	77. Expenditures on long-term care, stratified by care setting: reached consensus	
78.	LTC facility expenditures			
79.	Home and community-based care expenditures			
80.	LTC expenditures as % of the GDP	No consensus, revised for next round	No consensus, excluded from further rounds	
81.	LTC expenditures as % of total healthcare budget	No consensus, indicators merged	81. Cost shift in total care for older adults expenditures: reached consensus	
82.	Home and community-based care expenditures as a % of total LTC expenditures			
83.	Cost-shifting between institutional and home- and community-based care			
84.	LTC expenditures per capita	No consensus, indicators merged	84. Annual expenditures on long-term care for older adults related to older adult population: reached consensus	
85.	Per capita expenditures on LTC facility care			
86.	Per capita expenditures on home and community-based care			
87.	Expenditures per LTC facility bed	No consensus, excluded from further rounds		
88.	Home and community-based care expenditures on the provincial level	No consensus, excluded from further rounds		
89.	Municipal sum of primary care rehabilitation service expenditures	No consensus, indicators merged	89. expenditures on geriatric rehabilitation care: no consensus, excluded from further rounds	
90.	Per capita expenditures on specialist rehabilitation			
91.	Per capita expenditures on general practice care	No consensus, revised for next round	Reached consensus	
92.	Hospital expenditures	No consensus, indicators merged	92. expenditures on hospital and medical-specialist care: no consensus, revised for next round	No consensus
93.	Per capita expenditures on specialist care			
NEW9.	Expenditures on Medical Care for Specific Patient Groups (Geneeskundige Zorg voor Specifieke Patiëntgroepen, GZSP)		New indicator, proposed in round 2	No consensus

Supplementary material 5. Quantitative results — Round 1

Note: Indicators in this round were rated by panellists on two dimensions — "Fit for Purpose" (relevance of the indicator) and "Fit for Use" (feasibility/usability of the indicator) — each on a 5-point Likert scale. The "Prime indicator" / "Usable indicator" columns indicate whether the median rating was ≥ 4. "Level of consensus" reflects the degree of agreement across panellists.

Indicator	Fit for Purpose				Fit for Use			
	Mean	Std. Dev.	Prime indicator	Level of consensus	Mean	Std. Dev.	Usable indicator	Level of consensus
Domain 1: Health status of older adults								
1. Well-being of older adults, measured in quality-of-life scales	4.63	0.62	Yes	High	4.13	1.01	Yes	Low
2. Mental health status of older adults (measured in validated questionnaires, e.g. the MHI-5 scale)	4.53	0.61	Yes	High	4.18	0.73	Yes	Moderate
3. Functional abilities of older adults (ADL scores, care dependency scores)	4.47	0.75	Yes	Moderate	4.37	0.87	Yes	Low
4. Cognitive functioning of older adults (MMSE scores)	4.27	1.04	Yes	Low	3.84	1.22	No	Low
5. Prevalence of Disease-related factors (e.g. urinary tract infections, respiratory conditions, pressure ulcers, pain)	4.02	0.96	Yes	Low	3.84	1.07	No	Low
6. Mortality rates	3.17	1.27	No	Low	3.16	1.28	No	Low
7. Location of death (hospital, nursing home, home, other)	3.96	1.15	No	Low	3.84	1.12	No	Low
Domain 2: Informal caregiver burden								
8. Frequency of daily caregiving and the average weekly hours of informal care	4.61	0.66	Yes	High	4.32	0.81	Yes	Moderate
9. Informal caregiver distress, measured using a standardised questionnaire (e.g. Zarit Burden interview or Caregiver Strain Index)	4.72	0.49	Yes	High	4.52	0.63	Yes	High
10. General health of informal caregivers, measured in quality-of-life scales	4.24	0.76	Yes	Moderate	4	0.97	Yes	Low
11. Probability of sickness absence among informal caregivers	4.41	0.76	Yes	Moderate	4.28	0.83	Yes	Low
12. Effect of changes in home care payments on informal caregiver hours	4.39	0.89	Yes	Low	4.29	0.80	Yes	Low
13. Effect of informal caregiving on labour supply and weekly hours of labour participation	4.29	0.80	Yes	Low	4.02	0.93	Yes	Low
Domain 3: Health inequalities								
14. Differences in the use of formal home care between income or migration groups	4.48	0.69	Yes	High	4.45	0.74	Yes	Moderate
15. Differences in client satisfaction with long-term care between income or migration groups	4.07	0.98	Yes	Low	3.93	1.12	No	Low
16. Percentage of older adults who postpone care due to costs or distance	4.38	0.78	Yes	Moderate	4.14	0.85	Yes	Low
17. Percentage of older adults experiencing cultural or linguistic barriers in interactions with healthcare providers	4.07	1.07	Yes	Low	3.83	1.28	No	Low

Indicator	Fit for Purpose				Fit for Use			
	Mean	Std. Dev.	Prime indicator	Level of consensus	Mean	Std. Dev.	Usable indicator	Level of consensus
18. Differences in self-reported health, disaggregated by socioeconomic status	4.07	0.83	Yes	Low	3.93	0.99	No	Low
19. Differences in mortality rates between regions and income groups	4.04	0.88	Yes	Low	3.75	1.04	No	Low
Domain 4: Care satisfaction								
20. Client satisfaction with received long-term care services, measured on a 0-10 scale	4.24	1.03	Yes	Low	4	1.09	Yes	Low
21. Client satisfaction with received home care services, measured on a 0-10 scale	4.1	0.98	Yes	Low	4	1.05	Yes	Low
Domain 5: Person-centred care								
22. Extent to which physicians actively involve patients in decisions about care and treatment	4.44	0.92	Yes	Low	3.98	1.26	No	Low
23. Percentage of older adults who made an appointment with a healthcare practitioner online	3.24	1.16	No	Low	3.12	1.23	No	Low
24. Percentage of older adults who sought health-related information online	2.86	1.17	No	Low	2.84	1.18	No	Low
25. Extent to which patients feel that physicians spend sufficient time with them during consultations	3.87	1.08	No	Low	3.56	1.27	No	Low
26. Extent to which patients perceive physicians' explanations as clear and easy to understand	3.93	1.14	No	Low	3.64	1.26	No	Low
Domain 6: Quality of care								
27. Avoidable mortality among the population ≥ 65 years old	4.03	1.01	Yes	Low	3.77	1.06	No	Low
28. Avoidable hospital admissions due to chronic diseases (e.g. COPD, diabetes) among the population aged ≥ 65 years	4.29	0.57	Yes	High	4.13	0.81	Yes	Low
29. Percentage of chronic opioid users among the population aged ≥ 65 years	3.44	0.97	No	Low	3.23	1.07	No	Low
30. Older patients with prescriptions for benzodiazepines or similar medications	3.58	0.86	No	Low	3.5	0.91	No	Low
31. Perceptions of healthcare professionals regarding patient safety culture, measured using a standardised questionnaire (e.g. Hospital Survey on Patient Safety Culture)	3.9	0.98	No	Low	3.77	1.02	No	Low
Domain 7: Care availability								
32. Total number of long-term care facilities	3.66	1.18	No	Low	3.51	1.33	No	Low
33. Total number of LTC facility service providers	3.45	1.24	No	Low	3.22	1.25	No	Low
34. Total number of LTC facility openings and closures	3.58	1.25	No	Low	3.42	1.30	No	Low
35. Total number of LTC facility beds	4.25	0.79	Yes	Moderate	4.16	0.84	Yes	Low
36. Total number of different national home care programs	3.29	1.29	No	Low	3.12	1.25	No	Low
37. Total number of home care services providers	3.64	1.24	No	Low	3.51	1.23	No	Low
38. Total number of people on waiting lists of national home care programs	4.19	1.01	Yes	Low	4.08	1.09	Yes	Low

Indicator	Fit for Purpose				Fit for Use			
	Mean	Std. Dev.	Prime indicator	Level of consensus	Mean	Std. Dev.	Usable indicator	Level of consensus
Domain 8: Coverage of care								
39. Annual number of LTC beneficiaries under the public LTC insurance	4.24	0.83	Yes	Low	4.29	0.85	Yes	Low
40. LTC beneficiaries under the public LTC insurance as percentage of the population ≥ 65 years old	3.71	0.92	No	Low	3.76	0.97	No	Low
41. Number of people paying out-of-pocket contributions for private care	3.63	1.09	No	Low	3.54	1.11	No	Low
42. Annual co-payments as percentage of the total national LTC expenditures	3.56	1.31	No	Low	3.44	1.32	No	Low
43. Annual per capita LTC co-payments	3.8	1.01	No	Low	3.73	0.96	No	Low
44. Marketisation rate of home care service providers	3.59	1.06	No	Low	3.35	1.12	No	Low
Domain 9: Care utilisation								
45. Number of enrolments in specific LTC programs	3.67	1.02	No	Low	3.71	1.06	No	Low
46. Percentage of public formal LTC utilisation	3.92	0.94	No	Low	3.86	1.07	No	Low
47. Total number of LTC facility users	4.03	0.97	Yes	Low	3.86	1.07	No	Low
48. Number of LTC facility users as a percentage of the population ≥ 65 years old	3.84	1.03	No	Low	3.68	1.12	No	Low
49. Number of new placements in LTC facilities	4.18	0.84	Yes	Low	4.03	0.97	Yes	Low
50. Total number of resident days in LTC facilities	4.11	0.98	Yes	Low	3.84	1.16	No	Low
51. Annual total number of home care users	4.24	0.86	Yes	Low	4.08	1.01	Yes	Low
52. Total number of home care visits	3.66	0.98	No	Low	3.58	0.99	No	Low
53. Total amount of minutes or hours home care provided	3.69	0.95	No	Low	3.61	0.84	No	Low
54. Number of home care users as a percentage of the population ≥ 65 years old	4.03	1.08	Yes	Low	3.87	1.14	No	Low
55. Annual average number of home care visits per client	3.64	0.96	No	Low	3.58	0.91	No	Low
56. Annual home care hours per capita	3.35	1.07	No	Low	3.35	0.98	No	Low
57. Annual number of unique claims of home support services	3.65	0.95	No	Low	3.65	0.95	No	Low
58. Service utilisation specified in service type (in-home, day care, outpatient care)	4	0.86	Yes	Low	3.94	0.79	No	Moderate
59. Annual number of hospital visits of the older population ≥ 65 years old	3.47	1.03	No	Low	3.53	1.01	No	Low
60. Hospitalisations as a percentage of the older population ≥ 65 years old	3.62	0.98	No	Low	3.49	0.99	No	Low
61. Number of hospitalisations amongst LTC facility residents	3.46	0.89	No	Low	3.43	0.95	No	Low
62. Annual number of hospitalisations among home care users	3.76	0.90	No	Low	3.76	0.86	No	Low
63. Annual number of emergency department visits for adults ≥ 65 years old	3.95	0.89	No	Low	3.79	0.96	No	Low
64. Annual number of geriatric hospital visits	3.61	0.90	No	Low	3.57	0.88	No	Low

Indicator	Fit for Purpose				Fit for Use			
	Mean	Std. Dev.	Prime indicator	Level of consensus	Mean	Std. Dev.	Usable indicator	Level of consensus
65. National rate of acute hospitalisations per month	3.51	1.01	No	Low	3.49	0.98	No	Low
66. Annual number of specialists care visits for adults ≥ 65 years old	3.73	0.84	No	Low	3.51	0.93	No	Low
67. Hospital readmission rates	3.58	1.03	No	Low	3.63	1.05	No	Low
68. Average length of hospital stay	3.49	1.07	No	Low	3.51	1.07	No	Low
69. Number of bed blockers	4.05	0.97	Yes	Low	3.92	1.01	No	Low
70. Discharge destination after hospital stay (home, long-term care facility, other)	3.97	0.99	No	Low	3.97	0.96	No	Low
Domain 10: Workforce								
71. Annual number of LTC facility nurses	3.97	0.98	No	Low	3.76	1.06	No	Low
72. LTC staff casualization and turnover	4.06	1.06	Yes	Low	3.84	1.32	No	Low
73. Annual number of registered home care nurses and home help aids	4.2	0.90	Yes	Low	4.06	1.08	Yes	Low
74. Annual number of social workers	3.87	0.89	No	Low	3.74	0.99	No	Low
75. Annual number of physical therapist	3.55	1.03	No	Low	3.48	1.12	No	Low
76. Prevalence of informal caregivers	4.47	0.56	Yes	High	4.38	0.70	Yes	Moderate
Domain 11: Expenditures and financing								
77. Annual national LTC expenditures	4.17	0.99	Yes	Low	4.1	0.96	Yes	Low
78. Annual sum of LTC facility expenditures	3.48	1.09	No	Low	3.37	1.01	No	Low
79. Annual expenditures on home and community-based care programs	4.28	0.89	Yes	Low	4.16	0.90	Yes	Low
80. Annual LTC expenditures as percentage of the GDP	3.9	0.98	No	Low	3.9	0.98	No	Low
81. Annual LTC expenditures as percentage of the total healthcare budget	3.94	1.03	No	Low	3.97	0.95	No	Low
82. Annual expenditures on home and community-based care as a percentage of the total LTC expenditures	4.23	0.86	Yes	Low	4.23	0.86	Yes	Low
83. Cost-shifting between LTC facilities and home and community-based care on the national level	4.38	0.82	Yes	Low	4.43	0.84	Yes	Low
84. Annual LTC expenditures per capita	3.66	1.05	No	Low	3.59	1.09	No	Low
85. Annual per capita expenditures on LTC facility care	3.52	1.21	No	Low	3.48	1.21	No	Low
86. Annual average per capita expenditures on home and community-based care	3.52	1.18	No	Low	3.48	1.18	No	Low
87. Average annual expenditures per LTC facility bed	3.47	1.04	No	Low	3.43	0.97	No	Low
88. Annual home and community-based care expenditures on the provincial level	3.18	1.22	No	Low	3.14	1.27	No	Low
89. Annual municipal sum of primary care rehabilitation service expenditures	3.95	1.03	No	Low	3.75	1.21	No	Low
90. Annual per capita expenditures on specialist rehabilitation	3.35	1.29	No	Low	3.27	1.25	No	Low
91. Annual per capita expenditures on general practitioners care	3.37	1.25	No	Low	3.3	1.30	No	Low
92. Total annual hospital expenditures	3.21	1.25	No	Low	3.17	1.37	No	Low

Indicator	Fit for Purpose				Fit for Use			
	Mean	Std. Dev.	Prime indicator	Level of consensus	Mean	Std. Dev.	Usable indicator	Level of con-sensus
93. Annual per capita expenditures on specialist care	3.04	1.4	No	Low	2.93	1.41	No	Low

Supplementary material 6. Qualitative results — Round 1

Note: This table summarises the qualitative feedback received in Round 1 for each indicator, together with the resulting revision (or decision to remove the indicator) that was carried forward into Round 2. "NEW" rows reflect indicators newly proposed by panellists during the open-text questions.

Initial indicator	Summary feedback	New indicator
Domain 1: Health status of older adults		
1. Well-being of older adults, measured in quality-of-life scales	Quality of life is a key outcome measure influenced by multiple factors and should be assessed using a multidimensional scale that includes self-reliance, social support, safety, and mental and physical well-being.	1. Perceived well-being of older adults, measured using a validated multidimensional quality-of-life scale
2. Mental health status of older adults (measured in validated questionnaires, e.g. the Mental Health Inventory (MHI)-5 scale)	Mental health is a key outcome influenced by factors such as social environment and loneliness. The scale used should reflect these factors and be culturally sensitive.	2. Mental well-being of older adults measured with a short validated questionnaire (e.g. the MHI-5 scale)
3. Functional abilities of older adults (Activity of Daily Living (ADL) scores, care dependency scores)	Functional abilities are essential for independent living for older adults, but ADL- and care dependency scores are most meaningful when interpreted alongside contextual factors such as care availability and living environment.	3. Functional abilities of older adults (ADL scores, care dependency scores) in relation to available care and living situation
4. Cognitive functioning (Mini-Mental State Examination (MMSE) scores)	MMSE scores are not directly influenced by policy, but are useful for monitoring and identifying risk areas. The MMSE is less suitable for people with a migration background or lower educational level, important to consider alternatives such as the Rowland Universal Dementia Assessment Scale (RUDAS).	4. Cognitive functioning of older adults, measured with a short validated screening (e.g. MMSE or RUDAS)
5. Prevalence of disease-related factors (e.g. urinary tract infections, respiratory conditions, pressure ulcers, pain)	The prevalence of disease-related factors is primarily an indicator of quality of care or a signal of the ability to remain living at home. It is important to distinguish between chronic and acute conditions and, where possible, to compare between home- and institutional settings.	5. Prevalence of chronic and acute disease-related factors in older adults (e.g. urinary tract infections, pressure ulcers, pain), separated by home-based and institutional settings.
6. Mortality rates	Mortality rates alone offer limited insight, linking deaths to causes such as falls, infections, or complications of chronic conditions helps to identify risks for older adults living at home.	6. Mortality rates of home-dwelling older adults, separated by relevant causes (e.g. falls, infections, complications of chronic conditions)
7. Location of death (hospital, nursing home, home, other)	It could be relevant to know whether older adults die in their preferred location of death. The indicator should be considered alongside quality of life and autonomy. The hospice should be added as a potential location of death.	7. Alignment between the preferred and actual location of death among older adults (hospital, nursing home, home, hospice)
New Indicator derived from question about missing indicators within this domain*	In addition to care dependency and self-reliance, autonomy is highlighted as an important theme for ageing-in-place. It is important that older adults feel that they can still have control over their own lives.	NEW1. Percentage of older adults who report having sufficient control over their own lives
New Indicator derived from question about missing indicators within this domain*	The social well-being of older adults is mentioned as an important theme. Ageing-in-place may increase the risk of social isolation and loneliness, therefore important to include an indicator about this.	NEW2. Prevalence of (moderate or severe) loneliness among older adults, separated by home-based and institutional settings
Domain 2: Informal caregiver burden		
8. Frequency of daily caregiving and the average weekly hours of informal care	Indicator provides insights in how ageing-in-place policies rely on informal caregivers. Important to focus on informal caregiving for home-dwelling older adults.	8. Informal care for home-dwelling older adults, measured by frequency of daily caregiving and average weekly hours.

Initial indicator	Summary feedback	New indicator
9. Informal caregiver distress, measured using a standardised questionnaire (e.g. Zarit Burden interview or Caregiver Strain Index)	There is consensus that this is a relevant and useful indicator, which will therefore be included in the final framework. The only suggestion made is to include the *Ervaren Druk door Informele Zorg-plus* (EDIZ-plus, Experienced Burden of Informal Care scale, extended version), as this one is commonly used by Dutch policy research institutions.	9. Informal caregiver distress, measured using a standardised questionnaire (e.g. Zarit Burden interview, Caregiver Strain Index, or EDIZ-plus scale)
10. General health of informal caregivers, measured in quality-of-life scales	The indicator is relevant for understanding the sustainability of informal care. However, quality of life is influenced by many factors, which makes it harder to apply for policy. The indicator should capture both the positive and negative effects of caregiving.	10. Well-being of informal caregivers, measured with a validated quality-of-life scale that captures both the positive effects and negative effects of caregiving.
11. Probability of sickness absence among informal caregivers	Absenteeism is considered relevant to assess the impact of caregiving on work. However, it would be better to measure the actual absenteeism instead of the probability, and it is desirable to include the cause of absenteeism.	11. Sickness absence rate and frequency among working informal caregivers, supplemented with (if available) the proportion of absence episodes in which caregiving is recorded as a (partial) cause
12. Effect of changes in home care payments on informal caregiver hours	'Home care payments' is unclear, and using 'effect' as an indicator is confusing. In the Dutch context, it is useful to measure formal care — covered under the *Zorgverzekeringswet* (Zvw, Health Insurance Act), the *Wet maatschappelijke ondersteuning* (Wmo, Social Support Act), and the *Wet langdurige zorg* (Wlz, Long-Term Care Act) — relative to informal care. The indicator is revised to show the ratio of formal to informal care hours, highlighting the shift of care tasks from professionals to caregivers.	12. The ratio between formal care hours (Zvw, Wmo, Wlz) to informal care hours provided
13. Effect of informal caregiving on labour supply and weekly hours of labour participation	Using 'effect' as an indicator is confusing, and labour supply and weekly participation are different concepts. Measuring potential reduction in hours worked due to caregiving is relevant, as it reveals hidden social costs and financial risks.	13a. Average weekly hours worked by informal caregivers with paid employment 13b. Percentage of informal caregivers reporting reduced working hours or contract hours due to caregiving duties
New Indicator derived from question about missing indicators within this domain*	Shared caregiving has been mentioned as an important topic for ageing-in-place. Structurally sharing care tasks among multiple informal caregivers can help sustain caregiving and create a manageable situation.	NEW3. Percentage of caregiving situations in which care is regularly shared by two or more caregivers
Domain 3: Health inequalities		
14. Differences in the use of formal home care between income or migration groups	There is consensus within the panel that this is a relevant and useful indicator. However, it is noted that differences between groups should not only be tracked quantitatively, but that understanding the underlying causes or reasons is also relevant.	14. Differences in the use of formal home care between income or migration groups
15. Differences in client satisfaction with long-term care between income or migration groups	Client satisfaction is important, however it can be difficult to interpret, as it reflects personal opinions and individual contact. It would be better to focus on whether care and support match people's preferences.	15. Differences in perceived appropriateness and satisfaction with long-term care across income and migration groups
16. Percentage of older adults who postpone care due to costs or distance	Costs and distance represent different barriers with distinct underlying causes. Both are important but require different policy focus. Better to split the indicator.	16a. Percentage of older adults who delay care due to costs (including deductibles and co-payments) 16b. Percentage of older adults who delay care due to distance or lack of nearby providers

Initial indicator	Summary feedback	New indicator
17. Percentage of older adults experiencing cultural or linguistic barriers in interactions with healthcare providers	Language and cultural barriers can have different causes and policy implications. Language barriers also apply to low (health) literacy. Both factors affect accessibility and timely use of care services. Better to split the indicator.	17a. Percentage of older adults experiencing a language barrier understanding or accessing care options 17b. Percentage of older adults experiencing cultural barriers in interactions with care providers
18. Differences in self-reported health, disaggregated by socioeconomic status	The indicator highlights health disparities between SES groups, but was considered too general and subjective for ageing-in-place policies. It should be refined to "perceived health and functioning", capturing concrete aspects such as mobility and daily activities.	18. Differences in perceived health and functioning (e.g. mobility, daily activities) stratified by socioeconomic status among older adults
19. Differences in mortality rates between regions and income groups	The indicator is too indirect to evaluate ageing-in-place policies, as mortality is influenced by many factors. More insightful to focus on avoidable mortality related to quality and accessibility of home care, highlighting regional and income inequalities.	19. Differences in preventable mortality (potentially) related to the quality and accessibility of home care, stratified by region or income group
Domain 4: Care satisfaction		
20. Client satisfaction with received long-term care services, measured on a 0-10 scale 21. Client satisfaction with received home care services, measured on a 0-10 scale	Client satisfaction is considered relevant, but individual scores are hard to interpret due to their subjective nature and unclear measurement. It could be helpful to use the nationally validated and mandatory experience survey (Generiek Kompas), which provides a standardised and comparable outcome at the organisational level.	20. Perceived quality of care at the organisational level, among people with care needs in district nursing or long-term care (e.g. measured using the average scores of the Generiek Kompas).
Domain 5: Person-centred care		
22. Extent to which physicians actively involve patients in decisions about care and treatment	Shared decision-making is important, but there is insufficient connection to ageing-in-place policies. Decision about whether someone can continue living at home concern social and independent functioning, not just medical treatments.	22. The extent of shared decision-making about care and support options aimed at ageing-in-place, with active involvement of the client and informal caregiver (if relevant) by professionals (e.g. GPs, community nurses)
23. Percentage of older adults who made an appointment with a healthcare practitioner online	The connection with ageing-in-place is not clear. The percentage of persons making an online appointment mainly reflects the general digitalization. Having to arrange care online can actually be a barrier for older adults with limited digital skills, would be interesting to focus on digital accessibility (which makes it more appropriate to move the indicator to the health inequalities domain).	23. Percentage of older adults who report difficulty arranging care or making appointments due to digital skills or digital systems that pose a barrier
24. Percentage of older adults who sought health-related information online	The link between the indicator and ageing-in-place is not clear. Experts do not see the relevance (also reflected in low median scores on relevance and usability)	Decided to remove the indicator from the list
25. Extent to which patients feel that physicians spend sufficient time with them during consultations 26. Extent to which patients perceive physicians' explanations as clear and easy to understand	The indicators are similar to each other and are mostly individually determined, making them difficult to measure objectively and of limited relevance to ageing-in-place. It would be better to shift the focus to holistic, person-centred care, making it both more relevant and easier to measure. Based on these comments, the indicators have been combined.	25. Percentage of older adults who, during a consultation with a healthcare professional (GP, practice nurse, community nurse), feel that sufficient time is taken for them and that they are understood
Domain 6: Quality of care		

Initial indicator	Summary feedback	New indicator
27. Avoidable mortality among the population ≥ 65 years old	Provides insights into the quality of care, but the term "avoidable mortality" is not entirely clear. Should refer to death that could theoretically have been prevented, for example through prevention, treatment, or the organisation of care	27. Percentage of deaths among older adults considered avoidable, separated by relevant subcategories (e.g. fall incidents, chronic conditions)
28. Avoidable hospital admissions due to chronic diseases (e.g. COPD, diabetes) among the population aged ≥ 65 years	Indicator is relevant for prevention policy. However, it is needed to clearly define what "avoidable" means (for example, through optimal treatment at home or timely interventions).	28. The percentage of hospital admissions among older adults for conditions that are considered avoidable according to clinical guidelines with optimal prevention and treatment (e.g. COPD, diabetes)
29. Percentage of chronic opioid users among the population aged ≥ 65 years	Opioid use at home is relevant for safety and quality of care, due to risks such as falls or overdose. The indicator can be useful for monitoring vulnerable groups, with it being important to distinguish between community-dwelling older adults and those living in long-term care facilities.	29. Percentage of chronic opioid users aged ≥ 65 years, stratified by living arrangement (community-dwelling vs. institutionalised)
30. Older patients with prescriptions for benzodiazepines or similar medications	The number of older adults with prescriptions for benzodiazepines is mainly relevant for the quality and safety of care due to risks such as falls, dependence, and the need for supervision in home use. The indicator says little about national policy, but can help to identify risk groups and monitor medication safety.	30. Percentage of older adults with long-term care prescriptions for benzodiazepines or similar substances, stratified by living arrangement (community-dwelling vs. institutionalised)
31. Perceptions of healthcare professionals regarding patient safety culture, measured using a standardised questionnaire (e.g. Hospital Survey on Patient Safety Culture)	Measuring care professionals' perceptions through a standardised questionnaire can be valuable for gaining insight into the safety culture, but it is only an indirect indicator. It is relevant because a strong patient safety culture is needed to enable older adults to live safely at home.	31. Care professionals' perceptions of patient safety culture in care for older adults, assessed using a validated standardised instrument (e.g. the Hospital Survey on Patient Safety Culture, HSOPSC), stratified by care setting (home care vs. institutional care)
Domain 7: Care availability		
32. Total number of long-term care facilities	The total number of long-term care institutions does not adequately reflect actual care availability; capacity is more relevant (addressed in indicator 24). The term "long-term care institution" is not clearly defined. Regional distribution may still be relevant, as it provides insight into regional availability.	32. Regional availability of institutional long-term care, measured as the number of institutional care facilities per region and their actual available capacity (number of beds)
33. Total number of LTC facility service providers	The number of long-term care providers does not reflect actual care availability, as providers may operate multiple locations of varying size. Given staff shortages and rising demand, an indicator of institutional care availability, such as waiting list numbers, is more informative.	33. Number of persons on the waiting list for institutional long-term care, stratified by Wlz care profile
34. Total number of LTC facility openings and closures	The number of openings and closures is considered a difficult indicator to interpret. To better understand care supply, it is preferable to use an indicator that focuses on the proportion of public versus private institutions and changes over time.	34. Proportion of public versus private long-term care institutions (%)
35. Total number of LTC facility beds	The number of beds better reflects actual capacity, especially when including available crisis places. To monitor trends, the indicator should be related to the number of older adults, and "beds" has been replaced with "places."	35a. Total number of places in institutional care facilities relative to the total number of older adults 35b. Number of available crisis places in institutional care facilities

Initial indicator	Summary feedback	New indicator
36. Total number of different national home care programs 37. Total number of home care services providers	The number of national home care programs or providers does not reflect actual capacity or accessibility. Regional availability and whether capacity is sufficient to support ageing in place are more relevant. The indicators have been revised to reflect this.	36. Available home care hours per 100 older adults per region per year 37. Average travel time (in minutes) of home care providers to clients per region
38. Total number of people on waiting lists of national home care programs	The term "home care programs" is unclear. What is relevant is the number of people waiting for home care services, including the average waiting time. This provides insight into access to care, scarcity, and pressure on informal caregivers. The indicator has been split to reflect this feedback	38a. Number of people on the waiting list for home care services, stratified by type of service (Wlz – non-residential MPT/VPT, district nursing Zvw, domestic support Wmo) 38b. Average waiting time (in days) for each type of home care: Wlz non-residential (MPT/VPT/PGB), district nursing, and domestic support
Domain 8: Coverage of care		
39. Annual number of LTC beneficiaries under the public LTC insurance 40. LTC beneficiaries under the public LTC insurance as percentage of the population ≥ 65 years old	The indicators are considered of limited relevance and usefulness. It is important to distinguish between institutional care (with residence) and extramural care (at home with VPT/MPT/PGB), as this provides insight into trends in care use and financing.	39. Number of care recipients with a LTC/Wlz indication, stratified by institutional care (with residence) and extramural care (VPT, MPT, PGB)
41. Number of people paying out-of-pocket contributions for private care	It is unclear what is meant by "private care." Private expenditures can indicate insufficient accessibility of public care, which is relevant to track.	41. Percentage of older adults who purchase private (self-paid) care or support due to insufficient availability of public care
42. Annual co-payments as percentage of the total national LTC expenditures 43. Annual per capita LTC co-payments	It is insufficiently clear what the current indicator says about "ageing in place" policy. The affordability of care is an important issue, especially the difference between personal contributions for home care versus institutional care. It is therefore more relevant to focus the indicator on the level of personal contributions for different forms of long-term care.	42. Average personal contributions for home care (VPT/MPT/PGB) compared with Wlz care with residence
44. Marketisation rate of home care service providers	Market mechanisms alone provide little relevant information. It is better to look at collaboration between providers, as this gives more insight into the effects of policy changes.	44. Degree of collaboration between regional home care providers (district nursing, Wmo services, and Wlz home care)
Domain 9: Care utilisation		
45. Number of enrolments in specific LTC programs	The term "specific programs" within long-term care is unclear. Moreover, the number of enrolments alone says little about the success of ageing-in-place policy. Additionally, this indicator overlaps with previously formulated indicators on the number of Wlz care recipients.	Decided to remove this indicator from the list.
46. Percentage of public formal LTC utilisation	The indicator is unclearly formulated. A more relevant indicator is one that reflects the balance between formal and informal care, as this provides insight into care burden and accessibility.	46. Ratio between provided formal (professional) care to informal care for older adults living at home
47. Total number of LTC facility users	Intramural" can be made clearer by specifying that it refers to "care with residence." The indicator is only relevant if it is clearly distinguished from Wlz care without residence (such as VPT/MPT/PGB).	47. Total number of clients receiving Wlz care with residence (care in an institutional setting)

Initial indicator	Summary feedback	New indicator
48. Number of LTC facility users as a percentage of the population ≥ 65 years old	Most older adults in long-term care institutions are over 65, so it might be better to raise the age threshold. However, it is also important to capture the portion of older adults who are not (yet) using this care. To maintain consistency and enable comparisons, the age of 65 has been retained.	48. Number of clients receiving Wlz care with residence as a percentage of the population aged ≥65 years
49. Number of new placements in LTC facilities 50. Total number of resident days in LTC facilities	The number of admissions alone provides insufficient information. Length of stay is a better indicator. The indicators have therefore been combined. It is important to break down length of stay by Wlz care profile.	49. Average length of stay in Wlz care with residence, stratified by Wlz- care profile
51. Annual total number of home care users 52. Total number of home care visits 53. Total amount of minutes or hours home care provided	The three indicators provide insufficient insight into the actual volume and intensity of home care. The number of clients or visits alone says little; differences in how much care someone needs (intensity and duration) provide more meaningful insight. It was therefore decided to combine and reform the indicators into one focused on the total volume of home care.	51. Total number of home care hours provided per year, stratified by type of care (Zvw – district nursing, Wmo – support, Wlz care without residence such as VPT/MPT)
54. Number of home care users as a percentage of the population ≥ 65 years old	Most people using this care are older, however, it is also important to include those who are not (yet) using it in the percentage. Further age stratification can be added later. The term “home care” is unclear, so it is important to break it down by type of home care.	54. Number of home care clients as a percentage of the population aged ≥65 years, stratified by type of home care (Zvw – district nursing, Wlz care without residence, Wmo – support)
55. Annual average number of home care visits per client 56. Annual home care hours per capita	A more meaningful indicator is one that captures the intensity of home care, as this provides insight into the care dependency of community-dwelling older adults and the workload of district nursing.	55. Average number of care interactions per client per day
57. Annual number of unique claims of home support services	The term “unique claims” is unclear. A more relevant indicator shows whether low personal contributions for Wmo care lead to higher use by higher-income groups. The indicator will be revised and moved to the care coverage domain.	57. Number (and %) of users of publicly financed domestic support, broken down by income group
58. Service utilisation specified in service type (in-home, day care, outpatient care)	The categories (home care, day care, outpatient care) are too broad and confusing, especially as they cover different funding streams. The indicator has therefore been refined to a classification that aligns with policy and practice.	58. Care use, stratified by type of service (Zvw – district nursing, Wmo – support, Wlz care without residence: VPT/MPT, Wlz care with residence)
59. Annual number of hospital visits of the older population ≥ 65 years old 60. Hospitalisations as a percentage of the older population ≥ 65 years old 61. Number of hospitalisations amongst LTC facility residents 62. Annual number of hospitalisations among home care users 64. Annual number of geriatric hospital visits	These indicators on hospital use overlap significantly, it would be more valuable to integrate them together in one indicator providing information about hospital admissions among older adults. It would also be insightful to distinguish between care profiles, to compare the hospitalisations per group.	59. Number of hospital admissions (per 1,000 inhabitants) for people aged 65 and older, stratified by living situation (community-dwelling without care, community-dwelling with care [Wmo, Zvw, Wlz without residence], Wlz care with residence)

Initial indicator	Summary feedback	New indicator
63. Annual number of emergency department visits for adults ≥ 65 years old 65. National rate of acute hospitalisations per month	Both indicators relate to acute hospital care. It is better to combine them into a broader indicator that provides insight into the occurrence of crisis situations at home.	63. Number of acute hospital contacts (ER visits, emergency admissions) per 1,000 inhabitants aged ≥65 years, stratified by living situation (community-dwelling, WIz care without residence, WIz care with residence)
66. Annual number of specialists care visits for adults ≥ 65 years old	The indicator for medical-specialist care remains separate because it concerns a different type of care than hospital admissions. Use of outpatient or specialist treatment follows a different pattern and has different policy relevance.	66. Number of medical-specialist care contacts (outpatient visits, diagnostics, and treatment trajectories) per 1,000 inhabitants aged ≥65 years, stratified by living situation (community-dwelling, WIz care without residence, WIz care with residence)
67. Hospital readmission rates	Readmissions are a clear and relevant quality indicator. It is important, however, to link this to age (65+).	67. Percentage of hospital readmissions within 30 days after discharge among residents aged ≥ 65 years
68. Average length of hospital stay 69. Number of bed blockers 70. Discharge destination after hospital stay (home, long-term care facility, other)	This indicator (together with indicators 69 & 70) provides insight into flow problems and the availability of appropriate follow-up care for older adults. It is relevant to relate the indicators to age (65+), and it may also be important to distinguish between community-dwelling older adults and clients in long-term care institutions.	68. Average hospital length of stay for patients aged ≥ 65 years 69. Number of patients aged ≥ 65 years occupying unnecessary beds (“bed blockers”) 70. Discharge destination for patients aged ≥ 65 years (return home, primary care facility, geriatric rehabilitation, WIz care with residence)
Domain 10: Workforce		
71. Annual number of LTC facility nurses	It is important to distinguish by education level. For ageing-in-place policy, it is relevant how many nurses are actively involved in home care. A percentage of staff at a given level, in relation to care intensity, provides more insight than absolute numbers.	71. Percentage of qualified nurses (level 4/5) in long-term care institutions and home care, relative to the care intensity
72. LTC staff casualization and turnover	Turnover and flexible staffing are two different concepts. Turnover provides insight into staff satisfaction and continuity of care, while flexible staffing reflects organisational flexibility. It is therefore better to split the indicators.	72a. Staff turnover in long-term care institutions, expressed as the percentage of employee inflow/outflow per year, stratified by type of staff (e.g., level 4, 5, bachelor’s nurses) 72b. Degree of flexible staffing in long-term care (WIz care with residence, WIz care without residence), expressed as the percentage of FTE flexible staff (temporary workers, self-employed) relative to total FTE
73. Annual number of registered home care nurses and home help aids	The original indicator combines district nurses and domestic support workers, who differ in role, funding, and registration. Absolute numbers provide limited insight into ageing-in-place policy effectiveness. More important is understanding personnel capacity in home care by relevant professional groups.	73. Availability of staff providing home care, expressed as the annual number of active home care employees, stratified by: district nurses (level 4/5/bachelor’s), care and support staff, and domestic support workers

Initial indicator	Summary feedback	New indicator
74. Annual number of social workers	The original indicator is too broad, as "social workers" covers many roles and sectors. It is more relevant to track professionals directly supporting community-dwelling older adults to assess capacity for ageing in place.	74. Annual number of social professionals working with older adults, stratified by: care consultant, advisors, informal care counsellors, case managers
75. Annual number of physical therapist	The absolute number provides little insight, it is more relevant to track physiotherapists working with community-dwelling older adults.	75. Annual number of physiotherapists (expressed in FTE/work hours) working with community-dwelling older adults, stratified by type of service: preventive, curative, or rehabilitation
76. Prevalence of informal caregivers	The wording is unclear. Expressing it as a percentage for those caring for adults aged 65+ gives a clearer picture of informal care availability and support for ageing in place.	76. Percentage of the population providing informal care to persons aged 65 and older
New Indicator derived from question about missing indicators within this domain*	Workload for care professionals has been highlighted as an important theme. High perceived workload can affect the quality and continuity of care, as well as the employability and well-being of care professionals.	NEW6. Percentage of care professionals (stratified by district nursing, Wmo home care, Wlz care without residence, Wlz care with residence) reporting high workload
New Indicator derived from question about missing indicators within this domain*	It is highlighted that collaboration between care and support professionals is important for delivering good care. For this reason, an indicator has been formulated.	NEW7. Percentage of care professionals who report that collaboration and information exchange between district nursing, GPs/practice nurses, the social domain, and institutional care functions well
Domain 11: Expenditures and financing		
77. Annual national LTC expenditures 78. Annual sum of LTC facility expenditures 79. Annual expenditures on home and community-based care programs	These cost indicators overlap and are partly unclear (e.g., "long-term care"). It is important to scale costs relative to demographics and distinguish between home care and care with residence. The indicators have therefore been combined into a single clear cost indicator for older adult care.	77. Total annual national expenditures on long-term care for older adults, stratified by care setting (Wlz care with residence, Wlz home care VPT/MPT/PGB, Zvw home care/district nursing, Wmo support)
80. Annual LTC expenditures as percentage of the GDP	The indicator is relevant for macro-level insight to evaluate policy effects. Any increase is likely driven mainly by population ageing rather than policy. It is also important to clarify what is meant by "long-term care."	80. Annual expenditures on long-term care for older adults (Wlz with residence, Wlz without residence, Zvw/Wmo) as a percentage of Gross Domestic Product (GDP)
81. Annual LTC expenditures as percentage of the total healthcare budget 82. Annual expenditures on home and community-based care as a percentage of the total LTC expenditures 83. Cost-shifting between LTC facilities and home and community-based care on the national level	Shifts in costs are important for monitoring the effects of ageing-in-place policy, particularly the difference between Wlz care with residence and home care. For this reason, the indicators have been combined into a broader indicator.	81. Cost shift in total long-term care expenditures for older adults, expressed as the percentage of spending allocated to Wlz care with residence versus home care components (Wlz without residence, Zvw, Wmo)

Initial indicator	Summary feedback	New indicator
84. Annual LTC expenditures per capita 85. Annual per capita expenditures on LTC facility care 86. Annual average per capita expenditures on home and community-based care	Indicators expressed "per capita" are less relevant. It is better to relate costs to the number of older adults (65+), which makes relative cost increases more transparent.	84. Annual expenditures on long-term care for older adults, stratified by type of care (Wlz with residence, Wlz without residence, Zvw home care, Wmo support) per 1,000 inhabitants aged ≥ 65 years
87. Average annual expenditures per LTC facility bed 88. Annual home and community-based care expenditures on the provincial level	These indicators, in their current form, provide insufficient insight. It is better to distinguish between different types of care. However, this has already been done in earlier indicators. Therefore, it was decided to remove these indicators.	Decided to remove this indicator from the list.
89. Annual municipal sum of primary care rehabilitation service expenditures 90. Annual per capita expenditures on specialist rehabilitation	The original indicators for primary and specialist rehabilitation care are confusing, especially regarding funding and target group. Focusing on adults ≥65 years and geriatric rehabilitation makes the indicator more relevant for ageing-in-place policy.	89. Annual expenditures on geriatric rehabilitation care for adults aged ≥65 years
91. Annual per capita expenditures on general practitioners care	The original indicator is too broad and influenced by factors unrelated to ageing-in-place policy. Focusing on adults ≥65 makes it more relevant and allows tracking of primary care costs for the target population.	91. Annual expenditures on GP care for adults aged ≥65 years
92. Total annual hospital expenditures 93. Annual per capita expenditures on specialist care	The original indicators are too broad and affected by factors unrelated to ageing-in-place policy. Combining them and focusing on adults ≥65 makes the indicator more specific and relevant for monitoring care use in this population.	92. Annual expenditures on hospital and medical-specialist care for adults aged ≥65 years

Supplementary material 7. Quantitative results — Round 2

Note: From Round 2 onward, consensus was operationalised as ≥ 75% of panellists agreeing the indicator was a Prime indicator and a Usable indicator. Indicators that had reached consensus in Round 1 were not re-rated.

Indicator	Fit for Purpose		Fit for Use	
	% Agreement	Prime indicator	% Agreement	Usable indicator
Domain 1: Health status of older adults				
1. Perceived well-being of older adults, measured using a validated multidimensional quality-of-life scale	97.60%	Yes	88.10%	Yes
2. Mental well-being of older adults measured with a short validated questionnaire (e.g. the Mental Health Inventory-5 scale)	95.20%	Yes	75.00%	Yes
3. Functional abilities of older adults (Activities of Daily Living (ADL) scores, care dependency scores) in relation to available care and living situation	95.10%	Yes	83.00%	Yes
4. Cognitive functioning of older adults, measured with a short validated screening (e.g. Mini-Mental State Examination, or Rowland Universal Dementia Assessment Scale)	72.10%	No	64.10%	No
5. Prevalence of chronic and acute disease-related factors in older adults (e.g. urinary tract infections, pressure ulcers, pain), separated by home-based and institutional settings	66.70%	No	65.00%	No
6. Mortality rates of home-dwelling older adults, separated by relevant causes (e.g. falls, infections, complications of chronic conditions)	71.40%	No	64.10%	No
7. Alignment between the preferred and actual location of death among older adults (hospital, nursing home, home, hospice)	78.90%	Yes	76.90%	Yes
NEW1. Percentage of older adults who report having sufficient control over their own lives	78.50%	Yes	60.10%	No
NEW2. Prevalence of (moderate or severe) loneliness among older adults, separated by home-based and institutional settings	85.70%	Yes	76.20%	Yes
Domain 2: Informal caregiver burden				
9. Informal care for home-dwelling older adults, measured by frequency of daily caregiving and average weekly hours	92.00%	Yes	85.40%	Yes
9. Informal caregiver distress, measured using a standardised questionnaire (e.g. Zarit Burden interview, Caregiver Strain Index, or *Ervaren Druk door Informele Zorg-plus* (EDIZ-plus, Experienced Burden of Informal Care scale, extended version) scale)	Consensus reached in round 1			
10. Well-being of informal caregivers, measured with a validated quality-of-life scale that captures both the positive effects and negative effects of caregiving	95.90%	Yes	91.80%	Yes
11. Sickness absence rate and frequency among working informal caregivers, supplemented with (if available) the proportion of absence episodes in which caregiving is recorded as a (partial) cause	93.60%	Yes	76.10%	Yes

Indicator	Fit for Purpose		Fit for Use	
	% Agreement	Prime indicator	% Agreement	Usable indicator
12. Formal-to-informal care ratio. The ratio of hours of formal care — covering curative care under the Health Insurance Act (Zvw), social support under the Social Support Act (Wmo), and long-term care under the Long-Term Care Act (Wlz) — to hours of informal care provided.	83.30%	Yes	75.60%	Yes
13a. Average weekly hours worked by informal caregivers with paid employment	68.10%	No	59.60%	No
13b. Percentage of informal caregivers reporting reduced working hours or contract hours due to caregiving duties	Due to a mistake in the questionnaire, the indicator has not been rated. The indicator will be assessed in round 3.			
NEW3. Percentage of caregiving situations in which care is regularly shared by two or more caregivers	76.60%	Yes	67.40%	No
Domain 3: Health inequalities				
14. Differences in the use of formal home care between income or migration groups	Consensus reached in round 1			
15. Differences in perceived appropriateness and satisfaction with long-term care across income and migration groups	87.00%	Yes	56.50%	No
16a. Percentage of older adults who delay care due to costs (including deductibles and co-payments)	95.70%	Yes	95.60%	Yes
16b. Percentage of older adults who delay care due to distance or lack of nearby providers	77.20%	Yes	68.20%	No
17a. Percentage of older adults experiencing a language barrier understanding or accessing care options	87.00%	Yes	75.00%	Yes
17b. Percentage of older adults experiencing cultural barriers in interactions with care providers	75.00%	Yes	54.20%	No
18. Differences in perceived health and functioning (e.g. mobility, daily activities) stratified by socioeconomic status among older adults	70.80%	No	62.50%	No
19. Differences in preventable mortality (potentially) related to the quality and accessibility of home care, stratified by region or income group	78.30%	Yes	65.20%	No
23. Percentage of older adults who report difficulty arranging care or making appointments due to digital skills or digital systems that pose a barrier *-> moved from person-centred care domain*	73.90%	No	60.90%	No
Domain 4: Care satisfaction				
20. Perceived quality of care at the organisational level, among people with care needs in district nursing or long-term care (e.g. measured using the average scores of the Generiek Kompas)	78.60%	Yes	75.00%	Yes
Domain 5: Person-centred care				
22. The extent of shared decision-making about care and support options aimed at ageing-in-place, with active involvement of the client and informal caregiver (if relevant) by professionals (e.g. General Practitioners (GP), community nurses)	89.50%	Yes	83.30%	Yes

Indicator	Fit for Purpose		Fit for Use	
	% Agreement	Prime indicator	% Agreement	Usable indicator
25. Percentage of older adults who, during a consultation with a healthcare professional (GP, practice nurse, community nurse), feel that sufficient time is taken for them and that they are understood	89.50%	Yes	75.00%	Yes
Domain 6: Quality of care				
27. Percentage of deaths among older adults considered avoidable, separated by relevant subcategories (e.g. fall incidents, chronic conditions)	68.70%	No	55.90%	No
28. The percentage of hospital admissions among older adults for conditions that are considered avoidable according to clinical guidelines with optimal prevention and treatment (e.g. COPD, diabetes)	73.50%	No	69.70%	No
29. Percentage of chronic opioid users aged ≥ 65 years, stratified by living arrangement (community-dwelling vs. institutionalised)	53.10%	No	54.50%	No
30. Percentage of older adults with long-term care prescriptions for benzodiazepines or similar substances, stratified by living arrangement (community-dwelling vs. institutionalised)	64.50%	No	61.30%	No
31. Care professionals' perceptions on patient safety culture in care for older adults, measured using a standardised questionnaire (e.g. the Hospital Survey on Patient Safety Culture, HSOPSC), stratified by sector (home care or institutional care)	58.80%	No	54.50%	No
Domain 7: Care availability				
32. Regional availability of institutional long-term care, measured as the number of institutional care facilities per region and their actual available capacity (number of beds)	82.90%	Yes	73.20%	No
33. Number of persons on the waiting list for institutional long-term care, stratified by Wlz care profile	87.80%	Yes	82.90%	Yes
34. Proportion of public versus private long-term care institutions (%)	51.20%	No	46.10%	No
35a. Total number of places in institutional care facilities relative to the total number of older adults	78.00%	Yes	76.00%	Yes
35b. Number of available crisis places in institutional care facilities	82.90%	Yes	69.00%	No
36. Available home care hours per 100 older adults per region per year	82.10%	Yes	79.50%	Yes
37. Average travel time (in minutes) of home care providers to clients per region	63.40%	No	61.00%	No
38a. Number of people on the waiting list for home care services, stratified by type of service (Wlz – non-residential MPT/VPT, district nursing Zvw, domestic support Wmo)	90.00%	Yes	82.50%	Yes
38b. Average waiting time (in days) for each type of home care: Wlz non-residential (MPT/VPT/PGB), district nursing, and domestic support	87.80%	Yes	87.80%	Yes
Domain 8: Coverage of care				

Indicator	Fit for Purpose		Fit for Use	
	% Agreement	Prime indicator	% Agreement	Usable indicator
39. Number of care recipients with a Wlz indication, stratified by institutional care (with residence) and extramural care (VPT, MPT, PGB)	80.00%	Yes	80.00%	Yes
41. Percentage of older adults who purchase private (self-paid) care or support due to insufficient availability of public care	55.50%	No	55.50%	No
42. Average personal contributions for home care (VPT/MPT/PGB) compared with Wlz care with residence	88.90%	Yes	70.00%	No
44. Degree of collaboration between regional home care providers (district nursing, Wmo services, and Wlz home care)	70.00%	No	60.00%	No
57. Number (and %) of users of publicly financed domestic support, broken down by income group	75.00%	Yes	88.90%	Yes
Domain 9: Care utilisation				
46. Ratio between provided formal (professional) care to informal care for older adults living at home	85.20%	Yes	72.00%	No
47. Total number of clients receiving Wlz care with residence (care in an institutional setting)	84.00%	Yes	80.00%	Yes
48. Number of clients receiving Wlz care with residence as a percentage of the population aged ≥65 years	85.00%	Yes	85.00%	Yes
49. Median length of stay in Wlz care with residence, stratified by Wlz- care profile	84.00%	Yes	80.00%	Yes
51. Total number of home care hours provided per year, stratified by type of care (Zvw – district nursing, Wmo – support, Wlz care without residence such as VPT/MPT)	80.00%	Yes	80.00%	Yes
54. Number of home care clients as a percentage of the population aged ≥65 years, stratified by type of home care (Zvw – district nursing, Wlz care without residence, Wmo – support)	80.00%	Yes	84.00%	Yes
55. Average number of care interactions per client per day	84.00%	Yes	80.00%	Yes
58. Care use, stratified by type of service (Zvw – district nursing, Wmo – support, Wlz care without residence: VPT/MPT, Wlz care with residence)	81.00%	Yes	73.00%	No
59. Number of hospital admissions (per 1,000 inhabitants) for people aged 65 and older, stratified by living situation (community-dwelling without care, community-dwelling with care [Wmo, Zvw, Wlz without residence], Wlz care with residence)	85.00%	Yes	85.00%	Yes
63. Number of acute hospital contacts (ER visits, emergency admissions) per 1,000 inhabitants aged ≥65 years, stratified by living situation (community-dwelling, Wlz care without residence, Wlz care with residence)	88.90%	Yes	81.50%	Yes

Indicator	Fit for Purpose		Fit for Use	
	% Agreement	Prime indicator	% Agreement	Usable indicator
66. Number of medical-specialist care contacts (outpatient visits, diagnostics, and treatment trajectories) per 1,000 inhabitants aged ≥65 years, stratified by living situation (community-dwelling, Wlz care without residence, Wlz care with residence)	65.00%	No	64.00%	No
67. Percentage of hospital readmissions within 30 days after discharge among residents aged ≥ 65 years	85.00%	Yes	81.00%	Yes
68. Average hospital length of stay for patients aged ≥ 65 years	58.00%	No	55.60%	No
69. Number of patients aged ≥ 65 years occupying unnecessary beds (“bed blockers”)	81.00%	Yes	73.00%	No
70. Discharge destination for patients aged ≥ 65 years (return home, primary care facility, geriatric rehabilitation, Wlz care with residence)	96.30%	Yes	77.80%	Yes
Domain 10: Workforce				
71. Percentage of qualified nurses (level 4/5) in long-term care institutions and home care, relative to the care intensity	72.00%	No	64.00%	No
72a. Annual staff turnover in long-term care institutions, calculated as the percentage of inflow (newly hired staff) and outflow (staff leaving) over the course of the year, reported separately for each staff qualification level (e.g. vocationally qualified care workers and bachelor’s-level registered nurses)	62.50%	No	60.00%	No
72b. Degree of flexible staffing in long-term care (Wlz care with residence, Wlz care without residence), expressed as the percentage of FTE flexible staff (temporary workers, self-employed) relative to total Full Time Equivalent (FTE).	48.00%	No	56.00%	No
73. Availability of staff providing home care, expressed as the annual number of active home care employees, stratified by: district nurses (level 4/5/bachelor’s), care and support staff, and domestic support workers	88.00%	Yes	76.00%	Yes
74. Annual number of social professionals working with older adults, stratified by: care consultant, advisors, informal care counsellors, case managers	65.40%	No	65.40%	No
75. Annual number of physiotherapists (expressed in FTE/work hours) working with community-dwelling older adults, stratified by type of service: preventive, curative, or rehabilitation	76.00%	Yes	68.00%	No
76. Percentage of the population providing informal care to persons aged 65 and older	84.60%	Yes	88.50%	Yes
NEW6. Percentage of care professionals (stratified by district nursing, Wmo home care, Wlz care without residence, Wlz care with residence) reporting high workload	84.60%	Yes	76.90%	Yes
NEW7. Percentage of care professionals who report that collaboration and information exchange between district nursing, GPs/practice nurses, the social domain, and institutional care functions well	84.00%	Yes	80.00%	Yes
Domain 11: Expenditures and financing				

Indicator	Fit for Purpose		Fit for Use	
	% Agreement	Prime indicator	% Agreement	Usable indicator
77. Total annual national expenditures on long-term care for older adults, stratified by care setting (Wlz care with residence, Wlz home care VPT/MPT/PGB, Zvw home care/district nursing, Wmo support)	77.80%	Yes	77.80%	Yes
80. Annual expenditures on long-term care for older adults (Wlz with residence, Wlz without residence, Zvw/Wmo) as a percentage of Gross Domestic Product (GDP)	64.70%	No	61.10%	No
81. Cost shift in total long-term care expenditures for older adults, expressed as the percentage of spending allocated to Wlz care with residence versus home care components (Wlz without residence, Zvw, Wmo)	84.20%	Yes	79.00%	Yes
84. Annual expenditures on long-term care for older adults, stratified by type of care (Wlz with residence, Wlz without residence, Zvw home care, Wmo support) per 1,000 inhabitants aged ≥ 65 years	84.20%	Yes	78.90%	Yes
89. Annual expenditures on geriatric rehabilitation care for adults aged ≥65 years	73.70%	No	63.20%	No
91. Annual expenditures on GP care for adults aged ≥65 years	89.50%	Yes	78.90%	Yes
92. Annual expenditures on hospital and medical-specialist care for adults aged ≥65 years	78.90%	Yes	66.70%	No

Supplementary material 8. Qualitative results — Round 2

Note: This table reports the qualitative feedback for indicators that did not reach consensus in Round 2, together with the decision taken (further revision, split, merger, or exclusion) for Round 3.

Indicator	Summary feedback	Decision on indicator
Domain 1: Health status of older adults		
4. Cognitive functioning of older adults, measured with a short validated screening (e.g. Mini-Mental State Examination or Rowland Universal Dementia Assessment Scale)	Cognitive functioning is important for being able to continue living at home, but it doesn't have a strong connection to policy. It's useful as a screening factor, something you want to assess, rather than something policy can directly influence or control.	As there is no clear way to improve the indicator, it has been removed from the list.
5. Prevalence of chronic and acute disease-related factors in older adults (e.g. urinary tract infections, pressure ulcers, pain), separated by home-based and institutional settings.	This is important information to have, however, not clear how this relates to ageing-in-place policies. The relevance of the indicators in this context is considered low in comparison with other proposed indicators.	As there is no clear way to improve the indicator, it has been removed from the list.
6. Mortality rates of home-dwelling older adults, separated by relevant causes (e.g. falls, infections, complications of chronic conditions)	It could provide insights in risks, however causes of death are not always well reported. Furthermore, location of death is considered to be a more relevant indicator. The comments do mention the importance of the registration of falls and having insights in the fall risk of persons living at home vs. in a long-term care institution. Indicator changed to focus on fall risk.	*6. Fall incidents among older adults, separated by home-based and institutional settings*
NEW1. Percentage of older adults who report having sufficient control over their own lives	autonomy is important, but it is subjective and often perceived differently by older adults compared to their relatives or care professionals. Panellists also see overlap with existing indicators, such as quality of life.	As there is no clear way to improve the indicator, it has been removed from the list.
Domain 2: Informal caregiver burden		
13a. Average weekly hours worked by informal caregivers with paid employment	It would be more relevant to know whether someone has reduced their work hours due to informal caregiving.	This is reflected in indicator 13b. However, due to a mistake in the second questionnaire panellists had not yet seen this indicator, will be assessed in round 3.
NEW3. Percentage of caregiving situations in which care is regularly shared by two or more caregivers	Sharing care can be important and help sustain caregiving, but it can also create obstacles if family members have different expectations. Additionally, the indicator is difficult to influence through policy, making it less useful.	As there is no clear way to improve the indicator, it has been removed from the list.
Domain 3: Health inequalities		
15. Differences in perceived appropriateness and satisfaction with long-term care across income and migration groups	The indicator is important, but it is too broad, what is meant by "appropriateness" is unclear, and the term "long-term care" is also too vague.	*15. Perceived accessibility and satisfaction with care (long-term care with residency, long-term care without residency, district nursing, and domestic support)*
16b. Percentage of older adults who delay care due to distance or lack of nearby providers	Distance to care locations can be relevant, but it strongly depends on the regional context. Accessibility is broader than just physical distance, for example including patients' mobility and coordination between providers.	*16b. Percentage of older adults (65+) who delay care due to limited accessibility of care providers (e.g., distance, reachability, or mobility problems)*

Indicator	Summary feedback	Decision on indicator
17b. Percentage of older adults experiencing cultural barriers in interactions with care providers	Language barriers are more important and concrete to address through policy than cultural differences, which are context-dependent and constantly changing.	As there is no clear way to improve the indicator, it has been removed from the list.
18. Differences in perceived health and functioning (e.g. mobility, daily activities) stratified by socioeconomic status among older adults	An important policy goal, but the current form is confusing. Differences cannot be broken down as is, yet breaking them down would make these differences visible.	*18. Self-reported health and functioning (such as mobility, daily activities, and energy), separated by socioeconomic status among older adults (≥ 65 years)*
19. Differences in preventable mortality (potentially) related to the quality and accessibility of home care, stratified by region or income group	The concept of "preventable mortality" is difficult to operationalise and may oversimplify the complexity of causes of death.	As there is no clear way to improve the indicator, it has been removed from the list.
23. Percentage of older adults who report difficulty arranging care or making appointments due to digital skills or digital systems that pose a barrier	There were no comments provided for this indicator.	As there is no clear way to improve the indicator, it has been removed from the list.
Domain 4: Care satisfaction		
NEW4	Panellists proposed adding an indicator about unmet care needs, as this also provides insight into satisfaction, since it shows the extent to which care meets existing needs.	*NEW4. Percentage of older adults living at home who report having unmet care needs*
Domain 6: Quality of care		
27. Percentage of deaths among older adults considered avoidable, separated by relevant subcategories (e.g. fall incidents, chronic conditions)	Preventable mortality is difficult to define and can be misinterpreted. Sometimes people consciously choose to stay at home for a better quality of life, even if that involves risks like falling. A death caused by a fall might then be classified as preventable, but that does not necessarily mean it was the wrong outcome.	As there is no clear way to improve the indicator, it has been removed from the list.
28. The percentage of hospital admissions among older adults for conditions that are considered avoidable according to clinical guidelines with optimal prevention and treatment (e.g. COPD, diabetes)	Preventable hospital admissions are difficult to define and interpret. Outcomes depend on complex factors such as comorbidities, patient preferences, behaviour, and social context. The indicator risks oversimplifying reality and may misrepresent quality of care, especially when patients consciously accept certain risks to maintain quality of life.	As there is no clear way to improve the indicator, it has been removed from the list.
29. Percentage of chronic opioid users aged ≥ 65 years, stratified by living arrangement (community-dwelling vs. institutionalised)	It may be important for assessing fall risk and the ability to live at home, but its link to policy is indirect.	An indicator about fall risk is added to the domain 1.
30. Percentage of older adults with long-term care prescriptions for benzodiazepines or similar substances, stratified by living arrangement (community-dwelling vs. institutionalised)	Relevant for medication safety, but unclear link to living at home longer and difficult to measure reliably due to complex medication use.	As there is no clear way to improve the indicator, it has been removed from the list.

Indicator	Summary feedback	Decision on indicator
31. Care professionals' perceptions on patient safety culture in care for older adults, measured using a standardised questionnaire (e.g. HSOPSC), stratified by sector (home care or institutional care)	Considered important by experts, but "safety culture" is unclear and differs between home and institutional settings. For different setting, different elements need to be included in the assessment. Therefore, decided to split the indicator.	*31a: Perception of home care professionals regarding safety and risk management in the home setting, measured with a validated questionnaire, including attention to environmental factors* *31b: Perception of care professionals in long-term residential care (Wlz) regarding the safety climate and professional handling of risks within the institutional setting, measured with a validated questionnaire*
Domain 7: Care availability		
32. Regional availability of institutional long-term care, measured as the number of institutional care facilities per region and their actual available capacity (number of beds)	Important, but waiting lists are more important. The target group is not specified, and long-term care institutions also serve other populations.	*32. Regional availability of institutional long-term care, measured as the number of institutional care facilities for older adults per region and their actual available capacity (number of beds)*
34. Proportion of public versus private long-term care institutions (%)	It is important that everyone has access to care – the indicator says something about financing, but is too little relevant for evaluating 'ageing in place' policy.	As there is no clear way to improve the indicator, it has been removed from the list.
35b. Number of available crisis places in institutional care facilities	Crisis places are important, especially if their use increases due to policy changes. The indicator would be more relevant if linked to the number of older adults.	*35b. Number of available inpatient crisis beds for older adults, relative to the number of older adults*
37. Average travel time (in minutes) of home care providers to clients per region	Some experts think the indicator could say something about care availability, but most consider the link with policy insufficient and see few opportunities to steer policy based on it.	As there is no clear way to improve the indicator, it has been removed from the list.
NEW5.	Panellists emphasise that in addition to the indicator on the number of persons on the waiting list for Wlz care with residency, it would be relevant to add an indicator on the average waiting time.	*NEW5. Average waiting time for Wlz care with residency (VVT) for older adults, linked to urgency*
Domain 8: Coverage of care		
41. Percentage of older adults who purchase private (self-paid) care or support due to insufficient availability of public care	Indicator could provide important information, with regard to inequality, but it's not always clear why someone purchases care or support themselves. It is not always due to low availability. For example, someone with sufficient funds might hire a private cleaner instead of using services through the Wmo.	*41. Percentage of older adults who purchase private (self-paid) care or support due to insufficient availability of public care, separated by income-groups*
42. Average personal contributions for home care (VPT/MPT/PGB) compared with Wlz care with residence	Less relevant, as co-payments for home care are a fixed amount.	As there is no clear way to improve the indicator, it has been removed from the list.
44. Degree of collaboration between regional home care providers (district nursing, Wmo services, and Wlz home care)	It would be more interesting to have an indicator that could provide insights in the collaboration between formal care and informal care.	Similar comments were made in the workforce domain. Therefore, decided to add an indicator about this to domain 10 about workforce.
Domain 9: Care utilisation		
46. Ratio between provided formal (professional) care to informal care for older adults living at home	overlap with previous indicator in the informal caregiver domain. Other indicator is more clearly formulated.	Decided to remove this indicator, as the concept is already captured in an indicator in domain 2 that did achieve consensus.

Indicator	Summary feedback	Decision on indicator
58. Care use, stratified by type of service (Zvw – district nursing, Wmo – support, Wlz care without residence: VPT/MPT, Wlz care with residence)	It is not clear what is meant by 'care use'. In addition, previous indicators also look at the volume of home care and Wlz care with residency.	*58. Percentage of older adults using different types of long-term care (Zvw), district nursing, Wmo support, Wlz care without residency [VPT/MPT], and Wlz care with residency*
66. Number of medical-specialist care contacts (outpatient visits, diagnostics, and treatment trajectories) per 1,000 inhabitants aged ≥65 years, stratified by living situation (community-dwelling, Wlz care without residence, Wlz care with residence)	The indicator is of limited value because hospital or specialist contacts are largely independent of living situation, and frequent visits do not necessarily reflect care needs. While it could provide insight into differences by living situation, it overlaps with other measures and adds little actionable information, making it less relevant to include.	As there is no clear way to improve the indicator, it has been removed from the list.
68. Average hospital length of stay for patients aged ≥ 65 years	It is mentioned by multiple panellists that the origin of patients is needed to make the indicator relevant and useful	*68. Average length of hospital stay for patients ≥ 65 years, separated by living situation (community-dwelling, Wlz care without residence, Wlz care with residence)*
69. Number of patients aged ≥ 65 years occupying unnecessary beds ("bed blockers")	Clarify that the indicator refers specifically to hospital care. It would also be helpful to distinguish where patients come from.	*69. Number of older adults (≥65 years) occupying hospital beds unnecessarily ('bed blockers'), broken down by living situation (Wlz with residency, Wlz without residency, living at home with Wmo support, living at home with Zvw support, living at home without care)*
Domain 10: workforce		
71. Percentage of qualified nurses (level 4/5) in long-term care institutions and home care, relative to the care intensity	It's useful to get an overview of the staff mix, but level 3 caregivers should also be included. As it stands, it may seem they are less skilled, while they are essential too. This indicator should focus on Wlz care with residency, since a later indicator covers home care.	*71. Availability of staff for providing inpatient long-term care (Wlz care with residency), expressed as the annual number of active employees (and FTEs) within Wlz institutions, broken down by: nurses (MBO/HBO), certified caregivers (IG), assistants, and support staff*
72a. Staff turnover in long-term care institutions, expressed as the percentage of employee inflow/outflow per year, stratified by type of staff (e.g., level 4, 5, bachelor's nurses)	Relevance is insufficiently clear. Indicators that provide insight into staff availability is sufficient.	As there is no clear way to improve the indicator, it has been removed from the list.
72b. Degree of flexible staffing in long-term care (Wlz care with residence, Wlz care without residence), expressed as the percentage of FTE flexible staff (temporary workers, self-employed) relative to total FTE	This seems less relevant for ageing-in-place policy. The indicator says more about care/organisation policy regarding self-employed professionals (ZZPs).	As there is no clear way to improve the indicator, it has been removed from the list.
74. Annual number of social professionals working with older adults, stratified by: care consultant, advisors, informal care counsellors, case managers	Indicator represents a broad group of professionals, that are partly already captured in other indicators. Not needed to have specific indicator on this.	As there is no clear way to improve the indicator, it has been removed from the list.

Indicator	Summary feedback	Decision on indicator
75. Annual number of physiotherapists (expressed in FTE/work hours) working with community-dwelling older adults, stratified by type of service: preventive, curative, or rehabilitation	There were almost no open-ended responses for this indicator. Only a few mentioned agreement with the adjustment or suggested that physiotherapists could be used more to support ageing in place, but there was no guidance on how to modify the indicator.	As there is no clear way to improve the indicator, it has been removed from the list.
NEW8	Panellists emphasise that collaboration between professional care and informal care and support is also important – it would be good to include an indicator on this.	*NEW8. Collaboration between professional and informal care within district nursing and Wlz care with residency, expressed as the percentage of clients for whom structured coordination with informal caregivers and/or the informal network is documented*
Domain 11: Expenditures and financing		
80. Annual expenditures on long-term care for older adults (Wlz with residence, Wlz without residence, Zvw/Wmo) as a percentage of Gross Domestic Product (GDP)	Expenditures as a percentage of GDP are only useful for comparing sectors or countries over time, not for guiding local policy, so the indicator has limited practical relevance.	As there is no clear way to improve the indicator, it has been removed from the list.
89. Annual expenditures on geriatric rehabilitation care for adults aged ≥65 years	There were little comments about this indicator. Panellists seemed unsure about usability and provided no further directions to improve indicator.	As there is no clear way to improve the indicator, it has been removed from the list.
92. Annual expenditures on hospital and medical-specialist care for adults aged ≥65 years	Indicator would be more relevant if specified between costs for home-dwelling and inpatient older adults.	*92. Annual expenditures on hospital and medical specialist care for older adults (≥65 years), broken down by living situation (Wlz with residency, Wlz without residency, Zvw home care, Wmo support)*
NEW9.	It was mentioned that it might be helpful to add an indicator about the use of GZSP (medical care for specific groups). This type of care is provided under the Zvw by a specialist in care for older adults. It could be possible that this type of care will increase when older adults continue to live at home longer.	*NEW9. Annual expenditures on Medical Care for Specific Patient Groups (GZSP) for older adults (≥65 years), separated by living situation (Wlz with residency, Wlz without residency, Zvw home care)*

Supplementary material 9. Quantitative results — Round 3

Note: Round 3 was a final consensus round on the indicators still under consideration after Round 2, applying the same ≥ 75% agreement threshold.

Indicator	Fit for Purpose		Fit for Use	
	% Agreement	Prime indicator	% Agreement	Usable indicator
Domain 1: Health status of older adults				
6. Fall incidents among older adults, separated by home-based and institutional settings	90.32%	Yes	80.64%	Yes
Domain 2: Informal caregiver burden				
13b. Percentage of informal caregivers reporting reduced working hours or contract hours due to caregiving duties	86.05%	Yes	76.74%	Yes
Domain 3: Health inequalities				
15. Perceived accessibility and satisfaction with care (long-term care with residency, long-term care without residency, district nursing, and domestic support)	90.90%	Yes	81.81%	Yes
16b. Percentage of older adults (65+) who delay care due to limited accessibility of care providers (e.g., distance, reachability, or mobility problems)	92.31%	Yes	84.61%	Yes
18. Self-reported health and functioning (such as mobility, daily activities, and energy), separated by socioeconomic status among older adults (≥ 65 years)	76.92%	Yes	76.92%	Yes
Domain 4: Care satisfaction				
NEW4: Percentage of older adults living at home who report having unmet care needs	86.95%	Yes	78.26%	Yes
Domain 6: Quality of care				
31a Perception of home care professionals regarding safety and risk management in the home setting, measured with a validated questionnaire, including attention to environmental factors	76%	Yes	64%	No
31b Perception of care professionals in long-term residential care (Wlz) regarding the safety climate and professional handling of risks within the institutional setting, measured with a validated questionnaire	72%	No	52%	No
Domain 7: Care availability				
32. Regional availability of institutional long-term care, measured as the number of institutional care facilities for older adults per region and their actual available capacity (number of beds)	70.96%	No	74.19%	No
35b. Number of available inpatient crisis beds for older adults, relative to the number of older adults	81.25%	Yes	83.87%	Yes
NEW5. Average waiting time for Wlz care with residency (VVT) for older adults, linked to urgency	81.25%	Yes	75.00%	Yes
Domain 8: Coverage of care				

Indicator	Fit for Purpose		Fit for Use	
	% Agreement	Prime indicator	% Agreement	Usable indicator
41. Percentage of older adults who purchase private (self-paid) care or support due to insufficient availability of public care, separated by income-groups	85.71%	Yes	83.33%	Yes
Domain 9: Care utilisation				
58. Percentage of older adults using different types of long-term care (Zvw), district nursing, Wmo support, Wlz care without residency [VPT/MPT], and Wlz care with residency	70.96%	No	74.19%	No
68. Average length of hospital stay for patients ≥ 65 years, separated by living situation (community-dwelling, Wlz care without residence, Wlz care with residence)	86.36%	Yes	86.36%	Yes
69. Number of older adults (≥65 years) occupying hospital beds unnecessarily ('bed blockers'), broken down by living situation (Wlz with residency, Wlz without residency, living at home with Wmo support, living at home with Zvw support, living at home without care)	86.36%	Yes	86.36%	Yes
Domain 10: Workforce				
71. Availability of staff for providing inpatient long-term care (Wlz care with residency), expressed as the annual number of active employees (and FTEs) within Wlz institutions, broken down by: nurses (MBO/HBO), certified caregivers (IG), assistants, and support staff	68.18%	No	68.18%	No
NEW8: Collaboration between professional and informal care within district nursing and Wlz care with residency, expressed as the percentage of clients for whom structured coordination with informal caregivers and/or the informal network is documented	86.36%	Yes	86.36%	Yes
Domain 11: Expenditures and financing				
92. Annual expenditures on hospital and medical specialist care for older adults (≥65 years), broken down by living situation (Wlz with residency, Wlz without residency, Zvw home care, Wmo support)	78.57	Yes	71.00%	No
NEW9. Annual expenditures on Medical Care for Specific Patient Groups (GZSP) for older adults (≥65 years), separated by living situation (Wlz with residency, Wlz without residency, Zvw home care)	71.42%	No	71.42%	No

Supplementary material 10. Qualitative results — Round 3

Note: This table reports the qualitative feedback received for indicators that did not reach consensus in Round 3 and the resulting decisions on those indicators.

Indicator	Summary feedback	Decision on indicator
Domain 6: Quality of care		
31a. Perception of home care professionals regarding safety and risk management in the home setting, measured with a validated questionnaire, including attention to environmental factors	It is mentioned that safety and risk management in the home-setting is important when older adults remain at home. Homecare workers are considered to have a potential to signal changes/risk, as they have close contact with the person living at home. However, there are concerns about how to objectify this or interpret an indicator related to this topic. Concerns about the usability, without clear suggestion for improvement.	As there is no clear way to improve the indicator, it has been removed from the list.
31b. Perception of care professionals in long-term residential care (Wlz) regarding the safety climate and professional handling of risks within the institutional setting, measured with a validated questionnaire	Panellists have similar concerns (as previous indicator) about how interpret and objectify this indicator. Furthermore, it is considered less relevant as the previous indicator which refers to the home-setting.	As there is no clear way to improve the indicator, it has been removed from the list.
Domain 7: Care availability		
32. Regional availability of institutional long-term care, measured as the number of institutional care facilities for older adults per region and their actual available capacity (number of beds)	It is argued that the other indicator in this domain already give insights in the availability of different types of long-term care. The domain of health inequalities covers the accessibility of care. Therefore, this indicator does not add enough to the existing list, and can be removed.	As there is no clear way to improve the indicator, it has been removed from the list.
Domain 9: Care utilisation		
58. Percentage of older adults using different types of long-term care (Zvw), district nursing, Wmo support, Wlz care without residency [VPT/MPT], and Wlz care with residency	It is argued that the other indicators within this domain already give an overview of the use of different types of long-term care. Therefore, this indicators does not add enough to the current list.	As there is no clear way to improve the indicator, it has been removed from the list.
Domain 10: Workforce		
64. Availability of staff for providing inpatient long-term care (Wlz care with residency), expressed as the annual number of active employees (and FTEs) within Wlz institutions, broken down by: nurses (MBO/HBO), certified caregivers (IG), assistants, and support staff	Panellists are not sure about this indicator. Some argue that it can provide information on the availability of care. Others argue that it could be linked to quality of care, however, that the indicator does not provide sufficient information on competence of the employees. However, no concrete suggestions are offered to help improve the indicator.	As there is no clear way to improve the indicator, it has been removed from the list.
Domain 11: Expenditures and financing		
79. Annual expenditures on hospital and medical specialist care for older adults (≥65 years), broken down by living situation (Wlz with residency, Wlz without residency, Zvw home care, Wmo support)	Whilst some argue that it can be used to track changes or shifts in policy, others reason that this can be caused by many different factors. They are unsure what conclusion could be drawn from the indicator. No suggestions are provided to further adapt the indicator	As there is no clear way to improve the indicator, it has been removed from the list.

Indicator	Summary feedback	Decision on indicator
New indicator: Annual expenditures on Medical Care for Specific Patient Groups (GZSP) for older adults (≥65 years), separated by living situation (Wlz with residency, Wlz without residency, Zvw home care)	Uncertainty about this indicator. It is mentioned that GZSP is not one uniform product, which makes it harder to interpret this indicator. No suggestions are provided to further specify the indicator.	As there is no clear way to improve the indicator, it has been removed from the list.

Supplementary material 11. Results of the ranking exercise (Round 3)

Note: In the Round 3 ranking exercise, panellists prioritised the consensus indicators within each domain by allocating points to indicate relative importance. Higher sum scores indicate higher panel-rated priority. Indicators are listed within each domain in descending order of sum score.

Indicator	Sum score
Domain 1: Older adult health status	
1. Perceived well-being of older adults, measured using a validated multidimensional quality-of-life scale	151
2. Functional abilities of older adults (ADL scores, care dependency scores) in relation to available care and living situation	133
3. Mental well-being of older adults measured with a short validated questionnaire (e.g. the MHI-5 scale)	128
4. Prevalence of loneliness among older adults, separated by home-based and institutional settings	90
5. Fall incidents among older adults, separated by home-based and institutional settings	88
6. Alignment between the preferred and actual location of death among older adults (hospital, nursing home, home, hospice)	61
Domain 2: Informal caregiver burden	
1. Informal care for home-dwelling older adults, measured by frequency of daily caregiving and average weekly hours	191
2. Well-being of informal caregivers, measured with a validated quality-of-life scale that captures both the positive effects and negative effects of caregiving	171
3. Informal caregiver distress, measured using a standardised questionnaire (e.g. Zarit Burden interview, Caregiver Strain Index, or EDIZ-plus scale)	166
4. Sickness absence rate and frequency among working informal caregivers, supplemented with (if available) the proportion of absence episodes in which caregiving is recorded as a (partial) cause	147
5. The ratio between formal care hours (Zvw, Wmo, Wlz) to informal care hours provided	138
6. Percentage of informal caregivers reporting reduced working hours or contract hours due to caregiving duties	124
7. Percentage of the population providing informal care to persons aged 65 and older - *moved from domain 10: Workforce*	58
Domain 3: Health inequalities	
1. Percentage of older adults who delay care due to costs (including deductibles and co-payments)	51
2. Self-reported health and functioning (such as mobility, daily activities, and energy), separated by socioeconomic status among older adults (≥ 65 years)	46
3. Perceived accessibility and satisfaction with care (long-term care with residency, long-term care without residency, district nursing, and domestic support)	45
4. Percentage of older adults (65+) who delay care due to limited accessibility of care providers (e.g., distance, reachability, or mobility problems)	44
5. Differences in the use of formal home care between income or migration groups	42
6. Percentage of older adults experiencing a language barrier understanding or accessing care options	32
Domain 4: Care satisfaction	
1. Perceived quality of care at the organisational level, among people with care needs in district nursing or long-term care (e.g. measured using the average scores of the Generiek Kompas)	46
2. Percentage of older adults living at home who report having unmet care needs	23
Domain 5: Person-centred care	
1. The extent of shared decision-making about care and support options aimed at ageing-in-place, with active involvement of the client and informal caregiver (if relevant) by professionals (e.g. GPs, community nurses)	58
2. Percentage of older adults who, during a consultation with a healthcare professional (GP, practice nurse, community nurse), feel that sufficient time is taken for them and that they are understood	29

Indicator	Sum score
Domain 7: Care availability	
1. Average waiting time (in days) for each type of home care: Wlz non-residential (MPT/VPT/PGB), district nursing, and domestic support	164
2. Number of persons on the waiting list for institutional long-term care, stratified by Wlz care profile	148
3. Number of people on the waiting list for home care services, stratified by type of service (Wlz – non-residential MPT/VPT, district nursing Zvw, domestic support Wmo)	143
4. Average waiting time for Wlz care with residency (VVT) for older adults, linked to urgency	135
5. Number of available inpatient crisis beds for older adults, relative to the number of older adults	122
6. Available home care hours per 100 older adults per region per year	122
7. Total number of places in institutional care facilities relative to the total number of older adults	122
Domain 8: Care coverage	
1. Number of care recipients with a Wlz indication, stratified by institutional care (with residence) and extramural care (VPT, MPT, PGB)	15
2. Number (and %) of users of publicly financed domestic support, broken down by income group	14
3. Percentage of older adults who purchase private (self-paid) care or support due to insufficient availability of public care, separated by income-groups	7
Domain 9: Care utilisation	
1. Number of home care clients as a percentage of the population aged ≥65 years, stratified by type of home care (Zvw – district nursing, Wlz care without residence, Wmo – support)	223
2. Total number of home care hours provided per year, stratified by type of care (Zvw – district nursing, Wmo – support, Wlz care without residence such as VPT/MPT)	182
3. Number of clients receiving Wlz care with residence as a percentage of the population aged ≥65 years	180
4. Number of hospital admissions (per 1,000 inhabitants) for people aged 65 and older, stratified by living situation (community-dwelling without care, community-dwelling with care [Wmo, Zvw, Wlz without residence], Wlz care with residence)	169
5. Number of acute hospital contacts (ER visits, emergency admissions) per 1,000 inhabitants aged ≥65 years, stratified by living situation (community-dwelling without care, community-dwelling with care [Wmo, Zvw, Wlz without residence], Wlz care with residence)	154
6. Total number of clients receiving Wlz care with residence (care in an institutional setting)	149
7. Median length of stay in Wlz care with residence, stratified by Wlz- care profile	147
8. Average number of care interactions per client per day	115
9. Number of older adults (≥65 years) occupying hospital beds unnecessarily ('bed blockers'), broken down by living situation (Wlz with residency, Wlz without residency, living at home with Wmo support, living at home with Zvw support, living at home without care)	114
10. Discharge destination for patients aged ≥ 65 years (return home, primary care facility, geriatric rehabilitation, Wlz care with residence)	109
11. Average length of hospital stay for patients ≥ 65 years, separated by living situation (community-dwelling, Wlz care without residence, Wlz care with residence)	99
12. Percentage of hospital readmissions within 30 days after discharge among residents aged ≥ 65 years	90
Domain 10: Workforce	
1. Availability of staff providing home care, expressed as the annual number of active home care employees, stratified by: district nurses (level 4/5/bachelor's), care and support staff, and domestic support workers	94
2. Collaboration between professional and informal care within district nursing and Wlz care with residency, expressed as the percentage of clients for whom structured coordination with informal caregivers and/or the informal network is documented	73
3. Percentage of care professionals (stratified by district nursing, Wmo home care, Wlz care without residence, Wlz care with residence) reporting high workload	63
4. Percentage of care professionals who report that collaboration and information exchange between district nursing, GPs/ practice nurses, the social domain, and institutional care functions well	57

Indicator	Sum score
Domain 11: Expenditures and financing	
1. Cost shift in total long-term care expenditures for older adults, expressed as the percentage of spending allocated to Wlz care with residence versus home care components (Wlz without residence, Zvw, Wmo)	58
2. Annual expenditures on long-term care for older adults, stratified by type of care (Wlz with residence, Wlz without residence, Zvw home care, Wmo support) per 1,000 inhabitants aged ≥ 65 years	55
3. Total annual national expenditures on long-term care for older adults, stratified by care setting (Wlz care with residence, Wlz home care VPT/MPT/PGB, Zvw home care/district nursing, Wmo support)	50
4. Annual expenditures on GP care for adults aged ≥65 years	32

Supplementary material 12. Final list of indicators included in the framework

Final 53 actionable performance indicators for evaluating ageing-in-place reform in the Netherlands, by domain

Indicators are listed in descending order of priority within each domain, based on the Round 3 ranking exercise. Numbering within each domain corresponds to the ranking shown in Figure 4. Quality of care (Domain 6 in the original framework) is omitted because no indicators in that domain reached consensus.

#	Indicator
Domain 1: Older adult health status	
1	Perceived well-being of older adults, measured using a validated multidimensional quality-of-life scale
2	Functional abilities of older adults (ADL scores, care dependency scores) in relation to available care and living situation
3	Mental well-being of older adults measured with a short validated questionnaire (e.g. the MHI-5 scale)
4	Prevalence of loneliness among older adults, separated by home-based and institutional settings
5	Fall incidents among older adults, separated by home-based and institutional settings
6	Alignment between the preferred and actual location of death among older adults (hospital, nursing home, home, hospice)
Domain 2: Informal caregiver burden	
1	Informal care for home-dwelling older adults, measured by frequency of daily caregiving and average weekly hours
2	Well-being of informal caregivers, measured with a validated quality-of-life scale that captures both the positive and negative effects of caregiving
3	Informal caregiver distress, measured using a standardised questionnaire (e.g. Zarit Burden Interview, Caregiver Strain Index, or EDIZ-plus scale)
4	Sickness absence rate and frequency among working informal caregivers, supplemented (where available) with the proportion of absence episodes in which caregiving is recorded as a (partial) cause
5	Ratio between formal care hours (Zvw, Wmo, Wlz) and informal care hours provided
6	Percentage of informal caregivers reporting reduced working hours or contract hours due to caregiving duties
7	Percentage of the population providing informal care to persons aged ≥65 years
Domain 3: Health inequalities	
1	Percentage of older adults who delay care due to costs (including deductibles and co-payments)
2	Self-reported health and functioning (e.g. mobility, daily activities, energy), separated by socioeconomic status among older adults (≥65 years)
3	Perceived accessibility and satisfaction with care (long-term care with residency, long-term care without residency, district nursing, and domestic support)
4	Percentage of older adults (≥65 years) who delay care due to limited accessibility of care providers (e.g. distance, reachability, or mobility problems)
5	Differences in the use of formal home care between income or migration groups
6	Percentage of older adults experiencing a language barrier in understanding or accessing care options
Domain 4: Care satisfaction	
1	Perceived quality of care at the organisational level among people with care needs in district nursing or long-term care (e.g. measured using the average scores of the Generiek Kompas)
2	Percentage of older adults living at home who report having unmet care needs
Domain 5: Person-centred care	
1	Extent of shared decision-making about care and support options aimed at ageing in place, with active involvement of the client and informal caregiver (where relevant) by professionals (e.g. GPs, community nurses)
2	Percentage of older adults who, during a consultation with a healthcare professional (GP, practice nurse, community nurse), feel that sufficient time is taken for them and that they are understood

#	Indicator
Domain 7: Care availability	
1	Average waiting time (in days) for each type of home care: Wlz non-residential (MPT/VPT/PGB), district nursing, and domestic support
2	Number of persons on the waiting list for institutional long-term care, stratified by Wlz care profile
3	Number of people on the waiting list for home care services, stratified by type of service (Wlz non-residential MPT/VPT, district nursing Zvw, domestic support Wmo)
4	Average waiting time for Wlz care with residency (VVT) for older adults, linked to urgency
5	Number of available inpatient crisis beds for older adults, relative to the number of older adults
6	Available home care hours per 100 older adults per region per year
7	Total number of places in institutional care facilities, relative to the total number of older adults
Domain 8: Coverage of care	
1	Number of care recipients with a Wlz indication, stratified by institutional care (with residence) and extramural care (VPT, MPT, PGB)
2	Number (and %) of users of publicly financed domestic support, broken down by income group
3	Percentage of older adults who purchase private (self-paid) care or support due to insufficient availability of public care, separated by income group
Domain 9: Care utilisation	
1	Number of home care clients as a percentage of the population aged ≥65 years, stratified by type of home care (Zvw district nursing, Wlz care without residence, Wmo support)
2	Total number of home care hours provided per year, stratified by type of care (Zvw district nursing, Wmo support, Wlz care without residence such as VPT/MPT)
3	Number of clients receiving Wlz care with residence as a percentage of the population aged ≥65 years
4	Number of hospital admissions (per 1,000 inhabitants) for people aged ≥65 years, stratified by living situation (community-dwelling without care, community-dwelling with care [Wmo, Zvw, Wlz without residence], Wlz care with residence)
5	Number of acute hospital contacts (ER visits, emergency admissions) per 1,000 inhabitants aged ≥65 years, stratified by living situation (community-dwelling without care, community-dwelling with care [Wmo, Zvw, Wlz without residence], Wlz care with residence)
6	Total number of clients receiving Wlz care with residence (care in an institutional setting)
7	Median length of stay in Wlz care with residence, stratified by Wlz care profile
8	Average number of care interactions per client per day
9	Number of older adults (≥65 years) occupying hospital beds unnecessarily ('bed blockers'), broken down by living situation (Wlz with residency, Wlz without residency, living at home with Wmo support, living at home with Zvw support, living at home without care)
10	Discharge destination for patients aged ≥65 years (return home, primary care facility, geriatric rehabilitation, Wlz care with residence)
11	Average length of hospital stay for patients aged ≥65 years, separated by living situation (community-dwelling, Wlz care without residence, Wlz care with residence)
12	Percentage of hospital readmissions within 30 days after discharge among residents aged ≥65 years
Domain 10: Workforce	
1	Availability of staff providing home care, expressed as the annual number of active home care employees, stratified by district nurses (level 4/5/bachelor's), care and support staff, and domestic support workers
2	Collaboration between professional and informal care within district nursing and Wlz care with residency, expressed as the percentage of clients for whom structured coordination with informal caregivers and/or the informal network is documented
3	Percentage of care professionals (stratified by district nursing, Wmo home care, Wlz care without residence, Wlz care with residence) reporting high workload
4	Percentage of care professionals who report that collaboration and information exchange between district nursing, GPs/practice nurses, the social domain, and institutional care functions well

#	Indicator
Domain 11: Expenditures and financing	
1	Cost shift in total long-term care expenditures for older adults, expressed as the percentage of spending allocated to Wlz care with residence versus home care components (Wlz without residence, Zvw, Wmo)
2	Annual expenditures on long-term care for older adults, stratified by type of care (Wlz with residence, Wlz without residence, Zvw home care, Wmo support) per 1,000 inhabitants aged ≥65 years
3	Total annual national expenditures on long-term care for older adults, stratified by care setting (Wlz care with residence, Wlz home care VPT/MPT/PGB, Zvw home care/district nursing, Wmo support)
4	Annual expenditures on GP care for adults aged ≥65 years

Part II

Individual-Level Evidence: Lived Experiences and Care Preferences of Older Adults and Informal Caregivers Ageing in Place



Chapter 4

Eliciting preferences of persons with dementia and informal caregivers to support ageing in place in the Netherlands: a protocol for a discrete choice experiment

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Abstract

Introduction

Ageing in place (AIP) for persons with dementia is encouraged by European governments and societies. Healthcare packages may need reassessment to account for the preferences of care funders, patients and informal caregivers. By providing insight into people's preferences, discrete choice experiments (DCEs) can help develop consensus between stakeholders. This protocol paper outlines the development of a Dutch national study to cocreate a healthcare package design methodology built on DCEs that is person-centred and helps support informal caregivers and persons with dementia to AIP. A subpopulation analysis of persons with dementia with a migration background is planned due to their high risk for dementia and under-representation in research and care.

Methods and analysis

The DCE is designed to understand how persons with dementia and informal caregivers choose between different healthcare packages. Qualitative methods are used to identify and prioritise important care components for persons with dementia to AIP. This will provide a list of care components that will be included in the DCE, to quantify the care needs and preferences of persons with dementia and informal caregivers. The DCE will identify individual and joint preferences to AIP. The relative importance of each attribute will be calculated. The DCE data will be analysed with the use of a random parameters logit model.

Ethics and dissemination

Ethics approval was waived by the Amsterdam University Medical Center (W23_112 #23.137). A study summary will be available on the websites of Alzheimer Nederland, Pharos and Amsterdam Public Health institute. Results are expected to be presented at (inter)national conferences, peer-reviewed papers will be submitted, and a dissemination meeting will be held to bring stakeholders together. The study results will help improve healthcare package design for all stakeholders.

Strengths and limitations of this study

- This will be the first study to include informal caregivers and persons with dementia to identify AIP preferences that has been co-designed with health insurers, policymakers, patient advocacy groups, healthcare professionals, researchers, informal caregivers, and persons with dementia.
- Innovative and rigorous economic methods will be employed to evaluate AIP preferences.

- Pooling of persons with dementia with different migration background may lead to better understanding of their needs as they are typically underrepresented in research.
- A limitation of this study is the generalizability of results as not all migrant groups living in the Netherlands may be included.
- This study is conducted in the Netherlands, findings might be specific to the Dutch Healthcare setting.

Introduction

Nearly every country across Europe has reformed its long-term care policy to emphasise ageing in place (AIP) as a way to control costs associated with population ageing.[1] The Netherlands is the highest spender of long-term care per gross domestic product in the world.[2] Most Dutch long-term care services are paid by the national health insurance, with a low percentage of copayments.[3] To cope with the rising long-term care costs, the Netherlands reformed its long-term care policy in 2015.[4] The reform increased informal care duties and encouraged older adults to AIP.[4 5] A substantial component of the Dutch long-term care costs is attributed to dementia care, as it is the most costly disease encompassing 10.6% of the total Dutch healthcare budget.[6] The dementia population is known for its requirement of complex and costly care.[7] However, it remains unknown how AIP has affected this population. In the years after the reform, preliminary results indicate an increased need for support with crisis situations such as unplanned hospitalisations, acute nursing home admissions and hospital deaths.[8 9] These crises situations are not only costly, but can also compromise the safety and well-being of persons with dementia AIP, in addition to the informal caregivers expected to carry the load.

Despite the need for evidenced-based policy to ensure proper healthcare services, people with dementia and informal caregivers are frequently excluded from policy creation; therefore, services often do not fit with their needs or are not provided at the right time.[10 11] To support successful AIP, identifying the care preferences of persons with dementia and informal caregivers is crucial. While identifying these preferences, special attention should be given to persons with dementia and informal caregivers with a migration background, who are known to have a higher risk of developing dementia.[12 13] Despite their high risk, persons with a migration background are under-represented in research and care.[14] It is crucial that persons with a migration background be included in research so healthcare package evidence is representative of the dementia population. To provide

recommendations for healthcare packages, it is subsequently needed to quantify the identified care preferences, which can be realised with a discrete choice experiment (DCE).

DCEs are a popular stated preference method used to elicit patients' preferences in healthcare on a large scale.[15–17] In a DCE, participants are presented with a series of alternative hypothetical scenarios. Participants are repetitively asked to select in each alternative hypothetical scenario their preferred option from among a presented set of options, for example, care packages.[16] These choice options are characterised by their attributes and corresponding attribute levels.[15 16] An example of an attribute could be emotional support, described as the possibility to talk to someone about personal feelings or concerns. The corresponding attribute levels could be (1) peer support group, (2) psychologist or (3) telephone helpline. The outcomes (choices) from DCEs are analysed based on the assumption that participants act in a utility maximising manner, choosing their most preferred option based on the relative overall attractiveness of the included attributes and attribute levels.[16 18] This protocol paper will outline the development of a Dutch national study to create a healthcare package design methodology, built on DCEs, that is person centred and helps support both informal caregivers and persons with dementia to successfully AIP. Qualitative methods will be used to identify the care needs and preferences of persons with dementia and their informal caregivers. The results of the qualitative studies will provide insights into the attributes (ie, care components) that will be included in the DCE. For the DCE, a subpopulation analysis of persons with dementia with a migration background is planned.

Aim

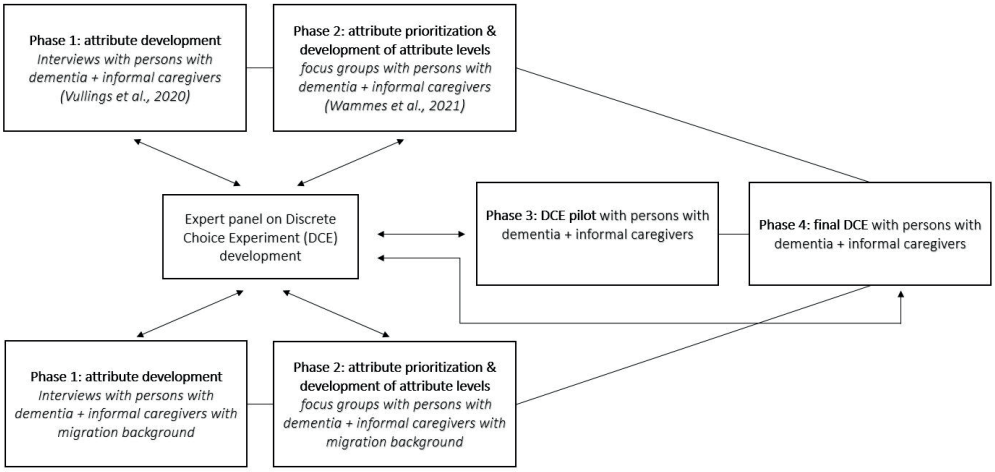
The aim of this study is to identify individual and joint preferences of persons with dementia and informal caregivers for in-home support that enables AIP. We also aim to create optimal healthcare packages for persons with dementia and informal caregivers to AIP. For this second aim, choice model inferences will be the basis for creating the most preferred care packages and testing the uptake in a subsample of participants. This will validate the national model inferences and provide policy-makers with high quality, understandable and implementable evidence.

Methods

Overview of the DCE

In this protocol paper, the different phases of designing an inclusive DCE study in which persons with dementia and their informal caregivers can participate will be outlined. The study will be conducted between April 2022 and May 2025. Figure 1 illustrates that the first phase is focused on attribute development, in which semi structured interviews are used to identify important components of care for persons with dementia and informal caregivers AIP. In the second phase, persons with dementia and informal caregivers are asked which of the care components are most important to them, leading to a prioritisation of the attributes and the development of attribute levels. For phases 1 and 2, the Consolidated criteria for Reporting Qualitative research guidelines for reporting qualitative research will be followed to ensure important aspects of the research team, reflexivity, study design, findings and analysis are reported.[19] The third phase consists of a pilot which is used to test if the content of the DCE is understandable for persons with dementia and informal caregivers, and if the list of included attributes and corresponding attribute levels is complete. Finally, in phase 4, the researchers conduct the DCE study. An expert panel will be consulted during all the different phases of the study to reflect on the research design and findings. Phases 3 and 4 will be reported according to the Strengthening the Reporting of Observational Studies in Epidemiology guidelines, developed as a tool for authors to ensure high-quality reporting of observational studies.[20] For constructing the DCE design, the International Society for Pharmacoeconomics and Outcomes Research (ISPOR) good research practices reports will also be followed.[21 22]

Figure 1. Flow chart study design to create healthcare packages based on discrete choice experiments.



Patient and public involvement

The DCE, including the framing of the questions, will be developed after focus group discussion and multiple individual interviews with persons with dementia and informal caregivers. Persons with dementia, informal caregivers and policy-makers are involved from the start of the study to ensure the appropriateness of the methodology and to help come to meaningful and implementable results.[23] Study materials, such as interview guides, will be discussed with persons with dementia and informal caregivers before the start of the study to ensure appropriateness and make necessary changes. Prior to the DCE, person with dementia, informal caregivers and patient advocacy groups will be asked to voice their opinion about the final list of attributes and corresponding levels included in the DCE. Patient advocacy groups, persons with dementia and informal caregivers, are to be included to make sure that the study properly represents these groups, and the study results reflect their needs and preferences. The patient advocacy groups and policy-makers are consulted through an expert panel, details of which can be found in the next section. The Guidance for Reporting Involvement of Patients and the Public 2 (GRIPP2) checklist will be followed to report the patient and public involvement.[24]

The DCE study will identify individual and joint preferences to AIP, allowing for this concept to be implemented elsewhere. The findings of this study will be published in peer-reviewed journals and an easy-to-understand summary of the results will be available through patient organisations such as Alzheimer Nederland and Pharos. Furthermore, the researchers will organise informative events to communicate the study results to persons with dementia and informal caregivers. These events will be organised together with the patient advocacy groups and informal caregivers. Finally,

a policy brief will be written to ensure that the study results are known to policy creators and can help to improve healthcare package design for older adults and informal caregivers.

Expert panel

Throughout the entire study, an expert panel will be consulted on the design and content of the DCE, and on the inferences made from its execution. The expert panel will include researchers who have experience with doing DCEs, policy-makers, health insurers, patient advocacy groups, persons with dementia and informal caregivers. The experienced researchers will be asked to provide guidance and feedback on the methodological choices made in the DCE design. Subsequently, the envisioned outcome of the DCE study will be discussed with policymakers and health insurers to gain insights concerning the comprehension and appropriateness of this envisioned outcome. The inclusion of policy-makers and health insurers in this phase will allow for the opportunity to make changes to the study design that help to realise implementation.

Participants

This study aims to identify preferences of persons with dementia and informal caregivers AIP; therefore, persons with dementia who live in a long-term care facility will not be included in this study. Additional exclusion criteria will consist of (1) persons who are cognitively impaired to the extent that no conversation can be held with them; (2) people who are unable to provide informed consent. It is know that dementia diagnoses are often delayed, especially in migration populations[25]; therefore, people without a formal diagnosis will not be excluded a priori. However, recruiting participants through healthcare professionals, day-care centres and social organisations that serve persons with dementia and informal caregivers will ensure that all persons have a dementia indication. For the final DCE, the telephone-based interview for cognitive screening (TICS) will be administered to describe the study participants.[26]

Prior to the interviews, focus groups, or DCE choice tasks, the researchers will go through the information letter and informed consent form together with the participants to ensure proper understanding and provide the opportunity to ask for clarifications. Subsequently, participants will be asked to provide written informed consent. If participants are unable to write, verbal continued informed consent will be used.[27] Throughout the study, participants will be continuously reminded that they are participating in research to ensure that they remain informed and are comfortable to continue.[27] It will be stressed that participation can be stopped at any moment.

Attribute and level development for Dutch persons with dementia and informal caregivers

Study phases 1 and 2 are already partly completed, as interviews and focus groups were held with persons with dementia and informal caregivers across the Netherlands to identify attributes and levels (table 1).[28 29] The identified attributes and levels were similar for persons with dementia and informal caregivers; however, they prioritised the care components differently.[29] People with dementia prioritised day-to-day help and social care, while for informal caregivers, priorities were information about dementia, organisation of care and emotional support.[29] Unfortunately, no persons with a migration background were included in these qualitative studies. Therefore, the interviews and focus groups will be repeated with persons with dementia and informal caregivers with a migration background to ensure the attributes and levels are applicable to this part of society as they have a higher risk for dementia compared with people with non-migration background.[12]

Table 1. Attribute description and corresponding levels

Attribute	Description	Possible levels
In-home care	I can get assistance at home with personal care such as showering, dressing, or medication	- Daily on a fixed time - 24/7 on demand
Help with daily activities	I can get assistance at home with household tasks such as groceries, laundry, cooking, cleaning, or help with doing my finances	- Once per week - Multiple times per week
Social activities	I can participate in social activities that I like to do	- At a day-care facility - At home
Emotional support	I can talk to someone when I feel down or want to share my worries	- Peer support group - Psychologist - Telephone helpline - Case manager
Information about dementia	I can get information about having dementia	- Telephone helpline - Case manager
Navigating the healthcare system	I can get assistance with organizing care, and help with insurances	- Telephone helpline - Case manager
Home adaptations and tools	I can get home adaptations and tools such as a stair lift, grips in shower and toilet, or a personal alarm	- No reimbursements - Fully reimbursed

Note: current list of attributes may need to be updated after expert panel review and interviews with persons with dementia and informal caregivers with a migration background.

Attribute identification for persons with dementia and informal caregivers with a migration background

To identify care preferences and needs of persons with dementia and informal caregivers with a migration background, semi-structured interviews will be performed across the Netherlands. Participants will primarily include persons with dementia and informal caregivers with a Turkish, Moroccan or Surinamese background as these are the largest groups of non-western immigrants in the Netherlands and they are known to have a high risk for developing dementia.[12] People living with dementia who do not speak Dutch as their first language will be welcome to participate.

Participants will be recruited with the help of daycare centres, general practitioners and organisations that serve persons with a migration background (Pharos and Netwerk van Organisaties van Ouderen Migranten (NOOM)). The organisations will inform potential participants about the study, and interested participants will be provided with a bilingual invitation letter. The interviews will be conducted in the preferred language of the participants: Turkish, Moroccan-Arabic, Tarifit or Dutch.[12] Interviews will be conducted by trained bilingual interviewers. Persons with dementia and informal caregivers will be interviewed separately. However, since it is important that participants feel comfortable, if they strongly wish to be interviewed together this will be permitted.

The interviews will be semi-structured, which means that an interview guide (online supplemental file 1) will be used to provide some structure, while leaving room for new topics to be brought up by the participants. The interview guide will generally be based on the guide (online supplemental file 2) of the interview study for persons with non-migration backgrounds,[28] with additions based on findings of previous studies that focused on persons with dementia and informal caregivers with a migration background.[30 31] The cultural sensitivity and understandability of the interview guide will be assessed by Pharos, centre of expertise in health disparities and experienced researchers (CS and ÖUB). The interviews will be transcribed and translated by the bilingual interviewer who conducted the interviews. Respondents will have the opportunity to review the translated transcripts, which will help to ensure proper interpretation and provide opportunities to give clarifications. It will be stressed that this is voluntary; participants are free to choose if they wish to read the translated transcripts. Interviews will be held until data saturation is reached, which is expected after approximately 10 interviews for each group.[32] Reflexive thematic analysis will be used to analyse and identify relevant patterns within the data.[33 34] Coding of the data will be done with both a deductive and inductive approach, starting with certain theoretical or empirical assumptions, with an open approach.[33] The results will provide a list of attributes (care components) that are important for persons with dementia and informal caregivers with a migration background.

Attribute prioritisation and the development of attribute levels

To understand the relative importance of the care components that are identified, mixed focus group sessions will be held with a new sample of persons with dementia and informal caregivers with a Turkish, Moroccan or Surinamese background.[12] Focus groups create an environment in which participants can share their experiences and build on each other's knowledge.[29] To ensure a free discussion, informal caregivers will not be participating in the same focus group as their person with dementia.[29] Participants will be recruited with the help of previously mentioned organisations. To facilitate dialogue between the participants, focus groups will include participants with similar migration backgrounds and linguistic preferences. The focus groups will be conducted by trained bicultural interviewers. The focus group session will include a quantitative ranking exercise in which persons with dementia and informal caregivers will be asked to list the care components from most important to least important.[29] For this ranking exercise, cards with the previously identified care characteristics, containing visual and written information will be used. During the focus group, the reasoning behind the choices made in the ranking exercise will be discussed.

Focus groups will be held until saturation is reached, which is expected after approximately six sessions, each including persons with dementia (n=4) and informal caregivers (n=4). Focus groups will be transcribed and translated by the trained bilingual interviewers. Participants will be provided with the opportunity to read the translated transcripts and, if necessary, provide clarifications. Reflexive thematic analysis will be used to analyse and identify relevant patterns within the data.[33 34] Coding of the data will be done with both a deductive and inductive approach, starting with certain theoretical or empirical assumptions, with an open approach.[33] The results will consist of a ranking of the attributes (care components) and a description of the attribute levels (characteristics of care components).

DCE pilot

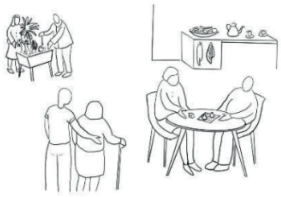
For the DCE pilot, the list of attributes that has previously been identified (table 1) will be updated with the findings of the qualitative studies with persons with dementia and informal caregivers with a migration background. The pilot will include both individual DCE rounds with the persons with dementia (n=4) and informal caregivers (n=4), and dyadic rounds with both the person with dementia and their informal caregiver. The in-person pilot will include the testing of respondents' understanding of choice tasks and the appropriateness of the included attributes and attribute levels. Furthermore, the pilot will help to illustrate if the length of the DCE survey is acceptable. Based on the pilot, changes might need to be made to the DCE survey to increase appropriateness and understandability, as well as manage survey complexity for persons with dementia.

The final DCE

The final DCE will include three rounds: (1) persons with dementia, (2) informal caregivers and (3) dyadic rounds with both the persons with dementia and informal caregivers. The first two rounds will help to elucidate individual preferences, while the dyadic round will help to elucidate joint preferences. Identifying joint preferences is important since decisions about care are often made by multiple individuals.[35–37] Furthermore, the dyadic DCE round can pose as an opportunity for the person with dementia and their informal caregiver to have an in-depth conversation about their preferences and needs, which could lead to better mutual understanding.[38] It is likely that preference adaptation will occur; however, as shown in previous research, this adaptation can be from both the person with dementia and the informal caregiver.[38] Informal caregivers were not primarily dominant in dyadic DCE rounds, in fact the informal caregivers were found to be helpful in assisting the person with dementia to complete more choice tasks.[38] An active role of the researcher administering the DCE choice tasks is needed to help guide the dialogue in the joint DCE rounds. People with dementia will be encouraged to state their preference and motivation first to minimise agency of informal caregivers.[38]

The complexity of a DCE can be challenging for persons with dementia.[39–41] However, a recent study found that persons with moderate cognitive impairment can complete DCE choice tasks.[38] Therefore, persons will not be excluded a priori based on their level of cognitive impairment. The following options in the DCE design will help to lower the cognitive burden for persons with dementia. First, illustrations will be used to visualise the choice sets and included attributes. Figure 2 provides an example of such an illustration.[38] The illustrations are made by a graphic designer who has experience illustrating pictures for persons with cognitive impairments. Second, the DCE will have binary choice tasks, asking participants to choose between packages A and B, instead of including multiple alternatives (eg, additional packages C or D). Participant will complete a maximum of six choice tasks, consisting of three attributes and two corresponding levels.[38] Blocked fractional factorial designs[42] will be created with the use of Ngene. Finally, the DCE will start with a practice round to test decision making skills.[38] Persons with dementia will be asked to think aloud while completing the choice tasks. The think-aloud technique is commonly used in research to make thought processes of participants observable for researchers.[43] It has been found useful in supporting persons with dementia to complete DCE choice tasks, as it enables researchers to observe difficulties and, if needed, provide guidance or remind persons with dementia about the rules of the choice tasks.[38]

Figure 2. Illustrated discrete choice experiment choice tasks.

	Package A	Package B
 I can participate in activities that I like and socialize with other people	**Once per week** activities are organized **at a daycare center**	**Multiple times per week** there is someone **coming to my house** to do activities together
 I can talk to someone if I want to share my worries or concerns	I can talk to a **peer support group**	I can talk to my **case manager**
Select your preference	☐	☐

Power calculation

Envisioning a two-alternative choice task and four replicates per dyad, a minimum sample size n≥576 is recommended for a DCE to reliably achieve 95% CIs on true uptake probabilities of 0.4.[44] Therefore, the goal will be to achieve a sample size of 600 dyads of persons with dementia and informal caregivers, covering all targeted groups. Purposive sampling of minority groups, people living in urban and rural areas, and people with different educational levels will be used. In addition, sampling across the country will help to make the healthcare package as nationally representative as possible.[45]

Participants will be recruited through general practitioners, geriatricians, day-care facilities and organisations that serve persons with dementia and informal caregivers (Alzheimer Nederland, Pharos, NOOM). The professionals will inform potential participants about the study, and provide them with the (bilingual) information letter. With the participants' consent, the researchers will obtain their contact information form the professionals. The researchers will contact the potential participant by telephone to answer any remaining questions and to administer the TICS.[26] The

researchers will schedule an appointment at the participants home to complete the DCE choice tasks in person.

Outcomes

The main outcome of the DCE study will be the relative importance of the attributes (care components). The relative importance of each attribute will be calculated as the difference between the preference weights of the most and least preferred level of that attribute.[46] The relative importance will be scaled so that 10 indicates the most preferred attribute. The difference between individual and joint DCE round will be analysed with summary statistics and bivariate comparisons.

A contingent valuation approach will be used to identify the participants' willingness to pay (WTP) for the most preferred programmes outside of the DCE.[47 48] While out-of-pockets costs for social care does not currently occur in the Netherlands yet, this may soon change. Therefore, an indication of the WTP is helpful for policy-makers and health insurers. At the end of the DCE, participants indicate their preferred envisioned package over their current service provision, they will be asked if they are willing to pay an additional monthly out-of-pocket fee of €50 for this package. If participants answer this question with yes, additional questions with out-of-pocket fees of €100 and €200 will be asked.[47] If participants answered no to the initial question of €50, similar questions with an amount of €25 and €12,50 will be asked.[47] Finally, participants will be asked to indicate their maximum WTP in an open-ended question.[47] For the analysis, the maximum price expressed in the open-ended question will be used and summarised through the median and IQR.[47]

Statistical analysis

The DCE data will be analysed with a random parameters logit (RPL) model.[46] For each attribute level, coefficient estimates will be estimated from the RPL model, which can be interpreted as the relative preference weight.[46] Individual and joint models will be created to evaluate preferences of persons with dementia and informal caregivers at the individual and joint DCE rounds.

To analyse if persons with dementia and informal caregivers with a migration background have different preferences, post hoc subgroup analysis will be conducted. Dummy coded variables will be added to the RPL model to identify participants that are part of given subgroups. The attribute levels in the RPL model will be interacted with the dummy variable, and all interaction terms will be added to the original RPL model.[46] The estimated parameters of the interaction terms will illustrate the difference in preferences between the subgroup (persons with a migration background) and the reference group (persons without a migration background).[46] This method can also be

used to analyse if there are different preferences based on other subgroups, such as socioeconomic status.

Finally, the attributes with the highest relative importance can be used to build most preferred programmes (healthcare packages). To ensure validity of these results for health insurers and government, the uptake of the most preferred programmes will be tested on a subsample of the target population. Model predictions will be verified by creating the most preferred programmes according to the preferences of persons with dementia and informal caregivers that were found in the DCE. A new sample will be collected of 50–60 participants to test the uptake of the most preferred programmes by asking participants which one they would rather have over their current service provision.[49]

Discussion

The discrete choice methodology described in this paper enables persons with dementia and informal caregivers to participate in policy formulation and evaluation. It is assumed that this will help to avoid crisis situations and improve the quality of life of persons with dementia and their informal caregivers. Furthermore, the outcome of the final DCE will be a ranking of the most preferred care components represented in a care package. This helps health insurers and the ministry of health to maximise their chances for designing healthcare packages that are appropriate, useful and meaningful.

Furthermore, this study protocol provides an important methodological contribution. It is a clear guide on how to build an inclusive DCE, covering the important methodological choices throughout the required study phases. Moreover, it provides guidelines on how to include under-represented groups in DCEs. The methodological choices described to help include persons with dementia with a migration background, can be used to include other under-represented groups such as people with low (health) literacy.[50 51] Finally, this study provides an example of how to overcome language barriers in research and knowledge dissemination.

Strengths and limitations of this study

A strength of this study will be that it is the first study to include informal caregivers and persons with dementia to identify AIP preferences that has been codesigned with health insurers, policy-makers, patient advocacy groups, healthcare professionals, researchers, informal caregivers and persons with dementia. Innovative and rigorous economic methods will be employed to evaluate AIP preferences. Another strength is the inclusion of persons with dementia with different migration backgrounds, which can lead to a better understanding of their needs since they are typically underrepresented in research.

A limitation of this study is the generalisability of results, as not all migrant groups living in the Netherlands may be included. In addition, the chosen recruitment strategies make it unlikely for persons who do not have a diagnoses to be included in this study. Persons with communication difficulties, such as hearing or vision loss, will have more difficulties to participate in DCEs. However, the participants ability to complete the DCE will be assessed with practice choice tasks. Finally, enabling persons to participate from their own homes helps to include persons with limited mobility. The research team strives to make the study as inclusive as possible

Ethics and dissemination

Based on the study protocol, the Ethics Committee (METC) of the Amsterdam University Medical Centre waived the obligation for the study to undergo formal ethical approval as is described under Dutch law in the Medical Research in Humans Act, January 2019 (ref W23_112 #23.137).

Consent

This is a prospective study and pseudonymised data are used; written and continued informed consent will be obtained from the participants prior to participation. This is consistent with current European legislation under the General Data Protection Regulation. This study will abide by the Declaration of Helsinki and present ethical requirements.

Contributors

JLM-V conceptualised the study and developed the study design together with the other researchers. IV and JW contributed to the development of the study design, data collection and analysis. The authors provided input for the study design from their own area of expertise; inclusive research (CS and ÖU-B), qualitative research (NHML), discrete choice experiments (EdB-G and JDS). IV wrote the manuscript, the coauthors read, edited and approved the final version.

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Competing interests

None declared.

Patient and public involvement

Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

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Supplementary material. Interview guide Dutch persons with dementia

Introduction: Thank you for participating in this study. My name is [short introduction interviewer]. The research that we are doing is focused on persons who are living at home. I would like to talk with you about your living situation at home, the daily things that you do and the help that you receive. If I ask a question that is not clear, feel free to let me know. There are no wrong answers, you can say anything that comes to mind. I would like to record the interview, if that is ok with you. The recordings will only be shared with my colleagues. The conversation will not be shared with your doctor or family. We will leave out your name. your name will be replaced by a number. *[reading information letter + informed consent – singing informed consent – start recording]*

Before we start, I have a few general questions that I would like to ask you: 1) What education did you receive? 2) Where were you born? 3) How old are you? 4) Where do you live? 5) Do you live alone? 6) Where does your family live?

Theme	Explanation theme	Examples of questions
Introduction	Start-up questions giving respondent room to talk and bring up topics	Can you tell something about yourself? How is it going at home? How is your health
Daily activities	Talk about: (help with) cleaning, cooking, showering, getting dressed etc.	What are daily activities that you do? What does your day look like?
	Find out if they get help with these activities, from who and how they value this help.	Do you receive help with these daily activities? How would you like to be helped with these activities?
Social activities	Talk about: social activities such as visiting other persons, playing cards etc.	What are things that you like to do? What are things that you like to do with other people?
	Ask if people go to a daycare facility + how they value this	With who do you like to do these activities? How would you like to be supported in this?
	For informal caregivers: ask if they have time for themselves, do their own thing.	
Adaptations in the home	Talk about: adaptations such as a stair lift, grips in the shower, alarm system etc..	What changes are made in your house? What are things that you would like to change about your house?
Information	Talk about: information received after diagnosis	Have you gotten information about what to expect (after diagnosis)? From who did you get this information? How was the support of your general practitioner/ case manager dementia?
	about what to expect or how to cope with dementia.	What questions do you have about dementia?
Cognitive training	Talk about: if people use tools to help them remember	How do your memory problem affect you? What tools do you use to help you remember?
Emotional support	Talk about: how people feel about their situation, their worries or concerns.	How do you feel about your situation (dementia diagnosis)?
	Do they talk about this and with whom.	do you have someone to discuss your concerns with?

Theme	Explanation theme	Examples of questions
Closing questions	Question to end the interview – ask if participants want to add something	What are things that you would like to get help with? Are there things that you would like to add?

Examples of probing questions

- With who do you do this? / Who helps you with this?
- How often do you do this? / How often do you get this help?
- What do you like about this help/support?
- What do you dislike about this (help/support)?

Thank you so much for sharing your story. *[ask if people wat to be informed about the results of the study]*

Supplementary material. Concept version interview guide persons with dementia with a migration background

Introduction: Thank you for participating in this study. My name is [short introduction interviewer]. The research that we are doing is focused on persons who are living at home. I would like to talk with you about your living situation at home, the daily things that you do and the help that you receive. If I ask a question that is not clear, feel free to let me know. There are no wrong answers, you can say anything that comes to mind. I would like to record the interview, if that is ok with you. The recordings will only be shared with my colleagues. The conversation will not be shared with your doctor or family. We will leave out your name. your name will be replaced by a number. *[reading information letter + informed consent – singing informed consent – start recording]*

Before we start, I have a few general questions that I would like to ask you: 1) What education did you receive? 2) Where were you born? 3) Where were your parents born? 4) How long have you lived in the Netherlands? 5) How old are you? 6) Where do you live? 7) Do you live alone? 8) Where does your family live?

Theme	Explanation theme	Examples of questions
Introduction	Start-up questions giving respondent room to talk and bring up topics	Can you tell something about yourself? How is it going at home? How is your health?
Daily activities	Talk about: (help with) cleaning, cooking, showering, getting dressed etc. Have attention for religious activities – praying, going to mosque/church Find out if they get help with these activities, from who and how they value this help.	What are daily activities that you do? What does your day look like?
Social activities	Talk about: social activities such as female/male groups, visiting other persons etc. Ask if people go to a daycare facility. For informal caregivers: ask if they have time for themselves, do their own thing.	What are things that you like to do? What are things that you like to do with other people?
Adaptations in the home	Talk about: adaptations such as a stair lift, grips in the shower, alarm system etc..	What changes are made in your house? What are things that you would like to change about your house?
Information	Talk about: information received after diagnosis about what to expect or how to cope with dementia.	Have you gotten information about what to expect (after diagnosis)? What questions do you have about dementia?
Contact care professionals	Talk about: how people experience contact with care professionals such as home care, general practitioner and the case manager dementia.	What do you think of the home care providers? How is your contact with the general practitioner?

Theme	Explanation theme	Examples of questions
Navigating the healthcare system	Talk about: does the person arrange care themselves or do they get help (from general practitioner, or case manager))	How is the care arranged? Who arranges this support/care?
	Do they struggle with this or not	How would you like to be supported with the arrangement of care?
Emotional support	Talk about: how people feel about their situation, their worries or concerns. Do they talk about this and with whom.	How do you feel about your situation (dementia diagnosis)? do you have someone to discuss your concerns with?
Closing questions	Question to end the interview – ask if participants want to add something	What are things that you would like to get help with? Are there things that you would like to add?

Examples of probing questions

- With who do you do this? / Who helps you with this?
- How often do you do this? / How often do you get this help?
- What do you like about this help/support?
- What do you dislike about this (help/support)?

Thank you so much for sharing your story. *[ask if people wat to be informed about the results of the study]*



Chapter 5

Important components for Dutch in-home care based on qualitative interviews with persons with dementia and informal caregivers

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Abstract

Background

Dementia care in the Netherlands is increasingly dependent on informal care and has the aim to keep persons with dementia at home for as long as possible. However, little is known about the preferences and needs of people with dementia living at home. Including people with dementia and their informal caregivers in research and policy creation could help to identify necessary forms of support, and tailor care to their personal preferences and needs.

Objective

To identify important components of in-home care for persons with dementia and their informal caregivers in the Netherlands.

Design

Semi-structured interviews across the Netherlands, between March and June 2019 using thematic analysis.

Setting and participants

Persons with dementia (n = 5) and informal caregivers (n = 14) were primarily recruited through dementia care organizations. Additionally, a case manager was recruited to reflect upon the semi-structured interviews findings.

Results

Five themes concerning important care components were identified including the need for: a social network, formal care, information, emotional support and easier access to care. The complexity of the dementia care system posed a common difficulty for persons with dementia and informal caregivers.

Conclusion

This study suggests that a dementia care package should be developed that includes both informal and formal care, the provision of information and emotional support, and help with access to care. The creation of this care package could help to tailor dementia care to the preferences and needs of the persons with dementia and their informal caregivers.

Keywords

accessibility of health services; dementia; health-care economics and organizations; home-care service; informal care; patient preference; qualitative research.

Introduction

The Netherlands has the highest long-term care expenditures compared to all other member countries of the Organization for Economic Co-operation and Development.[1,2]. It spends 3.7% of its gross domestic product on long-term care; double the average of other countries.[1] In 2015, the Netherlands implemented extensive reforms to their long-term care in an attempt to control expenditure growth and provide sustainable long-term care. The reform consisted of (a) reorienting norms, resulting in several social care services being provided by family members and local community networks instead of formalized care; (b) a shift from residential to non-residential care, (c) decentralization of non-residential care such as home care and (d) expenditure cuts.[3] Moreover, approximately 600 care homes and nursing homes were closed.[3-5]

As persons with dementia make up a substantial proportion of nursing home populations,[3] these reforms dramatically changed their care. Dementia is known as the one of the leading causes of death in older adults and the most costly disease[6] in the Netherlands, costing 6.6 billion euros in 2015, corresponding to 7.7% of the total Dutch health-care expenditures.[7,8] Franke et al[7] found that since the reforms, the number of crisis situations (unplanned hospitalizations and nursing homes admissions) and the burden on informal caregivers increased. These developments imply an increased need to understand how to prevent crisis situations for persons with dementia and their informal caregivers living at home.

Despite the need for evidenced-based policy to ensure proper health-care services, people with dementia and informal caregivers are frequently excluded from policy creation; therefore, little is known about their personal preferences or needs. There is a plethora of in-home support options available in the Netherlands, such as help with personal care or daycare facilities.[6] However, it is unclear if these options are known to the target population and if the care options are aligned with, or sufficient for the preferences and needs of the people with dementia and their informal caregivers.

A previous UK-based study by Chester et al[9] included person with early-stage dementia and their informal caregivers in research, identifying their personal preferences for home-care services. The results of this study indicated that persons with early-stage dementia preferred opportunities for social and recreational activities and support with their personal feelings and concerns.[9] The informal caregivers appeared to prefer support with personal feelings and concerns and information on coping with dementia.[9] Additionally, another UK study by Kampanellou et al[10] that investigated the care preferences of informal caregivers of people with later-stage dementia demonstrated that respite care and daily living assistance were the most preferred attributes for the informal caregivers

of people with later-stage dementia. However, as the Dutch health-care system differs from the health-care system in the UK, it is unclear if these findings are applicable to the Dutch dementia population.

In this study, we used semi-structured interviews and had an in-depth discussion with an expert, to identify important components of in-home care for persons with dementia and their informal caregivers in the Netherlands. By including not only informal caregivers, but also persons with dementia, unique insights about their preferences and needs can be obtained. These findings can be used to build dementia care packages for the improvement of dementia care, enabling persons with dementia to stay at home for as long as possible and to avoid crisis situations such as unplanned hospitalizations or nursing home admissions. Additionally, including persons with dementia and informal caregivers in research and the development of care packages is an important component of patient-centred care and will help patient empowerment.

Methods

Study design

This qualitative study was conducted between March and June 2019 across the Netherlands. In the first phase of the study, semi-structured interviews were held with persons with dementia and informal caregivers. Afterwards, there was an in-depth discussion with a case manager to reflect on the findings. All interviews were held in Dutch. Based on the study protocol, the Ethics Committee (METC) of the Amsterdam University Medical Center waived the obligation for the study to undergo formal ethical approval as described in the Medical Research in Humans Act, with the reference number: W19_126#19.159. Written informed consent was obtained from the participants prior to all interviews.

Study participants

Persons with dementia and informal caregivers were approached. Several organizations assisted with recruitment, including Odense Huis (daycare for persons with dementia) and Alzheimer Nederland (Dutch Alzheimer Association). Participants were recruited from rural as well as urban areas in the Netherlands. Participants were contacted via telephone or email to provide further explanation about the study and to confirm their willingness to participate. Exclusion criteria consisted of (a) people who were cognitively impaired to the extent that no conversation could be held with them; (b) people who did not provide informed consent; and (c) people who were unable to speak Dutch or English. In total, 13 interviews were held, including five people with dementia and 14 informal caregivers. Four persons with dementia were interviewed together with their informal

caregivers and in two interviews informal caregivers were interviewed simultaneously. The remaining participants were interviewed separately. Following these interviews, saturation was reached as no new themes or codes emerged from the data. Finally, a case manager was recruited to reflect upon the research findings of study phase one.

Data collection

All interviews were conducted at the participants' homes. The interview guide consisted of broad questions about the in-home care to identify the most important factors for the participants. Additionally, more detailed questions were included focused on the findings of previous research focusing on unmet needs of informal caregivers and persons with dementia.[9,10] Detailed information about the interview guide can be found in Table 1. The interview guide was improved through several rounds of feedback among the research team. During the interview process, the interview guide was iteratively reviewed and revised when new topics were introduced. All interviews were audio-recorded, transcribed verbatim and translated from Dutch into English by the research team. The interviews lasted between 22 and 93 minutes.

Table 1. Topics and probing questions of the interview guide

	Topic	Example of probing question
1.	Satisfaction related to in-home care	Which forms of care or support did you use lately? How did you experience this care?
2.	Help with activities of daily living	Do you receive help with household tasks? Are you satisfied with this help?
3.	Memory training	Do you use tools to help you remember?
4.	Adaptations in the home	Were there adaptations made to your home?
5.	Respite care/ Day care	Do you sometimes get a break for your caregiving tasks? Do you go to a daycare facility
6.	Education and advice	Do you get help or information on what dementia entails? Do you get help or information on coping with dementia?
7.	Emotional support	Is there somewhere you can go with you worries? Is there somewhere you can express your feelings?
8.	Social involvement	Do you participate in certain social activities (playing cards etc)?

Data analysis

To analyse and identify relevant patterns in the data set, thematic analysis was performed in which codes and themes were derived from the data.[11] Thematic analysis is useful when aiming to derive meaning from a data set, taking both an inductive and a deductive approach. That is, the data are analysed starting from certain (theoretically or empirically driven) assumptions, and with an open approach. The interviews were analysed and coded independently by multiple researchers (JMV, JW and IV). Subsequently, findings were compared and discussed, and a coding scheme was developed iteratively. MAXQDA 11[12] was used for data analysis.

Results

Participant characteristics

Table 2 presents an overview of the participants' characteristics. In total, 20 participants were included: five persons with dementia, 14 informal caregivers and one case manager. The five key themes concerning participants' care preferences and needs that emerged from the data consisted of: (a) importance of the social network, (b) importance of formal care, (3) need for information, (d) need for emotional support and (e) need for easier access to care. These will be discussed in detail below.

Table 2. Characteristics of the study population

NR.	Participant	Dementia stage	Living situation	IC involved	Social network involved
1.	Person with dementia	Later-stage dementia	With partner	Yes	Family, neighbours
2.	Person with dementia	Early-stage dementia	With partner	Yes	Family
3.	Person with dementia	Early-stage dementia	With partner	Yes	-
4.	Person with dementia	Early-stage dementia	With daughter	Yes	Family
5.	Person with dementia	Middle-stage dementia	Alone	Yes	Family, neighbours
NR.	**Participant**	**Relation to PwD**	**Employment status**	**Multiple IC**	**Social network involved**
6.	Informal caregiver	Neighbours of PwD	Retired	No	Neighborhood
7.	Informal caregiver	Partner of PwD	Retired	No	-
8.	Informal caregiver	Partner of PwD	Working	Yes	Family, neighborhood
9.	Informal caregiver	Partner of PwD	Working	Yes	Family
10.	Informal caregiver	Partner of PwD	Retired	Yes	Family
11.	Informal caregiver	Partner of PwD	Retired	Yes	Family
12.	Informal caregiver	Daughter of PwD	Working	Yes	Family
13.	Informal caregiver	Daughter of PwD	Retired	No	-
14.	Informal caregiver	Daughter of PwD	Working	Yes	Family, neighborhood
15.	Informal caregiver	Partner of PwD	Retired	Yes	Family
16.	Informal caregiver	Daughter of PwD	Retired	Yes	Family, neighborhood
17.	Informal caregiver	Son in law of PwD	Retired	Yes	Family, neighborhood
18.	Informal caregiver	Son of PwD	Working	No	-
19.	Informal caregiver	Grandchild of PwD	Student	Yes	Family, neighborhood

Abbreviations: IC: informal caregiver; NR.: number; PwD: person with dementia. a Multiple IC: only if multiple people provide informal care on a regular basis.

Importance of the social network

Informal care provided through the social network of the persons with dementia played an important role in the lives of persons with dementia and their ability to live at home. Informal caregivers helped the persons with dementia with a wide variety of tasks such as grocery shopping, finances or going to doctors' appointments. These were often tasks that fell outside the scope of the formal caregivers, who were not allowed to help with these sorts of activities. However, as the interviewed case manager emphasized, especially for persons with dementia, it is important that there is more time to help with other sorts of daily activities.

> *A lot of big home-care corporations say you (their home care staff) can only help with washing, taking medication, and bathing and then you have to go on to the next client. When especially in this patient group [persons with dementia] it is also important that you have some extra time. Participant 20 (case manager)*

This vision was shared by some of the informal caregivers that indicated that they felt there was a lot of attention to the more medical side of support but that more attention should be paid to the other aspects of daily living, such as nutrition, exercise and social contact.

> *Exercise, nutrition, and yes actually all aspects around living. There is a lot in the area of care, but I believe that you have to find things that support people in what they can do, and I really missed that. Participant 12 (informal caregiver)*

Importance of formal care

In addition to the satisfaction with informal care, most persons with dementia indicated that they were also pleased with the formal care provided. Both informal caregivers and persons with dementia indicated they had a lot of services available to them that they considered to be valuable and helpful to help stay at home for as long as possible. These valued services were as follows: the daycare facility, where people with dementia participated in various activities and came in contact with other people; help with daily activities, which included help with personal care, meal services, and someone that came to remind and help the person with dementia to take their medication; and finally adaptations (eg hand grips in the bathrooms) made in the home which increased the safety of the living situation.

Participants reported mixed satisfaction with case management services. Some persons with dementia and informal caregivers indicated that their case manager was very involved. These case managers provided them with information, guided them in the arrangement of care and provided a lot of attention for their personal needs and well-being.

Yes, he [the case manager] really helps with the entire process and things that you cannot foresee. (...) The case manager is an expert and has a very important task. He can comfort you, he can arrange things if necessary, for example, placement on a waiting list. (...). He can assess the situation and is a sounding board if the care at home needs to be scaled up. Then yes, it is nice if you can consult with someone. participant 18 (informal caregiver)

Other persons with dementia and informal caregivers described their case manager as less involved and concerned with their situation. They explained that the case manager did not help them sufficiently in the arrangement of care or search for information. Some informal caregivers also indicated that they were not always sure what their case manager was supposed to help them with and that they found it hard to know if they were asking the right questions.

[About the case manager] She was a nice person but, well, she was of no use to us. Things that we asked her to help us with, well she said she would like to help but in reality, it never got done. At some point it just kind of stopped. participant 3 (person with dementia)

These differences in satisfaction with case management were acknowledged by the case manager interviewed in this study. Additionally, the case manager indicated that there might be regional differences in case management. He explained that dementia care is operated regionally and that in some regional chains, things are organized better than in others. Additionally, the case manager indicated that there are differences among health insurers regarding the importance given to dementia care and the money available for dementia care. This means that in some regions, people are offered more hours of case management than the people in other regions.

Need for information

Even though some participants received useful and desired information from their case manager, all informal caregivers emphasized that a lot of questions were raised by the dementia diagnosis and the process of taking care for the person with dementia. This information need can be divided into three different areas. First, persons with dementia and informal caregivers expressed a need for information about what a diagnosis with dementia entails and how they can expect the disease to evolve in the future. Notably, many participants, especially informal caregivers, indicated that they found the provision of this information, at the point of diagnosis, insufficient.

An amazing geriatrician, whom my husband really liked (...) Who examined him, very pleasant and eventually he said I am sorry you have Alzheimer's [disease] and there is nothing more I can do for you. Well, there you are and the only thing he then said was it would be very nice if you want to participate in a study. (...) I have to say it was a disgrace. Participant 10 (informal caregiver)

Second, informal caregivers described a need for information and tips on how to cope with certain behaviours of the person with dementia. Informal caregivers indicated that they wanted to know which difficulties or aspects they should pay attention to in the home situation. Additionally, they wanted to know the best way to respond to certain dementia symptoms or behaviours of the person with dementia.

> *You have a lot of questions, but your parents [with dementia] have questions too (...) You are looking for practical tips, things you can expect, explanations for the behavior of your parents. How to react to them, what is wise, should you go along with it or not. participant 12 (informal caregiver)*

Finally, informal caregivers and persons with dementia indicated the need for information about the care and support options available. Many participants explained that it was hard to get an overview of the available care services and that they were often unaware of certain possibilities. This was also illustrated during the interviews when some informal caregivers appeared to be unaware that they had the right to a case manager or did not even know what a case manager was. Persons with dementia and informal caregivers indicated that it would be useful if they were provided with an overview of the possibilities in terms of care and support services.

> *Interviewer: Ok, but did you know that case management was a possibility? Was it offered to you by, for example, the general practitioner? Respondent: No. participant 16 (informal caregiver)*

Need for emotional support

In addition to the need for information, many participants indicated a need for emotional support. Especially the informal caregivers indicated that taking care of the person with dementia was emotionally trying and that they often felt the need to express their worries or feelings. Some informal caregivers found this emotional support in support groups with other informal caregivers. These groups gave them a space to talk about the things that they were going through. Additionally, the informal caregivers mentioned that they learned from the other informal caregivers as they discussed common issues and their solutions or coping strategies to these issues. These support groups were often offered by the daycare facilities or case managers.

> *I had a lot of help from the mornings here [daycare facility], the informal caregiver consultation hour, the informal caregiver support group. Where you could talk about things that you could not talk about anywhere else, things you did not want to talk about. (...) You learned from each other. We cried together, we laughed together. It meant a lot to me. participant 9 (informal caregiver)*

However, not all informal caregivers had access to, or knew about, these informal caregiver support groups. This left several informal caregivers with an unfulfilled need for emotional support. These participants indicated that they would have liked to have someone to share their worries or emotions with.

> *I think it would be a good plan that when something like that is over [taking care of a person with dementia], but also when it is still happening, that you [as informal caregiver] have help. Just someone to talk to sometimes. I think I really need that sometimes. participant 6 (informal caregiver)*

Need for easier access to care

The persons with dementia and informal caregivers also experienced difficulties with access to care. First, it is important to note that if people are unaware of the care services available to them, this means they will not be able to access these care services. Furthermore, both persons with dementia and informal caregivers expressed that they found the dementia care system complicated and fragmented. For example, how care was delivered and reimbursed by different institutions or legal acts was confusing to people. Some persons with dementia and informal caregivers who reported these difficulties with the access to care did not have a case manager or were dissatisfied with their case manager. They explained that they had to arrange care themselves, which they found complicated and time-consuming. The participants indicated that it was hard to get on overview of where they needed to be or who they needed to contact for which services or form of support.

> *In the end, you have to look into it yourself, and yes then you get telephone numbers and addresses and you have to get started with that. Well, yes you need to have a lot to offer in order to get that done. Cause I can imagine that many people do not know where they need to search for these things. That they are overwhelmed. participant 7, (informal caregiver)*

The Dutch legal framework for long-term care posed an additional problem for the accessibility of care for people with dementia living at home. These problems were caused by the Long-term Care Act (WLZ). The case manager in this study explained that when a person with dementia wants to be on the waiting list for a long-term care facility, they need to apply for a long-term care indication. When a long-term care indication is there, the indication for the Social Support Act (WMO) ends and care will no longer be financed through the WMO. This means that all care received by the persons living at home, waiting to be placed in a long-term care facility, will be financed through the WLZ. However, the budget of the WLZ is exponentially lower than the budget from the WMO and the Health Insurance act (ZVW), which means that either less care can be offered, or people need to start paying more out of pocket. As the out-of-pocket costs are quite expensive,

many people may not be able to afford the services based on their fixed retirement incomes. The case manager described this as worrisome, since people that are waiting to be moved to a long-term care facility are often vulnerable and in need of extensive care and support.

> *The moment you get a WLZ indication, your WMO indication stops and then you have to start paying your homecare, visits to the daycare facility, and domestic help through the WLZ indication. However, you have a weekly budget and that is lower with the WLZ indication than it was with the WMO indication. participant 20 (case manager)*

Discussion

Key findings

This study shows that Dutch persons with dementia as well as their informal caregivers are generally pleased with the formal and informal care that they received. This is consistent with a previous study in which Dutch informal caregivers had a positive judgement of the professional dementia care and support, throughout different regions in the Netherlands.[13] Both persons with dementia and informal caregivers in this study commonly used and valued services such as the daycare facilities, help with daily activities from home-care organizations and adaptations in the home to increase safety. Additionally, the participants in this study, especially the informal caregivers, indicated to have a need for emotional support and information. Even though some informal caregivers reported that they found and appreciated certain forms of emotional support, other informal caregivers reported to have unfulfilled support and information needs and were often unaware of the services available to them.

This need for information and emotional support, especially for the informal caregivers, has been identified in previous Dutch studies.[14,15] Additionally, a previous UK study by Chester et al[9] found that the most preferred home support options for caretakers of people with early-stage dementia included 'support with personal feelings and concerns – provided by a trained counsellor at home' and 'information on coping with dementia – provided by an experienced worker at home'. Furthermore, a study of Kampanellou et al[10] indicated that for the informal caregivers of people with later-stage dementia, respite care was the most preferred attribute for in-home support. The informal caregivers in this study did not talk about a need for respite care. However, almost all participants explained that the person with dementia went to a daycare facility several times a week. For the informal caregiver, this meant that they were temporarily released from their caregiving tasks, which could therefore be seen as a form of respite care.

Furthermore, this study shows that both persons with dementia and informal caregivers deem dementia care complex and express the need for guidance and help with the access to care. Some participants found this help and guidance in their case manager, whereas others were very dissatisfied with their case manager. These differences in satisfaction might be related to the fact that financing of dementia care is dependent on the policy of the municipalities, which puts the continuity of case management at risk.[16] Additionally, there are regional differences in the waiting times for case management, in some regions there are no waiting lists, while in other regions people have to wait months to get a case manager.[6] Furthermore, informal caregivers indicated that they did not always know what the case managers' tasks were and what they could expect from their case manager. This made it harder for the informal caregivers to know when they could turn to their case manager for advice or guidance.[16] Finally, there might be some individual differences between case managers in the way they realize their position. This might have to do with the differences in the position of the case manager in the care network, as well as case managers' background.[17] For example, case managers with a background in psychology might give more importance to the emotional well-being of the persons with dementia and informal caregivers, while case managers that do not have this background focus less on psychological aspects.

Finally, this study shows that there are some difficulties for persons with dementia who are on waiting lists for long-term care. Although these people are still at home, they are no longer applicable for the same services as provided by the social support act for community-dwelling older adults (WMO) but instead services are paid and provided through the Long-term Care Act (WLZ). This transition comes with a higher financial burden, which means that people that are living at home, waiting to be placed in a nursing home and often in need of a great amount of care, need to start paying exponentially more out of pocket. Francke et al[6] found persons with dementia in this transition phase, lost on average, five hours of care per week. It is unclear if this is the time when more persons with dementia have crisis situations. Regardless, we recommend that the WLZ law only apply once a person is actually residing in long-term care to avoid crisis situations.

Strengths and limitations

To the best of our knowledge, this study is the first interview study in the Netherlands to include persons with dementia and give them the opportunity to voice their opinions about the in-home care that they receive. This study shows that including people with dementia in research can lead to meaningful and unique insight into their personal preferences and needs, and the improvement points of care. This study can therefore be used as an example to demonstrate that, despite their cognitive impairments, people with dementia are very much capable of expressing themselves and to articulate their thoughts and opinions about the care that they receive.

There are certain limitations to this study. First, the recruited persons with dementia in this study all lived with a partner or relative, and all had an informal caregiver. Since informal care plays a crucial role in dementia care in the Netherlands,[18] it is only reasonable to assume that persons with dementia without an informal caregiver have different care preferences and needs than those who do have an informal caregiver. Additionally, most of the recruited persons with dementia had early-stage dementia. When dementia advances, people often become more dependent and demanding in terms of formal and informal care.[6-19] However, there were informal caregivers included who had their loved ones currently institutionalized or had recently died. In these cases, the informal caregivers provided recent retrospective information on the care needs for later-stage dementia.

Implications of the study

This study helps to tailor the dementia care to the reported preferences and needs of the persons with dementia and their informal caregivers. On the individual level, this could help to improve the quality of life of persons with dementia and informal caregivers and improve their living situation at home. On a societal level, this could help to maintain a safe sustainable living situation at home for persons with dementia and informal caregivers, which could help to save costs due to crisis situations such as acute hospitalizations or temporary nursing home admissions.

Based on the findings of this study, some aspects of dementia care that could be further improved were identified, such as the provision of information and emotional support. Information about the available care services should be increased, and the access to these care services should be simplified. The case manager should play an important role in these objectives since they are the central person when it comes to care for people with dementia living at home and their informal caregivers. Additionally, the financial problems with the transition of care from the WMO to the WLZ should be tackled, and the financing of care through the WLZ should start when the person with dementia actually moves to the long-term care facility. Further research is needed to identify the care preferences and unmet needs of persons with dementia that do not have an informal caregiver. Additionally, future studies should use quantitative approaches, such as surveys to validate the results of this study or discrete choice experiments to determine the relative importance of the five aspects for persons with dementia and informal caregivers. These studies could help to efficiently and effectively improve the current dementia care system for persons with dementia and informal caregivers.

To conclude, in this interview study, the important components of in-home care for persons with dementia and their informal caregivers in the Netherlands were identified. These important components included both informal and formal care, the provision of information and emotional sup-

port, and help with access to care. Creating one care package, with these identified components, would help elucidate what services are available for persons with dementia and informal caregivers and therefore make them more accessible. Moreover, including these components in dementia care packages would help to improve the dementia care in a way that it enables persons with dementia and their informal caregivers to live at home in a safe and responsible manner.

> *All aspects of living are important. There is a lot of support in the area of patient care, however, I believe you also need to support people in what it is they can do. You just need to look at the entire day and see what is needed in order to live it in good quality. participant 12 (informal caregiver)*

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Conflict of interest

There was no conflict of interest for any of the authors involved in this article.

Data availability statement

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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Chapter 6

Ageing-in-place care preferences of persons living with dementia and informal caregivers with a migration background: A qualitative interview study

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Abstract

Ageing-in-place for persons with dementia and informal caregivers is encouraged by governments and society. However, individuals with non-Western migration backgrounds are at higher risk of dementia yet underrepresented in research and care. This study aims to identify ageing-in-place care preferences of persons with dementia and their informal caregivers in the Netherlands. Semi-structured interviews (n=8 participants with dementia, n=20 informal caregivers) were analysed using reflexive thematic analysis. Findings reveal that informal caregivers feel a strong duty to care, assisting with various daily tasks. While they desire shared care with professionals, identifying concrete care needs is challenging, highlighting the need for proactive professional support. Participants also emphasized the importance of culturally sensitive in-home care, home adaptations, social care, and accessible dementia information. Additionally, the emotional impact of dementia on care recipients and caregivers underscores the need for emotional support. These insights enhance understanding of the care preferences of persons with dementia and their informal caregivers, aiding more efficient and culturally responsive health service planning.

Keywords: Dementia, ageing-in-place, person living with dementia, informal caregiver, care preferences, migration background

Background

Dementia is one of the leading causes of death, disability, and dependency among older adults globally (World Health Organization, 2017). In 2019, care for 55.2 million individuals with dementia resulted in an estimated global economic burden of 1.3 trillion US dollars (Wimo et al., 2023; World Health Organization, 2017). To cope with these growing expenditures, there has been a global policy shift towards ageing-in-place by minimizing long-term care institutionalizations for older adults and increasing the responsibilities of informal caregivers (Ranci & Pavolini, 2015; Spasova et al., 2018). Ageing-in-place is defined as "the ability of older people to live in their own home and community safely, independently and comfortably, regardless of age, income or level of intrinsic capacity" (World Health Organization, 2015 p. 36). Ageing-in-place with the help of community-based care is assumed to be less costly in comparison to institutionalized care (Spasova et al., 2018). However, the shift towards community-based care will only be successful if services are appropriate and accessible for everyone.

A systematic review found that dementia is 3.1 times more prevalent in persons with a non-western migration background compared to reference populations using European population-based samples (Selten et al., 2021). In the Netherlands, about two-thirds of migrants have a non-European background, with the largest groups being Turkish (457,100), Moroccan (429,176), Surinamese (365,352), and Indonesian (356,566) (Statistics Netherlands, 2024). Additionally, there is a sizable, younger group of migrants from other Asian countries (848,065) (Statistics Netherlands, 2022, 2024). In the Dutch context, the prevalence of dementia and mild cognitive impairment is three to four times higher for persons with a Turkish, Moroccan, or Surinamese background in comparison with the native Dutch population (Parlevliet et al., 2016). The higher prevalence is associated with cardiovascular risk factors and depression, that are more common for persons with a Turkish, Moroccan or Surinamese migration background (Parlevliet et al., 2016). Despite the higher prevalence of dementia, persons with a migration background are underrepresented in research and care (Schmachtenberg et al., 2020).

Individuals with a migration background are known to encounter numerous challenges in accessing dementia care (Duran-Kiraç et al., 2022). The access to dementia care starts with a diagnosis, however, persons with a migration background generally receive this diagnosis at a later stage of the condition (Cooper et al., 2010; Vissenberg et al., 2018). Furthermore, a strong sense of obligation to personally care for ageing parents, embedded within cultural and religious values, potentially leads to the perception of failing and fear of community stigma if one were to rely on formal support (Ahmad et al., 2020; Chaouni et al., 2020; van Wezel et al., 2016).Healthcare profession-

als need to be aware of these underlying constructs and strive to explore and understand care needs, whilst actively avoiding stereotyping and generalizing groups through 'othering' ideologies (Sagbakken et al., 2018). Finally, if care needs are successfully identified, the lack of culturally sensitive care options further complicates the access to formal care and support (Mukadam et al., 2013; Sagbakken et al., 2020). Even though it is clear that persons with a migration background face several barriers to access dementia care, it remains unknown what the implications of these barriers are for ageing-in-place.

In the Dutch context, there are some existing studies that focus on ageing-in-place for persons with a migration background, revealing the importance of neighborhoods with good housing, social cohesion, and proximity to facilities (Hussein et al., 2024; Nieboer & Cramm, 2024). However, these studies often do not include persons with dementia (Hussein et al., 2024), or are targeted at one specific aspects such as the importance of neighborhood characteristics (Nieboer & Cramm, 2024).

To successfully age-in-place persons with dementia often need support with a variety of daily activities, from both formal and informal caregivers (Pani-Harreman et al., 2021). Therefore, this study aims to identify ageing-in-place care preferences for persons living with dementia with a migration background and their informal caregivers in the Netherlands by conducting semi-structured interviews. Decisions about care are often made by more than one person, it is therefore important to include both the person with dementia and the informal caregiver (Groen-van de Ven et al., 2018). To our knowledge, this is the first paper to qualitatively report on the care preferences and needs of persons with dementia and informal caregivers with a migration background ageing-in-place in the Netherlands. The findings can be used to guide future research on building dementia care packages that are appropriate and accessible to avoid crisis situations such as, unplanned hospitalizations and long-term care admissions (Vullings et al., 2023).

Methods

Study design

For this qualitative explorative study, semi-structured interviews were conducted between March and August 2023 with persons with dementia and informal caregivers living across the Netherlands. The consolidated criteria for reporting qualitative health research (COREQ) checklist (Tong et al., 2007) was followed for the reporting of the study (Supplementary material).

Study participants

We approached adults with dementia and informal caregivers with a migration background. Purposive sampling was used to include persons across the Netherlands, in both urban and rural places. We primarily recruited first generation older adults with dementia and informal caregivers with an Indonesian, Turkish, Moroccan, or Surinamese background, because these are the largest ethnic minority groups in the Netherlands (Parlevliet et al., 2016). Inclusion criteria were: 1) adults aged 65 years and older; 2) persons who were living at home; 3) informal caregivers who were providing care to the care recipient on a regular basis. Exclusion criteria consisted of: 1) persons with dementia who were not able to engage in a conversation; 2) persons who were unable to provide informed consent; 3) persons with dementia who were living in a long-term care facility.

We recruited participants through: Pharos (Dutch centre of expertise on health disparities), general practitioners, daycare facilities, and (in)formal organisations that serve persons living with dementia and informal caregivers with a migration background. These professionals and organisations provided potential participants with a bilingual invitation letter, which contained information about the study. With the participants' consent, the researchers received their contact information and contacted them by telephone to explain more about the study and schedule an appointment for the interview.

Setting

To ensure that participants felt comfortable, the interviews were conducted in a place they preferred, mostly the participant's home, community centre, or daycare facility. Interviews were held in the preferred language of the participants, Turkish, Moroccan (Arabic dialect or Berber), or Dutch.

Data collection

The interviews were conducted by trained interviewers who were part of the research team (IV, SEJ, BAM), bilingual interviewers conducted the Moroccan (SEJ), and Turkish (BAM) interviews. We used an interview guide with a topic list (supplementary material) to provide a framework for the semi-structured interviews, while leaving room for new topics to be brought up by the participants. The interview guide was based on the results of a previous study on care preferences of Dutch persons with dementia and informal caregivers ageing -in-place (Vullings et al., 2020), and existing knowledge about the experiences of dementia care in families with a migration background (Ahmad et al., 2020, 2022; Duran-Kiraç et al., 2022). To maximize cultural sensitivity, the interview guide was modified accordingly by discussing and reviewing the guide together with researchers specialized in inclusivity. All interviews were audio-recorded and transcribed verbatim

in either Dutch or English by the researchers (BAM, SEJ & IV). The transcripts were anonymized, and field notes of the researchers were added. Transcripts were not returned to the participants, instead researchers summarized and asked for clarifications during the interviews to ensure proper interpretation and understanding.

Analysis

We used reflexive thematic analysis to analyse the data and develop themes (Braun & Clarke, 2019). Reflexive thematic analysis emphasizes the active role of researchers in creating themes, which are patterns of shared meaning (Braun & Clarke, 2019). The analysis was a combination of a deductive and inductive approach (Braun & Clarke, 2006, 2019). The researchers were guided by the empirical and theoretical knowledge of previous studies (van Wezel et al., 2016; Vissenberg et al., 2018), whilst staying close to the data and keeping an open approach.

According to the six steps of thematic analysis by Braun and Clarke (Braun & Clarke, 2006), the researchers (IV, SEJ & BAM) first familiarized themselves with the data by transcribing and reading the transcripts. Subsequently, the researchers generated initial codes using MAXQDA (Software, 2019). The first three interviews were all coded independently by the researchers, who then discussed what codes they assigned, where, and why. These discussions led to the development of a coding three, which was used for the coding of the remaining transcripts. The remaining transcripts were coded by one researcher (IV, SEJ or BAM), updates in the coding three were shared with the group. For the next step, the researchers started generating themes by clustering the data and codes per potential theme (Braun & Clarke, 2006). In the process of developing and analysing the codes, an initial thematic map was constructed with the most prominent themes. After reviewing, re-naming, refining the final thematic map, and discussing it in the research group, main themes were created regarding in-home care needs and preferences of people with dementia and informal caregivers with a migration background. Data saturation was reached since no new codes or themes emerged from the data (Hennink & Kaiser, 2022). The results of the study were communicated to the participants, allowing them to provide feedback on the findings.

Ethical considerations

The Medical Ethics Research Committee of the Amsterdam University Medical Centre confirmed that the Medical Research Involving Human Subject Act did not apply to this research project (W23_122 #23.137), because participants were asked to be involved in semi-structured interviews that did not pose any threats to the psychological integrity of the participants. Prior to the interviews, the researchers went through the information letter and informed consent form together with the participants to provide the opportunity to ask questions and ensure a thorough understanding. Subsequently, participants were asked to provide written informed consent. Verbal continued informed consent was used throughout the study, reminding participants that they were participating in research to ensure that they remained informed and felt comfortable (McKeown et al., 2010). It was stressed that participation could be stopped at any given moment. Where possible we connected study participants with health care professionals to help enable access to care.

Findings

Participants characteristics

Eight participants with dementia and 20 informal caregivers were interviewed; no participants withdrew from the research. Interviews lasted between 40 and 90 minutes. Participants lived across the Netherlands, in both rural and urban areas. Most informal caregivers were female (N= 17), whereas most participants with dementia were male (N= 6). All persons with cognitive impairment had a diagnosis of dementia, further details about the participant characteristics can be found in Table 1.

Table 1. Characteristics of the study population

NR.	Respondent	Gender	Age	Migration background	Duration of living in the Netherlands	Level of education	Relation to PwD	Living situation
1.	Person with dementia	Male	85	Turkish	50-60 years	Primary school	.	Alone
2.	Person with dementia	Male	82	Turkish	50-60 years	Primary school	.	With partner
3.	Person with dementia	Male	84	Surinamese	40-50 years	Secondary school	.	Alone
4.	Person with dementia	Female	85	Turkish	40-50 years	Primary school	.	Alone
5.	Person with dementia	Female	84	Turkish	50-60 years		.	With partner
6.	Person with dementia	Male	79	Turkish	50-60 years	Primary school	.	With partner
7.	Person with dementia	Male	86	Turkish	50-60 years	Higher education	.	Alone
8.	Person with dementia	Male	70	Turkish	20-30 years	Primary school	.	With partner
9.	Informal caregiver	Female	60	Moroccan	40-50 years	Secondary school	Daughter in law	Together with PwD
10.	Informal caregiver	Female	49	Moroccan	Born in the Netherlands	Higher education	Daughter	Separate from PwD
11.	Informal caregiver	Female	90	Surinamese	50-60 years	Secondary school	Partner	Together with PwD
12.	Informal caregiver	Male	59	Turkish	40-50 years	Higher education	Son	Together with PwD
13.	Informal caregiver	Female	45	Moroccan	40-50 years	Higher education	Daughter	Separate from PwD
14.	Informal caregiver	Female	54	Moroccan	20-30 years	Secondary school	Daughter	Together with PwD
15.	Informal caregiver	Female	72	Indonesian	40-50 years	Higher education	Partner	Separate from PwD
16.	Informal caregiver	Female	34	Moroccan	Born in the Netherlands	Higher education	Daughter	Separate from PwD
17.	Informal caregiver	Female	54	Moroccan	40-50 years	Primary school	Daughter	Together with PwD
18.	Informal caregiver	Female	48	Turkish	40-50 years	Secondary school	Daughter	Separate from PwD
19.	Informal caregiver	Male	62	Turkish	40-50 years	Secondary school	Son	Separate from PwD
20.	Informal caregiver	Female	49	Turkish	Born in the Netherlands	Higher education	Daughter	Together with PwD
21.	Informal caregiver	Female	89	Surinamese	50-60 years	Higher education	Partner	Separate from PwD
22.	Informal caregiver	Female	55	Surinamese	Born in the Netherlands	Higher education	Daughter	Separate from PwD
23.	Informal caregiver	Female	26	Moroccan	Born in the Netherlands	Higher education	Daughter	Together with PwD
24.	Informal caregiver	Female	53	Moroccan	20-30 years	Primary school	Partner	Together with PwD
25.	Informal caregiver	Male	23	Moroccan	20-30 years	Higher education	Son	Together with PwD

Main findings

Seven themes pertaining to care and support preferences were identified in the data: 1) Socio-cultural sense of duty towards taking care of the person with dementia, 2) proactive involvement of professionals, 3) culturally sensitive in-home care, 4) adaptations in the home, 5) culturally sensitive social care, 6) accessible information about dementia, 7) creating opportunities for emotional support.

Socio-cultural sense of duty towards taking care of the person with dementia

Informal care provided by the family of the person with dementia played an important role in enabling ageing-in-place. All informal caregivers described a strong feeling of responsibility and sense of duty when it came to providing care for their parents or partner, mainly embedded in socio-cultural and religious values. They helped the person with dementia with a wide variety of daily activities such as getting dressed, bathing, cooking, and cleaning the house. Many informal caregivers mentioned that they had a long history of caring for their parents, since they helped their parents overcome language barriers by accompanying them to appointments, helping them read letters, and fill in paperwork.

> *"Your parents you know, they're simply your parents. You must do everything for them. And of course, considering our religion, your parents are second to God. After Allah, it's your parents. So that also plays a significant role. Therefore, as a caregiver you are constantly in dialogue with yourself, thinking, But if I don't do this, I am falling short. It is my duty to do it, I just must. No matter how, I must do it, or else I won't be a good daughter." - Participant 10, informal caregiver*

In addition, the participants with dementia expressed that they preferred to be taken care of by their family members instead of care professionals. The participants with dementia often expressed their gratitude for the care that they received from their children.

> *"I am really satisfied with my children. I am so happy that I have my children. He [my son] said: 'we are happy that you are here dad. You took care of us, we have to take care of you.'" – Participant 6, participant with dementia*

Participants with dementia who did not receive care from their children expressed their disappointment.

> *I: "Would you like your children to live with you?"*
> *P: "Yes, I would very much like that, but they only visit me and then leave. They don't take care of me, don't clean the house. Nothing."- Participant 5, participant with dementia*

While informal caregivers described taking care of their parents or partners with dementia as fulfilling, they also experienced a considerable caregiving burden. Informal caregivers were willing to share care with professionals with the prerequisite that they remain in charge of the details of the care trajectory. Since this was not feasible in most cases, it led to more usage of the personal budget (PGB), which enables informal caregivers to arrange their own care and support.

> *"In the beginning I did everything by myself, I took care of him. However, it became too much for me, it was just too heavy. I needed some help and started using the Personal Budget, which helped me to arrange his care and save myself some time. I can coordinate the care to make sure that my father gets the support he needs in a way that he will also accept it." – Participant 23, informal caregiver*

Whilst informal care is of great importance and highly valued by both the participants with dementia and the informal caregivers, there is also a considerable caregiving burden. To help minimize the caregiving burden, informal caregivers have the desire to share care with professionals.

Proactive role of professionals

Many informal caregivers experienced problems with accessing formal care and support options. Informal caregivers indicated that the Dutch healthcare system is request-driven in the sense that without concrete questions regarding care, no support is offered. However, those who were not familiar with the healthcare system and unaware of existing services found it harder to formulate their concrete needs. Some felt that their lack of explicit and specific requests for help resulted in healthcare professionals assuming that they were comfortable in their situation and preferred to provide all the care themselves. These informal caregivers experienced a high caregiving burden and wanted to receive formal care or support.

> *"If we are talking about people with low health literacy, these are often people with a low socio-economic status, people with a migration background, or older adults. For older people with a migration background, this often means that they tick three of these boxes. If you then expect them to be able to formulate their care needs and to know where they need to be with these specific questions. [...] It is almost as if there is the idea that persons are comfortable in their situations, because they do not ask for anything. However, that is not the case, those conversations can be very awkward." - Participant 17, informal caregiver*

Informal caregivers emphasized that it would be helpful if general practitioners or case managers had a proactive attitude in asking patients about their needs. They emphasized that professionals need to take their time to understand the situation of the person with dementia while detecting possibilities for culturally sensitive formal care and support. This would enable the persons with

dementia to access the care they need and support their informal caregivers. Nevertheless, there were positive examples of a general practitioner or case manager who helped family carers to explore their wishes when it came to formal care and support.

> *"We come together as a team once every two/three months [general practitioner, case manager, person with dementia, and informal caregiver]. The professionals always start by asking questions. They ask if we have any wishes, because caring for someone can be tough. The involved healthcare professionals always want to make it easier for me and think along if there is anything that I want or that could help us." - Participant 11, informal caregiver*

For those who are less familiar with the healthcare system, it might be harder to formulate concrete care needs. Therefore, the proactive role of professionals is needed to help identify the care needs of both informal caregivers and persons with dementia.

Culturally sensitive in-home care

A potential way to relieve informal caregivers and maintain a sustainable living situation for the person with dementia is through formal in-home care, such as help with getting dressed and taking medicine. Unfortunately, participants had unpleasant experiences with formal in-home care. It was often mentioned that persons with dementia found it hard to accept home care, as they experienced having a "stranger" in their home as an invasion of their autonomy and privacy. Language barriers and a lack of knowledge about cultural values made it harder to connect with home care providers and build trusting relationships.

> *"At first, we had a nice agreement with the home care organisation, they would come to pray with her and she would let them in. However, at some point it changed. She [mother with dementia] did not want it anymore, she saw it as an invasion of her freedom and time (..) These ladies also only spoke Dutch. We are planning to switch to an organisation with people from the same culture, who speak Indonesian. Perhaps that would make it easier." - Participant 28, informal caregiver*

Many participants indicated that it would be helpful to have culturally sensitive in-home care. Having someone who speaks the same language and has a shared cultural history, would help to build a trusting relationship with the person with dementia.

> *"Our help is an Indonesian woman, I specifically requested it (..) I thought it would be easier, if my husband will start to speak more Indonesian, then it will just be easier. She also knows the habits of Indonesian people (..) If we talk about Indonesia, she understands what we are talking about." - Participant 27, informal caregiver*

However, not all participants were able to find appropriate, culturally sensitive in-home care. Limited availability of home care workers with a shared cultural history made it harder to find someone that could build a trusting relationship with the person with dementia. The organisations that did offer culturally sensitive in-home care services often had limited staff members and long waiting lists. Consequently, informal caregivers provide the in-home care themselves, even though they were overburdened.

> *"We had in-home care from two different organisation, one of them no longer exists because they had a shortage of staff. We are of course also looking for people who speak Arabic, that makes it more difficult. I understand, but we really need the care. It would allow me to have a break as the informal caregiver." – participant 10, informal caregiver*

Culturally sensitive in-home care is important to support the person with dementia and unburden the informal caregivers. Unfortunately, culturally sensitive in-home care is not always available for the persons who need it.

Adaptations in the home

Many participants talked about the importance of having a house that enables ageing-in-place. In some cases, children were taking care of their parents with dementia and moved in with them. This sometimes led to problems because the appartements where not suitable for older adults or there was limited space. It was often challenging to find a new home that was more suitable for providing informal care.

> *"We live in a social housing unit, but the apartment is too small for us. It is located on the second floor, but my mother has trouble getting up the stairs. It would really help me if I could find a bigger house that is more suitable for informal caregiving. I understand that this is something that is difficult, we have a housing shortage of course, but it would really help me." – participant 20, informal caregiver*

In most cases the participant with dementia was living alone or with their partner. Adaptations were made to the house such as installing a stair lift, grips in the bathroom, or a chair for in the shower. These adaptations helped the participants with dementia to remain at a level of independence, and increased their safety and well-being.

> *"I have grips in the bathroom and the toilet to help me. Someone from the municipality came to my house and arranged this for me"- Participant 6, participant with dementia*

Thus, having a home that supports persons with dementia in their daily activities and enables informal caregiving is a prerequisite for ageing-in-place.

Culturally sensitive social care

The importance of social activities that match the cultural background and language proficiency of persons with dementia was emphasized by both informal caregivers and participants with dementia. Many of them are first generation migrants who learned the language at a later stage in life and regressed to their native language because of their dementia. This led to them being unable to connect and feel at home in regular daycare facilities where the majority of the attendees only spoke Dutch and activities were tailored to the Dutch culture.

> *"The other visitors are foreign to me; I cannot really communicate with them. I am on my own, I sit here, I eat, I drink. I do not make a friendly connection with them." - Participant 2, participant with dementia*

Some participants found culturally sensitive daycare facilities where the persons with dementia felt at home and were able to connect with the other visitors and staff members. This was mainly because the setting was equipped to connect to the persons with dementia by adjusting to their mother tongue and providing opportunities for religious practices such as prayer. This was experienced as a meaningful activity for persons with dementia, and an important form of respite care for the informal caregivers.

> *"Daycare is important for persons with dementia, to make sure that they are stimulated and to lower the burden for the persons taking care of them (..). The facility is designed for migrants, so that is great. The Turkish language, Turkish food, halal, praying, everything is possible. They play games, listen to the news, or get music therapy." - Participant 12, informal caregiver*

However, not all participants had access to these culturally sensitive daycare facilities since these were primarily located in the bigger cities. Some participants found alternatives that worked for them, such as having a personal companion come to their home to interact with the person with dementia. It was important that these persons spoke the mother language of the persons with dementia and could relate to the activities that they liked to do.

> *"Most of the time, I am at home. She comes and helps me. I ask her to read the Quran, she does that. She is a very nice person.' - Participant 1, participant with dementia*

To summarize, the participants indicated that culturally sensitive social activities are important for the persons with dementia to connect with others, and offer a form of respite care for the informal caregivers. Unfortunately, the availability of culturally sensitive daycare facilities is limited.

Accessible information about dementia

It was evident that a lack of accessible and appropriate information was hindering participants with dementia and informal caregivers in receiving appropriate care. Many informal caregivers indicated that they had searched for information about 1) the condition, 2) how to recognize symptoms, 3) practical information on how to care for the persons with dementia, and 4) available care and support options. This quest for information and advice was often challenging. Participants had a hard time finding information in the right language, or on a level that was understandable to them.

> *"We sent videos to our aunt about Alzheimer. I found it hard to find videos in Arabic or Berber who were meant to inform people (..) If there were a database for this, with the right information that would be great for my parents. I use the website of Alzheimer Nederland because I speak Dutch. This is convenient for me, but for others it is more difficult." - Participant 14, informal caregiver*

Participants stated that places of worship, such as the mosque or church, could be locations where accessible information and support is provided. Since these places are already part of the daily lives of many persons with dementia with a migration background, more persons would be reached when organizing informative meetings or social activities.

> *"We started organizing senior groups in the mosque (..) Every municipality has community centers, however when you look around there you do not see anyone with a migration background. Then the question arises: do they not have a desire to come together? To talk and have a cup of coffee? Well, of course they do, but it is about the setting in which it is happening. If it is organized in the mosque, many people would come." - Participant 23, informal caregiver*

Thus, informal caregivers indicated a need for accessible information about dementia and envisioned a role for religious organisation in the delivery of this information.

Creating opportunities for emotional support

From the interviews, it was evident that the participants with dementia were worried about their situation. They stated that noticing their memory deteriorate made them anxious and fearing for the future. In the early stages, they were struggling with the idea that they would become more dependent on care and support from others.

> *"It makes me sad when the forgetfulness occurs. I pray to God that my body will work well. I pray to God that He may take my life without making me beg people for help." - Participant 2, participant with dementia*

Informal caregivers often felt a significant emotional burden as well. They struggled with dilemmas in choosing between their own needs and the needs of their parent or partner with dementia. They

stated that the general practitioner or case manager should understand this emotional burden and pay more attention to the needs of the informal caregivers. This could be achieved by explicitly inquiring about the wellbeing of informal caregivers and directing them to support options, such as informal caregiver support groups or a psychologist.

> *"The case manager introduced me to the informal caregiver support groups. He was the one who really emphasized that I also must take care of myself because it was a tough situation. He saw that I did not get support from the Church or from my family. Then you are alone and you really have to take care of yourself. It was very helpful that he kept saying that, it gave me the feeling that I deserved to have a break and for example, go on a vacation." - Participant 28, informal caregiver*

Participants emphasized the importance of initiating conversation about dementia and care within the community to raise awareness, address concerns, and dispel misconceptions about formal care. This could reduce guilt among informal caregivers and ease their emotional burden.

> *"My father was one of the first persons with a migration background to go to a daycare facility. I noticed people came to me with questions, they were curious or even a bit reproachful. I think that within the community the concept of respite care is not done, you are supposed to take care of your parents. However, when we started talking about it, I explained that it is also in the best interest of my father. I told them that it is the same as when the doctors tells your father to take antibiotics. This helped them to understand ." – participant 25, informal caregiver*

The informal caregivers described a similar negative connotation about nursing homes, stemming from the idea that it is a child's duty to care for their parents, making it difficult to consider alternative options. However, informal caregivers indicated that at a certain point caring for their parents with dementia was too overwhelming, leading them to consider a nursing home. These considerations were often accompanied by guilt and a sense of failure. Respondents suggested that open discussion on this issue could help to reduce feelings of guilt and isolation when such decisions become necessary.

> *"I think that this should be discussed more often from a religious perspective. That it is discussed more in the mosque, that it is okay if it is time. That it is not a sin, if you must bring your father or mother to a care home (..) We always talk about putting someone away, you are putting them away and it is very traumatic. But if someone is no longer safe at home, you do not really have a choice." - Participant 10, informal caregiver*

It is evident that dementia has a considerable emotional impact on both the older adults who receive the diagnosis and their parents or partners who are taking care of them. Informal caregivers

underscored the value of open discussion about dementia and care within the community to help increase awareness about care trajectories and provide emotional relief for informal caregivers.

Discussion

This study provides a first in-depth exploration of the care preferences of persons living with dementia and informal caregivers with a migration background ageing-in-place in the Netherlands. The findings highlight the socio-cultural sense of duty in caring for persons living with dementia, where participants with dementia prefer assistance from close family members, and informal caregivers find fulfilment in this role. However, due to a considerable caregiving burden, the inclusion of formal care is desired. Unfortunately, linguistic barriers and a lack of culturally sensitive care hinder access for those with migration backgrounds. The proactive involvement of professionals is essential for building trust, identifying opportunities to integrate formal care, and alleviate burden on informal caregivers. Furthermore, the findings emphasize the need for culturally tailored in-home care, social activities, accessible information about dementia, and emotional support. While these insights align with previous research on Dutch individuals with dementia (Vullings et al., 2020), differences emerge due to the socio-cultural contexts and challenges faced by minority groups, who often struggle to find appropriate care.

Consistent with international literature, the participants in our study feel a strong responsibility to provide informal care, motivated by moral considerations, filial and reciprocal love, and strong care norms (Ahmad et al., 2020; Stenberg & Hjelm, 2023). Previous research often describes a reluctance of informal caregivers to share care with professionals, stemming from the belief that the family should provide care for ageing parents, (Ahmad et al., 2020; Shrestha et al., 2023) and the fear that important religious or cultural values would be disregarded (Berdai Chaouni & De Donder, 2019). However, the findings of this study suggest that involving formal care is actually desired by informal caregivers and in some cases perceived as necessary to enable ageing -in-place.

Unfortunately, involving formal care proves to be challenging for several reasons. Firstly, there are individual-level barriers, such as limited health literacy (Gove et al., 2021), a lack of knowledge about dementia (Taiebine et al., 2024), and unfamiliarity with the healthcare system and available support options (Nielsen et al., 2021). Additionally, system-level factors play a role, such as a shortage of culturally sensitive care, which is an issue recognized in both the Netherlands, (Vissenberg et al., 2018) and other European countries (Duran-Kiraç et al., 2022; Sagbakken et al., 2020). The findings of this study reveal that the structure of the healthcare system itself poses an additional

barrier. In the Netherlands, the current demand-drive system assumes that individuals will actively seek care when necessary, typically by reaching out to their general practitioner. However, persons with a migration background may struggle to recognize and express their care needs due to cultural contexts and limited knowledge of available services. As a result, they may not seek formal help, even when this is needed. Healthcare professionals should not assume that no request means no need; instead, they should actively inquire about potential needs and opportunities for formal support. This might be particularly relevant for other countries where the general practitioner acts as a gatekeeper to services and support, such as the UK (Sripa et al., 2019) and Norway (Czapka & Sagbakken, 2020).

Additionally, the participants in this study envisioned a more prominent role for religious organisations in the dementia care trajectory. Whilst existing research often highlights the involvement of key community figures in bridging the gap between individuals with a migration background and healthcare institutions (Hurley et al., 2024; Steunenberg et al., 2014), our findings suggest that religious organisations, rather than traditional healthcare institutions, should play a central role in disseminating information about dementia. Echoing the results of a recent UK study, participants emphasized that mosques or churches are more familiar and accessible venues for individuals with a migration background, potentially reducing barriers to attending educational events on dementia (Hussain et al., 2024). In addition, participants suggested that religious organisations could play a vital role in opening up discussions about caring for parents with dementia. While caring for one's parents holds significant religious value, acknowledging the challenges of this responsibility and exploring different ways to provide care could reduce feelings of failure and stigma associated with seeking external support (Ahmad et al., 2020). Participants emphasized the importance of addressing this topic from a religious perspective, fostering dialogue within the community.

Finally, this study illustrated that receiving the dementia diagnosis has a considerable emotional impact on the older adults. Whilst emotional impact and support for informal caregivers is often discussed, emotional support for the person with dementia is less commonly addressed (Queluz et al., 2020). However, especially for persons with a migration background, who have often experienced traumatic events in the past related to their migration journey, emotional support is of great importance (Sun et al., 2022).

Strengths and limitations

To the best of our knowledge, this is the first qualitative interview study on ageing-in-place preferences in the Netherlands to include persons living with dementia with a migration background. Previous studies included mainly the informal caregivers of persons living with dementia, or

healthcare professionals (Duran-Kiraç et al., 2022). Including persons living with dementia with a migration background in research is crucial, as it provides insights in their own personal experiences and care preferences. We emphasize the importance of giving voice to all groups within the population, and enabling them to express their needs and preferences, rather than solely relying on informal caregiver proxies. The in-depth nature of the interviews and composition of the team consisting of bilingual researchers, also enabled us to include participants who were not proficient in Dutch.

A limitation of this study is the restricted diversity in migration backgrounds. While participants represented major non-western migration groups in the Netherlands (Moroccan, Turkish, and Surinamese), they do not capture the full cultural diversity present in the country. In addition, all the participants were living in the Netherlands for at least 20-30 years. People who migrated to the Netherlands in a later stage of their lives, might have different situations or face different challenges, however this was not the target population of our study. Future research should aim to include these groups to identify their care needs and preferences. Another limitation is the small sample size, requiring cautious interpretation of results.

Implications

This study found that while the preferences of older persons living with dementia and informal caregivers with a migration background ageing -in-place are similar to the general Dutch population (Vullings et al., 2020), the care organization does not meet their personal needs. Beside the challenges persons with a migration background experience regarding involving formal care, limited culturally appropriate dementia services and the predominantly one size fits all approach in healthcare enhances inequity in accessibility and utilization of care. Instead of solely focusing on individual-level barriers in accessing care, current dementia services should be evaluated and adjusted to meet all the needs and preferences of persons living with dementia regarding ageing-in-place. For example, instead of focusing on the language proficiency of persons with a migration background, it should be emphasized that the current provision of services and information is not linguistically inclusive.

Moreover, this study is an important example of inclusive research in which persons living with dementia and a migration background were included. Persons living with dementia can express their experiences and preferences. Important strategies to ensure inclusive research are illustrated, such as building trusting relationships, collaborations with informal organisations within the communities, involvement of religious institutions that are part participants daily life, composition

of diverse research teams, and seeking advice from experts that specialize in health inequality and inclusiveness.

This study highlights the need to centre person with dementia and a migration background in care discussions, promoting inclusivity. Whilst this study provides a first in-depth exploration of the care preferences of persons with a migration background, further research is required to quantify care preferences in larger, more diverse samples.

Conclusion

This study identified care preferences and needs related to ageing -in-place for persons with dementia with a migration background and their informal caregiver. It became evident that informal care is of great value as it enables persons living with dementia to age-in-place and provides the informal caregivers with strong feelings of fulfilment. However, providing informal care is also considered to be hard at times and the informal caregivers of this study were open to share care with professionals. Informal caregivers desire a more proactive role of professionals, such as the general practitioner, in identifying appropriate options for care and support. Thematic analysis of participants interviews identified that options for care and support should include: 1) culturally sensitive in-home care; 2) adaptations in the home; 3) culturally sensitive social care; 4) accessible information about dementia; and 5) emotional support. This study is relevant for professionals seeking to establish practice standards aimed at facilitating culturally sensitive and person-centered dementia care to persons living with dementia and informal caregivers with a migration background.

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Declaration of contribution of authors

JMV conceptualized the study and developed the study design together with the other researchers. IV and SEJ contributed to the development of the study design. IV, SEJ & BAM were responsible

for data collection and analysis. The authors provided input on the study design from their own area of expertise; inclusive research (CS & ÖUB), qualitative research (NL & JW), health economics (EBG). IV and SEJ wrote the manuscript, the co-authors read, edited and approved the final version.

Statement of ethical approval

The Medical Ethics Research Committee of The Amsterdam Medical Centre confirmed that the Medical Research Involving Human Subject Act did not apply to this research project (W23_122 #23.137). Written informed consent was obtained from participants prior to the interviews and ethical processes were maintained throughout.

Statement of competing interest

No competing interests to report

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Supplementary material 1. COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	6
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	1
Occupation	3	What was their occupation at the time of the study?	6
Gender	4	Was the researcher male or female?	6
Experience and training	5	What experience or training did the researcher have?	6
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	5-6
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	5-6
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	6
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	5
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	5
Method of approach	11	How were participants approached? e.g. facetoface, telephone, mail, email	5-6
Sample size	12	How many participants were in the study?	9
Nonparticipation	13	How many people refused to participate or dropped out? Reasons?	9
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	6
Presence of nonparticipants	15	Was anyone else present besides the participants and researchers?	6
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	9

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	6-7 + appendix
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	n.a.
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	7
Field notes	20	Were fi eld notes made during and/or after the inter view or focus group?	7
Duration	21	What was the duration of the inter views or focus group?	9
Data saturation	22	Was data saturation discussed?	8
Transcripts returned	23	Were transcripts returned to participants for comment and/or correction?	7
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	8
Description of the coding tree	25	Did authors provide a description of the coding tree?	appendix
Derivation of themes	26	Were themes identifi ed in advance or derived from the data?	8
Software	27	What software, if applicable, was used to manage the data?	8
Participant checking	28	Did participants provide feedback on the findings?	8
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	10-20
Data and findings consistent	30	Was there consistency between the data presented and the findings?	10-20
Clarity of major themes	31	Were major themes clearly presented in the findings?	10-20
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	10-20

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. International Journal for Quality in Health Care. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.

Supplementary material 2. Interview guide

Introduction: Thank you for participating in this study. My name is [introduction interviewer]. The research that we are doing is focused on persons who are living at home. I would like to talk with you about your living situation at home, the daily things that you do and the help that you receive. If I ask a question that is not clear, feel free to let me know. There are no wrong answers, you can say anything that comes to mind. I would like to record the interview, if that is ok with you. The recordings will only be shared with my colleagues. The conversation will not be shared with your doctor or family. We will leave out your name. your name will be replaced by a number. *[reading information letter + informed consent – singing informed consent – start recording]*

Before we start, I have a few general questions that I would like to ask you: 1) What education did you receive? 2) Where were you born? 3) Where were your parents born? 4) How long have you lived in the Netherlands? 5) How old are you? 6) Where do you live? 7) Do you live alone? 8) Where does your family live?

Theme	Explanation theme	Examples of questions
Introduction	Start-up questions giving respondent room to talk and bring up topics	Can you tell something about yourself? How is it going at home? How is your health?
Daily activities	Talk about: (help with) cleaning, cooking, showering, getting dressed etc. Have attention for religious activities – praying, going to mosque/church Find out if they get help with these activities, from who and how they value this help.	What are daily activities that you do? What does your day look like?
Social activities	Talk about: social activities such as female/male groups, visiting other persons etc. Ask if people go to a daycare facility. For informal caregivers: ask if they have time for themselves, do their own thing.	What are things that you like to do? What are things that you like to do with other people?
Adaptations in the home	Talk about: adaptations such as a stair lift, grips in the shower, alarm system etc..	What changes are made in your house? What are things that you would like to change about your house?
Information	Talk about: information received after diagnosis about what to expect or how to cope with dementia.	Have you gotten information about what to expect (after diagnosis)? What questions do you have about dementia?
Contact care professionals	Talk about: how people experience contact with care professionals such as home care, general practitioner and the case manager dementia.	What do you think of the home care providers? How is your contact with the general practitioner?
Navigating the healthcare system	Talk about: does the person arrange care themselves or do they get help (from general practitioner, or case manager)) Do they struggle with this or not	How is the care arranged? Who arranges this support/care? How would you like to be supported with the arrangement of care?

Theme	Explanation theme	Examples of questions
	Talk about: how people feel about their situation, their worries or concerns.	How do you feel about your situation (dementia diagnosis)?
Emotional support	Do they talk about this and with whom.	do you have someone to discuss your concerns with?
Closing questions	Question to end the interview – ask if participants want to add something	What are things that you would like to get help with? Are there things that you would like to add?

Examples of probing questions

- With who do you do this? / Who helps you with this?
- How often do you do this? / How often do you get this help?
- What do you like about this help/support?
- What do you dislike about this (help/support)?

Thank you so much for sharing your story. *[ask if people want to be informed about the results of the study]*

Supplementary material 3. Coding scheme

Code System	Frequency
Code System	35
behoeften	0
behoeften\ondersteuning behoeften	0
behoeften\zorg behoeften	0
behoeften\behoeften aan informatie	0
gezinsdynamiek	1
gezinsdynamiek\familie relaties	1
gezinsdynamiek\delen van zorg	0
gezinsdynamiek\verschillende overtuigingen goede zorg	0
gezinsdynamiek\verschillende perspectieven omgaan met dementie	0
bredere context	0
bredere context\invloed cultuur/religie	0
bredere context\invloed cultuur/religie\rol religieuze organisaties	0
bredere context\bewustwording gemeenschap dementie	0
bredere context\bewustwording gemeenschap dementie\perspectief op ziekten	0
bredere context\bewustwording gemeenschap dementie\bespreekbaar maken	0
bredere context\bewustwording gemeenschap dementie\informatie over dementie	0
leefwereld respondent	6
leefwereld respondent\blik op goede zorg	0
leefwereld respondent\ervaring met discriminatie	0
leefwereld respondent\reactie omgeving mbt dementie	0
leefwereld respondent\kijk op situatie (berusting)	4
leefwereld respondent\rol religie in dagelijks leven	0
leefwereld respondent\leven voor dementie	2
houdbaarheid thuissituatie	1
houdbaarheid thuissituatie\crisis	0
houdbaarheid thuissituatie\betrokkenheid buurt/gemeenschap	0
houdbaarheid thuissituatie\financiële situatie	1
situatie PMD	0
situatie PMD\daginvulling	0
situatie PMD\eenzaamheid	0
situatie PMD\behoeften sociale interactie	0
situatie PMD\gevoel kunnen uitdrukken	0
situatie PMD\zingeving	0
situatie PMD\autonomie	0
situatie PMD\zelfredzaamheid	0
situatie PMD\fysieke gezondheid	0
situatie PMD\cognitieve achteruitgang	0
situatie PMD\gedragsverandering	0

Code System	Frequency
situatie PMD\niet-pluis fase	0
mantelzorg	16
mantelzorg\partner	0
mantelzorg\partner\omgaan met dementie	0
mantelzorg\partner\fysieke gezondheid	0
mantelzorg\partner\dagelijks leven	5
mantelzorg\partner\lotgenootschap	0
mantelzorg\partner\belasting mantelzorger	2
mantelzorg\partner\belasting mantelzorger\emotionele belasting	0
mantelzorg\partner\ondersteuning mantelzorger	3
mantelzorg\partner\ondersteuning mantelzorger\emotionele ondersteuning	0
mantelzorg\partner\aanpassingen/opofferingen leven mz	1
mantelzorg\partner\sociale realties mantelzorger	2
mantelzorg\partner\ademruimte	2
mantelzorg\partner\verantwoordelijkheidsgevoel	1
mantelzorg\partner\zorgen over de toekomst	0
mantelzorg\kinderen	0
mantelzorg\kinderen\omgaan met dementie	0
mantelzorg\kinderen\fysieke gezondheid	0
mantelzorg\kinderen\dagelijks leven	0
mantelzorg\kinderen\lotgenootschap	0
mantelzorg\kinderen\belasting mantelzorger	0
mantelzorg\kinderen\belasting mantelzorger\emotionele belasting	0
mantelzorg\kinderen\ondersteuning mantelzorger	0
mantelzorg\kinderen\ondersteuning mantelzorger\emotionele ondersteuning	0
mantelzorg\kinderen\aanpassingen/opofferingen level mz	0
mantelzorg\kinderen\sociale relaties mantelzorger	0
mantelzorg\kinderen\ademruimte	0
mantelzorg\kinderen\verantwoordelijkheidsgevoel	0
mantelzorg\kinderen\zorgen over de toekomst	0
belemmerende factoren	2
belemmerende factoren\systeem	0
belemmerende factoren\systeem\toegang tot informatie	0
belemmerende factoren\systeem\gebrek aan inclusieve zorg	0
belemmerende factoren\systeem\taalbarriere	0
belemmerende factoren\systeem\culturaliseren	0
belemmerende factoren\persoonsniveau	0
belemmerende factoren\persoonsniveau\gebrek aan kennis	0
belemmerende factoren\persoonsniveau\geen hulp vragen	2
belemmerende factoren\persoonsniveau\toegang tot informatie	0
belemmerende factoren\persoonsniveau\ziektebeeld herkennen	0

Code System	Frequency
formele zorg	5
formele zorg\aanpassingen in huis	0
formele zorg\ADL	1
formele zorg\dagbesteding	1
formele zorg\betrokkenheid professionals	2
formele zorg\betrokkenheid professionals \case manager	0
formele zorg\betrokkenheid professionals \huisarts	0
formele zorg\thuiszorg	1
informele zorg	3
informele zorg\regelen van zorg	0
informele zorg\ADL	2
informele zorg\sociale interactie	0
informele zorg\administratie	1
informele zorg\contact professionals	0
impact covid	1



Chapter 7

Attribute Development and Level Selection for a Discrete Choice Experiment to Elicit Care Preferences of Older Adults and Informal Caregivers Aging in Place in The Netherlands

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Abstract

Background

The Netherlands reformed its long-term care policy to encourage older adults to age in place with the support of informal caregivers. It remains unclear whether the available care and support options align with the needs and preferences of older adults and caregivers. Discrete choice experiments (DCE) are increasingly used to identify individual preferences. This study describes the development of attributes (e.g., emotional support) and attribute levels (e.g., psychologist and case manager) for a DCE on aging-in-place preferences among older adults and informal caregivers in The Netherlands.

Methods

Semi-structured interviews were conducted with older adults and informal caregivers to identify key components for successful aging in place. Interviews were transcribed, and reflexive thematic analysis identified patterns that led to a list of attributes. Visuals of these attributes were created and presented to a new sample of informal caregivers and older adults in focus groups to rank attributes and define attribute levels.

Results

Attributes identified through the interviews (N = 28) included housing, personal care, household tasks, transportation, social activities, digital skills, and help navigating the healthcare system. Focus groups (N = 35) found that older adults prioritized housing, while informal caregivers prioritized navigating the healthcare system. Transportation and digital skills were ranked as the least important and were excluded from the final list of attributes.

Conclusions

Our findings provide a detailed understanding of aging-in-place preferences of older adults and informal caregivers. These insights will inform a DCE to quantify preferences and provide evidence for policymakers. This study increases transparency about the process of attribute development and level selection, contributing to the quality of the final DCE study.

1. Introduction

Aging in place, defined as growing old while living at home in the community, has become a widely adopted policy strategy to address the growing number of older adults and rising healthcare costs [1, 2]. In 2020, long-term care expenditures of The Netherlands accounted for 4.6% of its gross domestic product (GDP), making it the highest spender on long-term care among Organization for Economic Co-operation and Development (OECD) countries [3]. The Dutch long-term care system offers a range of health and social services, with nearly all costs for both home and institutional care publicly funded, requiring minimal co-payments [4]. To manage rising costs, The Netherlands implemented a long-term care reform [4, 5], shifting the focus from institutional care toward home- and community-based care, encouraging older adults to age in place with the support of informal caregivers [4, 6].

The policy of aging in place aligns with the preferences of care recipients and informal caregivers, who seek to remain at home as it represents well-being, personal security, and memories [7, 8]. However, the desire to age in place does not guarantee that older adults can do so successfully. Decreased physical health, cognitive impairment, and a shrinking social network affect the ability to live at home and increase the need for additional care [9, 10]. As older adults require more care, the needs and desires of informal caregivers may also change, as they bear the primary responsibility of daily caregiving [11]. Thus, it is essential to identify the care and support services needed to enable older adults and informal caregivers to realize their aging-in-place preferences. Special attention should be given to underserved groups, such as older adults with a migration background, who, despite higher rates of functional limitations and chronic conditions, are less likely to use home- and community-based care services [12, 13].

Discrete choice experiments (DCEs) are a method for identifying individual and joint preferences. A DCE consists of hypothetical choice scenarios, each requiring a respondent to choose their preferred alternative among two or more alternatives described by different characteristics [14,15,16]. The alternatives in the choice scenario are characterized by attributes and corresponding attribute levels [14,15,16]. For example, one attribute could be emotional support, with levels such as (1) a psychologist or (2) a peer-support group. Qualitative methods can be used to identify and select attributes and levels for DCE studies [17, 18]. The attribute development process is crucial for the quality of the DCE, as it determines the alternatives presented to the respondents and the choices about which the policy maker can be informed [18]. This paper details the process of attribute development and level selection for a DCE aimed at eliciting the aging-in-place preferences of older adults and informal caregivers.

1.1 Study Aims

This study seeks to identify aging in place-relevant attributes and attribute levels among older adults and informal caregivers in The Netherlands through semi-structured interviews and focus groups. The identified attributes and levels can inform the design of a future DCE study to help quantify the aging-in-place preferences to inform policymakers and health insurers. While attribute development for DCEs is often poorly reported [18], this paper aims to provide greater transparency about the methodological process, including sampling, data collection, and data analysis. This level of detail is uncommon in DCE studies and allows for assessment of whether the necessary steps were taken to create a complete and appropriate list of attributes and levels. In addition, this paper can guide other researchers in strengthening their methodological choices and the reporting of these choices for attribute development of DCE studies.

2. Methods

2.1 Design

This study used two different research methods: semi-structured interviews and focus groups with a quantitative ranking exercise. The Consolidated Criteria for Reporting Qualitative Health Research (COREQ) guidelines were used for the reporting of the qualitative research methods [19] (see Electronic Supplementary Material 1). In addition, the guideline for reporting qualitative research informing the design of quantitative health-preference studies was followed [17]. For the first phase, semi-structured interviews were conducted to identify context-specific attributes that were important for older adults and informal caregivers in The Netherlands. Semi-structured interviews facilitate an in-depth exploration of aging-in-place preferences by using open-ended questions that encourage participants to articulate their thoughts and share personal experiences [18]. This method offers researchers flexibility, enabling them to cover predetermined topics while also allowing new themes to emerge through the conversation [20]. As a result, it becomes possible to identify a comprehensive set of attributes.

For the second phase, focus group discussions were held to prioritize the previously identified attributes, refine the language used to describe the attributes, and determine attribute levels. The focus groups offered the opportunity to triangulate and validate the results from the semi-structured interviews, as researchers can present the previously identified attributes to a new sample of participants to check if they are understandable and complete [21]. To build a manageable DCE with minimal cognitive burden, it is common practice to reduce the initially identified attributes to a final list of, on average, five attributes [15, 22, 23]. The ranking exercise, together with the

qualitative reasoning underlying participants' choices, provided insights not only into how attributes were prioritized but also into why participants valued certain attributes over others, allowing researchers to determine if there are initial attributes that can be excluded [24]. Moreover, the interactive nature of the focus groups revealed both shared and divergent perspectives, providing rich contextual information about participants' experiences, helping to shape the levels for each attribute [21]. Finally, an expert panel, consisting of two experienced DCE researchers (L.P. and J.S.), was consulted throughout the study to help guide the process of attribute development and level selection, optimizing the design of the final DCE study.

2.2 Study Participants

We approached adults aged 65 years and older who were aging in place and their informal caregivers using purposive sampling to recruit persons with varying educational levels living across The Netherlands in both rural and urban areas. To represent the growing number of older adults with a migration background living in The Netherlands, we sought to include participants from diverse cultural backgrounds [25]. We recruited Dutch older adults as well as persons with a Turkish, Moroccan, Surinamese, or Indonesian background, as these are the largest groups of older migrants in The Netherlands [26]. We purposively sampled both older adults who were more self-reliant and older adults who were frailer and more dependent on care and support. The Groningen Frailty Indicator was used to identify the frailty level of the older adults included in the study [27]. Older adults were excluded if they were unable to provide informed consent, lived in a long-term care facility, or were under the age of 65 years. We included informal caregivers regularly involved in the older adults' care who identified themselves as informal caregivers.

Participants for the interviews were recruited in the fall and winter of 2023. A new sample of participants was recruited for the focus groups in the summer and fall of 2024. Participants were recruited with the help of older adult and informal caregiver panels, general practitioners, family care navigators, daycare facilities, community centers, municipalities, key community figures, and organizations that serve persons with a migration background. Professionals at these organizations provided potential respondents with an information letter (Electronic Supplementary Material 2). The information letter included important information about the study, the method of data collection, anonymity, and confidentiality. Along with the participants' consent, researchers obtained their contact information from the organizations or professionals. The researchers (I.V., J.R., and B.M.) contacted the respondents by telephone to schedule the interviews or focus group discussion.

2.3 Attribute Development through Semi-structured Interviews

2.3.1 Data Collection

In phase 1, semi-structured interviews were conducted to identify relevant characteristics (attributes) of aging in place for older adults and informal caregivers in The Netherlands (see Electronic Supplementary Material 3 for interview guide). The interview guide was based on the existing literature and included questions about five key themes of aging in place identified in a recent scoping review: the place (both physical place and attachment to place), social networks, support (both formal and informal), technology, and personal characteristics [28]. To complement these, we added from earlier interviews with persons living with dementia [29, 30], which highlighted challenges in organizing care and support and the need for help with daily activities. Although dementia specific, these issues are also pertinent in the broader Dutch context, where care provision is complex and often fragmented. Co-creation sessions with older adults (N = 3) and informal caregivers (N = 2) were held to assess the first version of the interview guide. Participants for co-creation were recruited through the co-authors' social networks, using the study's inclusion and exclusion criteria to ensure alignment with the intended interviewees. The older adults and informal caregivers had the opportunity to voice their opinion about the content of the interview guide and the topics included. On the basis of these co-creation sessions, more questions about meaningful daily activities, social interactions, and loneliness were included in the interview guide.

The interviews were conducted by three trained qualitative researchers (J.R., B.A.M., and I.V.), between November 2023 and February 2024. Most interviews (N = 24) were conducted in Dutch, while some interviews (N = 4) were conducted in Turkish by a trained bilingual interviewer (B.A.M.). To ensure that participants felt comfortable, interviews were mostly held at participants' homes or in community centers. At the start of the interview, the researchers introduced themselves, explained study details, and sought to build rapport [31]. The interviews were audio-recorded and transcribed verbatim in Dutch or English. The transcripts were anonymized, and researchers' field notes were incorporated. Transcripts were not returned to participants; instead, researchers provided summaries and sought clarifications during the interviews to ensure accurate interpretation and understanding. Interviews were held until saturation was reached, which meant that no new topics or findings emerged from the interview data [32].

2.3.2 Analysis for Interviews

Reflexive thematic analysis was used to analyze the data and develop the attributes [33]. The analysis combined a deductive and inductive approach, systematically using/coding previous insights of past participants [28], whilst staying close to the data with an open approach for new topics or themes mentioned by study participants. The reflexive thematic analysis was conducted on the basis

of the six phases defined by Braun and Clarke [33, 34]. The researchers (J.R. and I.V.) started by familiarizing themselves with the data through transcribing, reading, and re-reading the transcripts. For the second step, the researchers developed initial codes using MAXQDA [35]. The researchers coded the first three transcripts independently. They came together to discuss which segments they coded, what codes they assigned, and why they assigned these codes. On the basis of this discussion, an initial coding scheme was developed. As a third step, the researchers started clustering data and codes to form initial themes [34]. This process of developing and analyzing codes included the development of an initial thematic map that entailed the most prominent themes. The initial themes were renamed, refined, and the thematic map was reviewed and discussed within the research group. This led to a final list of seven themes (attributes) of aging-in-place preferences of older adults and informal caregivers. The seven attributes were discussed within the research team to ensure that they were comprehensible and accurately reflected the key themes identified in the interviews.

2.4 Attribute Prioritization and the Development of Attribute Levels through Focus Groups

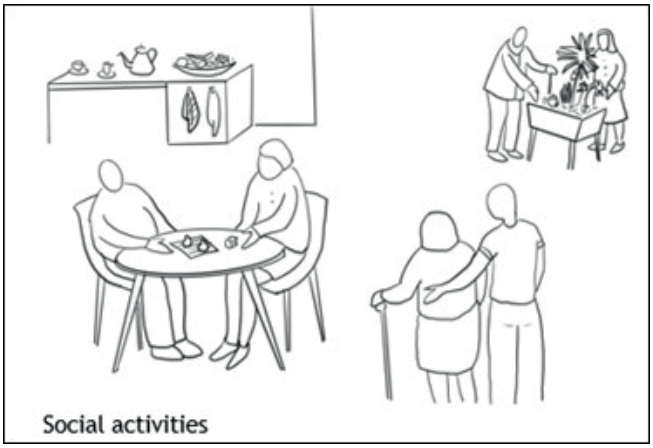
2.4.1 Data Collection

In phase 2, focus group discussions including a quantitative ranking exercise were conducted between August 2024 and February 2025 to understand the relative importance of the previously identified attributes and develop attribute levels. The focus groups enabled an environment for older adults and informal caregivers to share their experiences and build on each other's knowledge [36]. The focus groups were held in community centers and daycare facilities. The lead author (I.V.) facilitated the focus groups, which lasted between 40 and 75 min.

The focus groups consisted of three rounds. In the first round, the researchers explained the seven attributes identified in the interviews using flash cards containing easy-to-understand visual and written information. Figure 1 shows an example of a card used in the focus groups to describe the attribute of social activities; all cards are provided in Electronic Supplementary Material 4. The illustrations were developed in collaboration with a graphic designer experienced in creating materials for persons with cognitive impairment and were refined through several rounds of feedback. They visually complemented the attribute descriptions. The facilitator invited participants to share their first impression of the attributes, thereby initiating a discussion on their relevance and understandability. In addition, participants were asked whether the attributes presented provided a comprehensive overview of factors related to aging in place or if they perceived any important attributes to be missing. In the second round, the participants were asked to individually rank the aging-in-place attributes from most to least important using flash cards and sticky notes numbered

one to seven. In the final round, the results of the ranking exercise were shared in a group discussion. The facilitator asked questions to foster dialogue between the participants, who explained why they found certain attributes important. Follow-up questions were asked to identify how participants would like to give meaning to the attributes or receive certain forms of care or support.

Figure 1. Card for the attribute "social activities"



2.4.2 Data Analysis for Focus Groups and Ranking Exercise

To analyze the focus group sessions, the researcher (I.V.) transcribed the recordings and re-read the transcripts to familiarize herself with the data. The researcher developed initial codes using MAXQDA [35]. Open and axial coding was used to analyze the participants' reflection on the attributes, to understand their reasoning in the ranking exercise, and to identify attribute levels. To cross-validate the qualitative findings, the researcher calculated the sum scores of aging-in-place components from the quantitative ranking exercise, with lower scores indicating greater importance. Group differences in the ranking of older adults and informal caregivers were analyzed with a Mann–Whitney *U* test in SPSS. In addition, Kendall's tau-b correlation coefficient was calculated to evaluate the overall agreement between the rankings of older adults and informal caregivers. The qualitative findings and the results of the ranking exercise were discussed within the research team and expert panel to determine the implications of these findings for the design of the final DCE study.

2.5 Expert Panel

Expert opinions of experienced DCE researchers (J.S. and L.P.) were obtained after the interviews and focus group discussions. The experts helped to make sure that the list of attributes and attribute levels was conceivable for the design of the DCE and consistent with the assumptions of

the underlying random utility theory. The researchers presented their findings, discussing with the experts what the implications of these findings were for the design of the final DCE study. For example, the researchers discussed the results of the ranking exercise and complementing qualitative findings with the experts to determine if they should shorten the list of initial attributes identified after semi-structured interviews. In addition, it is important that attributes are nonoverlapping and not be inherent aspects of an individual's personality [18]. The researchers discussed their findings with the DCE experts in online meetings to ensure that the attributes and attributes levels complied with these criteria.

2.6 Ethical Considerations

On the basis of the study protocol, the Ethics Committee (METC) of the Amsterdam University Medical Centre waived the obligation for the study to undergo formal ethical approval as is described under Dutch law in the Medical Research in Humans Act, January 2019 (ref. no. W23_112 #23.137). Before starting the interviews or focus groups, the researchers went through the information letter and informed consent form together with the participants. Participants had the opportunity to ask for clarifications to ensure a proper understanding. Subsequently, participants were asked to provide written informed consent.

3. Results

3.1 Study Participants

For the phase of attribute development, 28 semi-structured interviews were conducted. There were 17 older adults who participated and 11 informal caregivers. For the second phase of the study, seven focus group session were held. There were 18 older adults who participated and 17 informal caregivers. No participants dropped out in the first phase of the study; for the focus groups, there were two participants who were unable to participate owing to illness. Participants were living across The Netherlands and had varying educational levels and cultural backgrounds. The characteristics of the study participants are presented in Table 1.

Table 1. Characteristics of participants in frequencies

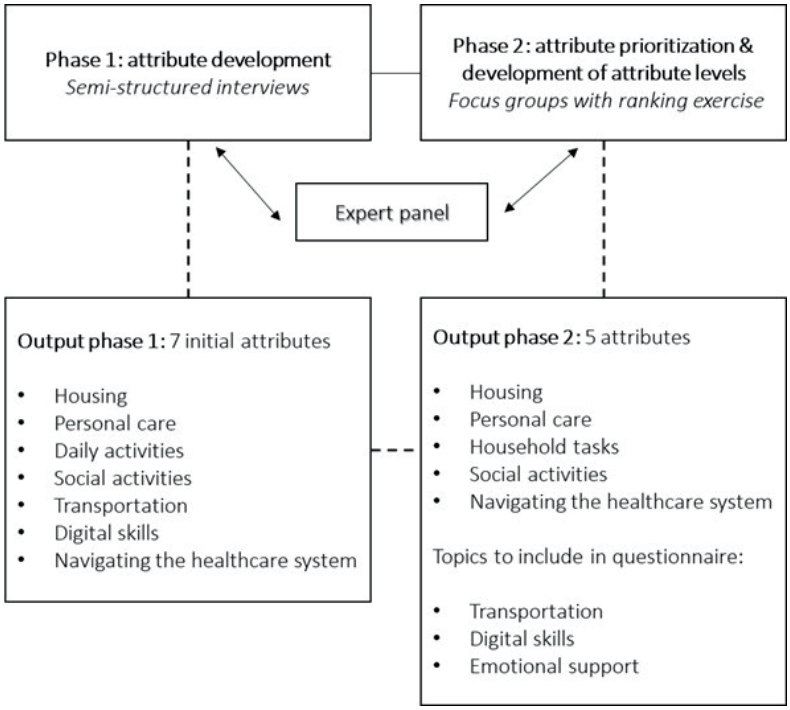
	Total	Interviews	Focus groups
Total (N):	63	28	35
Older adults (N):	35	17	18
Age (mean, SD):	80.1 (7.3)	81.1 (6.1)	79.6 (8.6)
Sex (N, %):			
Male	15 (43%)	7 (41%)	8 (44%)
Female	20 (57%)	10 (59%)	10 (56%)
Cultural background (N, %):			
Dutch	22 (63%)	13 (76%)	9 (50%)
Turkish	6 (17%)	2 (12%)	4 (22%)
Indonesian	7 (20%)	2 (12%)	5 (28%)
Educational level (N, %):			
Primary education	10 (29%)	5 (29%)	5 (28%)
Secondary education	12 (34%)	3 (18%)	9 (50%)
Higher education	13 (37%)	9 (53%)	4 (22%)
Frailty (GFI* mean, SD)	5.1 (2.2)	5.3 (2.1)	4.6 (2.6)
Informal caregiver (N):	28	11	17
Age (Mean, SD)	64.9 (10.5)	61 (9.8)	67.6 (11.1)
Sex (N, %)			
Male	8 (29%)	2 (18%)	6 (35%)
Female	20 (71%)	9 (82%)	11 (65%)
Cultural background (N, %)			
Dutch	18 (64%)	5 (46%)	13 (77%)
Turkish	2 (7%)	2 (18%)	.
Moluccan	3 (11%)	3 (27%)	.
Surinamese	3 (11%)	1 (9%)	2 (12%)
Moroccan	2 (7%)		2 (12%)
Educational level (N, %)			
Primary education	2 (7%)	2 (18%)	.
Secondary education	10 (36%)	4 (36%)	6 (35%)
Higher education	16 (57%)	5 (46%)	11 (65%)
Relation to older adult (N, %)			
Son/Daughter	15 (53%)	8 (73%)	7 (41%)
Partner	12 (43%)	2 (18%)	10 (59%)
Nephew/Niece	1 (4%)	1 (9%)	.

SD standard deviation; GFI Groningen Frailty Indicator, * Total score ≥ 4: frail older adult

3.2 The Number of Attributes

The seven attributes found in study phase 1 were used in the focus group discussions and ranking exercise in study phase 2. On the basis of the results of the ranking exercise and qualitative data analysis, a final list of five attributes was selected for inclusion in the DCE choice task. The topics that were excluded as DCE attributes (transportation and digital skills), together with one additional topic (emotional support) that was identified in the focus group discussions, will be addressed in a separate questionnaire that accompanies the final DCE choice task. This questionnaire will collect supplementary information beyond the choice tasks, allowing us to capture participants' views on relevant topics that could not be included directly in the DCE design. Figure 2 shows an overview of the different study phases and their output.

Figure 2. Overview of study phases and number of attributes.



Household tasks: new attribute name for daily activities, altered on the basis of focus group findings

3.3 Results from Phase 1: Semi-structured Interviews

3.3.1 Attribute Development

On the basis of the semi-structured interviews, the researchers developed seven themes or attributes related to aging in place: housing, personal care, daily activities, social activities, transportation, digital skills, and information and assistance about organizing care.

Housing was an important component of aging in place. Many participants indicated a desire to stay in their current home, which often led to adaptations to the home such as installation of a stairlift or grips in the shower and toilet. Moving to a smaller one-floor apartment was also mentioned as a housing choice to support aging in place. Participants who lived alone, often after losing a partner, expressed feelings of loneliness, so moving to communal housing was seen as an attractive alternative to mitigate such feelings. Communal housing was also envisioned as an intermediate step, a place where you could get more support and social interactions, whilst maintaining independence and privacy. Long-term care facilities were considered a last resort for when someone is completely care dependent.

I sometimes worry that I will not be able to stay in my house if I become more dependent. I would prefer to stay here for as long as possible. Here I have my own space and freedom. – older adult

Receiving help with *personal care*, such as showering, getting dressed, and taking medication was an important component that enabled aging in place. The older adults indicated that owing to temporary or more permanent physical setbacks, they were unable to shower or get dressed by themselves. Receiving help with this task was essential for them to be able to continue living at home. The informal caregivers indicated that these tasks could be overwhelming at times, which led them to involve formal caregivers, such as the district nurse.

It was getting to[o] much for me, helping her shower and get dressed, that is why we arranged formal care to support with these tasks. Now I have more time to focus on doing fun things with her and just having a good time. – informal caregiver

Both older adults and informal caregivers indicated that receiving help with other *daily activities* such as cleaning the house or cooking was of great importance. Older adults were often unable to perform all these tasks by themselves and therefore greatly appreciated the help that they received from either their informal caregiver or formal caregivers (for example home care or meal services). Informal caregivers valued the involvement of the wider social network and formal caregivers, since it relieved them from some of their caregiving duties and therefore made the situation more sustainable.

She [older adult] does not cook anymore. There is a Surinamese woman who lives around the corner and brings her food. We pay her a little money for this and she brings the food. – informal caregiver

The older adults expressed the importance of social interactions to combat feelings of loneliness that were especially present for people living alone. They emphasized the desire to engage in meaningful *social activities*, such as informal meetings at the community center with other older adults. Older adults also wanted to engage in meaningful social activities that allowed them to contribute to society, such as volunteering or being part of an older adult panel to advise local organizations and political parties.

The people at the community center are lovely. We come together there several times a week, just to drink some coffee and chat – older adult

To engage in these activities, many older adults had to overcome mobility issues. Therefore, the availability of *transportation* options was important for their daily lives. Public transport was not always a good solution, since the accessibility for older adults with more severe mobility issues was limited. A variety of formal (taxi or carpool service) and informal options (getting rides from

informal caregiver or persons in their social network) were used to participate in activities outside the house.

> *It is a service from the ANWB [Dutch traffic and tourism organization], where they arrange a volunteer to drive you. You have to call two days in advance and then they are going to look for someone to bring you with their car. I love it, because you also meet nice people and have a chat. – older adult*

Having *digital skills* was an important way to maintain independence. Older adults used these digital skills to order groceries or meals online to avoid asking their informal caregiver to go to the store for them. This also helped to unburden informal caregivers. Digital skills also helped to connect with family members who lived farther away. Video calling helped lower loneliness for older adults and enabled informal caregivers to monitor the care recipient. Unfortunately, not everyone possessed these digital skills.

> *I order everything online. I do not go to the shops anymore, so I order my clothes online. I also order the meals online, they bring them twice every week – older adult*

Both informal caregivers and older adults had difficulties *navigating the healthcare system.* It was expressed that it is hard to know which organization or professional to contact with certain questions. The care landscape was deemed fragmented and complex, with additional challenges for persons who do not speak the Dutch language. Having a case manager that would guide them through the aging process and organizing care was mentioned as a desirable feature of care support.

> *For Turkish or Moroccan older adults there might also be a language barrier. Not knowing where to go with your questions or not knowing how to access the organizations. – older adult*

The more detailed overview of themes, subthemes, and quotations is presented in Electronic Supplementary Material 5. Table 2 presents an overview of the attributes identified from the semi-structured interviews and their description. The DCE experts deemed the attributes and their description appropriate to continue to the next phase of the study.

Table 2. The identified attributes and their description after semi-structured interviews

Attribute	Description of the attribute
Housing	I can make changes to my current housing situation or arrange for these changes to take place when necessary.
Personal care	I can get assistance at home with personal care such as showering, taking medication, or getting dressed.
Daily activities	I can get assistance with daily activities, such as cleaning the house, cooking, laundry, gardening, or help with my finances.
Social activities	I can engage in social activities that I like to do and connect with other people.
Transportation	I can get transportation to activities outside of my house, such as doctor appointments or social gatherings.
Digital skills	I can get assistance to develop digital skills that allow me to arrange things online, such as ordering groceries or clothing, doing my finances, or having online interactions with family and friends.
Navigating the healthcare system	I can get assistance with organizing care and support options for my current or future situation.

3.4 Results from Phase 2: Focus Groups with Quantitative Ranking Exercise

3.4.1 Refining the Initial Attributes

In the first round of the focus group discussions, participants were asked to voice their initial opinion on the presented attributes. The participants mostly recognized the attributes, found them relevant, and understood their description. However, the attribute of *daily activities* led to some confusion. Participants indicated that the description made it clear that this attribute was related to household tasks such as cleaning and taking care of meals. However, the title of daily activities gave the impression that the attribute could relate to other daily activities, such as socializing with friends and family or going for a daily walk. Therefore, the research team decided to change the name of this attribute from *daily activities* to *household activities*.

It became evident that for some participants the attributes were only relevant if the service was provided in a culturally sensitive way. The participants with a migration background stressed that they would not be helped by a service designed for persons who do not share their cultural history or speak their language.

> *It is so important that they (case managers) can make a connection to the culture. Do you speak the same language, do you share the same cultural history. For example, can you talk about Surinam, can you recognize the stories, can you make room for this. That is the first step to form a connection that you can build on. – informal caregiver*

The research team discussed this finding with the expert panel, asking if the cultural sensitivity should be incorporated in the attribute levels or in the description of the attributes. The experts emphasized that on the basis of these findings, some attributes are only relevant for the participants with a migration background if they are culturally sensitive. Therefore, to meet the criteria that all attributes should be relevant for participants in their decision-making, the research team decided to include statements of cultural sensitivity in the description of the following attributes: personal

care, household tasks, social activities, and navigating the healthcare system. This approach helps to reduce heterogeneity in the DCE choice task, keeping the design manageable in terms of parameters to be estimated.

Finally, some participants indicated that they missed an attribute related to emotional support. These were mostly informal caregivers who were taking care of a person with dementia and indicated to feel a heavy emotional burden. It was stressed that dealing with the dementia symptoms of their loved ones and a changed reality was something that they needed support with.

> *I think that emotional support is also very important, at least it was for me as an informal caregiver. That you have someone with whom you can share everything and can speak freely about how the situation is affecting you. – informal caregiver*

The research team discussed this finding with the expert panel, debating whether they should include emotional support as an additional attribute. However, since it was something that seemed to be relevant only for a specific group, being informal caregivers of a person with dementia, the expert panel advised against including emotional support as an attribute. Instead, the choice was made to inquire about the need for emotional support in the questionnaire outside of the DCE choice task.

3.4.2 Prioritizing the Attributes

In the second round of the focus groups, participants were asked to rank the attributes from the most to least important. Table 3 presents the results of the ranking exercise, with lower scores indicating greater importance. Housing is the only attribute ranked significantly different by older adults compared with informal caregivers, with older adults ranking it as more important. Navigating the healthcare system is almost significant, with informal caregivers ranking it as more important than older adults. In addition, Kendell's tau-*b* analysis was conducted to examine the overall degree of agreement between the rankings of older adults and informal caregivers on the basis of the summed scores. The results show a very weak positive correlation between the groups (τ = 0.143, p = 0.652). This means that there is no significant agreement between older adults and informal caregivers in the order in which they prioritized the different attributes.

Table 3. Attribute ranking scores of older adults and informal caregivers

Attribute	Older adult (N=18) sum of ranks [a]	Informal caregivers (N=17) sum of ranks [a]	Group difference P-value [b]
Housing	41	71	.002
Social activities	56	52	.832
Household activities	62	56	.858
Personal care	68	55	.335
Navigating the healthcare system	70	41	.077
Transportation	103	102	.386
Digital skills	104	99	.732

[a] Sum score of ranked attributes, stratified for older adults and informal caregivers. Lower scores indicate greater importance, and higher scores indicate lower importance.
[b] Mann-Whitney U test: between group difference in ranking for older adults versus informal caregivers

Transportation and digital skills were ranked as the two least important attributes for both the older adults and informal caregivers, with considerably higher scores as the other five attributes. This is complemented by the qualitative findings, with participants indicating that they were less important when compared with the other attributes.

> *For me, it was easy to put digital skills at the bottom. It could be important in some situations, but it is just not as important as the others about organizing care and support and your living situation. These are the ones that are really essential. – informal caregiver*

> *The community center also has a service that you can use, you can call them to ask for transportation when you need it. There is also a regional taxi service, you could also use Valys [taxi service for persons with mobility issues]. There are so many possibilities, it is really not a problem. Therefore, I put it last. – older adult*

In addition, the participants often referred to digital skills in relation to other attributes, such as navigating the healthcare system or daily activities. For example, there were some older adults who possessed digital skills and used them to find information about care and support or help with tasks such as ordering groceries or meals. However, there were also many older adults who did not have digital skills and could not see themselves developing these skills in the future.

The research team discussed these findings with the expert panel, debating if this would be an issue, since attributes should be nonoverlapping and relevant for all participants in the decision-making process. It was agreed to exclude both digital skills and transportation as attributes because they do not seem to be as relevant to the participants as the other five attributes and would presumably be of little importance in the decision-making process. In addition, the digital skills attribute seems to overlap with some of the other, more important, attributes. In the discussion with the expert panel, it was suggested that transportation and digital skills were more contextual factors surrounding aging in place, rather than being at the core of care and support. To gain some insights into participants' experiences and needs regarding digital skills and transportation, questions will be asked about these topics in the questionnaire outside of the DCE choice tasks.

3.4.3 Development of Attribute Levels

In the final focus group round, participants explained their ranking choices, with follow-up questions probing care and support preferences. These transcript sections were coded to inform attribute-level development. The codes focused on the preferred locations for the delivery of care, the preferred frequencies, and involved healthcare professionals.

For the housing attributes, levels portrayed different options focused on modifying the current home or moving to enable aging in place. Assistance with personal care and household activities was of course provided within the home, mostly by care professionals or informal caregivers. The preferred frequency of care varied among respondents. For the social activities attribute, there was more variation in the way in which participants gave meaning to this aspect and the desired location of this form of support. Finally, to help navigate the healthcare system the participants mostly described a desire for one central contact person to assist them. However, the preferences of who this person should be varied between the participants. A detailed overview of the levels and corresponding quotes is provided in Electronic Supplementary Material 6. Table 4 presents an overview of the final attributes, with their descriptions and attribute levels.

Table 4. Final list of attributes and attribute levels

Attribute	Description of the attribute	Attribute levels
Housing	I can make changes to my housing situation.	1. Downsize to one-floor apartment 2. Move to communal housing/assisted living 3. Modify my own home (example stair lift or bathroom grips)
Personal care	I can get home assistance with showering, medication, or dressing from a same-sex professional who speaks my language.	1. Once a week 2. Twice a week 3. Daily
Household activities	I can get home assistance for groceries, laundry, cleaning, cooking or administrative tasks from someone who speaks my language.	1. Once every two weeks 2. Once a week 3. Twice a week
Social activities	I can engage in social activities that I enjoy and connect with people who share my background and language.	1. Attend a daycare facility 2. Having someone visit at home for socializing 3. Join a local club (cards, sports, reading)
Navigating the healthcare system	I can get help organizing care and support from someone who speaks my language.	1. Practice nurse (GP clinic) 2. Case manager/personal care counsellor 3. Contact person of my health insurer

3.5 Questionnaire Outside of DCE Choice Task

Through the process of attribute development and level selection, it became clear that there were some relevant topics not suitable to be included in the DCE choice task but nevertheless relevant in the context of older adults and informal caregivers aging in place in The Netherlands. For example, the contextual topics of transportation and digital skills, as well as the need for emotional support, were judged important but not feasible to include within the DCE choice tasks. Therefore, the decision was made to ask questions about these topics in the questionnaire accompanying the DCE choice tasks.

In line with the qualitative findings, which underscored the importance of culturally inclusive care, this dimension was incorporated into the attribute descriptions of the DCE. To further examine how cultural needs influence care preferences, the questionnaire includes targeted questions on culturally inclusive care, and subgroup analyses will be conducted to identify differences by migration background. The questionnaire will also allow us to examine more closely which types of care and support people prefer to receive from informal caregivers and in which situations they are more willing to rely on professionals. This will provide a deeper understanding of how preferences between informal and formal care providers affect care choices.

Finally, the questionnaire will include a willingness-to-pay question, using a contingent valuation approach [37]. This captures participants' views on potential financial contributions, which is relevant for policy given possible future co-payment reforms. The expert panel noted that Dutch older adults and informal caregivers currently face minimal out-of-pocket costs and are not accustomed to valuing care services financially. Including a cost-related attribute in the DCE therefore risked

creating a dominant attribute and biasing results. We chose to assess financial contributions outside of the DCE choice task.

4. Discussion

4.1 Key Findings

This study identified five attributes and corresponding attribute levels related to aging in place that will be used in a future DCE study to quantify the preferences of older adults and informal caregivers in The Netherlands. The first attribute, *housing*, refers to the ability to adapt one's living environment to support aging in place, with attribute levels including modifying the current home, moving to a smaller one-floor apartment, or relocating to communal housing. The second and third attributes involve *personal care* and *household activities*, with participants expressing a desire for professional support; attribute levels reflect different frequencies of care. The fourth attribute, *social activities*, includes levels such as attending a daycare facility, joining a local club, or receiving visits at home for social interaction. The final attribute, navigating the healthcare system, includes levels representing professionals who could provide support, such as a practice nurse, case manager, or contact person from the health insurer.

This study used a combination of semi-structured interviews and focus groups with a ranking exercise to come to a final list of attributes and attribute levels. The interviews provided rich, in-depth insights and allowed for flexibility in exploring participant-driven topics, which facilitated the identification of a comprehensive list of relevant attributes [18]. The follow-up focus groups, which included a ranking exercise, were instrumental in reducing the attribute list by highlighting which attributes participants prioritized and why. Similar to previous studies, we found the qualitative reasoning of the ranking exercise essential to the interpretation of the results, to make an informed decision about the exclusion of attributes [24, 38]. The group discussions also fostered rich interaction, allowing participants to reflect on and respond to each other's perspectives, which further clarified how different attributes were valued and informed the creation of attribute levels. This iterative, participant-centered process helped balance comprehensiveness with cognitive manageability, ensuring a final set of attributes that was both meaningful and feasible for inclusion in the DCE.

While the attributes included in this study offer valuable insights into aging-in-place preferences, other factors may also shape individual decisions. A recent review identified five key dimensions relevant to aging in place: place (both physical place and emotional attachment), social networks, formal and informal support, technology, and personal characteristics [28]. Although there is

some alignment between these dimensions and the attributes in our study, certain elements—such as social networks and personal characteristics—are not fully captured. The review emphasized that qualities such as resilience, independence, and adaptability affect an individual's ability to age in place and influence their need for care and support [28]. Moreover, older adults often feel more confident about aging in place when supported by strong social networks, typically involving regular contact with family members [28]. Recent preference research in related contexts, such as a best–worst scaling study on activities in dementia living arrangements, also highlighted the importance of social engagement, including walks and excursions, sports activities, gardening, and interaction with animals [39]. Despite their significance, some of these factors are difficult to include as attributes in a DCE because they are largely intrinsic and less amenable to experimental manipulation, which conflicts with the assumptions of random utility theory [18]. However, researchers can explore these differences through supplementary questions outside of the DCE choice task.

A recent German study argued that enabling aging in place increases the use of home- and community-based care services [40]. The study used a DCE to assess future preferences for such services among a general population sample aged 45–64 years [40]. Attributes included frequency of care, service level, quality of care, caregivers involved, and co-payments [40]. Participants identified quality of care as the most important factor and preferred a small, consistent group of professional caregivers over a rotating team [40]. A similar DCE study conducted in The Netherlands 15 years ago asked participants aged 50–65 years to consider long-term care preferences of a frail older adult or person with dementia [41]. Similar to the German study, Dutch participants valued continuity of care, particularly the same caregiver over time [41]. They placed less importance on punctuality and flexibility to adapt services to individual preferences. Notably, only 5% of participants were actual users of long-term care services [41]. In contrast, participants in our study emphasized the importance of adapting services to individual needs and preferences, such as culturally sensitive daycare facilities. These findings suggest that a so-called one-size-fits-all approach is insufficient. To ensure equitable benefit, care services must be personalized to reflect individual circumstances. This aligns with findings from a review of stated preference research on long-term care, which highlights the importance of tailoring services to maintain self-image, autonomy, and dignity [42].

4.2 Strengths and Limitations

This study demonstrates how qualitative methods can be used to develop attributes and levels for a DCE, integrating qualitative research into health economics. While using qualitative work for attribute development is highly recommended, few studies provide a detailed report of their methodological approach [18, 43]. In this study, we provide evidence and transparency by reporting key elements such as sampling, data collection, and analysis. We also describe how qualitative results

were translated to attributes and attribute levels with the help of DCE experts, ensuring alignment with random utility theory. This process strengthens the validity of our final DCE and serves as an important methodological reference for future research.

In addition, this study advocates for the inclusion of underserved groups, demonstrating how to build an inclusive DCE study. People with a migration background are often labeled as hard-to-reach groups, leading to their exclusion from research, even though their opinions and experiences are crucial [44]. We offer strategies to include these individuals, such as building a diverse research team and collaborating with (in)formal organizations that serve persons with a migration background.

This study has several limitations. First, participants were primarily recruited through family care navigators, daycare facilities, community centers, and organizations that serve persons with a migration background. As a result, most participants were already receiving some form of care, and our sample may underrepresent older adults who are more isolated or have limited access to formal or informal care. These individuals might have different needs and preferences that are not fully captured. In addition, all participants had an informal caregiver, reflecting a common situation in The Netherlands but limiting the generalizability of our findings. Preferences of older adults without informal caregivers may differ, particularly regarding the balance between informal and professional support. Moreover, our attribute design reflects the Dutch context, where long-term care is largely publicly funded and delivered by home care workers and district nurses. These system-specific arrangements may reduce variability in preferences for provider type, which in other countries or healthcare systems could play a more prominent role. Future research should therefore investigate how preferences differ across populations without informal caregivers, and in international settings where care provision and financing arrangements vary more widely.

4.3 Implications

The results of this study offer insights into care preferences and needs of older adults and informal caregivers aging in place in The Netherlands. These findings provide input (attributes and attribute levels) for a future DCE that will help to quantify these care preferences, helping to tailor care and support options to the needs of older adults and informal caregivers. Ultimately, this will support the realization of the policy ideal of aging in place, benefiting both individuals and the policymakers.

This study also makes an important methodological contribution to health economics and stated preferences research by detailing how qualitative methodologies and expert opinions can be combined to develop attributes and attribute levels for DCEs. Researchers can use this approach to help guide their own methodological choices and reporting.

5. Conclusions

This study identified key components of care and support (attributes and attribute levels) for older adults and informal caregivers aging in place in The Netherlands. It is clear that adequate housing, assistance with personal care and household tasks, opportunities for social engagement, and help navigating the healthcare system are essential for successful aging in place. To ensure that support services are accessible to all, they must be culturally sensitive. These findings lay the groundwork for further research into the priorities and needs of older adults and informal caregivers aging in place.

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Supplementary material 1. COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	5
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	1
Occupation	3	What was their occupation at the time of the study?	1
Gender	4	Was the researcher male or female?	5
Experience and training	5	What experience or training did the researcher have?	5
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	4
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	4,5
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	5
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	5,6
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	4
Method of approach	11	How were participants approached? e.g. facetoface, telephone, mail, email	4
Sample size	12	How many participants were in the study?	8
Nonparticipation	13	How many people refused to participate or dropped out? Reasons?	8
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	5
Presence of nonparticipants	15	Was anyone else present besides the participants and researchers?	5
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	8

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	5,6 + appendix
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	n.a.
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	5,6
Field notes	20	Were fi eld notes made during and/or after the inter view or focus group?	5,6
Duration	21	What was the duration of the inter views or focus group?	5,6
Data saturation	22	Was data saturation discussed?	5
Transcripts returned	23	Were transcripts returned to participants for comment and/or correction?	5
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	5,6
Description of the coding tree	25	Did authors provide a description of the coding tree?	appendix
Derivation of themes	26	Were themes identifi ed in advance or derived from the data?	5
Software	27	What software, if applicable, was used to manage the data?	5,6
Participant checking	28	Did participants provide feedback on the findings?	5
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	9-12 + appendix
Data and findings consistent	30	Was there consistency between the data presented and the findings?	9-12
Clarity of major themes	31	Were major themes clearly presented in the findings?	9-12
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	9-12

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. International Journal for Quality in Health Care. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.

Supplementary material 2. Participant information letter

Dear Sir/Madam,
We ask you to take part in a scientific study.
You decide yourself if you want to take part.

Janet Macneil-Vroomen and Isabelle Vullings organize the study.
Call them if you have any questions.
You do not have to decide today.

1. Why is this study important?

You live at home or you care for someone who lives at home. Maybe you get help with some things. We would like to hear what you think about different kinds of care and support.

What is important for you? What helps you to live at home in a pleasant way?
Your opinions and experiences help policymakers. They make decisions about living situations and care in the future.

2. What do you have to do if you take part?

If you take part, *[name interviewer] will ask you questions about your experiences living at home/ you will join a group conversation. The group will consist of other people living at home and/or caregivers.* During this conversation we will talk about different kinds of care and support, for example: home care, social activities, and organizing care. We would like to know how important this is for you and what your experiences are.
The conversation takes about 45 to 60 minutes. We would like to record the conversation. Then we can listen to it again later.

3. If you do not want to take part or if you want to stop

You choose yourself if you take part. If you do not take part, nothing changes. If you now receive care, that stays the same. You can also always stop if you do not want to take part anymore.

4. Confidential

Everything you tell us stays secret.
We will write the conversation on paper and then delete the recordings. Your name will not be on the paper. The conversation will get a number. The conversations will never be made public and cannot be used for legal purposes.

It is only for this scientific study and possibly for future studies. The written conversations will be stored in a protected folder on the Amsterdam UMC server.

5. And now?

Isabelle will call you about this study, to ask if you want to take part.
After that they will make an appointment. You will then sign the consent form.
We hope you want to take part in this study. Thank you very much,

Isabelle Vullings
i.vullings@amsterdamumc.nl
[telephone number]

Supplementary material 3. Interview guide

Introduction: I would like to thank you for participating in this study. Your answers are very important for the study. First, let me briefly introduce myself [short introduction researcher]. The research we are conducting is about people who live at home. I would like to talk to you about how things are going at home and the help that you receive. If I ask an unclear question, please let me know. You may say anything that comes to mind. There are no wrong answers. If it is okay with you, I would like to record the interview. This will allow us to use it for the study. I will only share the interview with my colleagues. The conversation will not be shared with your doctor, your family, or any other organization. After this interview, your name will be replaced with a number. [have the respondent sign the consent form] [start recording]

First I have a few general questions I would like to ask you: 1) How old are you? 2) Where do you live? 3) Where were you born? 4) Where were your parents born? 5) Do you live alone? 6) Have you received education? If so.. how many years? What education have you completed? 7) Do you have any chronic conditions?

Theme	Description theme	Example questions
Introduction	Staring questions – room for topics to be brought up by the participant	Can you tell me something about yourself? How is it going at home?
Daily activities	Talk about: what are things that someone does by themselves and where do they get support (both formal and informal) Cleaning, cooking, showering, getting dressed, religious activities, praying, going to church/mosque Ask informal caregivers how caregiving influences their daily lives	How do you spent your days? What is a normal day like for you? How do you do your groceries? Where do you receive help?
Social activities	Talk about: social interactions, feelings of loneliness, activities such as playing cards, male/female groups, community centers Can someone participate in the activities that he/she wants – are there barriers? Aks informal caregivers if they have time for themselves to engage in social activities.	What are activities that you like to do? What are activities that you like to do with others? With whom do you like to do these activities? How often do you get visitors? Do you sometimes miss others around you?
House	Talk about: is the house suitable for aging-in-place, one-floor, neighborhood, distance to services. Adaptations such as stair lift, grips in the bathroom, personal alarm for medical emergencies.	What do you find important about a home? How do you like living here? How far is it to the supermarket/doctor? Did you make changes to your home? Which changes would you like to make to your home?

Theme	Description theme	Example questions
Feeling at home	Talk about: how is the neighborhood in which the person lives. Find out if there is a lot of contact with the neighbors and if someone feels at home in the neighborhood. + which services there are in the neighborhood.	What do you think about the neighborhood in which you live? How often do you speak with the persons living in your neighborhood? How do you experience these interactions? Do you feel at home in this neighborhood?
Health	Talk about: how is their health, are there any (chronic) conditions. How is the mobility, are their mobility issues in their daily lives.	How is your health? What do you do to stay healthy? Do you experience problems with walking? Do you experience problems with hearing?
Formal support	Talk about: how do they experience home care workers/ hospital care How is their relation with the GP, physical therapist, social worker How do they experience organizing care – do they get help with this	Which form of care/support do you receive? Who delivers this care? How do you value this care? How is the contact with your general practitioner? What do you find important in the relation with your general practitioner? How did you experience the care at the hospital? How do you organize the care that you need?
Informal support	Talk about: does someone receive/give help to family/friends/neighbors What kind of help and how is it valued	Which people are involved in your life? Do you receive help from friends or family? Where do they help you with? How do you experience this help?
Desires and experiences about aging	Talk about: how does someone experience the process of aging. What are wishes/concerns for the future – does someone want to stay at home/move to other form of housing	How do you experience getting older? Where would you like to age? Who would you like to take care of you (if needed in the future)? What are your wishes in terms of aging? What are your concerns for the future?
Closing questions	Ask if there are any other import topics	Are there any other topics that you would like to discuss? Are there any other things that you would like to tell me?

Supplementary material 4. Illustrations of the attributes



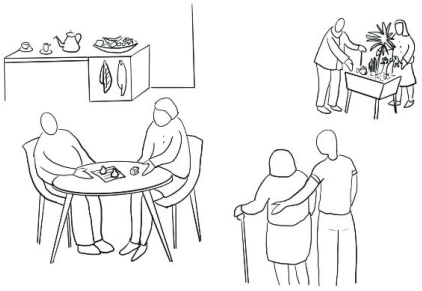
Housing



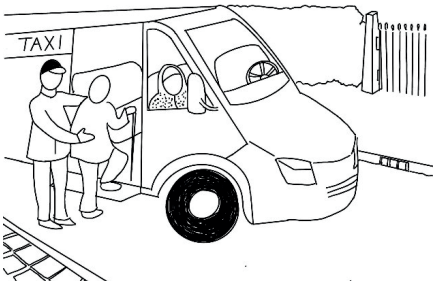
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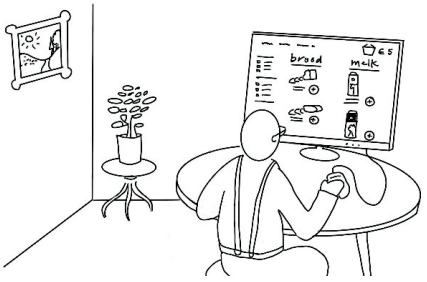
Household tasks



Social activities



Transportation



Digital skills



Navigating the healthcare system

Supplementary material 5. Coding scheme attributes

Theme	Subthemes	Quotes
Housing	Desire to age-in-place and stay in current house	*I sometimes worry that I will not be able to stay in my house if I become more dependent. I would prefer to stay here for as long as possible. Here I have my own space and freedom. – older adult*
	Changes made to a house to make is suitable for aging-in-place	*I have a stairlift and grips in the bathroom, this is really important. I would not be able to live in this house without it – older adult*
	Feelings of loneliness due to living alone and desire to move to communal housing for social interactions	*A place where you can live if you only need mild support, but where you can have more contact with others. You would not be alone, you have so many people to talk to. I would like that. – older adult*
	Willingness to move to assisted living or facility if person becomes more dependent of care and support	*We discussed that at some point we cannot do it anymore at home. If he becomes more dependent we have to think about other options, such as a nursing home or assisted living. He agreed to this. – informal caregiver*
Personal care	The importance of formal support to help the older adult with personal care (showering, taking medication, getting dressed)	*I have had a setback two times, I could not shower myself. I got help from the district nurse, without this help I would not have been able to manage at home. It was very nice that they could help me. – older adult*
	Formal support to relieve the informal caregiver	*It was getting to much for me, helping her shower and get dressed, that is why we arranged formal care to support with these tasks. Now I have more time to focus on doing fun things with her and just having a good time. – informal caregiver*
Daily activities	Receiving formal support with household tasks (mostly cleaning) to enable staying at home	*I have a problem with by back, so I cannot do things such as vacuuming or mopping the floor. She comes to help me once a week. She gives the bathroom a good clean, the other week the kitchen. This is very helpful. – older adult*
	Receiving support with groceries and cooking from informal caregiver, social network, or meal services	*She does not cook anymore. There is a Surinamese woman who lives around the corner and brings her food. We pay her a little money for this and she brings the food. Sometimes she is unable to do this, then we cook something and bring it to her. Then she has food again for a couple of days. – informal caregiver* *I used this meal service for a while, they came to bring me food twice a week. To be hones I did not like it very much. The food was not good, I rather have something fresh. – older adult*
Social activities	Importance of social interactions and feelings of loneliness	*Someone will not come up to you and say I am lonely, maybe because they are ashamed or something, but the loneliness is there. Older adults also want to have a chat, they want to connect with others – older adult*
	Social interactions through the community center, or a volunteer coming to the house	*The people at the community center are lovely. We come together there several times a week, just to drink some coffee and chat – older adult* *He has a buddy through the Zonnebloem [organization for older adults] that comes to his house every week to drink coffee and chat. They talk about everything, politics, history. He requested for someone that is intelligent and shares his interests – informal caregiver*
	The desire to engage in meaningful social activities that contribute to society	*My wife and I were both retired, we were just sitting at home. This was not good, we wanted to do something useful with our time so we started to look for volunteer work. I truly believe that this is important, to keep you mind sharp and feel that you are contributing. – older adult*

Theme	Subthemes	Quotes
Transport-ation	Having mobility problems that make it harder to participate in activities outside the house	*I cannot walk that far anymore, my condition has deteriorated. I cannot go that far anymore, which makes it harder for me to reach the shops for example, or the movie theater. – older adult*
	Hard to use the public transport since this is not always build for persons with mobility issues	*I cannot use the bus, because it cannot get in. the step is to high for me. I cannot get in the door – older adult*
	The use of formal (taxi, automaatje) or informal services (social network, informal caregiver) to reach destinations	*It is a service from the ANWB, where they arrange a volunteer to drive you. You have to call two days in advance and then they are going to look for someone to bring you with their car. I love it, because you also meet nice people and have a chat. – older adult*
Digital skills	The use of digital skills to remain level of independence. Ordering groceries or clothes online, or doing finances on the computer.	I order everything online. I do not go to the shops anymore, so I order my clothes online. I also order the meals online, they bring them twice every week – older adult
	Having online interactions with friends and family	I can videocall her or send a photo. For me, it is a relief to be able to quickly see her face and know that she is doing fine. I can send a photo if I am on vacation for example, then you have a little moment of contact. – informal caregiver
Information and assistance about organizing care	The complexity of finding the right information and getting care organized	It started when she fell more often, we decided that it would be good is she would get some help with showering and getting dressed. I found it quite tiring to arrange all of this. You call the health insurer, you call the general practitioner, then you see the long waiting lists. It is good because you get to know the system, but it was not easy. – informal caregiver For Turkish or Moroccan older adults there might also be a language barrier. Not knowing where to go with your questions or not knowing how to access the organizations. – older adult
	Desire for a person (case manager) that guides you through the process of aging and organizing care	That there is one keyperson that can help to bridge the gap and bring people in contact with the right organization. A sounding board for persons, someone they can rely on to help them through the process. – older adult
	Desire for one central point (website) with all the information about care and support	Sometimes I think why is there not just one person that I can call? One person who will then arrange it for me – informal caregiver One webpage with all the information, that you can find all the information in one place. That you can see which things you can apply for, which things you cannot apply for. Where you need to apply. One central point with all the information, that would have helped me. – informal caregiver

Supplementary material 6. Description of levels, coding scheme, and quotations

In the discussion about the housing attribute, many participants indicated to have they had made the decision to move to a smaller one-floor apartment, since their current home was not suitable for aging-in-place. Another commonly adopted strategy was to make changes to the current home, such as installing a stair lift or grips in the shower and toilet. Finally, participants would like to move to forms of communal housing, having their own apartment with opportunities for care and support nearby.

Assistance with personal care and household tasks was of course provided within the home. The older adults primarily received this support from either homecare professionals or informal caregivers. The informal caregivers often expressed a need for additional support from healthcare professionals. The preferred frequency of care varied among respondents: for personal care, it ranged from once a week to daily, while for household tasks, it ranged from once every two weeks to twice a week.

For the social activities attribute, there was more variation in the way in which participants gave meaning to this aspect and the desired location of this form of support. Many older adults went to a daycare facility to socialize with other older adults, but there was also a considerable group that used less formal options, such as playing cards or sports at a local club. Finally, there were participants who used services that had volunteers or professionals come to their house to socialize with them.

Finally, to help navigating navigate the healthcare system the participants mostly described to a desire for one central contact person to assist them. However, the preferences of who this persons should be varied between the participants. There were some participants who preferred a case manager (in case of dementia) or personal care counselor, whereas others thought it would be helpful to have a contact person from the health insurance.

Attribute	Levels	Quotes
Housing	Downsize to one-floor apartment	"We have moved to an one-floor apartment a few years ago, to ensure that we could remain living there when we would need more care and support." – older adult
		"I am still quite mobile myself, but my wife has some problems with the stairs, and then it is really nice when everything is on one level. I think that is very important for living well. The others things come after that, it starts with your living arrangements." – informal caregiver
	Move to communal housing/ assisted living	"I live in a communal housing unit, it is very enjoyable. I know the people, there is always someone to connect to. It is very nice." – older adult
		"there is automatically a form of social control, it is just there. You do not have to ask for it, you do not have to organize it, it is just there. If something happens to you, then you are not alone. The beautiful thing about this way of living is that you are free to do what you want. You can keep to yourself, but you can also be very sociable if you desire." – older adult
	Modify my own home (stair lift, bathroom grips)	"I have grips in the toilet and bathroom, this was very important. It sounds dramatic, but without them I would no longer be living here, it would not be possible." – older adult
		"We have made all sorts of arrangement to ensure that she can continue to live in her house. There is a stairlift, a chair in the shower, and there are grips in the toilet. We did that in consultation with her physical therapist." – informal caregiver
Personal care	Once a week	"I did it myself, I helped her shower. I liked to do it myself, but it would have been nice to have some help. To have someone who could come, even if it would be just once a week, to help with these things." – informal caregiver
		"Because I am a fall risk, that how they put it, but because of that someone comes once a week when I am showering. I can still do it myself, but they come to watch me and to see that I can do it safely." – older adult
	Twice a week	"I get help with showering, twice every week." – older adult
		"Help with personal care is two times per week for me, they come to help me shower. I am very happy for their help, because I am not able to do it myself." – older adult
	Daily	"The women of the homecare organization come every morning to help me get dressed." – older adult
		"They visit my mother every morning, to help put on her stockings and make sure that she takes her medication. They come again in the evening, before she goes to bed. They help her put on her pyjama's and just make sure that she is all right." – informal caregiver
Household activities	Once every two weeks	"We have a domestic help once every two weeks." – informal caregiver
		"There are still some things that I can do myself, just dusting of some shelves or things like that. However, the more heavy stuff such as vacuuming, mopping the floor, changing the bed. I really do need help with that, so luckily someone comes once every two weeks to do these tasks." – older adult
	Once a week	"Every Monday morning someone comes to help us clean the house." – older adult
		"I have someone who comes once a week, it was very important for me that she also speak Turkish. I want to be able to communicate with her." – older adult
	Twice a week	"I go to the stores for him, buy groceries, make sure that he has food for a few days I go every Sunday and Wednesday. " – informal caregiver

Attribute	Levels	Quotes
Social activities	Attend a daycare facility	"Going here [daycare facility] is about socializing, being with a group of people who are my age and share my background. I can speak my own language here, be myself. It is very important for me." – older adult
		"I am also going to the daycare facility for my wife. She is my informal caregiver and for her it is nice that I am away for a little bit. She can do her own thing, that is important as well." – older adult
	Having someone visit at home for socializing	"We used this service where they match you with someone based on your personal profile. They try to find someone who shares your interest, there is an initial meeting to see if there is a connection. My father loved history, they had this is common. The boy would come, I think he was a student, and they would talk about history (...) My father really enjoyed this." – informal caregiver
		"She comes to my house, and we socialize for a bit. Sometimes we go outside, if the weather is good or we play a game. I do enjoy the company." – older adult
	Join a local club (cards, sports, reading)	"I am very happy that he joined the choir. Every Saturday morning they come to pick him up, it a group of men. They pick him up and bring him home, he has a morning out." – informal caregiver
		"I play cards in the community centre every Wednesday. We are always with the same group of people, I have been doing this for years." – older adult
Navigating the healthcare system	Practice Nurse (GP clinic)	"We have help from the practice nurse of the GP, she reaches out to us on a regular basis. She comes to visit us, to see how we are doing and if we need more help." – informal caregiver
		"I really appreciate her involvement [practice nurse GP], she listens and asks the right questions. She also knows how to open doors, if there is something you need." – informal caregiver
	Case manager/personal care counsellor	"It would be nice to have someone who guides you through the process, as a case manager." – older adult
		"We had a case manager, really great. She emigrated, very nice for her but too bad for us. I had a very good connection with her. I could just call her and say: look, I have this problem, please tell me where I need to go, and then she would always know how to help. Now we have someone else, and well, there really is a difference." – informal caregiver
	Contact person of my health insurer	"I know that in some other countries you have one contact person of your health insurance. This person arranges all your things surrounding care and support, so you do not have to go to all these different organizations yourself. I think that would be very helpful, you could just call this person and they would have the full picture of your situation." – informal caregiver



Chapter 8

General discussion

The overall aim of this thesis was to develop an analytical approach for evaluating ageing-in-place (AIP) reform policies from a system-level perspective, while incorporating the voices of those ageing in place. In the first part of this thesis, we developed an assessment framework for evaluating AIP reform policies at the system level. We identified performance indicators used in the international literature to assess the effects of different AIP reform policies, and integrated this international evidence with Dutch stakeholder perspectives in a Delphi study. A diverse panel of AIP experts assessed the relevance and usability of indicators, building consensus on a context-specific, system-level tool to help evaluate AIP reform policies in the Netherlands.

The second part of this thesis offered evidence from an individual-level perspective. We provided guidance on developing methodologies that inclusively capture the preferences and needs of older adults and informal caregivers ageing in place, centring the perspectives of those directly affected by AIP reform policies. Using interviews, we provided in-depth knowledge of the AIP experiences and needs of Dutch persons living with dementia and their informal caregivers, including often-underrepresented groups such as those with a migration background. Finally, AIP preferences of the general older adult and informal caregiver population were identified in a mixed-methods study. This work guided the development of a future discrete choice experiment (DCE) to quantify AIP preferences; an important step towards generating population-level data that can inform policy development and service planning.

Reflection on the main findings

System-level framework for the evaluation of ageing in place reform policies

AIP reforms require a system-level evaluation approach that aligns with policy objectives and includes performance indicators capturing the inputs of the system in which care is delivered, the care provided, and the resulting impact on patients and society [1]. While existing health system performance assessment (HSPA) frameworks provide a foundation, they are too generic to capture the specific effects of AIP reform policies [1, 2]. To build a system-level evaluation framework for ageing in place, we reviewed the international literature to identify performance indicators used in AIP reform evaluation **(Chapter 2)**, and consulted a diverse panel of AIP experts to assess the actionability of indicators within the Dutch policy setting **(Chapter 3)**.

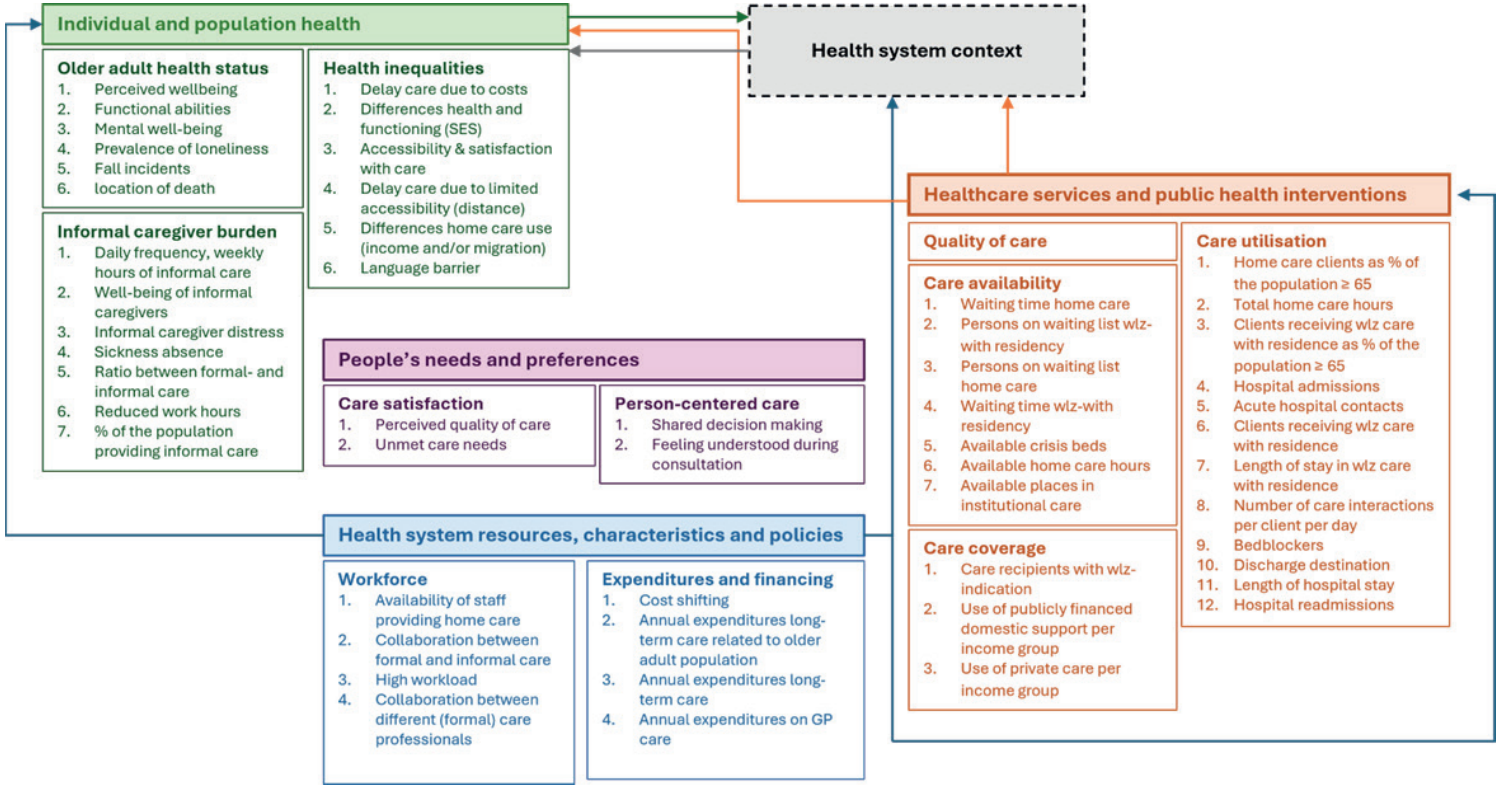
The literature review **(Chapter 2)** identified indicators across three levels: system structures (expenditures, care availability, workforce), processes (utilisation, quality, satisfaction) and outcomes for older adults and society (health status, informal caregiver burden). Some indicators overlap with existing HSPA frameworks, while others are specific to ageing in place, such as the shift in

costs from institutional care to home and community-based care [3, 4] or informal caregiver burden and wellbeing [5]. No indicators related to health inequalities were reported, despite an increasingly diverse older adult population and workforce scarcity [6, 7].

The Delphi study **(Chapter 3)** reached consensus on 53 actionable performance indicators, spanning 10 domains (older adult health status, informal caregiver burden, health inequalities, care satisfaction, person-centred care, care availability, coverage of care, care utilisation, workforce, and expenditures and financing), for evaluating national AIP reform policies in the Netherlands. The framework (Figure 1.) situates the health system within a broader socio-economic context that impacts and interacts with it. The needs and preferences of those ageing in place are placed at the centre of the framework, making them a core policy objective [1]. Outcome-oriented indicators capture effects on the health and wellbeing of older adults and informal caregivers, while structural indicators cover workforce capacity and expenditures. The services and interventions section addresses access, utilisation, coverage, and quality of care.

Notably, while no health inequality indicators were identified in the international literature **(Chapter 2)**, the Delphi panel endorsed health inequalities as a distinct domain of the framework. This reflects a shared view that equitable distribution of AIP outcomes across socioeconomic groups, regions, and increasingly diverse older adult populations, is essential to system-level performance, and addresses a gap in current AIP reform evaluation.

Figure 1. System-level framework for the evaluation of ageing-in-place reform policies in the Netherlands



Final framework with 53 actionable performance indicators for the evaluation of ageing-in-place reform policies in the Netherlands. The framework is based on the Health System Performance Assessment framework of the Organisation for Economic Cooperation and Development.. Indicators reached consensus when ≥75% of the panel rating them 4 or higher on a 5-point Likert scale on both criteria (Fit for Purpose and Fit for Use). Indicators are ranked within each domain according to their importance.

The framework illustrates a need to include more outcome-oriented indicators in AIP reform evaluation, such as wellbeing, mental health, informal caregiver burden, and health inequalities, which remain underrepresented in the literature [8, 9]. In addition, commonly used quality of care indicators, including preventable mortality and hospital admissions, were considered less actionable for AIP reform evaluation due to complex trade-offs between risk prevention and preserving autonomy and quality of life in care for older adults [1, 10]. These findings may reflect an ongoing reorientation in Dutch long-term care policy and practice, where quality of care is increasingly understood as needing to reflect individual preferences, personal experiences, and contextual factors [11]. Such dimensions are harder to capture in standardised population-level quality indicators.

> *"It is important that people can live their lives in the way they choose for as long as possible, maintaining their independence wherever possible. It is our role as care professionals to advise and support them, so that life can be lived as they wish." – AIP expert, Delphi-study*

These findings underline the importance of including people's needs and preferences as a central element in our framework and a key policy objective for ageing in place. However, capturing these concepts in measurable performance indicators is challenging, given the variation in individual experiences of care, values, and expectations [12]. In addition, preferences are dynamic, changing over time in response to health and social circumstances [13]. These challenges point to the need for complementary methodological approaches that can better capture the diverse and evolving AIP preferences of older adults and informal caregivers.

Identifying ageing-in-place preferences

Discrete Choice Experiments (DCEs) are a promising methodology to identify AIP preferences. We have developed a methodology to design DCEs identifying AIP preferences, applicable to different populations such as people with dementia and their informal caregivers **(Chapter 4)** or the general older adult population **(Chapter 7)**. To build a DCE study that captures AIP preferences, it is crucial to include appropriate attributes (e.g. care services) and attribute levels (e.g. characteristics of service delivery) [14]. We used two methods to identify attributes and levels. Semi-structured interviews were used to provide in-depth insights into participants' experiences and daily lives, creating an initial list of care and support services important for ageing in place (e.g. attributes). The subsequent focus group discussions helped to prioritise attributes, refine wording, and define how persons would like to receive those care and support services (e.g. attribute levels). The ranking exercise revealed the relative importance of the attributes and the underlying reasoning behind the preferences. Based on these qualitative findings, the final DCE is designed to quantify preferences.

This methodology can inform AIP reform evaluation in different ways. First, by identifying and quantifying AIP preferences, it offers a reliable and systematic way to generate evidence on what people value. When implemented in an inclusive sample, the DCE yields results that are generalizable to the broader population, generating population-level data on AIP preferences. Second, it offers important contextual and in-depth insights through its qualitative components. Semi-structured interviews and focus group discussions help to provide a deeper understanding of individuals' experiences, which can help to better understand their AIP preferences, contextualise findings from measurable performance indicators, and explore new topics that may not yet be captured in existing indicator sets. For example, whilst an indicator about the percentage of older adults living at home with unmet care needs provides relevant information, this can be complemented by in-depth qualitative data providing further insights into what these unmet care needs entail. Together, these quantitative and qualitative insights enrich the evaluation of AIP reforms by providing a more comprehensive understanding of people's needs and preferences, strengthening a domain that yielded a limited amount of actionable performance indicators.

Ageing-in-place preferences of older adults, persons with dementia, and informal caregivers

In addition to a detailed description of the methodological steps (**Chapter 4**), this thesis provides information on the findings of interviews and focus group discussions on AIP preferences for older adults, informal caregivers, and persons with dementia (**Chapter 5-7**). Throughout these studies, some important components of care and support for ageing in place emerged consistently. Participants highlighted the importance of suitable housing and home adaptations, access to personal care and household support, opportunities for social participation, accessible information, and help navigating the healthcare system. In addition, informal care played an important role in enabling older adults and persons with dementia to remain living at home for as long as possible.

To capture the diversity of AIP preferences and experiences, we recruited a heterogenous group of older adults and informal caregivers, with variation in socioeconomic status, educational background, frailty, living situation, and cultural background. This inclusive approach highlighted that preferences and experiences related to ageing in place are shaped by broader social and structural circumstances. The inclusion of persons with dementia and persons with a migration background provided information on how ageing in place is experienced under conditions of increased complexity and constrained access to care. These groups were prioritised because they are frequently excluded from research despite persons with dementia having complex and evolving care needs and persons with a migration background facing a higher risk of developing dementia and a greater prevalence of chronic conditions [15-18]. Participants with a migration background emphasised

the importance of culturally sensitive care and support services. They described how the care services available to them often did not align with their cultural background, limiting the usefulness and accessibility of available support. These findings underline the importance of inclusive methodologies when identifying AIP preferences and designing support services.

The interview studies with persons with dementia and informal caregivers (**Chapter 5** and **Chapter 6**) further illustrated how AIP experiences are shaped by care needs, social resources, and access to support. For both Dutch participants and participants with a migration background, common themes included the importance of both informal and formal support, the opportunity to engage in social activities, help with arranging care and support, information about dementia, and emotional support. Informal caregivers often described caregiving as meaningful and fulfilling, yet they also experienced a considerable caregiving burden. While Dutch participants generally encountered fewer barriers in accessing formal support and sharing care with professionals, participants with a migration background faced additional challenges related to language barriers, unfamiliarity with the healthcare system, and limited availability of culturally sensitive care options. They also emphasised a stronger socio-cultural and religious sense of duty towards caring for relatives, as well as the importance of a proactive involvement of care professionals to identify care needs and opportunities for support services. These findings suggest that although general care components and AIP needs are similar, important differences exist in how these care services must be shaped for different populations to support successful ageing in place.

The findings of our different qualitative studies help demonstrate how social and structural inequalities shape opportunities for ageing in place. A recent review study showed that ageing in place is more common among older adults with a higher socioeconomic status and stronger social resources [7]. This likely reflects their greater access to healthcare services and social support, which help to promote health and independence [7, 19], as well as their ability to adapt their living environments to support ageing in place [20]. Our findings similarly illustrated that participants with greater financial and social resources were often better able to create living situations that supported ageing in place, for example by moving to a different house or relying on broader social networks for assistance with daily activities. In contrast, participants with fewer resources, including some living in social housing, described difficulties finding housing suitable for declining health and mobility. Such inequalities are rooted in structural factors, including income, education, housing, and access to healthcare, that are unevenly distributed across the population [21]. These findings highlight that ageing in place is not equally accessible to all. Structural and social inequalities shape both the ability to remain safely at home and the range of choices available.

Taken together, this thesis emphasizes that support for ageing in place requires more than the availability of care services alone. Care and support must also be accessible, culturally sensitive, and responsive to differences in socioeconomic circumstances, social networks, and care needs. Recognising these differences is essential for developing policies and services that support equal opportunities for ageing in place among diverse groups of older adults and informal caregivers.

> *"To be able to organise good care for someone, it is crucial that you first immerse yourself thoroughly in their culture. Whether that is someone with a migration background or not, because even if you live in a small village somewhere in a rural area or somewhere in a big city, that can already make a huge difference. So truly understanding each other. How have people lived, what do they feel, what are they looking for, what makes them happy. Connecting on the basis of trust, that is crucial."*
> *– informal caregiver with a migration background, interview study*

Methodological considerations

Evaluating ageing in place from a health system perspective

In the first part of this thesis, we developed a system-level tool to evaluate AIP reform policies. In **Chapter 2** we identified potential performance indicators used to evaluate national or sub-national AIP reform policies, excluding studies that measure effects of policies or interventions implemented at the organisational level. Whilst this approach aligns with the goals of the final assessment framework, which is intended to inform policy evaluation at the national level, it also shaped the scope of the included indicators. For example, technology has been highlighted as a theme of significance in relation to ageing in place [22], with studies identifying technologies for communication, emergency assistance, or physical well-being [23]. However, this evidence is mostly based on evaluations of specific interventions, often using randomized-controlled trials at the organisational level, therefore falling outside of the scope of our review study. At the same time, national policy reports such as a recent Dutch progress report, also highlight the growing relevance of digitalization, which is measured through indicators focusing on older adults' digital skills, the use of digital healthcare applications, and care professionals' experiences with digital tools [24]. It is important to emphasize that although digitalization is increasingly recognized as an important topic for ageing in place, it was not captured in the performance indicators identified in our study. This highlights a limitation of the framework, reflecting both the scope of the review and a broader gap between emerging policy priorities and indicators currently used in the academic literature.

In addition, there are other broader societal factors relevant to ageing in place such as housing, age-friendly cities and communities, or transportation that are not included in our evaluation

framework [25]. A recent progress report on Dutch policies related to housing and social support included housing-related indicators, such as the proportion of older adults who live within walking distance of a general practitioner or supermarket [24]. In addition, indicators related to age-friendly cities, for example the accessibility of public transport, public spaces, and buildings, have been proposed by the World Health Organization [26]. Finally, older adults and informal caregivers emphasize that safe neighbourhoods, housing, and social support are essential to support ageing in place [27, 28]. These findings provide a strong argumentation for the inclusion of indicators related to housing and social environments in the evaluation of AIP reform policies. However, applying and adapting these indicators to ageing in place might require consultation with a broader group of experts, including professionals in housing and urban planning, alongside public health, ageing, and social care system experts.

Using consensus-based methodologies to build context-specific ageing-in-place evaluation frameworks

To build our AIP evaluation framework in **Chapter 3**, we used a consensus-building methodology. In a three-round Delphi study, we reached consensus on a set of actionable performance indicators for the evaluation of AIP reform policies. Since no standardized AIP performance indicators or frameworks exist, the ability to integrate different perspectives and identify shared beliefs and priorities was particularly valuable. Since ageing in place is a complex concept, shaped by healthcare systems and policy contexts, stakeholder input is helpful to identify which domains and indicators are important and should be included in reform evaluations [29, 30].

At the same time, the choice for a consensus-based methodology comes with some important implications for the interpretation of the findings. The final set of indicators is based on stakeholder values, reflecting a shared belief amongst a diverse panel of AIP experts on the actionability of the included indicators. It should therefore not be understood as a definitive finding of which indicators are actionable, but rather as what this particular group of experts agreed upon as important. Since the expert panel included a wide variety of Dutch AIP experts, the findings provide valuable insight within the Dutch policy context. This does mean that the selection and specification of indicators is context-specific, making them less transferable to other countries and policy settings. However, the identified domains may be relevant across different settings, as they represent more universal elements of the health system. The transferability of both the framework's structure and the two-step consensus-building approach used to develop it is discussed further in the implications section.

Building inclusive methodologies to capture diverse ageing-in-place preferences

Throughout this thesis, there is a focus on building inclusive methodologies. Persons with dementia are often excluded from research and policy creation, resulting in services that do not fit their needs or are not provided at the right time [31, 32]. To aid the development of evidence-based policy and healthcare services that align with AIP needs and preferences, we built methodologies that enabled persons with dementia and their informal caregivers to participate. In **Chapter 4** we designed a DCE study that facilitates the identification of AIP preferences for persons with dementia and their informal caregivers. In **Chapter 5** and **Chapter 6** we generated input for our DCE, by identifying important components of care and support that can be used as attributes. Persons with dementia and informal caregivers were recruited with the help of healthcare professionals, day-care centres, and social organisations that serve persons with dementia and informal caregivers. Due to this recruitment strategy, most of the included participants received some form of care or support. Whilst there was variation in which care or support services persons used and the intensity of this support, this does mean that perspectives of persons who are less connected to formal or informal support networks might be insufficiently captured in our studies. Despite our studies (**Chapter 5** and **Chapter 6**) making an important effort for the inclusion of persons with dementia, it should be noted that they were still underrepresented in comparison to the informal caregivers.

Furthermore, we focused on including persons with a migration background in our studies in **Chapter 4**, **Chapter 6**, and **Chapter 7**. Persons with a migration background are known to have a higher prevalence of chronic conditions and functional limitations, but make less use of home- and community-based care services [16, 33]. They face additional structural barriers in accessing care and support services [34-36], the same barriers our own qualitative findings confirmed **(Chapter 6)**. In addition, persons with a non-western migration background have a higher risk of developing dementia [15]. The inclusion of these groups can help to illustrate how structural challenges shape AIP trajectories and preferences.

Unfortunately, persons with a migration background are often labelled as 'hard to reach' groups, leading to their underrepresentation in research and policy creation [37]. This thesis shows that meaningful inclusion is achievable when grounded in deliberate methodological choices. Across **Chapters 4**, **6**, and **7**, four strategies supported the participation of persons with a migration background: (i) assembling a diverse research team with researchers from different cultural backgrounds; (ii) investing time in building trusting relationships with participants and the communities they belong to; (iii) collaborating with local communities and informal organisations that serve these groups; and (iv) seeking advice from organisations and experts on health inequalities

and inclusive care. It should be noted that we predominantly included persons from the biggest non-western migration groups in the Netherlands (Moroccan, Turkish, Surinamese, and Indonesian), who mostly have been living in the Netherlands for at least 20-30 years. This means that our results do not fully reflect the cultural diversity within society, or the perspectives of persons who migrated to the Netherlands more recently, who might have different needs and preferences.

Whilst this thesis focused on including persons with dementia, their informal caregivers, and persons with a migration background, it is important to acknowledge that there are other underserved groups that are not included in our studies. Persons with low (health) literacy have a higher health risk and need for support, but are often excluded from research [38]. In addition, LGBTQ+ older adults face substantial barriers to ageing in place, as they might experience discrimination that negatively impacts their access to care and support services [39]. Finally, persons with young-onset dementia have distinct life circumstances and care needs that are often poorly served by support services designed for older adults [40]. Future research should focus on including these groups, as their AIP trajectories and preferences may differ from those included in this thesis.

Implications for policy, practice and research

Strengthening system-level evaluation of ageing-in-place reform policies

This thesis emphasises the need to systematically evaluate AIP reform policies, considering the potential implications for older adults and society. Despite ongoing policy efforts, evaluation practices remain fragmented and largely driven by data availability rather than a comprehensive evaluation framework. In the Netherlands some important steps have been taken to monitor policy progress on Housing, Support and Care for Older Adults (WOZO) [24]. This report evaluates developments in several relevant domains, including independent living, self-sufficiency, digital care use, and life satisfaction, in relation to the policy goals of "self-sufficient if possible, at home if possible, digital if possible" [24]. As such, it captures several important domains of ageing in place, reflecting priorities set out by the Dutch government. However, it does not offer a comprehensive evaluation of ageing in place from a health system perspective, incorporating health system structures, processes, and outcomes.

The framework developed in this thesis complements these existing monitoring efforts by providing a more systematic evaluation approach rooted in HSPA. Rather than evaluating progress towards predefined policy goals, it aims to capture how the system functions in relation to ageing in place and what this means for older adults and society. In doing so, it expands the scope of evaluation to include underrepresented outcome-oriented domains, such as informal caregiver

wellbeing and burden, loneliness, mental wellbeing, and health inequalities, as well as system-level dimensions such as workforce capacity, working conditions in long-term care, and financial dynamics including cost-shifting between institutional care and home- and community-based care. By integrating these elements into a consensus-based set of actionable performance indicators, the framework offers a more comprehensive system-level tool to evaluate whether ageing in place is achieved in a way that is sustainable, equitable, and supportive for both care recipients, informal caregivers, and society.

Despite the framework being developed for the Dutch context, with selected indicators reflecting national policy priorities and system characteristics, its underlying structure can be applied more broadly. Because the framework is anchored in HSPA practices, it includes domains reflecting health system structures, processes and outcomes that can be adapted to different country or policy settings [1]. In addition, the Delphi methodology used to build consensus on actionable performance indicators provides a transferable approach for policy makers and researchers beyond the Dutch context. More specifically, the two-step approach used in this thesis, which combines a structured review of international evidence **(Chapter 2)** with national expert consensus on actionability **(Chapter 3)**, can be replicated in other settings. The international evidence provides a starting pool of candidate domains and indicators, and stakeholder deliberation is then used to adapt the framework to the relevant health system and policy context. This approach can help researchers and policy makers in other settings to define what should be measured to evaluate their own reforms, in a way that reflects local priorities and system structures.

Integrating the voices of older adults and informal caregivers in ageing in place in reform evaluation

This thesis underlines the importance of person-centred policies and care services for supporting ageing in place. Placing people's needs and preferences at the centre of healthcare systems has become a key policy objective [41]. This shift towards person-centred care represents an important step forward, but it also creates a challenge for the evaluation of quality of care. When quality of care is no longer defined by standardised clinical outcomes, but by whether care aligns with what matters most to individuals, it becomes harder to measure. High quality, person-centred care requires more than standardised protocols or clinical evidence alone, it demands clinical expertise, local knowledge, and an understanding of the living conditions, preferences, and values of those receiving care [11]. Such dimensions are difficult to capture in standardised population-level quality indicators, which cannot reflect the diversity of individual experiences and preferences. This points to the need for complementary approaches that create space for dialogue between care

professionals, older adults, informal caregivers, and policy makers about what good care entails in practice [11].

The importance of integrating the voices of those ageing in place is reflected in the evaluation framework developed in this thesis, which incorporates people's needs and preferences as a key policy objective. To capture these preferences, this thesis provides a range of methodologies. The qualitative studies conducted in this thesis, using semi-structured interviews and focus groups, generated rich insights into the lived experiences of older adults and informal caregivers, helping to understand preferences and how they are shaped by individual circumstances, social resources, and cultural backgrounds. These studies helped to identify what matters most to people in their daily lives. Building on these findings, we developed a DCE methodology that can be applied across different populations of older adults and informal caregivers to elicit and quantify their AIP preferences. The resulting preference data offers valuable input for policymakers into what people value, helping them to assess the extent to which current policies and services align with these preferences. Taken together, these methodologies help to better understand and interpret the needs and preferences of older adults and informal caregivers.

These methodological contributions are strengthened by the inclusive research strategies developed in this thesis (described in methodological considerations) to capture preferences and experiences of underrepresented groups, such as persons with dementia and persons with a migration background. We showed that older adults, including those with cognitive impairment, can meaningfully articulate their preferences for ageing in place when methods are designed inclusively. In addition to inclusive recruitment, inclusive research is about adapting methodologies and research environments to better reflect the social and cultural contexts of participants, thereby contributing to more equitable and representative findings that can inform person-centred AIP policies.

Tailoring care to diverse needs and circumstances

To support successful ageing in place for all older adults, it is essential that care and support services align with the diverse needs and preferences of older adults and informal caregivers. In addition to identifying those needs and preferences, it is essential that we create care services and policies that reflect these diverse preferences. This thesis highlights that core components of AIP care and support are similar for different groups of older adults and informal caregivers, including suitable housing, help with household tasks, personal care, social activities, information, and support navigating the healthcare system. However, important differences exist in how these services need to be designed and delivered for everyone to benefit from them. Differences in cultural background, health literacy, social networks, and financial resources mean that a one-size-fits-all approach does

not support equitable access [42]. For example, individuals with fewer resources or smaller social networks may need more intensive support to meet their daily needs, while culturally sensitive care options are essential to ensure services are accessible and meaningful for persons with a migration background. If we do not recognise and respond to these differences, AIP policies may further reinforce existing inequalities.

A resulting important implication for healthcare professionals is that providing good quality, person-centred care requires them to invest in truly understanding the older adults and informal caregivers they work with. This means that they need to invest in building trusting relationships and understanding a person's values, experiences, and what matters most to them in their daily life. This is particularly important for case managers and other professionals who guide older adults through complex and evolving care trajectories. Professionals may therefore need to develop new communication and decision-making skills, that are tailored to individual health priorities and consider both medical needs, social circumstances, and personal values [42]. For persons with a migration background, being able to communicate in a shared language, and having professionals who understand or share a person's cultural background, can be essential preconditions for building the trust and mutual understanding that person-centred care requires. Professionals can address this by working with bilingual or bicultural colleagues or partnering with key community figures.

"It is so important that case managers can make a connection to the culture. Do you speak the same language, do you share the same cultural history. For example, can you talk about Surinam, can you recognise the stories, can you make room for this. That is the first step to form a connection that you can build on." – informal caregiver with migration background, focus group study

Towards more integrated and accessible ageing-in-place care

This thesis advocates that navigating the Dutch long-term care system is experienced as complex and overwhelming by many older adults and informal caregivers. The Dutch long-term care system is divided between three separate legislative acts, the Social support act (Wmo), the Health insurance act (Zvw), and the Long-term care act (Wlz), each with different rules, funding streams, and responsible parties. The participants in this thesis described difficulties in understanding where to turn to for support and how to navigate the boundaries between these systems. Many experienced being passed from one organisation to another, having to repeatedly tell their story to different professionals, without feeling that anyone had a complete overview of their situation or needs. This fragmentation places a considerable burden on older adults and informal caregivers, who are expected to formulate a concrete care question to access support. In addition, this request-driven model of care provision systematically disadvantages those who are less familiar with the healthcare

system, including older adults with a migration background and those with lower health literacy. These groups may be unaware of available services or face language barriers in accessing information, making it harder to formulate their needs. Healthcare professionals should therefore adopt a proactive stance by explicitly enquiring about unmet needs, explaining available options, and revisiting these conversations over time, recognising that the absence of a request does not reflect the absence of a need.

An additional concerning consequence of this fragmented system is the "care gap" (zorgval), experienced by older adults who have received a Wlz indication and are on the waiting list for a nursing home, but still live at home. At this point, care and support previously provided under the Wmo and Zvw transition to the Wlz, which can result in both a higher financial burden and, in some cases, a reduction in the hours of care received. A worrying effect is that vulnerable older adults may postpone applying for a Wlz indication to avoid the higher co-payment, remaining outside the system when they should be placed on a waiting list. This delayed indication-seeking has been connected to more emergency admissions, greater informal caregiving burden, and additional pressures on waiting lists, creating a cycle of crisis-driven care [43]. In recent years, the introduction of the Modular Home Package (MPT) and the Fully Integrated Home package (VPT) has helped to partially address care continuity, by allowing Wlz-funded care to be delivered at home. However, the financial burden of this transition remains significant. Under the Wmo, older adults pay a fixed contribution of at most €21.80 per month. Upon transitioning to the Wlz, this is replaced by an income-dependent contribution. The MPT carries a minimum contribution of €30.40 per month, a modest increase, but the VPT comes with a minimum contribution of €212.60 per month [44]. These barriers underline the need for a more integrated care system, in which transitions between funding streams do not translate into gaps in care or added burden for those needing the most support.

Conclusion

AIP reforms are an understandable government response to population ageing and rising long-term care costs, however these reforms require a comprehensive evaluation to assess whether they meet policy objectives and to understand their broader implications. This thesis shows that evaluating AIP policies requires a system-level perspective that incorporates actionable performance indicators focusing on health system inputs and service delivery in addition to outcome-oriented indicators related to wellbeing, informal caregiver burden, and health inequalities. By developing a consensus-based, context-specific framework for the Netherlands, this thesis demonstrates how

evaluation frameworks can be aligned with policy goals and adapted to reflect specific policy contexts. At the same time, the findings highlight that person-centredness cannot be fully captured through standardized indicators. The integration of DCEs and qualitative methods provides a complementary approach to systematically identify the diverse and evolving preferences of older adults and informal caregivers, including those of underrepresented groups such as persons with dementia or individuals with a migration background. The results further underline that while many care needs are shared, equitable ageing in place requires services to be tailored to differences in cultural background, resources, and social networks. In conclusion, this thesis contributes to a more comprehensive and inclusive evidence base for AIP reform evaluation, demonstrating that effective policy evaluation should combine system-level performance assessment with a deeper understanding of lived experiences and preferences, ultimately supporting more sustainable, equitable, and person-centred long-term care systems.

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Addendum

Summary
Nederlandse Samenvatting
PhD portfolio
Author contributions
Curriculum Vitae
Dankwoord

Summary

Evaluating ageing-in-place reforms

developing policy assessment tools and understanding care preferences of older adults and informal caregivers in the Netherlands

The overall aim of this thesis was to develop a system-level framework for the evaluation of ageing-in-place (AIP) reform policies, whilst capturing the preferences and needs of older adults and informal caregivers ageing in place. **Chapter 1** described that the rapid ageing of the world population and corresponding rising long-term care (LTC) demand and costs are pressuring the LTC systems. Many Organisation for Economic Cooperation and Development (OECD) countries, including the Netherlands, have reformed their LTC systems in response, promoting ageing in place as a cost-saving alternative to institutionalised care. AIP reform policies commonly aim to shift care form institutional towards home- and community based settings, encouraging older adults to live at home for as long as possible with the support of informal caregivers.

Whilst ageing in place is often presented as a win-win solution, cost-saving and aligned with the preferences of older adults who commonly wish to continue living at home, it is important to assess whether ageing in place is fulfilling this policy ideal and what the potential societal implications are. From a system-level perspective, it is important to evaluate whether the goals of AIP reform policies are met, including whether these reforms are genuinely cost-saving, and what their impacts are on the demand for LTC, the utilisation of care services, and the continuity of care. From an individual-level perspective, it is important to assess the impact of AIP reform policies on the wellbeing of older adults and informal caregivers. Despite ageing in place being in line with their preferences, factors such as declining physical health, cognitive impairment, and a diminishing social network can affect their ability to live independently at home. When appropriate care is not provided, this may increase the risk of loneliness or crisis situations such as unplanned hospitalisa-

tions or falls. It is therefore important to identify the AIP needs and preferences of older adults and informal caregivers, including those of underrepresented groups such as persons with dementia and persons with a migration background, who have distinct care needs yet are frequently excluded from research and policy development. Persons with dementia often experience complex and evolving care needs, while persons with a migration background are at increased risk of developing dementia and have a higher prevalence of chronic conditions.

In the **first part** of this thesis, AIP reform policies were approached from a system-level perspective through the development of an assessment framework. The framework was developed to align with underlying policy objectives and incorporate a broad set of performance indicators covering health system structures, processes and outcomes.

As a first step towards building this AIP policy assessment framework, we reviewed the international literature to identify performance indicators used for AIP reform evaluation in **Chapter 2**. We included 58 articles that described one or more performance indicators in relation to a (sub) national AIP reform. Many of the included articles (28, 48.3%) reported performance indicators relating to the input of the health system, covering 71 nonunique indicators in the domains of expenditures, care availability, and workforce. In addition, many articles (36, 62.1%) discussed indicators related to the delivered care services, comprising of 80 indicators covering domains of care utilization, care service quality, and care satisfaction. In contrast, fewer articles (20, 34.5%) reported indicators demonstrating the impact on patients and society, with 34 indicators split between two domains: health status and informal caregiver burden. Even though some identified indicators are similar to those included in existing Health System Performance Assessment (HSPA) frameworks, others are more specific for ageing in place. For example, indicators related to the shift in costs from institutional care to home and community-based care, or informal caregiver burden and well-being. However, overarching developments such as the scarcity in healthcare professionals or the diversification of the older adult population might require additional performance indicators related to health equity.

Building on the findings from our review, **Chapter 3** focused on assessing the actionability of identified performance indicators in the Dutch policy setting. We conducted a Delphi study with a diverse panel of AIP experts, including policymakers or advisors, researchers, healthcare professionals, older adults, and informal caregivers, to develop a context-specific set of actionable performance indicators for evaluating AIP reforms in the Netherlands. Consensus was reached on 53 indicators across 10 domains (older adult health status, informal caregiver burden, health inequalities, care satisfaction, person-centered care, care availability, coverage of care, care utili-

zation, workforce, and financing), resulting in a comprehensive framework that places the needs and preferences of those ageing in place at is centre, whilst capturing the health system resources, healthcare services, and a broad range of outcome-oriented indicators. These findings highlighted a need to reorient AIP evaluation frameworks towards a stronger emphasis on the outcomes for older adults and informal caregivers, such as wellbeing, mental health, informal caregiver burden, and health inequalities. Commonly used quality of care indicators were considered less actionable for ageing in place, reflecting a tension between risk prevention and prioritising quality of life and autonomy in the care for older adults. Furthermore, capturing people's needs and preferences in standardised performance indicators was considered challenging, pointing to the need for complementary approaches to better capture the diverse and evolving preferences of older adults and informal caregivers ageing in place.

In the **second part** of this thesis, we focused on identifying the AIP preferences of older adults and informal caregivers, providing evidence from an individual-level perspective. Special attention was given to underrepresented groups with distinct care needs, including persons with dementia and persons with a migration background, who are frequently excluded from research and policy development despite being disproportionately affected by AIP reform policies. Qualitative methods were used to gain a deeper understanding of the experiences of those ageing in place, giving a voice to those directly affected by AIP reform policies. This evidence informed the development of future Discrete Choice Experiments (DCEs) to quantify AIP preferences, ultimately providing policymakers with guidance for person-centered policy development and service planning.

In **Chapter 4**, a methodology was developed to design DCEs identifying AIP preferences, applicable to different populations such as older adults, people with dementia, and their informal caregivers. DCEs present participants with a series of hypothetical choice scenarios, asking them to select their preferred option based on key care services (attributes) and characteristics of care service delivery (attribute levels), thereby capturing how people value and prioritise different aspects of care. To identify the most relevant characteristics and their levels, semi-structured interviews were conducted to explore participants' daily experiences and the types of care and support they considered important for ageing in place, followed by focus group discussions to further refine and prioritise these findings. The final DCE consisted of three rounds, one for older adults or persons with dementia, one for informal caregivers, and a joint round capturing shared preference. The outcomes provided insights into the relative importance of different care characteristics. Beyond generating population-level data on what care services people value, the qualitative components of this methodology provide important in-depth insights about the experiences of those ageing in place. To ensure that the methodology was inclusive and able to capture the AIP preferences of di-

verse populations, specific strategies were presented to include underrepresented and underserved groups such as persons with dementia and persons with a migration background. We explained the importance of assembling a diverse research team, building trusting relationships, collaborating with local community organisations serving these populations, and seeking advice from experts in health inequalities an inclusive care.

We provided more in-depth insight in the experiences and needs of Dutch persons with dementia and informal caregivers ageing in place in **Chapter 5**. Semi-structured interviews were conducted with persons with dementia (N=5) and informal caregivers (N=14) to identify important components of care and support that enabled ageing in place. Five themes were identified, including the need for informal support from a social network, formal care, information about dementia, emotional support, and help navigating the healthcare system. The informal caregivers of persons with dementia assisted them with a variety of activities of daily living that fell outside of the scope of formal caregivers, such as doing groceries, accompanying them to appointments, or administrative tasks. In addition, persons with dementia frequently used formal care services including daycare facilities, home care, meal services, and case management. The experiences with case management were mixed, as some participants considered their case managers to be highly involved in coordinating care and attending to person needs, whilst others were perceived less engaged, leaving informal caregivers and persons with dementia uncertain about what support hey could expect. Informal caregivers expressed a need for emotional support and information about how to cope with the behavioural changes of the persons with dementia. Finally, the dementia care system was considered complex and fragmented, with informal caregivers expressing that they found in hard to navigate the system and organise care and support.

In **Chapter 6** we presented the AIP preferences of persons with dementia (N=8) and informal caregivers (N=20) with a migration background through another interview study. The findings highlighted that informal caregivers felt a strong responsibility and sense to duty to care for their relatives with dementia. They assisted them with a variety of daily tasks, including personal care such as showering, getting dressed, or cleaning the house. Whilst informal caregivers expressed positive associations and feelings of fulfilment from the provision of care, they also experienced a considerable caregiving burden that led to the desire to share care with professionals. However, linguistic barriers, less familiarity with the healthcare system, and a lack of culturally sensitive care services made it harder to formulate concrete needs or access services. The proactive involvement of professionals is needed to build trust and identify opportunities to integrate formal care and support options, lowering the burden for informal caregivers. It was emphasized that care services such as daycare facilities, in-home care, and information about dementia need to be culturally sen-

sitive to be beneficial for persons with a migration background. Even though the identified key components of care and support aligned with our previous study on Dutch persons with dementia (chapter 5), differences exists in how these services must be shaped for different populations to benefit from them.

Chapter 7 described the findings of our mixed-methodology developed to identify and later quantify the AIP preferences of older adults and their informal caregivers. We recruited a heterogeneous sample of older adults and informal caregivers with variation in socioeconomic status, educational background, frailty, living situation, and cultural background. Through semi-structured interviews and focus group discussions with a ranking exercise, five attributes with corresponding levels were identified for use in a future DCE. The five attributes covered: housing, reflecting options to adapt the living environment such as home modifications, moving to a smaller apartment, or relocating to communal housing; personal care and household support, with levels capturing different frequencies; social activities, ranging from daycare attendance and local clubs to home-based social visits; and navigating the healthcare system, with levels reflecting support from different professionals such as a practice nurse, case manager, or contact persons from the health insurer. Beyond informing the development of our DCE, these finding provide valuable insights into the diversity of AIP preferences and experiences. Notably, cultural sensitivity emergers as an important prerequisite for the relevance of care services, as persons with a migration background indicated that they would not benefit from services designed for persons with different cultural or linguistic backgrounds. This underlines the importance of inclusive sampling in DCE development, to ensure that resulting preference data meaningfully reflects the diversity of AIP needs present in society.

Chapter 8 presented a general discussion, reflecting on main findings, and providing implications for policy, practice, and research. The findings underline the need to move beyond fragmented monitoring efforts towards a more systematic evaluation of AIP reform policies, incorporating actionable performance indicators across health system inputs, service delivery, and outcome-oriented domains such as informal caregiver burden, mental wellbeing, and health inequalities. The consensus-based, context-specific framework developed in this thesis demonstrates how evaluation approaches can be aligned with policy objectives whilst remaining adaptable to specific policy contexts. At the same time, person-centered care proved difficult to capture through standardised indicators alone, pointing to the value of complementary approaches such as DCEs and qualitative methods to identify and understand the diverse and evolving preferences of older adults and informal caregivers. From our qualitative studies, it became clear that opportunities for ageing in place are not equally distributed, differences in income, housing, social networks, and cultural backgrounds shape both the ability to remain safely at home and the range of support available. This

underlines that policies failing to account for this diversity risk deepening existing inequalities. Taken together, the findings of this thesis demonstrate that to support suitable, equitable, and person-centered LTC systems, a more comprehensive and inclusive evidence base is needed for AIP reform evaluation that combines system-level performance assessment with a deeper understanding of the experiences and preferences of those ageing in place.

Samenvatting

Het evalueren van hervormingen gericht op ageing-in-place

Het ontwikkelen van beleidsevaluatie-instrumenten en het begrijpen van zorgvoorkeuren van ouderen en mantelzorgers in Nederland

Het doel van dit proefschrift was het ontwikkelen van een systeem-level framework voor de evaluatie van beleidshervormingen gericht op ageing-in-place (het zo lang mogelijk zelfstandig thuis oud worden), waarbij de voorkeuren en behoeften van thuiswonende ouderen en mantelzorgers worden meegenomen. **Hoofdstuk 1** beschreef dat de snelle vergrijzing van de wereldbevolking en de daarmee samenhangende stijgende vraag naar en kosten van langdurige zorg, het langdurige zorgsysteem onder druk zetten. Veel landen van de Organisatie voor Economische Samenwerking en Ontwikkeling (OECD), waaronder Nederland, hebben hun langdurige zorgsystemen als reactie hierop hervormd, met ageing-in-place als een kostenbesparend alternatief voor institutionele zorg. Hervormingen gericht op ageing-in-place hebben doorgaans als doel de zorg te verschuiven van institutionele naar thuis- en wijkgerichte zorg, waarbij ouderen worden aangemoedigd zo lang mogelijk thuis te wonen met ondersteuning van mantelzorgers.

Hoewel ageing-in-place vaak wordt gepresenteerd als een win-win oplossing, kostenbesparend en in lijn met de voorkeuren van ouderen die doorgaans thuis willen blijven wonen, is het belangrijk te beoordelen of ageing-in-place dit beleidsideaal waarmaakt en wat de mogelijke maatschappelijke implicaties zijn. vanuit een systeem-perspectief is het belangrijk te evalueren of de doelen van de hervormingen gericht op ageing-in-place worden behaald, inclusief of deze daadwerkelijk kostenbesparend zijn en wat hun impact is op de vraag naar langdurige zorg, het gebruik van zorgdiensten en de continuïteit van zorg. Vanuit een individueel-perspectief is het belangrijk om de impact van beleidshervormingen op het welzijn van ouderen en mantelzorgers te beoordelen. Ondanks dat ageing-in-place in lijn is met hun voorkeuren, kunnen factoren zoals afnemende lichamelijke gezondheid, cognitieve beperkingen en een krimpend sociaal netwerk hun vermogen om zelfstandig thuis te wonen beïnvloeden. Wanneer er geen passende zorg wordt geboden, kan dit het risico op eenzaamheid of crisissituaties, zoals ongeplande ziekenhuisopnames of valincidenten, vergroten. Het is daarom belangrijk de behoeften en voorkeuren van ouderen en mantelzorgers in relatie tot ageing-in-place in kaart te brengen, inclusief die van ondervertegenwoordigde groepen zoals personen met dementie en personen met een migratieachtergrond, die specifieke zorgbehoeften hebben maar vaak worden uitgesloten van onderzoek en beleidsontwikkeling. Personen met dementie ervaren vaak complexe en veranderende zorgbehoeften, terwijl personen met een migratieachter-

grond een verhoogd risico lopen op het ontwikkelen van dementie en een hogere prevalentie van chronische aandoeningen hebben.

In het **eerste deel** van dit proefschrift werden beleidshervormingen gericht op ageing-in-place benaderd vanuit een systeem-perspectief door middel van de ontwikkeling van een systeem-level evaluatie framework. Het framework is ontwikkeld om aan te sluiten bij de onderliggende doelstellingen van beleid en bevat een breed scala aan prestatie-indicatoren die betrekking hebben op structuren, processen en uitkomsten van het gezondheidssysteem.

Als eerste stap naar het ontwikkelen van dit evaluatie framework voor beleidshervormingen gericht op ageing-in-place, hebben wij in **Hoofdstuk 2** de internationale literatuur onderzocht om prestatie-indicatoren te identificeren die worden gebruikt voor de evaluatie van deze beleidshervormingen. Wij includeerden 58 artikelen waarin een of meer prestatie-indicatoren werden beschreven in relatie tot een (sub)nationale beleidshervorming gericht op ageing-in-place. Veel van de geïncludeerde artikelen (28, 48,3%) rapporteerden prestatie-indicatoren met betrekking tot de input van langdurige zorg systemen, met 71 niet-unieke indicatoren in de domeinen uitgaven, beschikbaarheid van zorg en personeel. Daarnaast bespraken veel artikelen (35, 62,1%) indicatoren met betrekking tot de geleverde zorgdiensten, bestaande uit 80 indicatoren in de domeinen zorggebruik, kwaliteit van zorgdiensten, en tevredenheid over de zorg. Daarentegen rapporteerden minder artikelen (20, 34,5%) indicatoren die de impact op patiënten en de samenleving aantonen, met 34 indicatoren verdeeld over twee domeinen: gezondheid en mantelzorgbelasting. Hoewel sommige indicatoren vergelijkbaar zijn met die in bestaande frameworks voor Health System Performance Assessment (HSPA), zijn andere specifieker voor ageing-in-place. Bijvoorbeeld indicatoren met betrekking tot de verschuiving in kosten van institutionele zorg naar thuis- en wijkgerichte zorg, of de belasting en het welzijn van mantelzorgers. overkoepelende ontwikkelingen zoals de schaarste aan zorgprofessionals of de diversificatie van de oudere bevolking kunnen echter aanvullende prestatie-indicatoren vereisen die betrekking hebben op gezondheidsongelijkheid.

Voortbouwend op de bevindingen uit ons literatuuronderzoek richtte **Hoofdstuk 3** zich op het beoordelen van de bruikbaarheid van geïdentificeerde prestatie-indicatoren binnen de Nederlandse beleidscontext. Wij voerden een Delphi-studie uit met een divers panel van experts op het gebied van ageing-in-place, waaronder beleidsmakers en/of adviseurs, onderzoekers, zorgprofessionals, ouderen en mantelzorgers, om een context specifieke set van bruikbare prestatie-indicatoren te ontwikkelen voor de evaluatie van beleidshervormingen gericht op ageing-in-place in Nederland. Er werd consensus bereikt over 53 indicatoren verdeeld over 10 domeinen (gezondheid van ouderen, mantelzorgbelasting, gezondheidsongelijkheid, tevredenheid over zorg, persoonsgerichte

zorg, beschikbaarheid van zorg, zorgdekking, zorggebruik, zorgpersoneel, en financiering), resulterend in een omvattend framework dat de behoeften en voorkeuren van thuiswonende ouderen centraal stelt, terwijl het ook de middelen van het langdurige zorgsysteem, zorgdiensten en een breed scala aan uitkomstgerichte indicatoren omvat. Deze bevindingen benadrukten de noodzaak om evaluatie frameworks voor beleid gericht op ageing-in-place te heroriënteren naar een sterke nadruk op uitkomsten voor ouderen en mantelzorgers, zoals welzijn, geestelijke gezondheid, mantelzorgbelasting en gezondheidsongelijkheid. Veelgebruikte kwaliteitsindicatoren voor zorg werden als minder bruikbaar beschouwd voor de beoordeling van ageing-in-place beleid, wat een spanning weergeeft tussen risicopreventie en het prioriteren van kwaliteit van leven en autonomie in de zorg voor ouderen. Daarnaast werd het vangen van de behoeften en voorkeuren van mensen in gestandaardiseerde prestatie-indicatoren als lastig beschouwd, wat wijst op de behoeften aan aanvullende benaderingen om de diverse en veranderende voorkeuren van thuiswonende ouderen en mantelzorgers in kaart te brengen.

In het **tweede deel** van dit proefschrift richtten wij ons op het identificeren van de voorkeuren van ouderen en mantelzorgers ten aanzien van ageing-in-place, waarbij inzichten werden geleverd vanuit een individueel-perspectief. Bijzondere aandacht werd besteed aan ondervertegenwoordigde groepen met specifieke zorgbehoeften, waaronder personen met dementie en personen met een migratie achtergrond, die vaak worden uitgesloten van onderzoek en beleidsontwikkeling ondanks dat zij onevenredig worden beïnvloed door beleidshervormingen gericht op langer thuis wonen. Kwalitatieve methoden werden gebruikt om een verdiepend inzicht te krijgen in de ervaringen van thuiswonende ouderen en mantelzorgers, waarbij een stem werd gegeven aan degenen die direct worden beïnvloed door beleidshervormingen gericht op langer thuis wonen. Dit bewijs ondersteunde de ontwikkeling van toekomstige Discrete Choice Experiments (DCEs) om voorkeuren ten aanzien van langer thuis wonen te kwantificeren, waarmee beleidsmakers uiteindelijk worden voorzien van handvaten voor persoonsgerichte beleidsontwikkeling en zorgplanning.

In **Hoofdstuk 4** werd een methodologie ontwikkeld voor het ontwerpen van DCEs om voorkeuren ten aanzien van ageing-in-place te identificeren, toepasbaar op verschillende populaties zoals ouderen, personen met dementie en hun mantelzorgers. DCEs presenteren deelnemers een reeks hypothetische keuzes, waarbij hen wordt gevraagd hun voorkeur te selecteren op basis van belangrijke zorgdiensten (attributen) en kenmerken van de zorgverlening (attribuut levels), waarmee wordt vastgelegd hoe mensen verschillende aspecten van zorg waarderen en prioriteren. Om de meest relevante zorgdiensten en hun kenmerken te identificeren, werden semi-gestructureerde interviews afgenomen om de dagelijkse ervaringen van deelnemers te verkennen en de soorten zorg en ondersteuning die zij belangrijk achtten voor ageing-in-place, gevolgd door focusgroep gesprekken om

deze bevindingen verder aan te scherpen en te prioriteren. De uiteindelijke DCE bestond uit drie rondes: één voor ouderen of personen met dementie, één voor mantelzorgers en een gezamenlijke ronde om gedeelde voorkeuren vast te leggen. De uitkomsten boden inzicht in het relatieve belang van verschillende zorgkenmerken. Naast het genereren van populatieniveau-gegevens over welke zorgdiensten mensen waarderen, bieden de kwalitatieve componenten van deze methodologie belangrijke diepgaande inzichten in de ervaringen van thuiswonende ouderen en mantelzorgers. Om ervoor te zorgen dat de methodologie inclusief was en in staat om de voorkeuren van diverse populaties te identificeren, werden specifieke strategieën gepresenteerd om ondervertegenwoordigde en onderbedeelde groepen te includeren, zoals personen met dementie en personen met een migratieachtergrond. We lichtten het belang toe van het samenstellen van een divers onderzoeksteam, het opbouwen van vertrouwensrelaties, het samenwerken met lokale organisaties die deze populaties ondersteunen en het inwinnen van advies van experts op het gebied van gezondheidsongelijkheid en inclusieve zorg.

Wij boden meer inzicht in de ervaringen en behoeften van Nederlandse personen met dementie en mantelzorgers die langer thuis wonen in **Hoofdstuk 5**. Semigestructureerde interviews werden afgenomen met personen met dementie (N=5) en mantelzorgers (N=14) om belangrijke componenten van zorg en ondersteuning te identificeren die ageing-in-place mogelijk maakten. Vijf thema's werden geïdentificeerd, waaronder de behoefte aan informele ondersteuning vanuit een sociaal netwerk, formele zorg, informatie over dementie, emotionele ondersteuning en hulp bij het navigeren door het zorgsysteem. De mantelzorgers van personen met dementie ondersteunden hen bij een verscheidenheid aan dagelijkse activiteiten die buiten het takenpakket van formele zorgverleners vielen, zoals boodschappen doen, hen begeleiden naar afspraken of administratieve taken. Daarnaast maakten personen met dementie regelmatig gebruik van formele zorgdiensten, waaronder dagopvang, thuiszorg, maaltijdservices en casemanagement. De ervaringen met casemanagement waren wisselend: sommige participanten beschouwden hun casemanager als zeer betrokken bij de coördinatie van zorg en het inspelen op persoonlijke behoeften, terwijl anderen als minder betrokken werden ervaren, waardoor mantelzorgers en personen met dementie onzeker waren over welke ondersteuning zij konden verwachten. Mantelzorgers uitten een behoefte aan emotionele ondersteuning en informatie over hoe om te gaan met de gedragsveranderingen van personen met dementie. Tot slot werd het dementiezorgsysteem als complex en gefragmenteerd beschouwd, waarbij mantelzorgers aangaven dat zij het moeilijk vonden om door het systeem te navigeren en zorg en ondersteuning te organiseren.

In **Hoofdstuk 6** presenteerden wij de voorkeuren ten aanzien van ageing-in-place van personen met dementie (N=8) en mantelzorgers (N=20) met een migratieachtergrond door middel van

een tweede interviewstudie. De bevindingen benadrukten dat mantelzorgers een sterke verantwoordelijkheid en plichtsgevoel ervoeren om voor hun familieleden met dementie te zorgen. Ze ondersteunden hen bij een verscheidenheid aan dagelijkse taken, waaronder persoonlijke verzorging zoals douchen, aankleden of schoonmaken. Hoewel mantelzorgers positieve associaties en gevoelens van voldoening uitten over het verlenen van zorg, ervoeren zij ook een aanzienlijke mantelzorgbelasting die leidde tot de wens om zorg te delen met professionals. Taalbarrières, minder bekendheid met het zorgsysteem en een gebrek aan cultureel sensitieve zorgdiensten maakten het echter moeilijker om concrete behoeften te formuleren of toegang te krijgen tot zorgdiensten. De proactieve betrokkenheid van professionals is nodig om vertrouwen op te bouwen en mogelijkheden te ontdekken om formele zorg en ondersteuning te integreren, waardoor de belasting voor mantelzorgers wordt verlaagd. Er werd benadrukt dat zorgdiensten zoals dagopvang, thuiszorg en informatie over dementie cultureel sensitief moeten zijn om van meerwaarde te zijn voor personen met een migratieachtergrond. Hoewel de geïdentificeerde belangrijkste componenten van zorg en ondersteuning overeenkwamen met onze eerdere studie over Nederlandse personen met dementie (**Hoofdstuk 5**), bestaan er verschillen in de manier waarop deze diensten vormgegeven moeten worden om effectief te zijn voor verschillende populaties.

Hoofdstuk 7 beschreef de bevindingen van onze mixed-methodologie ontwikkeld om de voorkeuren ten aanzien van ageing-in-place van ouderen en hun mantelzorgers te identificeren en later te kwantificeren. We wierven een diverse groep van ouderen en mantelzorgers met variatie in sociaaleconomische status, opleidingsniveau, kwetsbaarheid, woonsituatie en culturele achtergrond. Door middel van semi-gestructureerde interviews en focusgroep gesprekken met een rangschikkingsoefening werden vijf attributen met bijbehorende levels geïdentificeerd voor gebruik in een toekomstig DCE. De vijf attributen omvatten: huisvesting, waarbij opties worden weergegeven om de woonomgeving aan te passen, zoals aanpassingen in huis, verhuizen naar een kleinere woning of verhuizen naar een gemeenschappelijke woonvorm; persoonlijke verzorging en huishoudelijke ondersteuning, met niveaus die verschillende frequenties weergeven; sociale activiteiten, variërend van dagopvang en lokale clubs tot sociale bezoeken aan huis; en het navigeren door het zorgsysteem, met niveaus die ondersteuning van verschillende professionals weerspiegelen, zoals een praktijkondersteuner, casemanager of contactpersoon van de zorgverzekeraar. Naast het ondersteunen van de ontwikkeling van ons DCE bieden deze bevindingen waardevolle inzichten in de variatie van voorkeuren en ervaringen ten aanzien van ageing-in-place. Met name culturele sensitiviteit komt naar voren als een belangrijke voorwaarde voor de relevantie van zorgdiensten, aangezien personen met een migratieachtergrond aangaven geen baat te hebben bij diensten die zijn ontworpen voor personen met een andere culturele of linguïstische achtergrond. Dit onder-

streept het belang van inclusieve werving bij de ontwikkeling van DCEs, om ervoor te zorgen dat de resulterende data de diversiteit aan behoeften ten aanzien van ageing-in-place in de samenleving op betekenisvolle wijze weerspiegelt.

Hoofdstuk 8 presenteerde een algemene discussie, reflecteerde op de belangrijkste bevindingen, en bood implicaties voor beleid, praktijk, en onderzoek. De bevindingen onderstrepen de noodzaak om verder te gaan dan gefragmenteerde monitoring naar een meer systematische evaluatie van beleid gericht op ageing-in-place, waarbij bruikbare prestatie-indicatoren worden opgenomen voor input van het gezondheidssysteem, dienstverlening en uitkomstgerichte domeinen zoals de belasting van mantelzorgers, welzijn en gezondheidsongelijkheden. Het op consensus gebaseerde, context specifieke framework dat in deze thesis werd ontwikkeld, laat zien hoe evaluatie kan worden afgestemd op beleidsdoelstellingen, terwijl het tegelijkertijd aanpasbaar blijft aan specifieke beleidscontexten. Persoonsgerichte zorg bleek moeilijk vast te leggen met alleen gestandaardiseerde indicatoren, wat wijst op de waarde van aanvullende benaderingen zoals DCEs en kwalitatieve methoden om de diverse en veranderende voorkeuren van ouderen en mantelzorgers te identificeren en te begrijpen. Uit onze kwalitatieve studies werd duidelijk dat de mogelijkheden voor ageing-in-place niet gelijk verdeeld zijn; verschillen in inkomen, huisvesting, sociale netwerken en culturele achtergronden beïnvloeden zowel het vermogen om veilig thuis te blijven wonen als het aanbod van passende ondersteuning. Dit onderstreept dat beleid dat geen rekening houdt met deze diversiteit het risico loopt bestaande ongelijkheden te verergeren. In conclusie tonen de bevindingen van deze thesis aan dat, om geschikte, rechtvaardige en persoonsgerichte langdurige zorg systemen te ondersteunen, een meer uitgebreide en inclusieve kennis basis nodig is voor de evaluatie van hervormingen gericht op ageing-in-place, die systeem-level evaluatie combineert met een dieper begrip van de ervaringen en voorkeuren van degenen die thuis oud worden.

PhD Portfolio

Name PhD student:	Isabelle Vullings
PhD period:	September 2022 – August 2026
Name of PhD supervisors:	Dr. J. L. MacNeil Vroomen
	Prof. Dr. T.H. Muller
Names Co-supervisors:	dr. N.H.M. Labrie
	Dr. Ö. Uysal-Bozkir

1. PhD training

General courses	*Year*	*ECTS*
Practical biostatistics	2022	1.4
Research data management	2022	0.1
Ds Endnote	2022	0.1
Clinical epidemiology: systematic reviews	2022	0.7
Project Management	2022	0.6
Didactical skills	2023	0.4
Research Integrity	2023	2.0
Clinical epidemiology: observational studies	2023	0.6
Ebrok	2024	1.5
Be Your Best Journey	2024	0.6
Specific courses		
Choice Modelling Course	2023	2.0
Qualitative health research	2023	1.9
APH Methodology: Delphi course	2025	0.6
Seminars, workshops and master classes		
Symposium Oud aan de Amstel, UNO Amsterdam	2022	0.25
Monthly geriatrics research meetings	2022-2026	1.5
Monthly coffee & research meetings	2023-2026	1.0
AmsCIS module: engagement of stakeholders	2022	0.1
INTERDEM academy Masterclass breaking the stigma, connecting and designing for dementia	2023	0.5
INTERDEM academy Masterclass Healthcare policy & Design	2024	0.25

Symposium A fresh look at long-term care: Learning from Dutch and international evidence, Erasmus School of Health Policy & Management	2024	0.2
Oral presentations		
Research meeting Geriatrics department, Amsterdam, the Netherlands Eliciting preferences of persons with dementia and informal caregivers to support aging in place in the Netherlands	2023	0.5
Coffee & Research meeting, Amsterdam, the Netherlands Eliciting preferences of persons with dementia and informal caregivers to support aging in place in the Netherlands: a discrete choice experiment	2024	0.5
INTERDEM academy masterclass, Milano, Italy Identifying aging-in-place preferences of older adults and informal caregivers in the Netherlands	2024	0.5
Mi Bosie (older adult organisation), Eindhoven, the Netherlands Aging-in-place preferences of older adults and informal caregivers in the Netherlands	2024	0.5
16th annual meeting of the International Academy of Health Preference Research, Enschede, the Netherlands. The evaluation of ageing-in-place reform policies	2024	0.5
Kraka-e-Sewa (daycare for Surinamese older adults), Amsterdam, the Netherlands. Culturally sensitive care for older adults living at home and informal caregivers with a migration background	2025	0.5
Poster presentations		
APH annual meeting, Amsterdam, the Netherlands Eliciting preferences of persons with dementia and informal caregivers to support ageing in place in the Netherlands: A discrete choice experiment protocol	2023	0.5

Alzheimer Europe, Helsinki, Finland A protocol for a Discrete Choice Experiment to identify preferences of Persons with dementia and informal caregiver ageing in place	2023	0.5
Dutch Dementia Conference, Utrecht, the Netherlands Ageing-in-place care preferences of persons living with dementia with a migration background and their informal caregivers	2024	0.5
ISPOR Europe, Barcelona, Spain Performance indicators for the assessment of ageing-in-place reform policies: a scoping review and evidence map	2024	0.5
ISPOR Europe, Barcelona, Spain. Attribute development and level selection for a discrete choice experiment to elicit care preferences of older adults and informal caregivers aging-in-place in the Netherlands	2024	0.5
APH Annual meeting, Amsterdam, the Netherlands Developing a Discrete Choice Experiment to identify care preferences of older adults and informal caregivers ageing in place in the Netherlands: the development attributes and levels	2025	0.5
(Inter)national conferences		
APH Annual meeting, Amsterdam, the Netherlands	2022	0.25
APH Spring meeting, Amsterdam, the Netherlands	2023	0.25
Alzheimer Europe, Helsinki, Finland	2023	0.25
APH Annual meeting, Amsterdam, the Netherlands	2023	0.25
Dutch Dementia Conference, Utrecht, the Netherlands	2024	0.25
APH Spring Meeting, Amsterdam, the Netherlands	2024	0.25
ISPOR Europe, Barcelona, Spain	2024	0.25
APH Annual Meeting, Amsterdam, the Netherlands	2025	0.25
Annual meeting of the International Academy of Health Preference Research, Enschede, the Netherlands	2025	0.25

Other

Organizing the monthly Coffee & Research meeting		0.5
Member of the Aging & Later Life research line junior council, APH		1.0
Member of the INTERDEM Academy		0.5

2. Teaching

Lecturing

Guest lecture: Qualitative research methods Media use in organizational contexts course, VU University, Amsterdam	2024	0.25
Guest lecture: Thematic analysis Media use in organizational contexts course, VU University, Amsterdam	2024	0.25

Tutoring, mentoring

Mentoring master students with qualitative data analysis, Geriatrics departments, Amsterdam UMC	2025	0.25

Supervising

Beyza Aydin Miscri, Master thesis, Clinical Psychology	2023	1.0
Julie Russchen, Master thesis, Medicine	2024	1.0
Keije Bongenaar, Bachelor thesis, Health & Life Sciences	2025	1.0

Peer reviewing

Health Research Policy and Systems	2025	0.25
BMC Geriatrics	2025	0.25
The Patient: Patient-centered Outcomes Research	2025	0.25
Health Economics Review	2025	0.25

3. Parameters of esteem

Grants

Amsterdam Public Health (APH) travel grant	2023
Amsterdam Public Health (APH) travel grant	2024
UVA travel grant	2024

4. Publications

Peer reviewed

Vullings, I., Pilli, L., Russchen, M.J.C.H., Labrie, N.H.M., Swait, J., Uysal-Bozkir, Ö., Wammes, J.D., & MacNeil Vroomen, J.L. (2026). Attribute development and level selection for a discrete choice experiment to elicit care preferences of older adults and informal caregivers ageing in place in the Netherlands. The Patient – Patient-Centered Outcomes Research. https://doi.org/10.1007/s40271025-00774-2 [**first author**]

Vullings, I., el Jaouhari, S., Wammes, J.D., Smits, C., Labrie, N., Aydin-Misirci, B., Uysal-Bozkir, Ö., de Bekker-Grob, E., & MacNeil Vroomen, J.L. (2025). Ageing-in-place care preferences of persons living with dementia and informal care-givers with a migration background: a qualitative interview study. Ageing and Society. https://doi.org/10.1017/S0144686X25100111 [**joint first author**]

Wammes, J.D., Vullings, I., Kringos, D.S., Wouterse, B., Daams, J.G., Langendam, M., & MacNeil Vroomen, J.L. (2024). Performance indicators for the assessment of ageing-in-place reform policies: a scoping review and evidence map. Journal of the American Medical Directors Association. https://doi.org/10.1016/j.jamda.2024.105249 [**joint first author**]

Visser, K., Mollenhorst, G., Schutjens, V., & Vullings, I. (2024). Young adults' perceptions of intergenerational solidarity and conflict: the renegotiation of compliance with restrictions during the COVID-19 pandemic. YOUNG. https://doi.org/10.1177/11033088231206663 [**co-author**]

Vullings, I., Wammes, J.D., Uysal-Bozkir, Ö., Smits, C., Labrie, N.H.M., Swait, J.D., de Bekker-Grob, E., & MacNeil-Vroomen, J.L. (2023). Eliciting preferences of persons with dementia and informal caregivers to support ageing in place in the Netherlands: a protocol for a discrete choice experiment. BMJ Open. https://doi.org/10.1136/bmjopen-2023-075671 [**first author**]

Vullings, I., Labrie, N., Wammes, J.D., de Bekker-Grob, E.W., & MacNeil-Vroomen, J. (2020). Important components for Dutch in-home care based on qualitative interviews with persons with dementia and informal caregivers. Health Expectations. https://doi.org/10.1111/hex.13118 [**joint first author**]

Author contributions

Chapter 1

General introduction

Concept and design	I. Vullings
Data collection	Not applicable
Data analysis	Not applicable
Interpretation of the data	Not applicable
Drafting the manuscript	I. Vullings
Critical revision of the manuscript	J.L. MacNeil Vroomen, T.H. Muller, N.H.M. Labrie, Ö. Uysal-Bozkir

Chapter 2

Performance Indicators for the Assessment of Aging-In-Place Reform Policies: A Scoping Review and Evidence Map. (2024) Journal of the American Medical Directors Association, 25, 105249

Concept and design	J.D. Wammes, I. Vullings, J.L. MacNeil Vroomen
Data collection	J.D. Wammes, I. Vullings, J.G. Daams
Data analysis	J.D. Wammes, I. Vullings, J.L. MacNeil Vroomen
Interpretation of the data	J.D. Wammes, I. Vullings, D.S. Kringos, B. Wouterse, M. Langendam, J.L. MacNeil Vroomen
Drafting the manuscript	J.D. Wammes, I. Vullings
Critical revision of the manuscript	D.S. Kringos, B. Wouterse, J.G. Daams, M. Langendam, J.L. MacNeil Vroomen

Chapter 3

Actionable performance indicators for evaluating ageing-in-place reforms in the Netherlands: a three round Delphi consensus study. (Submitted)

Concept and design	I. Vullings, J.L. MacNeil Vroomen, J.D. Wammes, D.S. Kringos, B. Wouterse, N.H.M. Labrie, T.H. Muller, Ö. Uysal-Bozkir
Data collection	I. Vullings, K. Bongenaar
Data analysis	I. Vullings, K. Bongenaar
Interpretation of the data	I. Vullings, J.L. MacNeil Vroomen, J.D. Wammes, D.S. Kringos, B. Wouterse, N.H.M. Labrie, T.H. Muller, Ö. Uysal-Bozkir, H.C. Willems
Drafting the manuscript	I. Vullings
Critical revision of the manuscript	B. Wouterse, J.D. Wammes, D.S. Kringos, K. Bongenaar, H.C. Willems, Ö. Uysal-Bozkir, N.H.M. Labrie, T.H. Muller, J. L. MacNeil Vroomen

Chapter 4

Eliciting preferences of persons with dementia and informal caregivers to support ageing in place in the Netherlands: a protocol for a discrete choice experiment. (2023) BMJ open, 13: : e075671

Concept and design	I. Vullings, J.D. Wammes, J.D. Swait, E.W. de Bekker-Grob, J. L. MacNeil Vroomen
Data collection	Not applicable
Data analysis	Not applicable
Interpretation of the data	Not applicable
Drafting the manuscript	I. Vullings

Critical revision of the manuscript	J.D. Wammes, Ö. Uysal-Bozkir, C. Smits, N.H.M. Labrie, J.D. Swait, E.W. de Bekker-Grob

Chapter 5

Important components for Dutch in-home care based on qualitative interviews with persons with dementia and informal caregivers. (2020) Health Expectations, 23(6)

Concept and design	I. Vullings, N.H.M. Labrie, J.L. MacNeil Vroomen
Data collection	I. Vullings
Data analysis	I. Vullings, N.H.M. Labrie, J.D. Wammes, J.L. MacNeil Vroomen
Interpretation of the data	I. Vullings, N.H.M. Labrie, J.D. Wammes, J.L. MacNeil Vroomen
Drafting the manuscript	I. Vullings
Critical revision of the manuscript	N.H.M. Labrie, J.D. Wammes, E.W. de Bekker-Grob, J.L. MacNeil Vroomen

Chapter 6

Ageing-in-place care preferences of persons living with dementia and informal caregivers with a migration background: A qualitative interview study. (2025) Ageing & Society, 45(11)

Concept and design	I. Vullings, J.D. Wammes, C. Smits, N.H.M. Labrie, Ö. Uysal-Bozkir, J.L. MacNeil Vroomen
Data collection	I. Vullings, S. El Jaouhari, B. Aydin-Misirci
Data analysis	I. Vullings, S. El Jaouhari, B. Aydin-Misirci
Interpretation of the data	I. Vullings, S. El Jaouhari, J.D. Wammes, C. Smits, N.H.M. Labrie, B. Aydin-Misirci, Ö. Uysal-Bozkir, J.L. MacNeil Vroomen

Drafting the manuscript	I. Vullings, S. El Jaouhari
Critical revision of the manuscript	J.D. Wammes, C. Smits, N.H.M. Labrie, B. Aydin-Misirci, Ö. Uysal-Bozkir, E.W. de Bekker-Grob, J.L. MacNeil Vroomen

Chapter 7

Attribute Development and Level Selection for a Discrete Choice Experiment to Elicit Care Preferences of Older Adults and Informal Caregivers Aging in Place in The Netherlands. (2025) The Patient – Patient-Centered Outcomes Research, 19, 131-144

Concept and design	I. Vullings, L. Pilli, J.D. Swait, J.L. MacNeil Vroomen
Data collection	I. Vullings, M.J.C.H. Russchen, B. Aydin-Misirci
Data analysis	I. Vullings, M.J.C.H. Russchen
Interpretation of the data	I. Vullings, L. Pilli, N.H.M. Labrie, J.D. Swait, Ö. Uysal-Bozkir, J.D. Wammes, J.L. MacNeil Vroomen
Drafting the manuscript	I. Vullings
Critical revision of the manuscript	L. Pilli, M.J.C.H. Russchen, N.H.M. Labrie, J.D. Swait, Ö. Uysal-Bozkir, J.D. Wammes, J.L. MacNeil Vroomen

Chapter 8

General discussion

Concept and design	I. Vullings
Data collection	Not applicable
Data analysis	Not applicable
Interpretation of the data	Not applicable
Drafting the manuscript	I. Vullings

Critical revision of the manuscript	J.L. MacNeil Vroomen, T.H. Muller, N.H.M. Labrie, Ö. Uysal-Bozkir

Curriculum vitae

Isabelle Vullings was born on January 11, 1997 in Horst, Netherlands. After graduating from high school she completed a bachelor's degree in Health Sciences at the Vrije Universiteit Amsterdam. She continued her studies, obtaining a Master of Science in Management, Policy Analysis and Entrepreneurship in Health and Life Sciences in 2021. For her master thesis, she conducted a study on the important components of care for persons with dementia and informal caregivers ageing in place in the Netherlands. In September 2022, she started her PhD trajectory at the Department of Geriatrics, Amsterdam UMC, Location AMC. She combined her PhD trajectory with a role as junior council member of the Ageing & Later Life committee of the Amsterdam Public Health Research Institute.

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