

#### **Measuring social exclusion in routine public health surveys** Bergen, A.P.L. van

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## Measuring social exclusion in routine public health surveys

## Addi van Bergen



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## Measuring social exclusion in routine public health surveys

#### PROEFSCHRIFT

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No Man is an Island

by John Donne,

*Meditation XVII from 'Devotions Upon Emergent Occasions, and several steps in my Sickness'*, 1624.

### **Chapter 1**

General introduction

#### Introduction

People living in the Netherlands and other Western countries are living longer, better educated, more self-reliant and healthier than ever before [1, 2]. This, however, does not apply equally to all citizens. In general, the lower a person's socioeconomic position is, the poorer his or her health and shorter his or her life is [3, 4]. Health inequalities in Western countries are persistent and possibly even worsening over time [5-8]. Some groups at the bottom of the social ladder are seriously lagging behind. They rely on food banks or support from churches [9, 10], experience homeless [11], suffer from severe mental illness without access to specialised care [12], and endure severe loneliness [13] or marginal positions in society [14]. Social exclusion (SE) is considered one of the driving forces of health inequities [15-18]. People have become isolated from the opportunities that mainstream society has to offer and lack the ability to fully participate in society, which may lead to a loss of control over their lives and ultimately even to homelessness [19, 20]. Measuring SE in routine public health surveys may help to identify and quantify at-risk groups and gain better insight into their characteristics and health risks. Reliable information obtained thusly, would help policy makers develop more effective policies to tackle health inequities, provide a baseline from which to monitor and assess the effects of policies and programs, and raise the profile and visibility of socially excluded groups and their problems [16, 17].

The introductory chapter of this dissertation starts by elaborating on the concept of social exclusion, its use in social exclusion policies, definitions and models of SE and the measurement of social exclusion. This is followed by an outline on the relation between social exclusion and health and an introduction to the Dutch Preventive Care Cycle and public health monitoring in the Netherlands. Finally, the aim and outline of this dissertation are presented.

#### The concept of social exclusion

In general, social exclusion refers to the inability of people to participate fully in the society in which they live. The question 'what exactly constitutes full participation?' is, however, answered in different ways at different times. The historical origins of the concept of social exclusion go as far back as Aristoteles. He introduced the concept of an impoverished life, i.e., a life without the freedom to undertake important activities that a person has reason to choose and to take part in the life of the community [21].

In recent history the concept was rediscovered by the French Secretary of State, René Lenoir [22]. His book, 'Les Exclus', published in 1974, is widely regarded as the origins of the modern conception of social exclusion within the context of European social policies [23-25]. Lenoir uses the term 'excluded' for groups at the margins or at the bottom and fringes of society, such as mentally and physically handicapped individuals, those with substance abuse issues, those who commit crimes and those living in multi-problem households [22, 25].

Since the 1990s, the concept of social exclusion has been widely applied in the policy contexts of European and other Western countries. In Australia, a comprehensive plan was launched to tackle SE and build an inclusive nation in which all Australians have the opportunity to participate and be treated with dignity and respect [26]. Canada's social policy focuses on groups at risk of SE, such as recent immigrants, persons with disabilities, and sexual, religious and racial minorities [27]. The fight against poverty and social exclusion has taken a central place on the EU's social agenda [28, 29]. Social exclusion has also been adopted as a priority by international organisations such as the World Health Organization (WHO) and the United Nations Development Programme UNDP [15, 17, 30-32].

In the Netherlands social exclusion has been a recurrent theme in national politics and social policy from 1995 onwards. It stood for insufficient willingness and ability to participate in economic and social relationships [33]. Social exclusion has been linked to the threaten of social dichotomy and seen as both a social phenomenon and an individual characteristic [5, 33]. Currently, social exclusion policies in the Netherlands are limited to targeting poverty reduction, ensuring financial self-sufficiency and boosting labour market participation [34-36]. However, at the municipal and regional levels, social exclusion has found a place in policies on social care for vulnerable groups such as multi-problem families, persons with serious mental illness and people experiencing homelessness [37]. Social exclusion is depicted as a downward spiral of loss and disaffiliation rooted in an interplay between society (insufficient access to social and community resources) and the individual (inadequate self-regulation).

<u>In short</u>, social exclusion is primarily a political term, and the meaning given to the term reflects particular institutional, political, historical and geographic contexts [24, 25, 38].

#### **Defining social exclusion**

A scientific approach to social exclusion requires a clear definition and an operationalisation that closely reflects the underlying concept. Scholars have identified a number of key elements shared among the wide variety of meanings given to the concept of social exclusion. General consensus exists across the literature that social exclusion is multi-dimensional, dynamic, relative, relational and recognises agency [16, 17, 21, 31, 33, 39, 40].

- 1. Multi-dimensional. Social exclusion encompasses social, political, cultural and economic dimensions, and operates at different social levels including micro (individual, household), meso (neighbourhoods) and macro (nation state, global regions).
- 2. Dynamic. Social exclusion is understood as a dynamic process which impacts people in various ways and to different degrees over time.
- 3. Relative. Social exclusion is context specific and gradual. There is no natural boundary between being excluded or not.

- 4. Relational. Social exclusion is the product of social interactions characterised by differential power.
- 5. Agency. Social exclusion lies beyond the narrow responsibility of the individual concerned. It implies an act or acts by an agent or agents, e.g., societal institutions, businesses or citizens.

The above elements are reflected in the definition of social exclusion by the World Health Organization (WHO). The WHO defines social exclusion as:

'dynamic multidimensional processes driven by unequal power relationships interacting across four main dimensions - economic, political, social and cultural and at different levels including individual, household, group, community, country and global levels' [18].

This definition provides a wider lens to understand the causes and consequences of social exclusion and avoids the stigma of labelling particular groups as 'excluded'. Instead, social exclusion is understood as a continuum rather than a dichotomous construct.

The most commonly used definition of social exclusion in the Netherlands was developed by the Netherlands Institute for Social Research (SCP) on the basis of comprehensive research [33, 41]. The SCP concluded that in essence, all definitions come down to a distinction between two main domains: relational/immaterial versus distributional/material aspects. The relational approach finds its origins in the French tradition, which builds upon Durkheim's theories of social cohesion and solidarity, the importance of collective values and norms, and the risk of social alienation (anomie) [41]. Social exclusion refers here to the socio-cultural aspects of people's lives, the extent to which people are integrated into society and their connection with others. The distributional approach comes from the Anglo-Saxon line of thinking, which centres around the notion of 'relative deprivation': the idea that people typically regard themselves as badly off or well-to-do based on the comparison with others they deem important (their reference group). Social exclusion refers here to the structural-economic aspects of people's lives, relative deprivation and unequal access to income, basic goods, public services and citizen rights.

Social exclusion is then defined as the accumulation of deficiencies in four dimensions:

- Socio-cultural dimension:
  - 1. insufficient social participation;
  - 2. insufficient normative integration (insufficient compliance with core norms and values associated with active social citizenship);
- Economic/structural dimension:
  - 3. material deprivation;
  - 4. insufficient access to social rights (education, housing, health care, safety etc.). [33]

In the SCP conceptual model (Figure 1), a clear distinction is made between the features of social exclusion (status characteristics) and factors that increase the risk of social exclusion (process) [33]. A low income, for example, is a risk factor and not a constituent part of social exclusion. Low income increases the chance of social exclusion, but social exclusion occurs only if material deprivation actually results (payment arrears, debts, insufficient money for daily necessities) [33]. Risk factors operate at the micro level of the individual, at the meso level of formal and informal organisations and social settings, and at the macro level of government and society at large [42]. Risk factors at the macro level include GDP, income inequality, expenditures on social protection and life expectancy [42].

<u>In short</u>, in this dissertation, we use the multidimensional definition of social exclusion and the corresponding conceptual model as developed by the SCP.



Contextual risk factors



#### Social exclusion and health

Social exclusion is one of the structural drivers of health inequities and forms part of the WHO Social Determinants of Health framework [3, 16, 43]. Inequities in health arise because of the circumstances in which people grow up, live, work, and age and the systems put in place to deal with illness [43]. The conditions in which people live and die are shaped by political, social, and economic forces [43]. The individuals involved are not necessarily passive victims of these social processes; they may actively resist exclusionary processes and the ensuing negative consequences [17].

Several theories exist about ow social determinants impact health. Brunner and Marmot propose a link between social structure and health through material, psychosocial and behavioural pathways, in combination with genetic, early life and cultural factors [44]. Diderichsen identifies three main processes: differential exposure (e.g. residential conditions and physical environment), differential vulnerability (e.g. clustering and interaction of other risk factors and earlier exposures) and differential disease consequences (e.g. barriers to access to care and the job market) [45].

The WHO Social Exclusion Knowledge Network specifies two pathways linking SE to health: constitutive and instrumental. The constitutive perspective looks at the intrinsic value of social inclusion: the experience of inequality and exclusion tends to have pronounced psychological effects and negatively impacts health, well-being and agency [19, 46-49]. The instrumental perspective looks at the circumstances associated with SE: material deprivation, social isolation, poor housing – often in deprived neighbourhoods – and reduced access to care all have a negative impact on health. Additionally, disease and ill health can themselves generate and reinforce exclusionary processes [17].

The relationship between SE and health is theoretically well founded but lacks systematic empirical evidence. A number of literature reviews have been published on SE or social inclusion (SI) and health [17, 38, 50-53], but due to a general lack of clarity and diversity of the meanings ascribed to SE/SI, the wide variety of SE/SI measures and the complexity and sheer magnitude of the literature, no inferences could be made. Most reviews have therefore been limited to describing and discussing the concepts, operationalisations and instruments used to measure SE or SI [17, 38, 53, 54] and/or the characteristics of the retrieved studies, e.g., research designs, countries, years of publication [51, 52]. One study systematically reviewed the impact of interventions on SI in adults with intellectual disabilities [50]. None of the reviews reported systematically on the relationship between SE/SI and health.

<u>In short</u>, the relationship between SE and health is theoretically well founded but lacks systematic empirical evidence.

#### Measuring social exclusion

Not surprisingly, given the information in the previous paragraph, a generally accepted measure of social exclusion is lacking in health research [17, 38, 51, 53, 54]. The most common approach to measuring social exclusion is to use indicator lists with data that are usually drawn from pre-existing datasets [38]. The number, type and dimensions of indicators used to define exclusion vary greatly [17, 38, 55, 56]. Usually, measures focus either on participatory aspects of SE, social relationships and networks or on poverty and labour market participation [17, 38, 56]. The whole construct of SE is rarely represented. A further issue is the general lack of clarity as to whether the items included are risk factors or outcomes of SE, i.e., indirect or direct indicators of SE [17, 38]. Studies rarely attempt to quantify SE using indicators across a number of domains or dimensions [38]. Typically, no composite measure is calculated, or simple sum scores are used with equal weights given to all items or dimensions, which is unlikely to be empirically correct [57]. Few or none of the measures of SE identified were formally validated [38, 54].

Over the past two decades, significant research has been done by the SCP on the measurement of SE in social and economic policy research [29, 33, 41, 42, 58]. In this dissertation, we build on the knowledge and experience gained in this process. In particular, the SE index developed by Hoff and Vrooman [29, 59] has the potential to be developed as a standard in the health domain if adapted to the needs and preferences of users.

This index, here referred to as the SCP social exclusion index, consists of 15 items measuring the four dimensions of SE, 'lack of social participation', 'material deprivation', 'lack of normative integration' and 'inadequate access to basic social rights'. The selection of items was not defined a priori but was determined empirically.

Four focus groups were conducted with 'average citizens' to test the relationship between the SCP theoretical concept and the everyday meaning of social exclusion in the Netherlands. Persons with low levels of education and/or low income were overrepresented. Some typical answers on what social exclusion in the Netherlands currently means, were: 'being very lonely, breaking down a little day by day', 'having no contacts', 'having no respect for other people', 'not holding the door for somebody, not saying 'thank you' when receiving change', 'being in debt', 'not having much money, because that means you have fewer opportunities', and 'people who are disabled or don't know the language, or who have no idea where to turn to' [29]. In each session, the participants evaluated whether the items of a lengthy master questionnaire gave an accurate and complete picture of the subject matter. Based on their comments, questionnaire items were supplemented, reformulated or removed. The amended version then served as input for the next group session.

In the next step, individual cognitive interviews were held with eight 'average citizens' to test the interpretation and comprehensibility of the questions and answer options.

Finally, the revised questionnaire was administered to a sample of the Dutch population (N=648). The questionnaire contained 45 items on social participation e.g. on sports, culture, leisure and other activities outside the house, voluntary work, informal care, membership of clubs and associations, frequency of contacts with family, friends and acquaintances, and feelings of loneliness; 26 items on material deprivation i.e. difficulty of making ends meet, debts and payment arrears, ownership of consumer durables, insurance against risks and insufficient means for basic necessities; 81 items on access to basic social rights e.g. on right to health care, housing, education, a safe and clean living environment, equal treatment and access to business and social services; and 38 items on normative integration e.g. on work ethic, abuse of social security, voting, and beliefs about 'being a good citizen'.

For each of the dimensions, a subscale containing three to four items was constructed using nonlinear canonical correlation analysis. The 15 items form a general index that measures the degree of social exclusion at the individual level, with a higher index score for persons simultaneously deprived in several dimensions [29, 59]. The SCP social exclusion index was validated in the same sample and replicated in a new sample two years later [60].

<u>In short</u>, the social exclusion index developed by Hoff and Vrooman [29, 59] is used as the gold standard for measuring the multidimensional concept of social exclusion.

### Local public health policy: the preventive care cycle and monitoring

#### Preventive care cycle

According to the Dutch Public Health Act (In Dutch: Wpg), municipalities in the Netherlands are tasked with protecting, monitoring and promoting the health of their inhabitants based on epidemiological analyses. The relationship between national and local governments is formalised in a four-year preventive care cycle. As shown in Figure 2, the national policy document on health – which sets out governmental health policy ambitions – is based on the Public Health Status and Forecasts Report (PHSF). This report is published every four years by the National Institute for Public Health and the Environment (RIVM) and gives an overview of the current state of public health in the Netherlands, including an estimation of what the situation will be in ten to twenty years based on the results of the most recent national and local monitoring efforts by Statistics Netherlands and the GGDs (community health services) [61].

The next step in the preventive care cycle occurs on a local level: municipalities and GGDs develop local health policies based on the main priorities and recommendations of the national health policy and epidemiological data provided by the GGD about the local health situation.

At the end of the cycle, the IGZ assesses the state of the public health system, and its findings are used as input for the next PHSF document. [62]



Figure 2. Preventive care cycle in the Dutch health system.

#### Public Health Monitor

The Public Health Monitor (PHM) is a large-scale survey conducted by the Association of Regional Public Health Services (GGD GHOR Nederland), the RIVM and Statistics Netherlands (in Dutch: CBS). It provides data to the PHSF and guidance for setting national and local public health policies. Once every four years, approximately half a million Dutch citizens age 19 or older are contacted to participate.

The survey uses a 'mixed-mode' design, i.e., a combination of several survey modes (online, in writing, face-to-face or by telephone). In the four major cities, translated questionnaires and foreign language interviewers are available. [63] A stratified sample is used to allow for analyses at the neighbourhood level and with subpopulations. To account for the complex sampling design and selective non-response, sample weights are calculated by Statistics Netherlands based on a linear model with 9 sociodemographic variables and their interaction terms [64].

The questionnaire covers a broad spectrum of health outcomes and (social) determinants. In addition to a mandatory national set of questions on gender, age, education, chronic conditions, height, weight, loneliness, smoking habits, alcohol consumption and informal care, some extra topics can be included to address local policy priorities formulated by municipalities. By linking the dataset to other datasets from Statistics Netherlands, the PHM dataset is enriched with data on, for example, standardised household income (in quintiles) and migration background. [63]

Its central place in the preventive care cycle, wide coverage and high-quality standards make the PHM a unique vehicle for measuring social exclusion in the health domain. The space in the PHM for extra local topics is, however, limited, and competition is fierce. Important considerations for GGDs when choosing the extra items are the

relevance of the topic for local public health, the length of the questionnaire and need to avoid unnecessary overlap with the mandatory national set. These are the challenges tackled by this dissertation.

<u>In short</u>, the PHM is the best vehicle to measure social exclusion, given its wide coverage and prominent place in the preventive care cycle at the national and local levels.

#### Aim and outline of the dissertation

The aim of this dissertation is threefold: a) to systematically review the evidence base for the association between the multidimensional concept of SE, as defined in this study, and health; b) to develop a reliable and valid instrument to measure social exclusion in public health surveys, more specifically in the Public Health Monitor conducted by the GGDs in the Netherlands; and c) to explore the potential use of this instrument for public health research and policy.

In Chapter 2, we start with a systematic review into the association between SE and health. As we saw above, the relationship between SE and health is theoretically well founded but still lacks systematic empirical evidence. The problem is not that there are no studies on SE and health; the opposite seems more the case. It is the wide variation in the concepts used and the operationalisation of SE that severely limit the synthesis of the evidence in these studies. To circumvent this obstacle, we confine our review to only one concept and operationalisation of SE and of its antipode, social inclusion (SI).

In Chapter 3, we explore, as a first step in the development of a reliable and valid instrument to measure SE in routine public health surveys, whether the multidimensional concept of social exclusion can be validly approximated with items that are already used in the PHM.

In Chapter 4, we describe the construction and validation of the Social Exclusion Index-for Health Surveys (SEI-HS). In this step, we address the limitations of our previous study. We requested that GGDs include an extra set of items in their 2012 PHM questionnaire and used these data to construct a national index.

In Chapter 5, we examine whether the stronger SE among adults with Surinamese, Moroccan and Turkish backgrounds compared with native Dutch citizens in the four largest cities of the Netherlands (G4) can be explained by shortcomings in the cross-cultural validity of the SEI-HS. In this study, we use a sequential explanatory mixed methods design, combining quantitative analyses of 2021 PHM data and interviews with respondents with a high score on the SEI-HS from different migration backgrounds. In Chapter 6, we explore possible applications of the SEI-HS in public health monitoring, research and policy. We test SE, as measured with the SEI-HS, against traditional social stratifiers in terms of the ability to identify high-risk/high-need population segments. For this study, we use G4 2016 Public Health Monitor data.

Chapter 7 summarises the main findings, reflects on the limitations and strengths of the study, and discusses its main findings. Finally, implications for local public health monitoring as well as future research, policy and practice are discussed.

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#### Het leven van Corrie

In Amsterdam woont één van onze geïnterviewden, Corrie van 70 jaar. Zij woont samen met haar man en een bont gezelschap van huisdieren in een flatwoning op de begane grond. Corrie heeft verschillende gezondheidsproblemen die onder andere opspelen als de situatie thuis gespannen is. Eén van de problemen die spanningen veroorzaken is het alcoholgebruik van haar man. In de jaren '80 is haar man hiervoor onder behandeling geweest en een paar jaar geleden nog eens, maar helaas heeft dat niet geholpen. Corrie lijkt er in te berusten dat dit de situatie is waarin zij leeft. 'Ook gewenning aan de situatie en dat je dan je eigen grenzen een beetje gaat verleggen. (...) Ja, ik bedoel de situatie is zo en dan ga je het misschien meer accepteren.' Hulp zoeken ze niet meer. 'Je kan wel over dingen praten en dat geeft dan wel wat opluchting maar als het de situatie niet echt verbetert.'

Energie krijgt Corrie van haar vrijwilligerswerk voor De Zonnebloem en af en toe een uitje met haar dochter(s) naar het strand. Echt vakantie schiet er al een paar jaar bij in. 'Soms zou je wel even weg willen. (..) Dat je gewoon een paar dagen uit kan waaien, of een andere omgeving eventjes.' Maar de financiën laten dit niet toe.

Gebaseerd op Sociaal Uitgesloten in de grote stad, van Bergen et al. 2014.

The association between social exclusion or inclusion and health in EU and OECD countries: a systematic review

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#### ABSTRACT

**Background.** Social exclusion (SE), or the inability to participate fully in society, is considered one of the driving forces of health inequalities. Systematic evidence on this subject is pertinent but scarce. This review aims to systematically summarise peer reviewed studies examining the association between the multidimensional concepts of SE and social inclusion (SI) and health among adults in EU and OECD countries.

**Methods.** The protocol was registered on Prospero (CRD42017052718). Three major medical databases were searched to identify studies published before January 2018, supplemented by reference and citation tracking. Articles were included if they investigated SE or SI as a multidimensional concept with at least two out of the four dimensions of SE/SI i.e. economic, social, political, and cultural. A qualitative synthesis was conducted.

**Results.** Twenty-two observational studies were included. In the general population, high SE/low SI was associated with adverse mental and general health. For physical health, the evidence was inconclusive. In groups at high risk of SE, support was found for the association between high SE/low SI and adverse mental health but no conclusions could be drawn for physical and general health.

**Conclusions.** This review found evidence for the association between high SE/low SI and adverse health outcomes, particularly mental health outcomes. The evidence is mainly based on cross-sectional studies using simple and often ad hoc indicators of SE/SI. The development and use of validated measures of SE/SI and more longitudinal research is needed to further substantiate the evidence base and gain better understanding of the causal pathways.

#### INTRODUCTION

According to the World Health Organization (WHO), social exclusion (SE) is one of the driving forces of health inequalities [1-3]. SE refers to the inability of people to participate fully in society [4], while its antipode, social inclusion (SI) refers to the situation in which individuals are fully involved in the society in which they reside, including the economic, social, cultural and political dimensions of that society [5]. The pathways linking SE (and lack of SI) to poor health are complex and diverse[1]. The situation of SE encompasses deprivations in areas such as social relations, material resources, access to health services and housing, which are in itself well known determinants of health [6, 7]. In addition, pathways leading to poor health may occur via direct and indirect causation as well as through reverse causation. The experience of exclusion, e.g. low social standing, feelings of alienation and lack of belongingness may directly impact health and well-being via psycho-neuroendocrine mechanisms or work indirectly through stress-related unhealthy behaviours [8-10]. SE may also give cause to other deprivations e.g. poor labour conditions or poor nutrition, which also contribute to ill-health [1]. Reverse causation occurs when poor health and disability generate and reinforce exclusionary processes [2].

Although SE and SI have considerable public health significance from a theoretical perspective, the empirical evidence-base on this topic is still sparse. Literature reviews on social exclusion or inclusion and health mostly discuss the concepts, operationalisations and instruments used to measure SE or SI [2, 11-13] or describe characteristics of the retrieved studies (research design, country, year of publication etc.) [14, 15]. One study systematically reviewed the impact of interventions on SI in adults with intellectual disability [16]. None of these reviews reported systematically on the relationship between SE/SI and health. The lack of clarity and diversity of meanings associated with SE/SI, the wide variety of SE/SI measures used, the focus on only one dimension of SE/SI and the complexity and sheer magnitude of the literature, severely limited the inferences that could be made from these studies [2, 11-16].

In this study, we conducted a systematic literature review that addressed one of the main obstacles encountered in previous reviews i.e. lack of clarity and diversity of meanings. SE/SI represents a broad concept that, by its nature, can be defined and operationalised in various ways. Multidimensionality is one of the agreed upon characteristics [17], but the number and nature of the dimensions vary. Burchardt, for example, used four dimensions: consumption, production, political engagement, and social interaction [18]; others distinguished six [19] or even seven [20] elements or dimensions of SE/SI. The WHO defines social exclusion as "dynamic multidimensional processes driven by unequal power relationships interacting across four main dimensions - economic, political, social, and cultural - and at different levels including individual, household, group, community, country, and global levels" [1]. These processes may lead to a state of SE characterised by a cumulation of deprivations in multiple dimensions [1, 10, 21]. We choose the WHO definition and classification into four societal domains as a template for our study. To further improve homogeneity we made a distinction

between often large general population studies and smaller studies in specific groups, mostly at high risk of SE.

The purpose of this study is to systematically summarise the evidence on the association between multidimensional SE and health and to evaluate six hypotheses i.e. that high SE/low SI is associated with: 1) adverse mental health, 2) adverse physical health, and 3) adverse general health outcomes in a) the general population and b) populations at high risk of SE.

#### **METHODS**

We followed PRISMA guidelines for reporting this systematic review [22, 23]. The review protocol is registered on the PROSPERO database (registration number CRD42017052718) and is available at <u>https://www.crd.york.ac.uk/PROSPERO</u>.

#### **Electronic search**

We developed and executed, with the help of a qualified librarian, a search strategy to identify all studies that reported the association between SE/SI and health. The following three major electronic health databases were searched up to January 2018: PubMed, EMBASE, and CINAHL. Searches were conducted in March 2015 and January 2018. The terms 'social exclusion' and 'social inclusion' were searched in title and abstract. Search strategies can be found in Supplementary file 1.

#### **Study selection**

Two authors (AvB, plus MB or KS) independently screened all records identified by the electronic search on title and abstract using a sequentially applied algorithm previously introduced by Curran et al. [14] (Figure 2). First, records without an abstract and inconclusive title were moved to a separate database to be assessed on the basis of full text.

Next, language, study population, country and type of publication/study design were checked. Studies had to be written in English, Dutch, German, Spanish, or French; involve an adult population; and be set in EU-countries or OECD-countries [https://www.oecd.org/about/members-and-partners/], because of their relatively similar welfare regimes. Only research articles published in peer-reviewed journals describing quantitative studies were included. Articles had to test the relationship between SE/SI and a health measure and report statistical results. Next, we excluded studies not using a multidimensional construct of SE/SI (minimum two of four dimensions), studies in which health formed part of the SE/SI measure and studies using an ecological measure of SE/SI. We did not exclude studies on sample size criteria.

We retrieved full-texts of all articles considered potentially eligible by at least one reviewer. Two reviewers (AvB, plus MB, KS or BC) then independently assessed the full texts to ascertain that the inclusion criteria were met. In case of disagreement, one of the other reviewers was consulted to decide. To complement the electronic searches, we hand-searched the reference lists of included studies and other reviews. Citation tracking was performed using Web of Science (WoS) or Google Scholar if studies were unavailable in WoS. Studies identified through reference and citation tracking were screened and assessed by AvB. When uncertain, BC or HS were consulted.

#### **Data extraction**

For each included study, the following data were extracted: study design, country, study population, sample size, dimensions and measures of SE/SI, health measure(s), confounding variables, statistical analysis and key results. We classified the health outcomes into three groups: mental health related (MH), physical health related (PH), and general health related (GH). In this, we were guided by the lists of mental and physical adult health measures in the Patient-Reported Outcomes Measurement Information System (PROMIS http://www.healthmeasures.net/explore-measurementsystems/promis/intro-to-promis/list-of-adult-measures) and UK experience on general health measures [24]. Mental illness and its impacts, emotional distress and cognitive functioning were classified under MH, as were intravenous drug use and compulsory hospitalisation on grounds of health and safety risks due to mental illness. Physical functioning, impairments, and symptoms such as headache and sleeplessness, were classified under PH. Whereas physical health refers to the physiologic and physical status of the body, general health refers to overall health status. Typical general health measures are self-rated health, presence of chronic diseases (yes/no), and limitations due to health problems (yes/no) [24].

Indicators of SE/SI were classified into the four WHO dimensions of SE/SI: social (S), economic (E), political (P), and cultural (C) as operationalised by the Netherlands Institute for Social Research SCP [3, 25, 26]. In the social dimension, we classified SE/SI indicators relating to social isolation, participation in formal and informal social networks, and social involvement. In the economic dimension, we classified SE/SI indicators relating to deficits that people experience as shown by debts and the absence of certain basic goods and services; in the political dimension we classified indicators on the ability to exercise the rights people normally have, such as adequate health care, sufficient education, proper housing, a safe living environment and access to public and commercial services; and finally, in the cultural domain, we categorised indicators referring to a lack of normative integration i.e. non-compliance with core values of society such as low work ethic, low training readiness, not voting, social security abuse or delinquent behaviour. Study populations were classified into two groups: 1) general population and 2) population groups at high risk of SE. Studies among adults in HIV treatment, problematic drug users and single mothers were classified in the latter category. We classified elderly as general population, viewing them as a demographic group rather than a high-risk group. Data extraction was performed by one reviewer (AvB, MB or KS) and checked by a second (AvB, BC or HS).

#### **Risk of bias assessment**

As there is currently little consensus on the critical elements for assessing risk of bias in observational studies [27], we opted for a two-track approach. The general methodological quality of each study was evaluated independently by two reviewers (AvB and MB KS BC or HS) using the Critical Appraisal Skills Programme (CASP) tools for cross-sectional and cohort studies (Supplementary files 2-3). The respective CASP checklists consist of 10 and 11 questions (e.g. "Was the outcome accurately measured to minimise bias?" and "Was the cohort recruited in an acceptable way?"), that can be answered with: 'yes' (1 point), 'can't tell', or 'no' (0 points). The option to answer 'yes moderately' (0.5 points) was added by the reviewers. Disagreements were resolved through consensus and, if necessary, a third reviewer was consulted (BC). A commonly used cut-off point of 60% was used to distinguish between low and acceptable quality studies [28]. Only acceptable quality studies were included in the synthesis. As done by De Silva et al. [29], we assessed, in addition to the CASP, a number of specific methodological limitations with a high risk of bias for our research question. We examined whether the definition, operationalisation and measurement of SE/SI were adequately substantiated, whether testing of the association between SE/SI and health was a stated objective of the study and whether adjustment for confounding factors was performed. Details can be found in Supplementary file 4.

#### Data analysis

Given the variation in health measures and study designs, it was not possible to conduct a meta-analysis. Instead, we used the method of grouping results as originally described by Ramirez et al. [30]. To examine the six research hypotheses, we grouped the results for each hypothesis into four qualitative patterns. These were: 1) positive, when a significant (p<0.05) concordant relationship was found for all measured SE/SI dimensions (high-SE/low SI corresponds to low health outcome), 2) negative, when an inverse association was found, 3) no association, when the relationships between the SE/SI dimensions and health were not statistically significant, and 4) partly (+/0), when studies reported multiple associations. We classified the result as partly when 30-70% of the tested relations were positive and the remaining 70-30% not significant. If studies reported findings for multiple, non-overlapping, research groups, e.g. men and women, these were included separately in the data analysis and counted as separate instances. When both unadjusted and adjusted results were presented, only adjusted results were reported. Results were combined by counting the number of instances in each category and weighting by sample size.

#### RESULTS

#### Study selection

The digital search yielded 4,032 non-duplicated articles: 2,038 references in PubMed, 1,219 in EMBASE and 775 in CINAHL (Figure 1). On the basis of title and abstract screening, 3,847 articles were excluded (Figure 2). The most common reason for exclusion was publication type (editorials, posters etc.) and study design. Articles that were excluded on language were mostly written in Portuguese. In total 185 articles were selected for full-text screening of which 19 met the inclusion criteria. An important reason for exclusion in this stage was the use of the term SE or SI for a single dimension of SE/SI or for a different concept (e.g. exposure to forms of mistreatment, problems with daily activities or fear for SE). The interrater agreement for the selection of the publications was good (Cohen's  $\kappa = 0.77$  [31]). Through reference and citation tracking 1,792 more papers were identified of which three met the inclusion criteria. Main reasons for exclusion in this stage were subject (58%) and publication type (22%).



Figure 1. Flowchart of study selection.

#### **Description of studies**

The studies included five cohort studies, four case control studies and thirteen studies with a cross-sectional design. The majority of the studies were conducted in Europe (15), mostly in England (6). Eleven studies were conducted in the general population and eleven investigated SE/SI in groups at high risk of SE. The sample sizes ranged from 67 to 25,498 participants. Sixteen papers addressed mental health (MH), six physical health (PH) and six general health (GH). Five papers addressed more than one type of health outcome. The studies are presented in Supplementary file 5 Table S1a-b for MH, Tables S2a-b for PH and Tables S3a-b for GH.

#### **Risk of bias assessment**

The methodological quality of each study is summarised in Supplementary file 5. Details on the measurement of SE/SI and confounding variables can be found there as well. All studies had CASP scores of 6 or more, indicating acceptable quality. Figure 3 shows that the most frequent methodological limitations were incomplete measurement of SE/SI (< 4 dimensions) and lack of an existing SE/SI measurement instrument.



Figure 2. Exclusion algorithm title and abstract screening.

Most studies used self-chosen indicators without testing the psychometric properties. Only two studies used an existing instrument for SE/SI, that is, the Social Inclusion Questionnaire User Experience (SInQUE) [32, 33] and Social exclusion index [34, 35]. Three studies used existing scales to measure dimensions of SE/SI [36-38]. In two studies an index of social exclusion was constructed and partly validated [39, 40]. The majority of studies did not use a composite measure for SE/SI, and those that did, mostly calculated simple sum scores [39, 41-46]. In ten studies, the data were not originally designed to measure SE/SI (e.g. case files, registration or monitoring data). One in three studies lacked a theoretical underpinning of SE/SI. Control for confounding factors was missing or incomplete in 7 of the 22 studies.

	high-risk	Johner et al. (62)	٠	٠	•	٠	•	٠	٠	
nealth	on	Urbanos-Garrido (61)	٠	٠				٠	٠	]
eral ł	eral l pulat	Halleröd & Larsson (43)	•		٠					
Gene	l pop	Sacker et al. (41)	•			٠		٠	•	
	nera	Gannon & Nolan (60)	•	•				٠	•	
	ge	Bryngelson (59)	٠			$\checkmark$	•	٠	$\checkmark$	
h	high-risk	O'Brien et al. (56)	٠	•	•	٠	•	٠	V	
healt	uo	Richter & Hoffmann (45)	٠	٠				٠	$\lor$	
ical ]	ical h ulatic	Halleröd & Larsson (43)	٠		٠					
Phys	l pop	Bayram et al. (42)	٠	•	٠		•	٠	$\vee$	
H	nera	Waterstone et al. (58)	٠		٠	٠		٠	٠	
	ge	Saito et al. (57)	•			٠		٠	٠	
		O' Brien et al. (56)	٠			٠		٠	$\vee$	
		March et al. (55)		٠				٠	٠	
		Maia et al. (54)		٠		$\checkmark$		٠	٠	
	sdno	Killaspy et al. (53)	٠	•	٠		•	٠	•	
	k grc	Fakhoury & Priebe (53)					•	٠	٠	
	h-risl	Cole et al. (51)	٠	•		•	$\checkmark$	٠	٠	ent
lth	hig	Choi et al. (50)	٠	•		•	$\checkmark$	•	٠	pres
hea		Webber & Huxley (49)				٠	$\checkmark$	•	٠	tion
ental		Todd et al. (48)	•	٠	•	•	•	•	٠	imita
Μ		Flores et al. (47)	٠	٠	٠	٠		٠		
		Van de Beek et al. (46)	•	•			$\checkmark$	٠	$\checkmark$	ent;
	ation	Richter & Hoffmann (45)	٠					٠	$\lor$	pres
	general popula	Honey et al. (44)				•	$\checkmark$		•	artly
		Halleröd & Larsson (43)	٠		٠					on p
		Bayram et al. (42)	٠	٠	٠		•	٠	$\checkmark$	nitati
		Sacker et al. (41)	٠			•		٠	٠	리
			, Theoretical motivation SE/SI	, Data set originally designed to measure SE/SI	, All dimensions of SE/SI measured	, Composite measure SE/SI	, Existing SE/SI measure	, Testing of association SE/SI - health was a stated objective	, Adjustment for confounding	ey: • Limitation not present; <

Figure 3. Summary of study specific limitations with a high risk of bias.

Limitations: 1, no theoretical motivation of the concept SE/SI; 2, data set not originally designed to measure SE/SI; 3, not all dimensions of SE/SI measured; 4, no composite measure SE/SI; 5. no existing SE/SI measure; 6, testing of association SE/SI - health was not a stated objective; 7, no adjustment for demographic and other potential confounding factors.

Abbreviations: MH = Mental Health; PH = Physical Health; GH = General Health; high risk = high risk groups. Note: Studies may appear more than once if they relate to more than one health category.

#### Mental health in the general population

Figure 4 shows evidence in favour of our hypothesis that high SE/low SI is associated with adverse health outcomes for MH in the general population. Our hypothesis is supported by 92% of the combined sample (27,881 persons, 6 instances, 5 studies) [37, 38, 46-48] and partly supported by 8% of the sample (2,493 persons; 1 instance) [34]. All but one study were cross-sectional in design. A retrospective cohort study showed an association between high psychological distress in elderly persons and later SE. High levels of SE, in turn, were found to be predictive of high psychological distress[46]. Three cross-sectional studies found positive associations between a large number of SE indicators and self-reported anxiety and anguish [47], common mental illness and severe mental illness [48]; depressive symptoms and psychotic experiences [38].



Figure 4. Significance and direction of the relationship between SE/SI and health: total sample size (X-axis) and number of instances (between brackets).

Another supportive study [37] found that the relationship between disability and MH was moderated by the social and economic dimensions of SE (operationalised as low social support and financial hardship respectively); and that the combination of the two dimensions strengthened the effect. The study with partial evidence [34] found a significant relation between low MH and the social dimension of SE but not with the cultural and economic dimension. Within the political dimension one indicator (adequate housing and safe neighbourhood) showed a concordant relation with MH whereas the other did not (access to institutions).

#### Mental health in high-risk groups

Figure 4 shows that the association between SE/SI and MH was tested in 13 highrisk study populations. Due to the typically small samples, the total sample size is modest compared to the general population sample (Figure 4; Tables S1a-b). This does not indicate less evidence per se. Our hypothesis was supported by 80% of the combined sample (4,646 persons; 8 out of 13 instances) and partly supported by 12% of the sample (692 persons; 3 instances). Supporting evidence was derived from two case control studies [42, 49] and five cross-sectional studies [36, 40, 45, 50, 51]. The case control studies showed an elevated prevalence of DSM III personality features associated with SE in men with AIDS and/or drug addiction [42]; and an elevated prevalence of substance use disorders in clients of mental health services with SE characteristics [49]. The cross-sectional studies found significant associations between SE/SI and, respectively, perceived stress in patients in substance abuse treatment [36]; elevated intravenous drug use in drug users in public places [50]; symptoms of depression [45] and mental symptoms and impairments in HIV patients [51] and higher levels of complex post-traumatic symptoms in torture survivors [40].

Partial evidence was found in a study among patients of Assertive Outreach teams [52]. In this population, alcohol abuse and dependency was associated with the social and cultural dimensions of SE, but not with the political dimension. Drug abuse and dependency was associated with the political and part of the cultural dimension of SE and not with the social dimension. Partial evidence was also found by Killaspy et al. [33]. Patients interviewed after developing a psychotic illness showed a significant deterioration in two of the four SI dimensions measured i.e. the social and economic dimensions. Older age at onset of illness and longer duration of illness were associated with greater changes in the economic dimension. Higher current quality of life was associated with less decline in the social dimension.

Our hypothesis was not supported by two case control studies (490 persons, 2 instances) [39, 49]. One study found that in clients with substance use disorder, the co-occurrence of mental health problems was not associated with higher levels of SE [49]. The authors suggest that the association between substance abuse and SE is stronger than between mental health and SE. The second study [39] showed that SE increased the likelihood of compulsory admission among people assessed under the Mental Health Act, but, when other factors such as diagnosis, life-threatening self-neglect and physical aggression towards others, were taken into account, the association became non-significant. It is plausible that these factors might act as mediators in the relation between SE and compulsory admission.

#### Physical health in the general population

Figure 4 shows a more mixed picture for PH in the general population. Two studies support the hypothesis that high SE is associated with adverse PH (56% of the combined sample, 21,058 persons), two studies partly support the hypothesis (33%, 7,879 persons) and two studies do not (21%, 9,001 persons). Findings from a prospective cohort study [43] showed that elderly Japanese women who were excluded both in the social and in the economic dimension were 1.7 times more likely to die prematurely than those who were not socially excluded. In elderly men, the association between SE and mortality was not significant. The results were adjusted for age, marital status, education, municipality, disease and impairment. Supporting evidence was also found from cross-sectional studies on severe obstetric complications in general, on severe
pre-eclamptic conditions and severe haemorrhage specifically [44], on headache and sleeplessness [47] and severe physical illness or disability [48]. No significant associations were found with severe haemorrhage and uterine rupture [44], with obesity [47], and with the PH domain of the WHOQOL-BREF [34]. This domain covers among others pain, physical problems, sleep and energy.

### General health in the general population

Evidence was found for the association between high SE/ low SI and adverse GH in the general population. Our hypothesis was supported by 80% of the combined sample (32,537 persons, 3 out of 6 instances) [46, 53, 54], partly supported by 16% of the sample (6,481 persons; 2 instances) [41, 47] and not supported by 4% of the sample (1,604 persons; 1 instance) [41]. The results were heavily influenced by one large cross-sectional study in 25,498 adults in Spain which found significant relationships between SE factors and socioeconomic inequalities in self-assessed health, presence of any chronic disease and limitations in daily activity due to health problems [54]. Two cohort studies showed positive associations between SE and disability onset and persistent disability [46, 53], and onset and persistence of low self-assessed health. A third cohort study showed partial evidence [41]. In women, long-term sickness absence adjusted for age and previous SE increased the risk of the combination of economic and social exclusion, but not of the combination of economic and cultural exclusion. In men, no significant associations were found between dimensions of SE and long-term sickness [41]. Partial evidence was also found in a cross-sectional study among 4,941 adults demonstrating a positive association between the presence of any chronic disease and the social, economic and part of the political dimensions of SE/SI, but not with the cultural dimension [47].

### Physical health and general health in high-risk groups

The literature did provide little evidence on the association between SE/SI and PH or GH in high-risk groups. The number of studies was low, with one study on PH [51] and one study (2 instances) on GH [55]. In HIV patients, physical symptoms and impairments and difficulties in day-to-day activities due to illness were associated with low SI [51]. In single mothers, self- assessed health was not associated with SE. This was true for both single mothers on social assistance as for single mothers without social assistance [55].

# DISCUSSION

We set out to systematically summarise existing evidence on the association between SE/SI and health and evaluate the hypotheses that high SE/low SI is associated with adverse MH, PH, and GH outcomes, in the general population and in groups at high risk of SE. The evidence base is currently strongest for the association between SE/SI

and MH. The hypotheses that high SE/low SI is associated with adverse MH outcomes are supported by studies with various designs, sample sizes and settings, in both the general population and high-risk groups. Conflicting evidence was only found in two studies [39, 49], in which the relation between SE/SI and MH appeared to be mediated by other factors.

This review also found support for the association between SE/SI and GH in the general population. The outcomes included some that are widely used in public health monitoring such as self-assessed health, presence of any chronic disease, and limitations due to health problems. Two aspects deserve closer attention. First, the results are confined to the social and economic dimensions of SE/SI. The cultural and social rights dimensions were not well presented and little or no significant relations with these dimensions were found. Second, none of the studies used a composite measure for SE/SI, and only one study provided insight into the cumulative impact of the underlying dimensions [41].

Our review failed to confirm or refute a direct association between high SE/ low SI and adverse PH in the general population. The wider literature provides ample evidence for associations between aspects of SE/SI and PH outcomes, for example, between social relations and mortality [6] and between neighbourhood characteristics and cardiovascular health [7]. We expected that a cumulation of these aspects would also be associated with adverse PH outcomes. One reason for the absence of association may be the much broader spectrum of PH outcomes included in this study, ranging from headache and obesity to severe obstetric complications. Another reason may be that these studies use other terms such as deprivation or precariousness and did not get included in this review.

Lastly, as our review identified only a few studies focusing on the relation between SE/SI and PH or GH in high-risk populations, no conclusions can be drawn about the hypotheses on PH and GH in high-risk groups.

### **Causality and directionality**

The studies we found employ different assumptions about the relationship between SE/SI and health. Some authors consider SE as a cause of adverse health [42-44] while others regard SE as a consequence of adverse health [33, 51, 53] or as a mediator [37]. The observational design of these studies does, however, preclude firm causal inference. The few longitudinal studies give us some insight in directionality. One longitudinal study showed that SE preceded negative health outcomes i.e. mortality in Japanese elderly women [43]. A second longitudinal study [41] points to a reverse directionality; long-term sickness absence was associated with a deterioration of the economic and social dimensions of SE in women, independent of their earlier situation. A reciprocal relation was found in two longitudinal studies [46, 53]. Further longitudinal studies may contribute to unravel the dynamic relation between SE/SI and health.

#### **Risk of bias within studies**

In line with previous reviews we found almost no study using a valid measure for SE/ SI. Most studies used self-chosen indicators and in nearly half of the studies the data were not originally designed to measure SE/SI. The lack of valid measures for SE/SI prevents very firm conclusions being drawn from this review. We agree with previous reviews that the development and use of validated multidimensional measures [12, 13, 16, 56] is warranted in future research. As SE is a multi-interpretable concept that can be operationalised in various ways depending on one's theoretical perspective, political position and purpose, it is not obvious that one agreed upon measure for SE/SI will surface. This need not be problematic as long as choices are explicated and substantiated. Finally, seven of the 22 studies did not adjust for demographic and other potential confounding factors. As confounding may affect the results of our review through over-estimation, the evidence was also analysed without these seven studies and the inferences remained unchanged. It is important to note that in all observational studies, residual confounding may account for part of the associations observed.

### Strengths and limitations of this review

The principal strengths of this review are its systematic approach, tactical search strategy, and clear conceptual framework. These made it possible, despite the great diversity of studies, to take a step further than previous reviews, which did not report on the relationship between SE/SI and health, or did not do this systematically, but merely as exemplary descriptions [2, 12-16]. Another strong points is the inclusion of papers in languages other than English.

There are limitations too. The method we used to summarise the evidence is based on p-values. P-values give an indication of the compatibility of the data with the null-hypothesis of each paper, and not of the effect size or the importance of the results [57]. To enable interpretation of the results we reported for each paper effect sizes and/or other statistics in the tables and provided some qualitative context in the main text. Another limitation arises from the classification of health outcomes, which was not always straightforward. In a number of studies no clear distinction could be made between MH and PH components, for instance, when researchers considered other, non-congruent, classes of diseases. As these results were classified as GH, this category may have become somewhat ambiguous. Yet another limitation is that our review is not exhaustive. The downside of applying strict selection criteria is that e.g. studies not using a multidimensional construct of SE/SI were left out. As a previous review using a comprehensive search strategy yielded unmanageable amounts of 100,000 plus titles [14], we choose a narrow search strategy to identify papers that focus specifically on SE/SI and not on related subjects such as income, housing, social cohesion etc. This way we may have missed relevant papers not using the specific terms SE or SI in title or abstract, but we do not expect there to be many, for two reasons. First, studies on only one dimension of SE/SI or on a constituent element,

such as social isolation, housing or access to health care, are beyond the scope of this review as our focus was solely on papers employing a multidimensional interpretation of the concept SE/SI. Second, more comprehensive concepts such as social cohesion, social capital, citizenship or (multiple) poverty, were deliberately kept out of the study too, because of the general consensus in the literature that these concepts, although appearing similar to SE/SI, differ in important ways [2, 10-12, 20, 26]. Studies on socio-economic position or ethnicity and health are also out of the scope of this review as occupation, education and ethnic background are regarded as risk factors for SE and not as constituent parts [21]. Nevertheless, bias to the use of key words cannot be ruled out and a more extensive search strategy could be considered in future reviews.

#### **Implications for future research**

Our paper revealed a great number of weaknesses in research methodology and provides ideas and directions for future research. A research agenda required to have a better understanding of potential mechanisms and putative pathways should include longitudinal studies, studies into mediating and modifying factors such as gender and previous disadvantage; and into the accumulation and interaction of SE/SI dimensions. Equally important for enhancing the knowledge base on SE/SI and health, is a more systematic and standardised terminology of SE/SI domains and the development and validation of composite measures of SE/SI. The WHO/SCP model used in this paper may serve here as a useful template [3, 25, 26].

#### **Policy implications**

The association between high SE and poor MH came most clearly to the fore in people with severe mental illness and substance use disorder. Through the implementation of recovery-orientated services, the mental health sector can contribute to the SI of their clients [58], but more may be needed. As several studies in our review show an association between the economic and political dimensions of SE/SI and MH, e.g. with income, economic deprivation, employment, education and housing, we expect that there may be little chance of improving the situation of those with mental health problems without attention being given to these other problems. These need to be addressed by social and economic policies [58], involving not just the health sector but a range of sectors and services such as housing, employment, education, income support, debt counselling, and community building [59-62]. The evidence on the association between SE/SI and poor mental and general health in the general population also calls for more macro level policies and interventions, targeting the general population and not only those at highest risk.

# CONCLUSIONS

To our knowledge, this is the first paper that succeeded in systematically synthesizing evidence on the association between the multidimensional concept of SE/SI and health. Preliminary evidence was promising. Most studies confirmed the expected relationship between high SE/low SI and adverse health outcomes, particularly for mental health. We recommend a greater focus on the valid measurement of SE/SI in future research.

# **KEY POINTS**

- Social exclusion is generally regarded as an important social determinant of health, yet, its evidence base is still weak.
- In this systematic review we operationalised social exclusion as the cumulation of deprivations in four dimensions i.e. social, economic, political and cultural and social inclusion as full involvement in these dimensions.
- Evidence was found for the interconnectedness of social exclusion and inclusion and health. Available evidence is stronger for mental and general health than for physical health.
- There is need for the development and use of validated multidimensional, and preferably composite, measures for social exclusion and inclusion.

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# SUPPLEMENTARY MATERIALS

Supplementary file 1: Literature search strategy details

Supplementary file 2: CASP risk of bias tool for cross-sectional studies

Supplementary file 3: CASP risk of bias tool for cohort studies

Supplementary file 4: Details about the specific methodological limitations

Supplementary file 5: Tables S1a-S3b Description of observational studies: mental health, physical health and general health in the general population (a) and in high risk groups (b)

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#### **Emine's verhaal**

Emine is 46 jaar en woont in Den Haag. Zij heeft drie kinderen, twee zoons en een dochter. Haar dochter is helaas 1,5 jaar geleden verongelukt. Dit is voor Emine een groot verlies, waar zij zeer emotioneel over vertelt: '*Ik heb haar het graf in moeten dragen. Ze was mijn alles, mijn mama, mijn anne (Turks voor moeder), mijn zielsverwant, mijn leven, mijn vriendin, mijn man.*'

Emine is iemand die graag voor anderen klaar staat, zij omschrijft zichzelf als: 'Ik ben iemand die houdt van mensen, die weet hoe een goede buur te zijn, die geeft om haar omgeving en de mensen om haar heen, iemand die helemaal niet van zichzelf houdt. Iemand die heel erg op zijn familie en kinderen is gericht.'

In het gezin zijn er veel financiële problemen, die tot kopzorgen leiden. Ook al werkt haar man hard, ze hebben niet genoeg geld om alle rekeningen te betalen. Emine heeft ook het gevoel dat dit komt doordat zij als Turken een achterstand hebben in de maatschappij.

Onderzoeker: 'Je hoort tegenwoordig vaak dat iedereen moet meedoen en moet participeren in de maatschappij (...) Wat vindt u daarvan? 'Mevrouw: 'Ik ben het ermee eens, maar was het maar toegankelijk voor iedereen. Werd iedereen maar toegelaten. Ik word eruit gehaald ik word buitengesloten, mijn kinderen worden buitengesloten wij worden er als buitenlanders steeds uitgepakt en ten onrechte wordt ons van alles verwijt.'

Uit Sociaal Uitgesloten in de grote stad, van Bergen et al. 2014.

# **Chapter 3**

Measuring social exclusion in routine public health surveys: construction of a multidimensional instrument

> Addi P. L. van Bergen Stella J. M. Hoff Erik J. C. van Ameijden Albert M. van Hemert

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# ABSTRACT

**Introduction.** Social exclusion is considered a major factor in the causation and maintenance of health inequalities, but its measurement in health research is still in its infancy. In the Netherlands the Institute for Social Research (SCP) developed an instrument to measure the multidimensional concept of social exclusion in social and economic policy research. Here, we present a method to construct a similar measure of social exclusion using available data from public health surveys.

**Methods.** Analyses were performed on data from the health questionnaires that were completed by 20,877 adults in the four largest cities in the Netherlands. From each of the four questionnaires we selected the items that corresponded to those of the SCP-instrument. These were entered into a nonlinear canonical correlation analysis. The measurement properties of the resulting indices and dimension scales were assessed and compared to the SCP-instrument.

**Results.** The internal consistency of the indices and most of the dimension scales were adequate and the internal structure of the indices was as expected. Both generalisabiliy and construct validity were good: in all datasets strong associations were found between the index and a number of known risk factors of social exclusion. A limitation of content validity was that the dimension 'lack of normative integration' could not be measured, because no relevant items were available.

**Conclusions.** Our findings indicate that a measure for social exclusion can be constructed with available health questionnaires. This provides opportunities for application in public health surveillance systems in the Netherlands and elsewhere in the world.

### INTRODUCTION

Social exclusion is generally considered as one of the social determinants of health and a major factor in the causation and maintenance health inequalities [1-3]. Social exclusion is a broad term that refers to the inability of certain groups or individuals to participate fully in society. The World Health Organization defines social exclusion as " dynamic multidimensional processes driven by unequal power relationships interacting across four main dimensions - economic, political, social and cultural - and at different levels including individual, household, group, community, country and global levels" [4]. Important features of social exclusion are multi-dimensionality, relativity (i.e. social exclusion is context specific) and agency [5]. Agency refers to the fact that the excluding is done by someone or something, which can be the government or private institutions, the social environment or the individual itself. It is common that exclusion processes in one dimension affect those in other dimensions [2,6,7]. For example the loss of paid employment may lead to loss of social contacts and loss of income, which in turn may result in debts, poor housing, insecure living environment or reduced access to health care [6]. All these factors increase the risk of health problems directly or indirectly. In addition the experience of being excluded affects health negatively [1,2]. Health risks thus tend to accumulate in socially excluded individuals and groups.

In the Netherlands, Community Health Services are responsible for public health monitoring at the local level. At least once every four years they conduct routine public health surveys among the adult population. The questionnaires that are used for this cover a broad spectrum of health outcomes and determinants. In addition to mandatory questions on a national level, topics can be included to address local policy priorities. If available, validated and standardised measures are used [8]. Measurement of social in these health surveys is desired, but acceptable measurement instruments are lacking.

Recently, the Netherlands Institute for Social Research|SCP (SCP) has developed an instrument to measure social exclusion in social and economic policy research [9,10]. Based on an extensive literature review, the SCP has first defined and then operationalised the concept of social exclusion [7]. The definition is rooted in two scientific traditions i.e. the French tradition, which focuses on the extent to which people are integrated into society and connected to others (socio-cultural exclusion); and the Anglo-Saxon tradition, which emphasises relative deprivation, the notion that people or groups consider themselves disadvantaged compared to others with similar characteristics (their reference group). Nowadays, research within the Anglo-Saxon tradition is focused on a more 'objective' approach in terms of social indicators that measure differences in socio-economic status and rights (structural-economic exclusion). [9].

The SCP definition of social exclusion distinguishes two forms of social-cultural exclusion: "lack of normative integration" and "limited social participation" and two

forms of structural-economic exclusion i.e. "material deprivation" and "inadequate access to basic social rights". A person is socially excluded to some extent if there is accumulation of deficiencies on one or more of these four dimensions. The greater the number of deficiencies and the larger these deficiencies are, the higher the degree of social exclusion. See Table 1 for the operationalisation of the dimensions. To construct an instrument to measure the four dimensions, the SCP administered a questionnaire to a sample of the Dutch population. The initial questionnaire consisted of 232 items derived from previous SCP research, literature, focus groups and cognitive tests. For each of the dimensions, a subscale containing three to four items was constructed by using nonlinear canonical correlation analysis. Together, these 15 items make a general index that reflects the underlying construct of social exclusion. The general index score for persons deprived simultaneously on several dimensions. [9,10].

Dimension of social exclusion	Operationalisation
Lack of normative integration	Non-compliance with core values of society. In the Dutch context, this relates to issues like "having no respect for other people", "not saying 'thank you' when receiving change" or "putting out your garbage on a Tuesday when it's only allowed on a Wednesday "*.
Limited social participation	Social isolation, limited participation in social networks and inadequate social involvement.
Material deprivation	Deficits that people experience as shown by debts and the absence of certain basic goods and services, such as a washing machine or a daily hot meal.
Inadequate access to basic social rights	Inability to exercise the rights people normally have. This dimension is operationalised as having access to adequate health care, sufficient education and a proper living environment.

Table 1. Operationalisation of the four dimensions of social exclusion. [9,10].

\* The quotations are from participants in the focus groups organised by the SCP [10].

Although the SCP measurement instrument for social exclusion has been adapted and validated for the Dutch context, its suitability for routine public health surveys is limited. The Community Health Services consider the measure, with 15 items, too long to include in their health questionnaires. The total number of items that can be included in the questionnaires is limited and there is fierce competition between topics. Moreover, there is substantial overlap of the SCP-questionnaire of Social Exclusion with current topics of the health surveys, such as loneliness, social capital, financial situation and housing. This last observation prompted us to explore whether the multidimensional concept of social exclusion can validly be approximated with items from the health questionnaires that are already used in the public health surveys in the

Netherlands. We had access to the data collected in the surveys of 2008 with health questionnaires from the Community Health Services of the four largest cities in the Netherlands. Our ultimate goal is to develop a nationally validated and standardised measure to monitor social exclusion in routine public health surveys.

### **METHODS**

#### **Ethics statement**

Ethical approval was not required as this study relied on secondary anonymised data collected in the context of performing statutory tasks (Public Health Act of the Netherlands), in strict accordance with the national standard. At no point in time did the datasets contain direct identifiers. Codes to track response were removed from paper questionnaires directly upon receipt and processed separately, as were online access codes. The risk of re-identification of individuals from indirect identifiers such as age (in years) and sex, was very low.

The datasets are freely available for non-commercial research purposes.

#### Data source and participants

We conducted secondary analysis on data of four public health surveys that were collected in 2008 by the local Community Health Services in the cities of Amsterdam, Rotterdam, The Hague and Utrecht, using a uniform research methodology. The content of the questionnaires was only dissimilar for items that were selected according to local policy priorities.

In each city an a select sample was drawn from the non-institutionalised population aged 16 years and older, stratified by district, neighbourhood, age and ethnicity. A total of 42,686 persons received a questionnaire by mail. These questionnaires could be filled out in writing or via the Internet. Non-responders received a reminder after two weeks. In addition, difficult to reach groups such as non-Western immigrants and residents of deprived neighbourhoods were contacted after four weeks by telephone or home visit and invited to participate by mail or personal interview in the language preferred by the respondent. For Turkish respondents, the main non-Dutch speaking minority in the Netherlands, a translated questionnaire was available.

The overall response rate was 50% (20,877 respondents) and ranged between 47% in Rotterdam and 54% in Utrecht. Despite the intensive follow-up, the response was lower among difficult to reach groups. Through oversampling these groups were still well represented in each of the four studies. [11]. In line with the age standard for public health surveys in the Netherlands, we limited our analyses to respondents aged 19 years and older (19,658 respondents).

#### **Construction of measurement instrument**

Following the SCP procedures, we applied non-linear canonical correlation analysis (OVERALS) to the different sets of survey data. OVERALS is an optimal scaling technique developed by the University of Leiden, which is available in the SPSS software package. Canonical correlation analysis is often used to explore relationships between two sets of variables, an independent and dependent set, and to reduce the dimensionality to a few linear combinations of the measures under study [13]. In the context of the current study, we used canonical correlation analysis to construct a composite index based on selected sets of variables, each measuring one of the four dimensions of social exclusion (Figure 1).

OVERALS differs in three ways from standard linear canonical correlation analysis: variables can be nominal, ordinal or interval; there can be more than two sets of variables; and instead of maximizing correlations between the variable sets, the sets are compared to an unknown compromise set that is defined by the object scores [13]. If the correlation between the sets is sufficient, it is assumed that these sets refer to an underlying concept. [9,12].



Figure 1. Measurement model for social exclusion. The model illustrates the construction of a composite index based on selected sets of variables, that each measures one of the four dimensions of social exclusion.

From each dataset we selected items matching one of the four dimensions of social exclusion as operationalised by the SCP. All items were coded in the same direction, so that a high score refers to more exclusion. Records with one or more missing values on all dimensions were removed from the analyses. As the items in The Hague and Rotterdam datasets matched exactly, these were merged. The analysis thus resulted in three indices: Amsterdam (Index1), Rotterdam / The Hague (Index2) and Utrecht (Index3).

Initially all items were entered in the OVERALS analysis. Using category quantifications, the most appropriate measurement level of the items was chosen. Similar to the SCP method [9,12], items with component loadings less than 0.300 were removed one by one, starting with lowest correlations. Subsequently, items with weights less than 0.100 were removed, as well as items that scored in the opposite direction. Finally, scores on the subscales were computed using category quantifications and weights (for formulas see [12]).

#### **Measurement properties**

We used a series of methods to evaluate the measurement properties of the constructed indices, i.e. content validity, internal consistency, internal structure and construct validity.

To assess the content validity, we examined whether the constructed indices encompassed all dimensions of social exclusion and whether the included items were representative for the dimensions they were expected to measure. In addition, we inspected the distributions of the index scores and compared these with the SCP index. To assess the internal consistency of the indices we calculated the canonical correlation, which measures the degree to which the items contribute to the underlying latent variable. A canonical correlation of 0.300 was defined as the lower limit to ensure reliability of the indices [9,13]. Cronbach's alpha was used to measure the internal consistency of the subscales, where we considered  $\alpha \ge 0.70$  to be good [14].

For the assessment of the internal structure of the instruments, we computed the intercorrelations of the subscales and the general indices. Construct validity was assessed by testing predefined hypotheses [14]. For this purpose we selected a number of items that measure risk factors and correlates of social exclusion, derived from previous SCP research [7,10]. None of these were selected for the construction of the indices. The factors and correlates included were:

- Sociodemographic variables: low educational level; non-Western ethnic background; single-parent; living alone; unemployed and/or recipient of social security or disability benefits; no paid job; income below modal (1,700 Euros net per month); and living in a deprived neighbourhood;
- Health related factors: fair or poor self-rated health (versus good or very good); being diagnosed with at least one of eighteen chronic conditions; impaired in daily activities at home, at school, at work or in their leisure time due to chronic conditions (light to strong) and high risk for anxiety and depression disorder (score 30 or higher on Kessler psychological distress scale);
- *Variables on self-reliance*: low perceived life control (Pearlin & Schooler Mastery Scale, score <=19); and need of help to complete the health questionnaire.

We expected higher levels of social exclusion in these groups. The construct validity was considered satisfactory if at least 75% of the associations were in correspondence with these expectations. [14].

### **Index selection**

Based on the results of the measurement properties analyses, we identified the best performing index. Generalisability of this index was subsequently examined by testing the items in the other datasets, where available.

### Statistical analysis

Analyses were performed with SPSS 19.0. Group differences were tested with Pearson Chi Square test (categorical variables) or Anova F-test (continuous variables). Linear regression analyses were used to assess relationships between risk factors and social exclusion indices.

# RESULTS

### Characteristics of the study populations

Table 2 shows the sociodemographic characteristics of respondents in the four cities. As can be seen in Table 2, risk groups for social exclusion such as persons of non-Western origin, lower educated persons and persons living in deprived neighbourhoods were well represented in all four samples. Significant differences were found between the samples with regard to sex, age, ethnical background, educational level and the proportion of individuals living in deprived neighbourhoods. The observed differences reflect demographic variation between the four cities and the degree of oversampling in difficult to reach groups.

	Total	Amsterdam sample	Rotterdam sample	The Hague sample	Utrecht sample	р
	(N=19,658)	(N=6,511)	(N=5,127)	(N=4,220)	(N=3,800)	
Sex (male, %)	43.3	41.1	45.8	44.2	42.5	.000 *
Age (mean, SD)	51.0 (19.1)	58.2 (20.0)	49.3 (17.6)	48.8 (17.6)	43.3 (16.9)	.000 &
Non-Western ethnic background (%)	20.4	19.1	23.4	24.8	13.7	.000 *
Low educational level (%) #	16.1	19.8	15.8	14.8	11.5	.000 *
Living in a deprived neighbourhood (%)	34.2	39.6	30.7	36.2	27.2	.000 *

Table 2. Sociodemographic characteristics of the respondents per sample (unweighted).

\* The P values were obtained by using Pearson's Chi Square analysis.

<sup>&</sup> The P value was obtained by using One-way Anova F-test.

# No education and primary school.

### Construction of the measurement instruments

In the four health questionnaires, we identified 11 items that matched the SCP operationalisation of the dimension limited social participation. All of these items belong to the loneliness scale of De Jong Gierveld [15]. In addition, in the Utrecht questionnaire 3 items were available on the frequency of social contacts.

For the measurement of the dimension 'material deprivation' 2 items were available in each of the cities. These items relate to the financial situation of the household and difficulties in making end meets.

We found no items to measure 'inadequate access to basic social rights' in the Amsterdam sample. In the questionnaires of The Hague, Rotterdam and Utrecht we found 18 items that matched the operationalisation of this dimension by the SCP, including 5 items on neighbourhood cohesion, 2 items on satisfaction with housing and living environment and 11 items on environmental and nuisance problems in the neighbourhood. The questionnaires from The Hague and Rotterdam included 2 additional items on feeling unsafe during the day or night. From the Utrecht questionnaire 26 additional items were selected that related to the presence of moisture or mold in the home, to the need for information or assistance with health problems and to the need for facilities in the neighbourhood.

Items for the dimension 'lack of normative integration' were not available in any of the questionnaires.

With the aforementioned 62 items, three indices were constructed: Index1 was based on the items from the Amsterdam questionnaire, Index2 on the items from the Rotterdam and The Hague questionnaires combined and Index3 on the items from the Utrecht questionnaire. In Index1, 8 of the 13 items were retained, in Index2 14 of the 33 items and in Index3 17 of the 57 items. With one exception, items were removed because of low component loadings or low weights. The item on 'mold and moisture in the home' from the Utrecht questionnaire was removed because of a reverse association with the other items. The centroid plots generated by the OVERALS analyses are given in Figures S1, S2 and S3.

Table 3 shows the selected items per index and per dimension. From the 14 items that were present in two or more datasets, 10 were included in all relevant indices and 4 items were included in some indices but not in others. For example, the item 'There are enough people I feel close to' was incorporated in the indices 2 and 3 but not in Index3. Instead, Index3 contained the item 'I miss having people around', which was absent in the indices 1 and 2.

Dimension	Items SCP	Items health questionnaires	Index1 (Amsterdam)*	Index2 (Rotterdam/ The Hague)*	Index3 (Utrecht)*
1. 'Limited social participation'	There are people who genuinely understand me	There are enough people I feel close to	+	+	,
	I feel cut off from other people	I experience a general sense of emptiness	+	+	+
	There are people with whom I can have a good conversation	There is always someone I can talk to about my day-to-day problems	+	ı	+
	I have contact with neighbours	Little contact with neighbours and people in the street			+
		There are plenty of people I can lean on when I have problems	+	+	+
		I miss the pleasure of the company of others	+	+	+
		I often feel rejected	+	+	+
		I miss having people around		ı	+
2. 'Material deprivation'	I have enough money to heat my home				
	I have enough money for club memberships				
	I have enough money to visit others				
	I have enough money to meet unexpected expenses				
		Had difficulty past year getting by on the household income	+	+	+
		Current financial situation of the household: have to go into debt	+	+	+
3. 'Inadequate access to basic social rights'	We all get on well in our neighbourhood	People in this neighbourhood generally do not get along with each other		+	+
	I am satisfied with the quality of my home	Degree of satisfaction with housing		+	+

Table 3. Summary of items which were incorporated in the SCP index or in one of the three constructed indices, by dimension and index.

	I didn't receive a medical or dental treatment				
		The people in my neighbourhood help each other		+	
		People in this neighbourhood can be trusted		+	+
		I prefer not to socialise with people in my neighbourhood		+	+
		Feeling unsafe during the day		+	
		Feeling unsafe in the evening and at night		+	
		Need for information or assistance: stress reduction			+
		Need for information or assistance: coping with depression			+
		Need for information or assistance: coping with loneliness			+
		Need for information centre on care and welfare			+
4. 'Lack of normative integration'	I give to good causes (no)				
	I sometimes do something for my neighbours (no)				
	I put glass items in the bottle bank (never)				
	Work is just a way of earning money (agree)				
The table lists the item	s that became included in one of the thr	ee constructed indices as well as the items that form	n nart of the SC	P index The S	CP index is

shown for reference purposes only. Per index the following information is displayed:

\* + retained in OVERALS analysis; - removed in OVERALS analysis; . item not available in respective dataset.

	Index	k1 Amstero	lam	Index2 The	e Hague &	Rotterdam	In	dex3 Utrecl	ıt
		(n=6,368)			(n=9,238)			(n=3,763)	
	Component loading <sup>a</sup>	Weight <sup>b</sup>	Cronbach's alpha	Component loading <sup><i>a</i></sup>	Weight <sup>b</sup>	Cronbach's alpha	Component loading <sup><i>a</i></sup>	Weight <sup>b</sup>	Cronbach's alpha
Set 1: 'Limited social participation'			0.81			0.80			0.79
There are enough people I feel close to (rev)	0.50	0.11		0.52	0.16				
I experience a general sense of emptiness	0.64	0.20		0.62	0.17		0.61	0.20	
There is always someone I can talk to about my day-to-day problems (rev)	0.50	0.13					0.57	0.20	
Little contact with neighbours and people in the street							0.32	0.16	
There are plenty of people I can lean on when I have problems (rev)	0.57	0.19		0.55	0.20		0.56	0.20	
I miss the pleasure of the company of others	0.63	0.20		0.64	0.21		0.63	0.14	
I often feel rejected	0.66	0.30		0.68	0.33		0.66	0.25	
I miss having people around							0.62	0.13	
Set 2: 'Material deprivation'			0.72			0.75			0.71
Had difficulty past year getting by on the household income	0.80	0.66		0.73	0.54		0.68	0.56	
Current financial situation of the household: have to go into debt	0.63	0.26		0.63	0.30		0.54	0.23	
Set 3: 'Inadequate access to basic social rights'						0.68			0.65
The people in my neighbourhood help each other (rev)				0.35	0.12				

People in this neighbourhood can				
be trusted (rev)	0.44	0.13	0.36	0.11
People in this neighbourhood generally do not get along with each other	0.39	0.14	0.36	0.15
I prefer not to socialise with people in my neighbourhood	0.38	0.13	0.33	0.10
Degree of satisfaction with housing	0.57	0.39	0.48	0.29
Feeling unsafe during the day	0.44	0.18		
Feeling unsafe in the evening and at night	0.42	0.14		
Need for information or assistance: stress reduction			0.47	0.19
Need for information or assistance: coping with depression			0.50	0.12
Need for information or assistance: coping with loneliness			0.57	0.34
Need for information centre on care and welfare			0.34	0.16
Canonical correlation of the general 0 index <sup>c d</sup>	.35	0.40		0.44
Analyses were performed with SPSS OVERALS module. OVERAI	S calculates a.o. com	ponent loadings, weights	and eigenvalu	les.

<sup>ab</sup> Component loadings in OVERALS are similar to factor loadings in a factor analysis. Weights are similar to standardised regression coefficients. [9, 12]. <sup>c</sup> The canonical correlation is calculated with the formula:  $r_{d} = ((K \times E_{d}) - 1) / (K - 1)$ , whereby K = number of sets, d=factor number (in this case only one factor was calculated), and E = the eigenvalue of the factor/index.

<sup>*d*</sup> SCP index: canonical correlation = 0.38 [10].

### **Measurement properties**

#### Content validity

To examine the degree to which the indices cover the multidimensional concept of social exclusion, we compared, for each dimension, the items in the constructed indices with those in the SCP index. The dimension 'limited social participation' of the SCP index comprises items on social isolation and on participation in social networks. From Table 3 we can see that all three constructed indices included items on social isolation, but only Index3 contained an item on participation in social networks i.e. contacts with neighbours. In the dimension 'material deprivation' the SCP index includes items on the financial situation of the household and on the lack of basic goods and services. The three constructed indices did contain 2 items on the financial situation of the household, but items on the lack of basic goods and services, were absent in all three indices. In the dimension 'inadequate access to basic social rights' the SCP index contains aspects of good living environment and access to health care. Index2 and Index3 contained similar items on good living environment, but only Index3 contained additional items on access to healthcare. These items however, referred to the need for information or assistance and not the actual lack of access, as does the SCP questionnaire.

As floor or ceiling effects may limit the content validity [14], we examined the frequency distributions of the three indices. All three distributions were right-skewed, which corresponds well with the distribution of the SCP index and is consistent with the expectation that a large part of the population is not excluded, while the degree of exclusion at the right end of the scales varies widely.

#### Internal consistency

Table 4 shows the findings on the internal consistency of the indices and subscales. The canonical correlations of three constructed indices ranged from 0.35 (Index1) to 0.44 (Index3), which is sufficient. Index2 and Index3 had even higher canonical correlations than the SCP index ( $r_a$  =0.38). The Cronbach's alphas of the transformed subscales were good for dimensions 1 and 2. For dimension 3 Cronbach's alphas were not calculated.

#### Internal structure

Table 5 provides the correlations between the subscales and the general indices and between the subscales themselves. The correlations between the subscales and the general indices ranged from 0.68 to 0.82, and were similar to those of the SCP index. As expected, the correlations between the subscales were weaker than with the general indices. They ranged from 0.33-0.55, which is in line with the internal structure of the SCP index.

	SCP	Index1	Index2 Rotterdam	Index 3
<b>Correlation between:</b>	Index a	Amsterdam	& The Hague	Utrecht
General index x dimension 1	0.76	0.78*	0.76*	0.82*
General index x dimension 2	0.70	0.79*	0.72*	0.68*
General index x dimension 3	0.77		0.73*	0.81*
Dimension 1 x dimension 2	0.35	0.30*	0.34*	0.33*
Dimension 1 x dimension 3	0.43		0.39*	0.55*
Dimension 2 x dimension 3	0.44		0.34*	0.38*

 Table 5. Pearson correlations coefficients between general indices and dimension subscales,
 SCP and the four cities.

\* p<.01

<sup>a</sup> Vrooman and Hoff [10].

#### Construct validity

As can be seen from Table 6 all predefined hypotheses were confirmed. Without exception, the indices were positively associated with the selected risk factors and correlates. Regression coefficients showed the expected direction and were statistically significant (p<0.01). Persons with lower income were more often socially excluded than people with a higher income. People in poor health, persons of non-Western origin and those with low perceived self- control were also at higher risk. The same holds for lower educated persons, people living in deprived neighbourhoods, jobless adults, single persons and single parents. In contrast to the SCP, we also found significant associations with low labour market position and need of assistance in filling in the questionnaire. In general, the associations found in the current research were stronger than in the SCP study.

#### Index selection and generalisabilty

When compared with the other indices, Index3 performed best on content validity and performed equally well with regard to internal consistency, internal structure and construct validity. For that reason we continued our analysis with Index3. Generalisability of the items from Index3 was tested in the datasets of Rotterdam/The Hague and Amsterdam, where available. We performed analyses with 2 and 3 sets of variables. In all cases, the OVERALS analysis yielded indices with comparable measurement properties i.e. a distribution of index scores, internal validity, internal structure and construct validity that was similar to Index3.

# **DISCUSSION AND CONCLUSIONS**

Our approach to construct a scale for social exclusion based on items from routine public health surveys was successful in all four cities as far as relevant items were available in the surveys. Data reduction with canonical correlation analysis yielded fairly similar selections of items consistently with the original SCP index. This corroborates the assumption that similar constructs were measured. Both the general indices and the underlying dimension scales had good internal consistencies, with the exception of the dimension scale 'inadequate access to basic social rights'. In line with the SCP index, the internal structure of our indices reflected the multidimensional character of the concept social exclusion. Moreover, the indices demonstrated strong associations with risk factors and correlates, which may be considered as a confirmation of the construct validity of the indices. On the whole, Index3, based on the Utrecht dataset, performed most consistent due to better content validity in the dimensions 'limited social participation' and 'inadequate access to basic social rights'. The OVERALS analyses demonstrated good generalisability to the other cities.

The usability of the constructed instrument is not confined to the studied cities. The use of multiple datasets allowed us to replicate the measurement properties in other populations, which improved the generalisability of our findings beyond the population in which the instrument was developed. This makes it a promising instrument for other cities and countries as well. Further strengths of our study are the large sample size, the broad representation of the study population and the intensive approach of hard-to-reach high risk groups.

A limitation of our study is that the routine public health surveys used in this study did not contain items on the dimension 'lack of normative integration'. It has been reported previously that such items are not standardly available in (health) questionnaires [10]. Normative integration relates to the duties of social citizenship and is reflected in e.g. compliance with dominant values, social commitment and responsibility towards fellow citizens. Failure to comply with these obligations is as much a cause of social (self-)exclusion as are the rights associated with social citizenship [7]. As normative integration is considered an important theoretical dimension of social exclusion, we recommend to include in future research additional items from the validated SCP index, such as 'giving to good causes' and 'sometimes doing something for one's neighbours' (Table 3). Although the other three dimensions were well represented in Index3, some improvements can be made. Items that could be included in the dimension 'material deprivation' are lack of basic goods and services and in the dimension 'inadequate access to basic social rights' items that refer to the actual lack of access to healthcare.

Furthermore, we were not able to assess the concurrent validity of our indices. As the study was based on secondary data, we could not examine the agreement between the indices and the SCP index in the same dataset. However, the evidence suggests

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rimary school) 0	(n=63(	(8)	(n=92	38)	(n=37	63)	(n=57,	(†
rimary school) 0	β	d	β	d	β	d	β	d
	0.22	*	0.24	*	0.24	*	0.12	*
0	0.28	* *	0.34	*	0.33	*	0.18	*
0	0.11	*	0.13	* *	0.10	*	0.13	*
0	0.14	*	0.13	* *	0.15	*	0.16	*
l security or disability 0	0.34	* *	0.36	* *	0.32	* *	-0.03	su
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			0.31	* *	0.46	* *		
0	0.15	*	0.24	*	0.24	* *		
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and n-values on the instants \$ hdardieed ŧ -1-1-040 m rich facto nd bue avolusion indices امنصه 5 Tahla 6 Association hetw Explanatory note. Linear regression analyses were used to assess relationships between social exclusion indices and known risk factors and correlates. Construct validity was considered satisfactory if at least 75% of the associations were in correspondence with predefined hypotheses.

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that the constructed indices will be closely interrelated with the SCP index, given the similarities in content and good agreement in measurement properties between the constructed indices and the SCP index.

The main contribution of this paper is the development of a social exclusion index that can be measured reliably and validly with routine public health survey data. Until now, no generally accepted and validated instrument has been developed to measure social exclusion in health research [3.22-25], even though such an instrument is considered paramount to improve our understanding of how social exclusion influences health and health inequalities [2-4,22,26,27]. The index discussed in this article is not only relevant for the Netherlands, but may be applied in other public health surveillance systems as well, such as the Centers for Disease Control and Prevention National Health Interview Survey [28], the Health Survey for England [29] and the Italian risk factor surveillance system PASSI [30]. Once included in routine public health monitoring, large amounts of data will become available with which social exclusion can be quantified, risk groups identified and developments monitored over time. Relations with health outcomes and determinants can be assessed by combining social exclusion data with other health surveillance data. Such information is relevant from several perspectives. Social exclusion is considered an important determinant of health inequalities and offers a broader range of policy options than more simple concepts like low income and poverty [26,31,32]. Valid and reliable information can help policy makers to develop more effective policies to reduce health inequalities. Moreover, it can provide a baseline from which to monitor and assess the effects of policies and programmes [2,3,33]. Finally, the measurement of social exclusion can raise the profile and visibility of excluded groups and draw attention to the diverse causes and consequences of social exclusion [24].

This study set out to explore whether the multidimensional concept of social exclusion can be measured with the health questionnaires that are currently used in the public health surveys in the Netherlands. This question can be answered positively. We succeeded in constructing a brief measure for social exclusion with good measurement properties and high acceptability, which is suitable for use in routine public health surveys. The use of this measure in other countries and regions will enable the development of effective policies and programmes to tackle health inequalities.

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## SUPPLEMENTARY MATERIALS

Figure S1. Centroid plots Index1: Quadrants I and II (A); Quadrants III and IV (B).

Figure S2. Centroid plots Index2: Quadrants I and II (A); Quadrants III and IV (B).

Figure S3. Centroid plots Index3: Quadrants I and II (A); Quadrants III and IV (B).

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#### Jan & Annie

Het interview is met Jan, maar Annie zit er ook bij, want Jan en Annie doen alles samen. Ze zijn een echtpaar van 60 jaar, wonend in een Utrechtse volksbuurt. Jan en Annie hebben twee zoons, die een gezin hebben en in de buurt wonen. Ze zien elkaar regelmatig. Omdat Jan hartpatiënt is, krijgt hij sinds 2007 een WAO-uitkering.

Vanwege de stadsvernieuwing zijn Jan en Annie vijf jaar geleden verhuist naar een andere buurt binnen hun wijk. Ze denken met heimwee terug aan hun oude buurt en vooral aan de gezelligheid en saamhorigheid die daar was. 'Zijn hele andere mensen daar weer en wij zijn niet zo spraakzaam. We gaan ook niet op de mensen af om te vragen of... Een praatje, of zo.' Helaas hebben ze bijna geen contact meer met hun oude buren. Mensen zijn verhuisd naar andere wijken of teruggekeerd in de nieuwe huurhuizen die daar zijn geplaatst.

Naast de praatjes op straat en het contact met hun zoons, hebben Jan en Annie weinig mensen om zich heen. Ze vinden het goed zo met z'n tweeën:

Onderzoeker: 'Wanneer vindt u het gezellig?' Jan: 'Gewoon, zo met z'n tweetjes. Vind ik wel genoeg.'

Uit Sociaal Uitgesloten in de grote stad, van Bergen et al. 2014.

# **Chapter 4**

Social Exclusion Index-for Health Surveys (SEI-HS). A prospective nationwide study to extend and validate a multidimensional social exclusion questionnaire

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# ABSTRACT

**Background.** Social exclusion (SE) refers to the inability of certain groups or individuals to fully participate in society. SE is associated with socioeconomic inequalities in health, and its measurement in routine public health monitoring is considered key to designing effective health policies. In an earlier retrospective analysis we demonstrated that in all four major Dutch cities, SE could largely be measured with existing local public health monitoring data. The current prospective study is aimed at constructing and validating an extended national measure for SE that optimally employs available items.

**Methods.** In 2012, a stratified general population sample of 258,928 Dutch adults completed a version of the Netherlands Public Health Monitor (PHM) questionnaire in which 9 items were added covering aspects of SE that were found to be missing in our previous research. Items were derived from the SCP social exclusion index, a well-constructed 15-item instrument developed by the Netherlands Institute for Social Research (SCP). The dataset was randomly divided into a development sample (N =129,464) and a validation sample (N=129,464). Canonical correlation analysis was conducted in the development sample. The psychometric properties were studied and compared with those of the original SCP index. All analyses were then replicated in the validation sample.

**Results.** The analysis yielded a four dimensional index, the Social Exclusion Index for Health Surveys (SEI-HS), containing 8 SCP items and 9 PHM items. The four dimensions: "lack of social participation", "material deprivation", "lack of normative integration" and "inadequate access to basic social rights", were each measured with 3 to 6 items. The SEI-HS showed adequate internal consistency for both the general index and for two of four dimension scales. The internal structure and construct validity of the SEI-HS were satisfactory and similar to the original SCP index. Replication of the SEI-HS in the validation sample confirmed its generalisability.

**Conclusion.** This study demonstrates that the SEI-HS offers epidemiologists and public health researchers a uniform, reliable, valid and efficient means of assessing social exclusion and its underlying dimensions. The study also provides valuable insights in how to develop embedded measures for public health surveillance.

## BACKGROUND

Socioeconomic inequalities in health are one of the major challenges in the field of public health today. Social, material, cultural and political conditions shape our lives and our behaviours and thereby influence our health [1]. Social exclusion (SE) is understood to be one of the drivers of inequalities in health [1-3]. SE refers to the inability of certain groups or individuals to participate fully in society due to personal and societal factors. SE is a multidimensional concept, involving cumulative disadvantages in the social, economic, cultural and political domains [4-7]. The concept of SE is regarded as a promising entry for addressing health inequalities [6-8]. Not only do the circumstances associated with SE such as poverty, poor housing, few social contacts and reduced access to care, have a negative impact on health, also the actual experience of exclusion may impact negatively on health status via psychosocial stress mechanisms [2, 7, 9, 10]. Poor physical and mental health, in turn, can be a barrier to social and economic participation [11].

To address health inequalities at local or national level, it is important to gain insight into the prevalence and nature of SE and its relationship with health. However, a generally accepted measure of SE does not yet exist in public health research [6, 8, 12-15]. Health research typically focuses on a single dimension of SE, such as poverty, labour market exclusion or access to services [6, 8, 16]. Other limitations include the lack of theoretical grounding [16-18], conceptual justification for indicator choice and overall measurement validation [6, 8]. SE measures that have been validated are, to our knowledge, not particularly suited for use in public health surveys. These measures were developed for use in specific target populations instead of the general population [19-29], are too lengthy for use in population surveys [20, 30], do not allow for self-report [26-28] or measure health as a constituent part of SE [15, 31].

The lack of a suitable measure for SE prompted us in a previous study to develop our own instrument using existing routine public health survey data of the four major cities in the Netherlands [32]. As the gold standard we used the social exclusion index of the Netherlands Institute for Social Research|SCP (SCP) [33, 34], which was developed for use in social and economic policy research. This index does not suffer from the above limitations: it is multidimensional, theoretically sound, thoroughly validated, designed for use in the general population, brief, with only 15 items, suitable for self-report, not including a health domain and providing an overall index [33, 34].

The SCP index is the result of a decade of research and reflection [5, 35]. It is rooted in two main theoretical conceptualisations of SE: the French scientific tradition, in which SE refers to the socio-cultural aspects of people's lives, the extent to which people are integrated into society and their connection with others; and the Anglo-Saxon line, in which SE is associated with structural-economic aspects of people's lives, with relative deprivation and unequal access to income, basic goods, public services and citizen rights [5], [33], cf. e.g.[17, 36-39]. The SCP index is composed of two dimensions that concur with the French tradition i.e. (lack of) Social Participation (regarding social isolation and limited participation in social networks) and (lack of) Normative Integration (referring to non-compliance with core values of society); and two dimensions that concur with the Anglo-Saxon line i.e. Material Deprivation (deficits that people experience as shown by debts and the absence of certain basic goods and services) and (inadequate access to basic) Social Rights (referring to the people's inability to exercise their citizens' rights).

The SCP Index, however, proved ill-suited for use in routine public health monitoring due to a substantial overlap with current topics, such as loneliness, social capital, financial situation and housing, and lack of space for 15 additional items. Our previous study [32] showed that in all four cities, the above described multidimensional concept of SE could be validly approximated with existing data from public health questionnaires. From each questionnaire we had selected the items that corresponded to those of the SCP-instrument and entered these into a nonlinear canonical correlation analysis. The internal consistency of the resulting indices was adequate to good, and so were the internal structure, generalisability and construct validity. The content validity however, was only moderate. The dimension scales for Material Deprivation and Social Rights did not cover the full width of the theoretical constructs. The Material Deprivation scales missed items on lack of basic goods and services such as club membership and heating one's home. The Social Rights scales missed an item on the actual lack of access to healthcare. Such items were not available in the health questionnaires of the four cities. One of the SE dimensions, i.e. the dimension Normative Integration, could not be measured at all due to lack of appropriate items in the survey questionnaires. Another limitation of our study was that replication of the indices was confined to urban areas only.

In the current prospective study we addressed these limitations by 1) extending the study to the national level and harmonizing with the Netherlands Public Health Monitor and 2) adding extra items to enhance content validity. Our ultimate goal is to develop a nationally validated and standardised measure to monitor SE in routine public health surveys among adults, that optimally employs available survey items.

In the Netherlands, routine public health monitoring is carried out by 28 Community Health Services, in cooperation with Statistics Netherlands (CBS) and the Netherlands National Institute for Public Health and the Environment. Every four years, health questionnaires are distributed to a large sample of the Dutch adult population. The monitoring forms part of the health status assessment stage of the Dutch four year preventive care cycle, on the basis of which specific objectives for and the implementation of national and local health policies are defined, implemented and adjusted [40, 41]. Besides mandatory nationwide questions, the health questionnaires also contain optional questions that address local health policy priorities. Community Health Services are obliged to use standard questions developed within the framework of the Netherlands Public Health Monitor (PHM). Only when PHM standard questions are unavailable about a particular subject, can Community Health Services employ other, local, questions [41, 42]. In our effort to construct a national measure for SE, we aimed at making maximum use of the available PHM standard questions, and using supplementary items from the SCP index only where the PHM fell short. In this paper we describe the construction and validation of this embedded measure for SE, the Social Exclusion Index for Health Surveys (SEI-HS).

## METHODS

#### **Data source and participants**

This survey study was conducted fall 2012 by 19 of the 28 Dutch Community Health Services who were involved in the implementation of the PHM. These 19 Community Health Service regions cover 71% of the Dutch population. In each Community Health Service region a sample was drawn from the non-institutionalised population aged 19 years and older (as of September 1, 2012), stratified by municipality, neighbourhood and age category (19-64 years and 65 years and older). In total, the 19 samples contained 566,521 persons.

Selected persons received an announcement letter by mail, followed one week later by a questionnaire. The questionnaires could be filled out in writing or online. Nonresponders received at least one written reminder. The four largest cities, having a higher proportion of hard to reach groups, made additional efforts such as home visits after the second written reminder, providing translated questionnaires (Turkish, English and Arabic) and offering personal assistance in completing the questionnaire if needed. Questionnaires were excluded if two third or more of the SE questions were not answered or in the case of lacking information on at least two thirds of the core questions. According to the national protocol, core questions include a.o. educational level, employment status, body weight and smoking. The net response rate was 45.7% (258,928 respondents).

Weighting was used to correct for selective non-response and unequal selection probabilities caused by the stratified sampling design. Adjustment weights were calculated for the national sample, based on a linear model with auxiliary variables Community Health Service region (28 categories), gender (2), age (13), marital status (4), degree of urbanisation (5), household size (5), ethnicity (3), income (5) and municipality (391), and their interaction terms [43]. We adjusted these weights in accordance with the sample composition of our study.

## **Item selection**

In our previous research [32] we identified with nonlinear canonical correlation analysis 16 PHM items from a pool of 62 potential items, measuring various aspects.

Items Netherlands Pubic Health Monitor (PHM) identified in prior research	Items SCP index &	ttems in the routine public health survey 2012	Excluded in OVERALS analvsis
<b>Dimension 1: Limited social participation</b>			6
*PHM1.I experience a general sense of emptiness #4	SCP1. I feel cut off from other people	PHM1. I experience a general sense of emptiness #	
*PHM2. There is always someone I can talk to about my day-to-day problems $\#^a$	SCP 2. There are people with whom I can have a good conversation	PHM2. There is always someone I can talk to about my day-to-day problems #	
*PHM3. There are plenty of people I can lean on when I have problems $\#^a$		PHM3. There are plenty of people I can lean on when I have problems #	
*PHM4. I miss the pleasure of the company of others # <sup>a</sup>		PHM4. I miss the pleasure of the company of others #	
*PHM5. I often feel rejected # <sup>a</sup>		PHM5. I often feel rejected #	
*PHM6. I miss having people around # <sup>a</sup>		PHM6. I miss having people around #	Yes
*PHM7: There are enough people I feel close to $\#^a$		PHM7: There are enough people I feel close to #	Yes
	SCP 3. There are people who genuinely understand me		
*PHM8. Little contact with neighbours and people in the street \$	SCP 4. I have contact with neighbours	PHM8. Little contact with neighbours and people in the street \$	
Dimension 2: Material deprivation			
*PHM9. Had difficulty past year getting by on the household income #		PHM9. Had difficulty past year getting by on the household income #	
	*SCP 5. I have enough money to heat my home	SCP5. I have enough money to heat my home	
	*SCP 6. I have enough money for club memberships	SCP6. I have enough money for club memberships	
	*SCP 7. I have enough money to visit others	SCP7. I have enough money to visit others	
	*SCP 8. I have enough money to meet unexpected expenses	SCP8. I have enough money to meet unexpected expenses	Yes

Table 1. Summary of items available for the construction of the SEI-HS, by dimension and source.

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Dimension 3. Inadeauate access to basic social r	iahts	
*PHM10. People in this neighbourhood generally do not get along with each other \$	SCP 9. We all get on well in our neighbourhood	PHM10. People in this neighbourhood generally do not get along with each other \$
PHM11. The people in my neighbourhood help each other \$		
PHM12. People in this neighbourhood can be trusted \$		
PHM13. I prefer not to socialise with people in my neighbourhood \$		
*PHM14. Degree of satisfaction with housing \$	SCP 10. I am satisfied with the quality of my home	PHM14. Degree of satisfaction with housing \$
PHM15. Feeling unsafe during the day \$		
PHM16. Feeling unsafe in the evening and at night \$		
	*SCP 11. I didn't receive a medical or dental treatment	SCP 11. I didn't receive a medical or dental treatment
Dimension 4: Lack of normative integration		
	*SCP 12. I give to good causes	SCP 12. I give to good causes
	*SCP 13. I sometimes do something for my neighbours	SCP 13. I sometimes do something for my neighbours
	*SCP 14. I put glass items in the bottle bank	SCP 14. I put glass items in the bottle bank
	*SCP 15. Work is just a way of earning money	SCP 15. Work is just a way of earning money
* Item included in the routine public health surve Vrooman and Hoff [34].	y 2012; # Netherlands Pubic He	:alth Monitor (PHM) mandatory [41]; $\$ PHM optional [41]; $\&$
<sup>1</sup> . De Jong Gierveld J, Kamphuis FH (1985) <sup>7</sup> 10.1177/01466216850090030.	The development of a Rasch-	ype loneliness-scale. Appl Psychol Meas 9: 289–299. doi:

Social Exclusion Index-f or Health Surveys (SEI-HS)

of the four dimensions of SE (Table 1 column 1). Eight of these 16 items are also part of the mandatory national questionnaire (PHM1 to PHM7 and PHM9). These items are included routinely in the health surveys. The other eight PHM items are optional, meaning that cities could choose not to include these items. After comparison with the SCP index, five of these eight items were considered redundant and were not included in the health surveys. The three remaining optional PHM items were PHM8, PHM10 and PHM14 (Table 1 column 1). From the SCP social exclusion index nine items were added to the surveys to enhance the content validity of the SEI-HS (Table 1 column 2). These items were selected in previous research from an item pool of 232 items covering the broad spectrum of SE [34]. Four SCP items (SCP12 to SCP15) were added to measure Normative Integration, four items (SCP5 to SCP8) to measure Material Deprivation and one item (SCP11) on not receiving medical or dental treatment was added in the dimension Social Rights. In total, 20 items were available for the construction of the SEI-HS.

## **Construction of the SEI-HS**

Nonlinear canonical correlation analysis (OVERALS module in SPSS 19.0) was used to construct a multidimensional index and four underlying dimension scales. OVERALS is a suitable method for the construction of a composite measure as it allows multiple sets of variables (here dimensions of SE), different measurement levels (nominal, ordinal or interval) and distributions [44, 45]. The OVERALS algorithm compares the variable sets to an unknown comprise set that is defined by the object scores [44]. If the correlation between the sets is sufficient, it is assumed that these sets refer to a shared underlying concept [45]. In order to test the generalisability of the extended measure, the dataset was randomly split with SPSS "Select Cases" into a development sample (N = 129,464) and a validation sample (N = 129,464). All analyses were carried out in the development sample and replicated in the validation sample.

The 20 items were coded in the same direction (low score = little or no exclusion). Based on the OVERALS category quantifications, their measurement level was set as ordinal. Initially all items were entered in the OVERALS analysis, after which items with low component loadings or low weights were removed one by one, until a workable set of items remained. OVERALS weights are considered low at a value of less than 0.100, component loadings at a value of less than 0.300 [44]. Partial cases with maximum three missing values in total and maximum one per dimension were included in the OVERALS analyses.<sup>a</sup> Since OVERALS does not calculate scores on the subscales, we calculated these by the formula: scale score =  $\Sigma$  transformed item score \* item weight. Maximum one missing value was allowed.

## Trichotomisation

As an important application of the SEI-HS in public health policy will be the comparison of SE rates between population groups and monitoring changes over time, we trichotomised both index and scaling scores. The P85 and P95 have been chosen as cut-off points in consultation with Community Health Service epidemiologists. Scores less than or equal to the 85<sup>th</sup> percentile in the weighted population were labelled "little or no" exclusion, scores greater than the 85<sup>th</sup> percentile but smaller than or equal to the 95<sup>th</sup> percentile "some", and scores greater than the 95<sup>th</sup> percentile were labelled "moderate to strong" exclusion.

## **Measurement properties**

The final version of the SEI-HS was evaluated on (1) content validity, (2) internal consistency, (3) structure, (4) construct validity, and (5) generalisability. The analyses were carried out in the development sample and replicated in the validation sample.

- 1. <u>Content validity</u>: We examined whether all dimensions and aspects of SE of the SCP index were measured by the SEI-HS and compared the distributions of the SEI-HS and the SCP index.
- Internal consistency: The canonical correlation in OVERALS measures the degree to which the items contribute to the underlying construct of SE. The internal consistency of the index was considered sufficient if the canonical correlation was 0.30 or higher [33, 45]. The internal consistency of the underlying dimension scales was considered sufficient if Cronbach's alpha was 0.70 or higher [46].
- 3. <u>Internal structure</u>: We computed the intercorrelations between the subscales and the general index. We expected strong positive correlations between the subscales and the general index (r>= 0.60) and sufficient but not strong positive correlations between the subscales  $(0.20 \le r < 0.40)$  [47, 48]. If the correlations between the subscales are sufficient, it is assumed that these scales refer to a shared underlying concept [45]. Additionally, we conducted confirmatory factor analysis in AMOS. We considered a root mean square error of approximation (RMSEA) < 0.05 and upper bound of 90% confidence interval (HI90) < 0.06, Tucker-Lewis index (TLI)  $\ge$  0.95, comparative fit index (CFI) > 0.90 and Hoelter's .05 Index  $\ge$  200 to indicate good model fit [49].
- 4. <u>Construct validity</u>: We tested a number of hypotheses using linear regression analysis (point biserial correlation). Based on previous research, we expected a positive correlation between the SEI-HS and the following risk factors and correlates: low educational level, non-Western ethnic background, single-parent family with minor children, living alone, low labour market status (and/ or recipient of social security or disability benefits), not having paid work, low household income, health problems and living in a deprived neighbourhood. Household income referred to the standardised disposable household income after payment of income tax and social contributions. Low household income

corresponded to the lowest income quintile in 2010 (data source: CBS). Health problems included in the study were: fair or poor self-rated health (versus good or very good); being diagnosed with at least one chronic condition; impaired hearing, sight and / or mobility; and high risk for anxiety and depression disorder (score 30 or higher on Kessler psychological distress scale). The significance level for testing was set at 0.001. Construct validity was considered adequate if at least 75% of the hypotheses were confirmed [46].

5. <u>Generalisability</u>: We replicated the construction of the SEI-HS in the validation sample. As suggested in the literature we compared for similarities of the canonical functions [44, 47]. If marked differences are found, the results may be specific to the sample data only and cannot be generalised to the population.

## Statistical analysis

Analyses were carried out using SPSS version 19.0 and SPSS AMOS version 22.0.

## RESULTS

## Participants

Table 2 presents the socio-demographic characteristics of the study sample. The average age in the unweighted sample was 54.8 years and there were slightly more women than men. Compared to the Dutch population as a whole, our study sample was substantially older and included a lower percentage of respondents from (very) highly urbanised areas and from rural areas. Also, men, respondents of non-Western ethnic background and respondents with low income were under-represented in the study sample. These differences largely disappeared after weighting for sample coverage and non-response (Table 2).

 Table 2. Sociodemographic characteristics of the respondents in the study sample (N=258,928) compared to the Dutch population.

Characteristics	Study sample Unweighted	Study sample Weighted	Dutch population <sup>a</sup>
Sex: male (%)	45.2	49.1	49.0
Age (mean, SD)	54.8 (17.7)	48.7 (17.6)	48.8
Ethnic background: non-Western (%)	5.2	10.4	10.2
Educational level: very low (%) <sup>b</sup>	8.7	7.4	7.8
Employment status: Unemployed, recipient of social security or disability benefits. (%)	9.6	10.3	10.6
Income: low (%) <sup>c</sup>	10.5	14.1	14.4
Family situation: living alone (%)	17.3	17.2	17.8
Geographic area: highly urbanised (%) <sup>d</sup>	14.9	20.2	20.2
Geographic area: rural (%) <sup>e</sup>	14.5	10.7	10.7

- <sup>a</sup>. Data source: Sex, ethnicity and urbanisation: Statistics Netherlands 2012 (statline.cbs.nl); Other data: PHM 2012
- <sup>b</sup>. No education and primary school
- <sup>c</sup>. Low income = lowest quintile standardised yearly household income (2010) i.e. below 15.200 Euro. Data obtained from Statistics Netherlands (CBS)
- <sup>d</sup>. Municipality with area address density >=2500 adresses per km<sup>2</sup> (2012). Data obtained from Statistics Netherlands
- <sup>e</sup>. Municipality with area address density <500 adresses per km<sup>2</sup> (2012).Data obtained from Statistics Netherlands

### **Construction of the SEI-HS**

Three of the 20 available items were removed in the final model of the OVERALS analysis (Table 1 last column), while 17 items remained. As shown in Table 3, the dimension (inadequate) Social Participation was measured with 6 items, the dimensions Material Deprivation and (insufficient) Normative Integration were both measured with 4 items, and the dimension (inadequate access to basic) Social Rights with 3 items. Transformed item scores are shown in Figure 1 (Material Deprivation), Additional file 1 (Social Participation), Additional file 2 (Social Rights) and Additional file 3 (Normative Integration).





Figure 1 shows for each item of the dimension Material Deprivation the relationship between the original category and the quantification resulting from the canonical correlation analysis. Categories indicating little or no social exclusion received the lowest quantifications and categories indicating high levels of social exclusion received the highest values. The category quantifications were used to calculate the Material Deprivation scale score by multiplying them with their item weights (Table 3); and adding up the results.

SEI-HS (n=1	21,910)			SCP index (1	n=574) <sup>a</sup>		
Component loading <sup>b</sup>	Weight <sup>c</sup>	Eigenvalue	σ	Component loading <sup>b</sup>	Weight c	Eigenvalue	α
		0.54	0.75			0.58	0.42
0.49	0.13			0.43	0.27		
0.42	0.13			0.39	0.18		
0.48	0.36			0.52	0.43		
0.44	0.15						
0.51	0.16						
0.52	0.23						
				0.51	0.33		
		0.49	0.73			0.49	0.57
0.56	0.31			0.53	0.29		
760	00.0			0.45			
0.50	0.09			0.47	0.10		
0.52	0.21			0.44	0.24		
		0.53	0.30			0.59	0.24
0.54	0.43			0.49	0.42		
0.56	0.45			0.52	0.42		
	SEI-HS (n=1 Component loading <sup>b</sup> 0.49 0.48 0.48 0.44 0.44 0.52 0.56 0.56 0.58 0.56 0.58 0.56 0.56 0.54	SEI-HIS (n=121,910)ComponentWeight $^{\circ}$ loading $^{b}$ Weight $^{\circ}$ 0.490.130.420.130.440.150.440.150.510.160.520.230.560.310.580.300.540.430.540.450.560.43	$\begin{array}{ c c c c c c c c c c c c c c c c c c c$	$\begin{array}{ c c c c c c c c c c c c c c c c c c c$	SEI-HS (n=121,910)       SCP index (n         Component loading $^{b}$ Weight $^{c}$ Eigenvalue       a       Component loading $^{b}$ Component loading $^{b}$ 0.54       0.75       Component loading $^{b}$ 0.49       0.13       0.54       0.75       Component loading $^{b}$ 0.49       0.13       0.54       0.636       0.43         0.42       0.13       0.54       0.52       0.39         0.48       0.36       0.36       0.36       0.52         0.44       0.15       0.52       0.52       0.52         0.51       0.16 $0.73$ 0.52       0.53         0.51       0.16 $0.73$ $0.51$ $0.51$ 0.52       0.23 $0.73$ $0.51$ $0.51$ 0.52       0.23 $0.73$ $0.51$ $0.53$ $0.56$ $0.31$ $0.73$ $0.73$ $0.74$ $0.52$ $0.30$ $0.73$ $0.74$ $0.74$ $0.52$ $0.23$ $0.30$ $0.49$ $0.49$ $0.54$ $0.53$ $0.52$ $0.52$ $0.52$	SEI-HS (n=121,910)       SCP index (n=574) a         Component weight $c$ Eigenvalue b       Component weight $c$ Component loading $b$ Weight $c$ Component loading $b$ O.43       O.27         O.49       0.13       0.54       0.27         0.42       0.13       0.54       0.29       0.18         0.42       0.13       0.54       0.23       0.43       0.27         0.44       0.15       0.52       0.52       0.43       0.33         0.44       0.15       0.52       0.52       0.43         0.51       0.16       1       1       1         0.51       0.16       1       1       1       1         0.51       0.16       1       1       1       1         0.51       0.16       1       1       1       1         0.51       0.16       0.73       0.51       0.33       1         0.52       0.23       0.31       0.51       0.33       0.29         0.52       0.23       0.23       0.23       0.23       0.29         0.52       0.23       0.49       0.49       0.24         0.54<	

I didn't receive a medical or dental treatment	0.27	0.20		0.44	0.38		
Set 4: Lack of normative integration			0.43	0.34		0.47	0.31
I give to good causes (rev)	0.40	0.28		0.38	0.20		
I sometimes do something for my neighbours (rev)	0.41	0.32		0.50	0.43		
I put glass items in the bottle bank (rev)	0.31	0.21		0.38	0.27		
Work is just a way of earning money	0.36	0.29		0.31	0.25		
Eigenvalue index			0.50			0.53	
Canonical correlation <sup>d</sup>			0.33			0.38	

Explanatory note. The table displays component loadings and weights per item, eigenvalue and Cronbach's alpha per subscale and canonical correlation per index.

<sup>a</sup> Vrooman and Hoff [34].

- <sup>be</sup> Component loadings in OVERALS are similar to factor loadings in a factor analysis. Weights are similar to standardised regression coeffi
  - cients. [44, 45]. <sup>*d*</sup> The canonical correlation is calculated with the formula:  $r_d = ((K \times E_d) 1) / (K 1)$ , whereby K = number of sets, d=factor number (in this case only one factor was calculated), and E = the eigenvalue of the factor/index. rev = recoded in reverse order.

## Trichotomisation

The 85<sup>th</sup> and 95<sup>th</sup> percentile scores of the index and dimension scales were calculated in the weighted total sample (Figure 2). This resulted in corollary prevalence rates between 5.0 and 5.2 percent "moderate to strong" exclusion and between 8.6 and 11.8 percent "some" exclusion on the general index and the dimensions scales. Prevalence rates in the development and validation samples were very similar.



Figure 2. Distribution of SEI-HS scores.

## Validation of the SEI-HS

### 1. Content validity

The data in Table 3 show that the SEI-HS items covered all the aspects of SE that form part of the SCP index. All four dimensions of SE were measured with three or more items. Only one item had a low component loading i.e. 'didn't receive medical or dental treatment' (component loading 0.27); and one item had a low weight i.e. 'I have enough money to heat my home' (weight 0.09). The eigenvalues of the dimension scales ranged from 0.43 for Normative Integration tot 0.54 for Social Participation and Social Rights, which is largely consistent with the eigenvalues of the SCP dimension scales. As expected, the scores on the SEI-HS were right-skewed (Figure 2) with mean 0 and standard deviation 1, i.e. similar to the SCP Index.

### 2. Internal consistency

The SEI-HS has a sufficient canonical correlation (0.33). This is somewhat lower than the correlation found for the SCP Index (0.38). Cronbach's alpha for the dimension

Each dot represents 1% of the weighted study population. The pink square marks the 85 percentile. The red triangle marks the 95 percentile.

scales Social Participation and Material Deprivation were sufficient ( $\alpha \ge 0.70$ ). The Social Rights and Normative Integration scales, however, had insufficient Cronbach's alpha coefficients of respectively 0.34 and 0.30. The internal consistencies of the SEI-HS scale were all higher than those of the SCP dimension scales.

### 3. Internal structure

Table 4 presents the intercorrelations between the dimension scales and general index. As expected, the SEI-HS showed strong positive correlations between the scales and the general index ( $r \ge 0.60$ ) and weak positive correlations between the dimension scales interact ( $0.20 \le r \le 0.40$ ), which are comparable to those of the SCP Index. The results showed an acceptable model fit with all factor loadings significant at the 0.001 level <sup>1</sup>; RMSEA =0.057 (HI90=0.057); TLI=0.827; CFI=0.872 and Hoelter's .05 Index=407.

Table 4.	Pearson correlations between the subscales	(dimensions <sup>a</sup> )	and the	general	index,	SEI-
	HS (development sample) and SCP index.			-		

Correlation between:	SEI-HS	SCP index <sup>b</sup>
General index x SP	0.73*	0.76
General index x MD	0.69*	0.70
General index x SR	0.72*	0.77
General index x NI	0.64*	0.68
SP x MD	0.34*	0.35
SP x SR	0.37*	0.43
SP x NI	0.31*	0.41
MD x SR	0.34*	0.44
MD x NI	0.26*	0.28
SR x NI	0.28*	0.34

\* p<0.001

<sup>a</sup> SP=Social Participation; MD=Material Deprivation; SR=Social Rights; NI=Normative Integration

<sup>b</sup> Vrooman and Hoff [34].

#### 4. Construct validity

As shown in Table 5, all construct validity hypotheses were confirmed at the .001 level of confidence. Poor labour market position and poor health (poor perceived health and high risk for anxiety and depression disorder) had the strongest relationships with the SEI-HS. Also the factors non-Western ethnic background, low income, living alone, low education, living in a deprived neighbourhood and single parenthood, were all associated with a higher level of SE. The associations were generally stronger with the SEI-HS than with the SCP index (Table 5). An exception was the factor 'single parenthood'.

<sup>&</sup>lt;sup>1</sup>The factor loadings in the dimensions Social Participation ranged from 0.26 to 0.77; Material Deprivation from 0.52 to 0.59; Social Rights from 0.23 to 0.44; and Normative Integration from 0.30 to 0.41.

### 5. Generalisability

No marked differences in the canonical functions were found between the analysis in the development and validation samples. The eigenvalues of the index and subscale Social Participation were similar in the two samples. The eigenvalues of the subscales Material Deprivation, Social Rights and Normative Integration were almost similar: 0.50, 0.52 and 0.44 respectively in the validation as opposed to 0.49, 0.53 and 0.43 in the development sample. The same holds true for component loadings and weights.

# DISCUSSSION

The findings of this study show that we succeeded in developing a reliable and valid multidimensional measure for SE, the Social Exclusion Index for Health Surveys or SEI-HS. The OVERALS analyses empirically confirmed our multidimensional model with SE as the underlying latent construct. The limitations we encountered in previous retrospective research with regard to content validity and generalisability were successfully tackled in this nationwide prospective study. Content validity was enhanced by the addition of extra items. Instead of three dimensions in our previous study, the SEI-HS measured all four dimensions of SE. Generalisability was enhanced by successful replication of the SEI-HS in a representative validation sample. Other psychometric properties were found to be satisfactory to good and in line with the original SCP Index. Low to moderate intercorrelations between index and subscales confirmed the internal structure of the SEI-HS and construct validity was established through hypothesis testing.

The internal consistencies of two of the SEI-HS dimension scales were found to be weak. Both the Social Rights and Normative Integration scales had Cronbach's alpha coefficients lower than 0.70. By using canonical correlation analysis to construct a measure for SE, we selected those elements from the underlying theoretical dimensions that interrelate with one another and form a coherent construct. Of course, social participation, material deprivation, access to basic social rights and normative integration are broader concepts than the dimension scales resulting from these analyses. Access to basic social rights, for example, also comprises e.g. access to other public and private services such as education, legal aid, acceptance for insurance and banking and help with finding a job. When empirically tested, these forms of access proved not relevant to the concept of SE, at least not in the general population in the Netherlands [33, 34]. These aspects of basic social rights were therefore not included in the Social Rights scale. The SEI-HS dimension scales are thus relevant and of value only in the context of the concept SE.

One of the study's strengths is the use of a sound and validated instrument to supplement items on domains where the Netherlands PHM fell short. The SCP items were originally selected by the SCP with nonlinear canonical correlation analysis from an item pool of 232 items derived from extensive literature and empirical research, focus groups and cognitive tests [5, 33, 34, 49]. Thus, the selected items not only

Table 5. Association	between SEI-HS and known risk factors and correlates (development sample)	and comp	arison with	SCP index	
		SEI-HS		SCP inde	×a (X)
		(Develo) sample:	pment N=129.464)	(N=574)	
		β <sub>P</sub>	d	β <sup>b</sup>	d
Educational level	Low educational level (no education and primary school)	0.18	* *	0.12	* *
Ethnic background	Non-Western ethnic background	0.27	* * *	0.18	* *
Family situation	Single parent with underage child(ren)	0.07	***	0.13	* *
	Living alone	0.19	***	0.16	* *
Labour market position (64 years or vounger)	Unemployed and/or recipient of social security or disability benefits. (SCP: Receives unemployment benefit, disability benefit or social assistance benefit)	0.31	* * *	-0.03	Su
)	No paid job	0.21	* * *	0.02	su
Income	Low income <sup>c</sup> (SCP: Less than average household income)	0.26	* *	0.23	**
Health	Self-rated health fair or poor	0.31	* * *	0.19	**
	Diagnosed with at least one chronic condition. (SCP: Suffers from a disability or a chronic condition)	0.13	* * *	60.0	*
	Severe functional limitations in mobility, vision or hearing	0.27	***		
	High risk for anxiety and depression disorder. (SCP: Low subjective well-being) <sup>d</sup>	0.36	* * *	0.30	* *
Neighbourhood	Living in deprived neighbourhood	0.18	* *		
Explanatory note. Lii validity was con * Significant effect, r <sup>a</sup> Vrooman and Hoff <sup>b</sup> Standardised regres: <sup>c</sup> Low income = lowes: <sup>d</sup> Kessler psychologic	tear regression analyses were used to assess relationships between SEI-HS ar sidered satisfactory if at least 75% of the associations were in correspondence <0.05; ** Significant effect, p<0.01; *** Significant effect, p<0.001; ns Not s 34] sion coefficients at quintile standardised of yearly household income (2010) i.e. below 15.200 Eu al distress scale (K10), score 30 or higher	d known r with pred gnificant, ro. (Data o	isk factors a efined hypot p>=0.05 obtained fron	nd correlat heses n Statistics	es. Construct Netherlands)

Social Exclusion Index-f or Health Surveys (SEI-HS)

have a strong theoretically basis, but also a strong empirical basis. The findings of this study supported our choice. The SCP items perfectly complemented the existing PHM items. Together, they covered the full width of the theoretical construct and produced an empirically sound and valid instrument.

Another strong point is the study's large and representative sample. Over half a million adults were invited to participate in this study and data from over 250.000 respondents were available for analysis. The widespread participation allowed us to extend the generalisability of the SEI-HS to the whole Dutch adult population and calculate national reference data, by sex, age group, urbanicity, ethnical background and educational level; thus providing a benchmark for Community Health Services and municipalities to compare their local data with [50]<sup>c2</sup>. The high number of Community Health Services that took part in this study not only advanced the quality of the research, it also indicates the pertinence of SE to the field of public health in the Netherlands. The fact that 19 out of 28 Dutch Community Health Services (covering over 70 percent of the Dutch population) made space available in their surveys for additional SE items is illustrative of the importance given to SE. Most Community Health Services have since published local figures and reports on SE, with local policy recommendations [51-56]. This provides a good demonstration of the value and potential of a SE measure for the public health sector.

The response rate of this study was 45.7%, which is typical for population surveys in the Netherlands [57, 58]. The Dutch PHM employs a systematic strategy to minimise non-response error. The strategy includes measures to increase the general response rate such as pre-survey notification and media coverage in e.g. local newspapers and social media, a mixed mode approach combining web and paper questionnaires, multiple reminders and specific measures to increase representation of hard to reach groups e.g. home visits, translated questionnaires, assistance in completing the questionnaire and oversampling.

Lastly, it includes robust weighting procedures to reduce non-response error. We believe that sample representativity is sufficiently guaranteed by the taken measures, particularly for our purpose, the estimation of the parameters of the SEI-HS measure. Although additional analyses (not shown) indicate that the level of SE in the study population has relatively limited effect on the parameters of the SEI-HS, we recommend to retest the SEI-HS in different samples with full inclusion of population groups that are particularly vulnerable to SE. As is common practice in population health surveillance, only persons living in private households were included into the Dutch PHM, thereby excluding groups such as homeless persons and detainees. In the Netherlands, 0.2% of the adult population was estimated in 2012 as being homeless and 1.6% lived in an institutional household, mostly elderly persons [CBS Statline]. Prevalence rates should therefore be interpreted with caution.

 $<sup>^{\</sup>rm 2}$  The syntax to calculate SEI-HS index and scale scores are available from the corresponding author.

The index and scale scores were trichotomised using 85<sup>th</sup> and 95<sup>th</sup> percentile scores, resulting in three categories of SE: "moderate to strong" exclusion (score>P95), "some" exclusion (P85<score<P95) and "little or no" exclusion (score<P85). There are a number of reasons for selecting P85 and P95 as cut-off points. Firstly, using these cut-off points enhances the applicability of the instrument in public health policy. Municipalities prefer to target comprehensive (and costly) interventions at welldefined small population groups with the highest risk, while more general preventive policies may focus on wider population groups. 5% and 10%, respectively, are considered here as useful guidelines. Secondly, the categorisation fits the right-skewed distribution of the index scores, indicating that the largest part of the population is not excluded (Figure 2). Lastly, the choice of the two cut-off points does justice to the relative and continuous character of SE. It allows for the possibility of social groups being differentially included rather than suggesting an artificial dichotomy between included and excluded groups and avoids the stigma of labelling particular groups [7]. Despite this substantiation, the choice of P85 and P95 as cut-off points remains arbitrary. A certain degree of arbitrariness is inevitable in a continuous phenomenon such as SE, where there is no set point at which a person is or is not excluded. Using objective methods such as ROC curves for determining cut-off points would only disguise the inherent arbitrariness.

Although the SEI-HS was designed specifically for inclusion in the Netherlands PHM, it is highly suitable for application in public health surveys in countries with similar physical, economic and social conditions where it complements the current validated SE measures. Because of its potential for calculating composite scores and the absence of health as a constituent part of the index, the SEI-HS. allows researchers to study the relationship between SE and health, knowledge indispensable for designing effective policies to diminish socioeconomic health inequalities. This is a promising development as SE provides a broader and thereby potentially more effective range of policy options than concepts like poverty and loneliness [3, 59, 60]. The SEI-HS can be used in identifying risk groups for targeting specific interventions and monitoring their impact over time [6, 7, 60], and in raising the profile and visibility of excluded groups and alerting professionals to the diverse causes and consequences of SE [13]. Finally, our approach to the development of a short embedded index with canonical correlation analyses, may serve as an example to the further development of key public health measures.

## CONCLUSIONS

We have described the development of an instrument to measure the multidimensional concept SE and its validation in a major national public health survey. All four dimensions of SE could be measured and overall, the SEI-HS showed satisfactory to good psychometric properties. The SEI-HS enables researchers to take a next step in the advancement of much needed knowledge on SE and health. The study also provides valuable insights in how to develop embedded measures for public health surveillance.

# ABBREVIATIONS

- CBS: Statistics Netherlands
- PHM: Public Health Monitor
- rev: Recoded in reverse order
- SCP: Netherlands Institute for Social Research
- SE: Social exclusion
- SEI-HS: Social Exclusion Index-for Health Surveys

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# SUPPLEMENTARY MATERIALS

Additional file 1. Category quantifications SEI-HS items dimension (limited) Social Participation.

Additional file 2. Category quantifications SEI-HS items dimension (inadequate access to basic) Social Rights.

Additional file 3. Category quantifications SEI-HS items dimension (lack of) Normative Integration.

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In een mooie straat in een populaire wijk in Utrecht woont Mehmed. Een alleenstaande man, 52 jaar oud en van Turkse komaf. Mehmed is de enige bewoner die in deze straat nog huurt, de rest van de huizen zijn inmiddels verkocht door de woningbouwcorporatie.

Mehmed is 28 jaar drugsverslaafd. Hij heeft zijn verslaving onder controle, maar het maakt wel dat hij een kluizenaarsbestaan leidt. Iedere dag brengt hij een bezoek aan het revalidatiecentrum. Daar verblijft zijn oude vader, die elke dag opnieuw uitkijkt naar een bezoek van zijn zoon. 'Ik ga elke dag naar mijn vader. Ik zorg voor hem en ook voor andere mensen daar. Ik werk daar net als de vrijwilligers. (...) ik vind het leuk om die oudere mensen te helpen.'

Uiteindelijk wil Mehmed terug naar Turkije, dit is iets waar hij naar verlangt en uitkijkt. 'Ik wil terug naar mijn eigen land.'

Uit Sociaal Uitgesloten in de grote stad, van Bergen et al. 2014..

Evaluating the cross-cultural validity of the Dutch version of the Social Exclusion Index for Health Surveys (SEI-HS): a mixed methods study

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# ABSTRACT

**Background.** The recently developed Social Exclusion Index for Health Surveys (SEI-HS) revealed particularly strong social exclusion in non-Western immigrant groups compared to the native Dutch population. To qualify such results, cross-cultural validation of the SEI-HS in non-Western immigrant groups is called for.

**Methods.** A sequential explanatory mixed methods design was used, employing quantitative data from the Netherlands Public Health Monitor along with qualitative interviews. Data from 1,803 adults aged 19 years or older of Surinamese, 1,009 of Moroccan and 1,164 of Turkish background and 19,318 native Dutch living in the four largest cities in the Netherlands were used to test the factorial structure of the SEI-HS and differential item functioning across immigrant groups. Additionally, 52 respondents with a high score on the SEI-HS and from different background were interviewed on the item content of the SEI-HS and subjective feelings of exclusion. For each SEI-HS item the semantic, conceptual and contextual connotations were coded and compared between the immigrant groups and native Dutch.

**Results.** High levels of social exclusion were found in 20.0% of the urban population of Surinamese origin, 20.9% of Moroccan, 28.7% of Turkish and 4.2% of native Dutch origin. The 4-factor structure of the SEI-HS was confirmed in all three immigrant groups. None of the items demonstrated substantial differential item functioning in relation to immigration background. The interviews uncovered some methodological shortcomings, but these did not substantially impact the observed excess of social exclusion in immigrant groups.

**Conclusions.** The present study provides evidence in support of the validity of the SEI-HS in adults of Surinamese, Moroccan and Turkish background and confirms the major social exclusion of these immigrant groups in the main cities in the Netherlands. Policy measures to enhance social inclusion and reduce exclusion are urgently needed.

## INTRODUCTION

Social exclusion (SE) refers to the inability of people to participate fully in the society in which they live [1]. It is characterised by an accumulation of disadvantages on multiple dimensions: 1) social e.g. sense of belonging and social support; 2) economic e.g. material deprivation; 3) political e.g. lack of access to housing and health care; and 4) cultural e.g. acceptance of values, norms and ways of living [2, 3]. SE has a profound impact on people's lives. Socially excluded persons report feelings of loss and shame, alienation, powerlessness and insecurity [4-6] resulting in loss of aspirations [4], withdrawal [7, 8], reduced self-confidence [6, 8] and high risk behaviour [9, 10]. SE is considered as one of the driving forces of health inequalities [2, 3, 11, 12] and is particularly relevant in the context of immigrant health [13, 14].

In the past decades, the number of immigrants living in Western Europe has increased significantly [15]. In the Netherlands on average 13 per cent of the population is of non-Western origin, with higher representation in urban areas [16]. In the four largest cities, Amsterdam, Rotterdam, The Hague and Utrecht, one in three citizens is of non-Western origin (34%), with first and second generation immigrants of Surinam, Morocco and Turkey constituting the largest groups (7.3%, 7.7% and 6.1% respectively). Immigration from Morocco and Turkey was initially labour-related dating back to the 1960's, while the Surinamese immigration is related to the colonial past and had its highest influx in the period before Surinam's independence in 1975 [17].

The Netherlands is one of the few EU-countries with a strong record of monitoring immigrant health and health related factors [18]. The Dutch Public Health Monitor (PHM), a four-yearly national health survey that routinely includes data on migration background, employs a large stratified sample, includes strategies to enhance response rates in cities with a diverse ethnic makeup and makes use of culturally validated questionnaires [19-23].

In 2012 we developed an index to measure the four dimensions of social exclusion: the Social Exclusion Index for Health Surveys (SEI-HS) [24]. It was developed as an embedded measure using items from the PHM and where the PHM fell short, supplemented with items from the Social Exclusion Index of the Netherlands Institute for Social Research|SCP [20, 24]. The SEI-HS was validated for the adult population of the Netherlands, including 5.2% respondents with a non-Western origin [24], but it was not validated specifically for immigrant groups. In cross-cultural research group differences may result from systematic biases in the way people from different cultures respond. Response style behaviour is reported to differ between cultural groups, with non-Western immigrants showing higher acquiescence and midpoint responding [25] or preferring extreme categories more than other groups [26]. Additionally, items that contain content or language that is differentially familiar or has a different connotation for various groups may compromise the cross-cultural validity [27].

Particularly high levels of SE were observed in adults of non-Western background measured with the SEI-HS in 2012. One in five adults (21.0%) of non-Western background was classified as moderate to strong SE, while the prevalence rates in adults of native Dutch and western migration background were 2.7% and 6.5% respectively [28].

Differences in SE might be expected given that risk factors for SE, such as low educational level, low income, low labour market position, linguistic problems and poor health [20], tend to occur more frequently in non-Western immigrant groups than in native Dutch and western immigrant groups [29, 30]. The magnitude of the differences was so large, however, that suspicion has been raised on a potential cultural bias of the SEI-HS.

The leading question for the present study was whether the strong SE among adults of Surinamese, Moroccan and Turkish background compared with native Dutch citizens in the four largest cities in the Netherlands, can be explained by shortcomings in the cross-cultural validity of the SEI-HS.

To answer the research question, a mixed methods approach was chosen. In addition to quantitative testing of the cross-cultural validity through confirmatory factor analysis and differential item functioning (DIF) analysis [31], qualitative interviews were conducted with socially excluded respondents of immigrant background and native Dutch origin. Qualitative data contribute insight into the individual experience of socially excluded people and can be used to explore whether items sufficiently represent the same content across cultures [32].

# MATERIALS AND METHODS

## Mixed methods design

The present study has a sequential explanatory mixed methods design consisting of a dominant quantitative and a less dominant qualitative phase [33, 34]. Fig 1 shows the sequence, priority and integration of the two phases. In phase I survey data were collected on SE in the general population. In phase II, data from phase I were used to select a sample of socially excluded persons of Surinamese, Moroccan, Turkish and native Dutch origin. Semi-structured interviews were conducted on the perspective of the respondents on their situation and responses on the SEI-HS. The Medical Ethics Review Committee of the AMC confirmed that under Dutch law, medical ethics approval was not required for phase I (AMC, W12\_146 no. 12.17.0163) nor for phase II (AMC, W13\_311 # 14.17.0007) as participants were not subjected to any intervention or treatment.



Figure 1. Flowchart study design.

### I Quantitative phase

#### Data collection

The quantitative data were collected by the Public Health Services of the four largest cities in the Netherlands, as part of the Public Health Monitor (PHM) 2012. The PHM is a nationwide self-report survey of non-institutionalised adults aged 19 years or older, conducted every four years. To ensure that elderly and people living in neighbourhoods with a low socioeconomic status were well represented, stratified samples were drawn by Statistics Netherlands, based on age and neighbourhood. In total 71,627 residents of Amsterdam, Rotterdam, The Hague and Utrecht were invited to participate. Non-responders received two written reminders, and in the case of non-Western immigrants, an extra telephone call or home visit. Questionnaires in Turkish, Moroccan Arabic and English translation could be used and trained interviewers were available to assist respondents face-to-face or by phone in their preferred language (Dutch, Arabic, Berber, Turkish or English). The response rate was 40% (Surinamese 28%, Moroccan 26%, Turkish 26%, Dutch 48%). Statistics Netherlands enriched the PHM data with information on zip code, migration background and standardised household income [35]. Participation in the research was anonymous and voluntary. In accordance with the Dutch Law, participants were informed by letter that by completing the questionnaire they consent with anonymous use of data for research.

#### Measurement

Social exclusion. The SEI-HS consists of 17 items which measure four dimensions and an overall index of SE [24]. The four dimensions are: 1) lack of social participation, 2) material deprivation, 3) inadequate access to basic social rights and 4) lack of normative integration. Scores on the index and the four dimensions are categorised into 'little or no', 'some' and 'moderate to strong' exclusion. The SEI-HS was validated in the general Dutch population. The items were derived from various validated questionnaires such as the Loneliness scale of De Jong Gierveld [36], the SCP Social Exclusion Index [20] and Social Cohesion and Trust [22]. The internal consistency, internal structure, construct validity and generalisability were found satisfactory [24].

<u>Migration background.</u> In line with the Dutch standard definition, country of birth or, in case of second-generation immigrants, country of birth of the mother and/ or father, as registered in the municipal population registers, were used to define migration background.

### Quantitative data analysis

### Descriptive statistics

Analyses were restricted to respondents of Surinamese, Moroccan and Turkish origin with native Dutch respondents as the reference group. In order to control for the stratified sampling design and selective non-response, we used SPSS Version 22 Complex Samples Likelihood tests for the descriptive analyses of the prevalence of SE. Sampling weights were calculated by Statistics Netherlands based on a linear model with 9 sociodemographic variables and their interaction terms [37]. The significance level  $\alpha$  was set at 0.001 to reflect the large sample size.

### Structural validity

To test whether the SEI-HS factor structure holds across the three migrant groups, we conducted confirmatory factor analyses in data subsets per migrant group using SPSS Amos 22.0. Five of the standard goodness-of-fit statistics given in Amos were used to assess model fit i.e. root mean square error of approximation (RMSEA), upper bound of 90% confidence interval (HI90), Tucker-Lewis index (TLI), comparative fit index (CFI) and Hoelter's .05 Index [38]. The Chi square statistic was not considered given its sensitivity to large sample sizes. The model fit was considered good if RMSEA< 0.05, HI90) < 0.06, TLI  $\ge$  0.95, CFI > 0.90 and Hoelter's .05 Index  $\ge$  200 [38]. These same criteria were used in the development of the SEI-HS [24].

### Differential item functioning (DIF)

DIF occurs when one group of individuals responds differently from another group on a given questionnaire item, even though both groups are equivalent on the underlying construct that is assessed, or in DIF terminology, if both groups show the same ability on the matching variable. In this study the categories 'little or no', 'some' and 'moderate to strong' of the relevant dimension scale were used as the ability levels. The cut-off points for these categories were based on the 85<sup>th</sup> and 95<sup>th</sup> percentile in the Dutch adult population of 19 years or older in 2012 [24]. For each immigrant group, three hierarchical models were calculated with SPSS ordinal logistic regression, with Y being the SEI-HS item tested, M the matching variable (i.e. the corresponding SE dimension) and G the grouping variable (i.e. Surinamese, Moroccan or Turkish versus Dutch): Model 1:  $\mathbf{Y} = \boldsymbol{\beta}_0 + \boldsymbol{\beta}_1 \mathbf{M}$ ; Model 2:  $\mathbf{Y} = \boldsymbol{\beta}_0 + \boldsymbol{\beta}_1 \mathbf{M} + \boldsymbol{\beta}_2 \mathbf{G}$ ; Model 3 :  $\mathbf{Y} = \boldsymbol{\beta}_0 + \boldsymbol{\beta}_1 \mathbf{M} + \boldsymbol{\beta}_2 \mathbf{G} + \boldsymbol{\beta}_3 \mathbf{M} * \mathbf{G}$ .

An item was considered to exhibit substantial DIF if the difference between model 1 and 3 in log-likelihoods was statistically significant ( $\alpha$ =0.001) and the change in R<sup>2</sup> at least moderate according to the Jodoin-Gierl effect size criteria by which  $\Delta R2 < 0.035$  is classified as negligible;  $0.035 \le \Delta R2 \le 0.070$  as moderate and  $\Delta R2 > 0.070$  as large. [39-41]. In case of substantial DIF further analyses were made to characterize the type of DIF into uniform DIF (significant difference between model 1 and 2) and/ or non-uniform DIF (significant difference between model 2 and 3). Criteria can be found in S1 Tables A-C.

## II Qualitative phase

In the qualitative part of the study we set out to describe, analyse and compare the experiences of social exclusion and the responses on the SEI-HS in the four research groups. We followed the consolidated criteria for reporting qualitative research (COREQ) checklist [42].

## Participant selection

The sampling frame consisted of the respondents of Surinamese, Moroccan, Turkish and Dutch background, with a high score on the SEI-HS who had given the Public Health Services written consent to re-contact (Table 1). Respondents from the city of Rotterdam could not be included as permission had not been requested. To reflect the variability in gender, age and neighbourhood across the four research groups, in total 50 cases were selected at random from the different strata. In case of non-response a replacement was selected as similar as possible to the original case.

	Quantitative survey		Qualitati	ve interview	
	Phase I Response (%)	High score on SEI-HS	Agreed to follow-up *	Phase II Sample	Phase II Response (%)
Surinamese	1,803 (28%)	277	101	27	11 (41%)
Moroccan	1,009 (26%)	174	72	43	9 (21%)
Turkish	1,164 (26%)	235	72	43	10 (23%)
Dutch	19,318 (48%)	277	71	64	22 (34%)
	23.294 (42%)	879	316	177	52 (29%)

Table 1. Number of respondents qualitative and quantitative phase

\* Follow-up from Amsterdam, The Hague and Utrecht.

### Data collection

Interviews took place between March and September 2014. During this period 177 respondents were contacted by letter, telephone and home visits. Up to three attempts were made to get in touch. The response rates are shown in Table 1, with no contact being the main reason for non-response (not at home or moved house).

Interviews took place at a time and location convenient to the respondent, generally at their home address. Signed informed consent was obtained at the time of the interview. Each respondent received a 20 euro gift card as compensation for their time. The interviews were conducted by two experienced members of the research team (CB, AvL), of Dutch and Indonesian background respectively, and students of Surinamese, Moroccan and Turkish background. Students were trained by members of the research team and closely supervised in their work. The supervision not only focused on methodological aspects but also on emotional wellbeing and safety of the students.

To explore the perceptions of the respondents, a semi structured topic guide was used which comprised open-ended questions accompanied by probes and prompts to expand, clarify and understand responses. The 17 items of the SEI-HS were asked exactly as worded, but further explanation was given if the respondent asked for it. Other topics included health and health behaviour, feelings of being left out of society, locus of control and expectations for the future. To create a pleasant and personal atmosphere, respondents were invited, at the start of the interview, to tell something about themselves and the things they enjoy doing. Interviews lasted 20-90 minutes (53 minutes on average), depending on the willingness and ability of the respondents. Interviews were audio-recorded and transcribed verbatim by independent transcriptionists.

### Qualitative data analyses

The transcribed interviews were entered in MaxQDA and analysed by two research team members (BC, AvB) using thematic coding techniques. The initial coding framework was based on the structure of the topic guide. Subsequently, for each SEI-HS item text references were analysed on semantic, conceptual and contextual evidence and categorised [32]. Semantic evidence included all text references referring to the meaning of the language used and the comprehensibility of the item. The text references were coded '0' if respondents correctly understood the wording of the item, '1' if that was not the case and 'x' if there was no conclusive evidence. Conceptual evidence included all text references referring to the general idea or notion captured by the item. The conceptual connotations were compared with the intended concept of the item and coded as either equivalent (0), deviating (1) or inconclusive (x). Contextual evidence included all text referring to the contextual specificity of items. This specificity only becomes apparent through between-group comparison [32].The text references were coded per respondent as: '0' if no culturally specific context

was mentioned or appeared to play a role in the respondents answer, '1' if culturally specific context was mentioned and 'x' if there was no conclusive evidence.

Scores were calculated for each research group and each type of evidence. If 30% or more of the responses was problematic i.e. coded '1', we categorised this as 'yes, there may be a reason for concern'; if 10-30% was problematic, we categorised this as 'perhaps, there is a reason for concern; and 0-10% was categorised as 'no reason for concern'. Cases with inconclusive evidence were excluded from the calculation.

Finally, all responses coded 'yes, there may be a reason for concern' were compared between the groups and analysed for their potential effect on the cross-cultural validity.

Reporting in this manuscript follows the STROBE guidelines for cross-sectional studies [43].

# RESULTS

## I Quantitative phase

### Descriptive statistics

<u>Background characteristics</u>. Table 2 shows that the Dutch respondents of phase 1 are generally older than the three immigrant groups and live less often in neighbourhoods with a low socioeconomic status (SES).

Table 2. General characteristics of respondents by migration background, Phase I and II (%)

	Women	19-39 years	40-64 years	65 years and older	Low SES neighbourhood	Ν
PHASE I: Qua	ntitative s	survey				
Surinamese	59.1	30.1	37.4	32.6	49.3	1,803
Moroccan	50.4	41.1	40.1	18.7	60.8	1,009
Turkish	52.0	46.1	36.9	17.0	66.3	1,164
Dutch	55.2	28.9	28.1	43.0	26.2	19,318
PHASE 2: Qua	alitative ir	nterview				
Surinamese	63.6	36.4	36.4	27.3	54.5	11
Moroccan	44.4	33.3	55.6	11.1	77.8	9
Turkish	50.0	20.0	80.0	0.0	70.0	10
Dutch	50.0	18.2	40.9	40.9	59.6	22

<u>Social exclusion</u>. The data presented in Table 3 confirm that in the four cities SE is more prevalent in adults of Surinamese, Moroccan and Turkish origin compared to native Dutch adults. High levels of SE were found in 20.0% of the urban population of Surinamese origin, 20.9% of the Moroccan, 28.7% of Turkish and 4.2% of native Dutch origin. Elevated levels were also found on the underlying dimension scales. Especially material deprivation was increased in all three immigrant groups by a factor of 6 to 7. Inadequate access to basic social rights was highest in adults of Moroccan origin. Only in Turkish adults, the prevalence of 'Lack of normative integration' was not increased compared to adults of native Dutch origin (p=0.023).

	Surin (N=1	amese ,803)	More (N=1	occan ,009)	Tur (N=1	kish ,164)	Dutch (N=19,318)
	%	р	%	р	%	р	%
SEI-HS index	20.0	.000	20.9	.000	28.7	.000	4.2
Dim1: limited social participation	13.4	.000	11.6	.000	17.2	.000	4.4
Dim 2: material deprivation	24.1	.000	22.6	.000	25.2	.000	3.6
Dim 3: inadequate access to basic social rights	16.5	.000	27.2	.000	22.7	.000	5.3
Dim 4: lack of normative integration	15.7	.000	12.4	.000	9.5	.023	6.4

 
 Table 3. Prevalence rates of moderate to strong social exclusion in adults of Surinamese, Moroccan, Turkish and Dutch origin #

# Prevalence rates were weighted for sample design and selective non-response. SPSS Complex Samples Likelihood-test was used to test the difference with the Dutch reference group. P-value italic if significant at < 0.001 level.</p>

### Confirmatory factor analyses

The results showed an acceptable model fit for the three immigrant groups (Table 4). In all cases the Hoelter's .05 Index indicated good model fit. Factor loadings were all significant at the 0.001 level except for item 17 'Work is just a way of earning money' (Table 4). The factor loadings of this item were not significant in the Moroccan and Turkish groups. The RMSEA, CFI and TLI coefficients were comparable to the fit of the original SEI-HS model.

### Differential item functioning

Of the 17 items examined, none displayed substantial DIF i.e. p < 0.001 and  $\Delta R^2$  0.035 or higher (S1 Tables A-C).

## **II Qualitative phase**

In total 52 interviews were conducted, with respectively 11 Surinamese, 9 Moroccan, 10 Turkish and 22 Dutch persons. Four in five were interviewed by an interviewer of the same migration background (81%). Characteristics of respondents are presented in Table 2.

	RMSEA	06IH	TLI	CFI	Hoelter's .05 Index	Factor loadings significant
	(< 0.050)	(< 0.060)	$(\geq 0.950)$	(> 0.900)	( <u>&gt;</u> 200)	(p<0.001)
Surinamese	0.056	0.060	0.846	0.887	334	All items
Moroccan	0.063	0.069	0.781	0.838	246	All but Item#17 (p=0.052) <sup>a</sup>
Turkish	0.058	0.062	0.839	0.881	320	All but Item#17 (p=0.299) <sup>a</sup>
Validation in Dutch adult population	0.057	0.058	0.827	0.872	407	All items

**Table 4.** Confirmatory Factor Analysis of the SEI-HS in adults of Surinamese, Moroccan and Turkish origin compared with prior validation results in the Dutch adult population [24]

RMSEA = root mean square error of approximation; HI90 = upper bound of 90% confidence interval; TLI = Tucker-Lewis index; CFI = comparative fit index. Results in italic and bold if RMSEA < 0.05, HI90 < 0.06, TLI ≥ 0.95, CFI > 0.90 and Hoelter's .05 Index ≥ 200, indicating good model fit.

<sup>a</sup> Item 17: Work is just a way of earning money. For more details see S2 Table.
For each SEI-HS item the semantic, conceptual and contextual connotations reported by the respondents were coded and compared between the four research groups. As can be seen from Table 5 the items of dimension 4 caused most reason for concern. Semantic problems were identified for all groups (including native Dutch respondents) in item 17. The item was misunderstood by more than a third of the respondents (12 out of 33). Instead of 'working is just a way of earning money' most of them understood the item as 'working is an unjust way of earning money'. Coincidentally, a negative answer indicates in both cases normative integration and a positive answer the lack thereof. Semantic problems with item 15 (I sometimes do something for my neighbours) concerned primarily Moroccan respondents.

Items 14, 15 and 17 of dimension 4 showed conceptual problems in all four groups. Item 14 measured in almost half of the respondents (15 out of 32) lack of money instead of noncompliance to the core values of Dutch society: "*I have a few charities that are my favourites, they really need it. But my finances are at a pretty low ebb at the moment.*" Item 15 measured in one third of the respondents (18 out of 37) lack of opportunity to do something for your neighbours (e.g. in case of conflict or no contact with neighbours) and/or inability to help (e.g. due to old age or ill health). Item 17 measured in one fifth of the respondents (7 out of 35) work ethic instead of noncompliance to core values. These respondents found work a good way to earn money: "*If you don't work, you won't eat*". Contextuality played a role in item 14. One Moroccan and one Turkish respondent mentioned payment to the mosque. This works both ways: "*If they come from the mosque, I pretend I don't hear anything, they think 2 or 3 euros is too little.*" One Moroccan respondent paid medical costs for poor family members in the home country.

The items of dimension 2 and 3, 'Material deprivation' and 'Access to basic social rights', gave less reason for concern. A number of respondents had difficulty in understanding the wording of the items 8 and 12. Three Surinamese respondents (3 out of 7) did not answer item 8 if they have enough money to heat the house properly, but whether the house can be heated well: "*I hope so, I have not experienced the winter here yet*". Five Moroccan respondents (5 out of 9) were not able to translate their (dis) satisfaction with their home (item 12) into a corresponding grade. Our analysis did not suggest any conceptual problems: all respondents interpreted the items of dimension 2 and 3 as intended. Contextuality only played a role in item 10. Having enough money to visit others did not only depend on the financial situation of the household but also on the travel costs incurred. Family of immigrants generally live further away, making travel costs more difficult to pay.

The items of dimension 1 also functioned much as expected, with some exceptions. Item 1 was not understood by a quarter of the respondents (6 out of 24), both immigrants and one native Dutch respondent: "*Emptiness? What do you mean by that?*". Item 5 showed comparatively the most validity problems. Six respondents, both immigrants (3 out of 17) and native Dutch (3 out of 18), reported that they

felt rejected by their employer or by institutions like the tax office or the Employee Insurance Agency. Conceptually this interpretation belongs more to dimension 3 'Access to institutions' than to 'Social Participation'. In four cases the events or cases referred to were specific to the cultural group, for example forced marriage in case of a Turkish respondent. Contextuality also plays a role in item 6. The degree of contact that Moroccan, Turkish and Dutch respondents have with their neighbours is influenced by the migration background of these neighbours. According to a Turkish respondent they just say "*hi*" to the Dutch neighbours, but visit their Turkish neighbours regularly at home. The concept that is being measured, however, does not differ between the groups.

# DISCUSSION

Our objective was to examine possible shortcomings in the cross-cultural validity of the SEI-HS that might explain the high prevalence of SE in adult immigrant groups found in the 2012 health monitor. The study was conducted among adults of Surinamese, Moroccan, Turkish and Dutch origin in the four largest cities in the Netherlands. The quantitative part of the study showed no cross-cultural validity issues. CFA confirmed the 4-factor structure of the SEI-HS in the three immigrant groups and none of the SEI-HS items exhibited problems with differential item functioning. Item scores did not differ significantly between respondents of Surinamese, Moroccan, Turkish origin and native Dutch respondents at the same level of SE. The qualitative part uncovered little differences in understanding and interpretation of items between the population groups, but some general methodological shortcomings were identified, especially in the normative integration dimension of the SEI-HS.

The socially excluded respondents we interviewed did not always interpret the items as intended, due to unfamiliarity with words, complicated sentence structures and different connotations. Potential cultural biases were limited to the semantics of items 8,12 and 15 and contextuality of items 5 and 10. The interviews showed that particularly Moroccan respondents had problems understanding certain items. Rewording or rephrasing of semantically difficult items could be considered. In general, these findings underline the importance of offering assistance to respondents face-to-face or by phone in their own language (Berber or Arabic). Items 5 (I often feel rejected) and 10 (I have enough money to visit others) showed contextual differences that might threaten the cultural validity of the items. This was however not reflected in the quantitative analyses.

Most validity issues were as noteworthy in native Dutch respondents as in Surinamese, Moroccan and Turkish respondents. This was not expected since all SEI-HS items originate from widely used and/or validated questionnaires [20-23]. The content of items 8-10 and 13-17 was derived from literature and interviews, judged by four focus groups and tested through individual cognitive interviews [20]. Efforts were made to include people with a higher risk of SE i.e. with low income and low educational

	Semanti	c evidence			Concept	ual evider	nce		Context	ual evider	ıce	
	Surin.	Moroc.	Turkish	Dutch	Surin.	Moroc.	Turkish	Dutch	Surin.	Moroc.	Turkish	Dutch
<b>Dimension 1: Limited set</b>	ocial parti	cipation										
1. I experience a general sense of emptiness <sup>1</sup>	x	x	yes	no	perhaps	x	x	no	x	x	perhaps	no
	2/3	1/2	2/6	1/13	1/6	0/2	0/4	0/13	1/2	0/4	2/7	1/13
2. There is always someone I can talk to about my day-to-day problems <sup>1</sup>	no 0/5	x 1/3	x 1/3	no 1/11	no 0/5	x 0/4	x 1/3	perhaps 3/11	no 0/5	x 3/4	x 1/3	no 0/11
3. There are plenty of people I can lean on when I have problems <sup>1</sup>	x 0/3	x 2/3	x 1/4	no 1/11	on 0/6	perhaps 1/5	perhaps 1/6	no 1/11	0/6	no 0/5	0/0	no 0/11
4. I miss the pleasure of the company of others <sup>1</sup>	perhaps	x	x	no	on	no	x	ou	no	no	x	on
	1/7	1/4	0/3	0/8	0/7	0/5	0/3	0/0	0/7	0/5	0/3	0/9
5. I often feel rejected <sup>1</sup>	perhaps	perhaps	perhaps	no	perhaps	х	perhaps	perhaps	no	x	yes	no
	1/7	1/6	1/7	0/19	2/7	0/4	1/8	3/18	0/7	1/3	3/8	0/17
6. Little contact with neighbours and people in the street <sup>2</sup>	x	x	no	no	x	no	no	no	x	yes	yes	no
	0/3	0/3	0/5	0/13	0/3	0/5	0/5	0/13	0/3	3/5	4/5	1/13
<b>Dimension 2: material</b> o	leprivatio	1										
7. Had difficulty past year getting by on the household income <sup>2</sup>	no	x	no	no	no	on	no	no	no	on	no	no
	0/5	1/3	0/5	0/18	0/10	0/9	0/10	0/22	0/10	0/9	0/10	0/22
8. I have enough money to heat my home <sup>3</sup>	yes 3/7	x 0/4	on 0/7	no 0/16	0/6	no 0/6	no 0/8	no 0/14	no 0/6	no 0/6	no 0/8	no 0/14
9. I have enough money	perhaps	x	perhaps	no	no	no	no	no	no	no	no	no
for club memberships <sup>3</sup>	1/6	1/3	2/8	1/17	0/8	0/5	0/8	0/20	0/8	0/5	0/8	0/20
10. I have enough money to visit others <sup>3</sup>	/ no	х	no	no	no	on	no	no	yes	yes	yes	perhaps
	0/5	1/4	0/7	0/14	0/10	0/9	0/10	0/19	4/10	4/9	8/10	2/19

Table 5. Qualitative findings on content-related validity by migration background: extent of reason for concern \*

Chapter 5

<b>Dimension 3: inadequat</b>	e access to	basic soci	al rights									
11. People in this												
neighbourhood	perhaps	х	no	no	no	no	no	no	no	no	no	no
generally do not get along with each other <sup>4</sup>	1/9	0/4	9/0	0/15	6/0	0/8	0/8	0/15	6/0	0/8	0/8	0/15
12 Degree of satisfaction	00	Ves	nerhans	Ott	ou	04	ou	04	10	04	04	
with housing <sup>2</sup>	0/11	5/9	2/9	0/22	L/0	0/8	0/8	0/22	0/7	0/8	0/8	0/22
13. I didn't receive	no	perhaps	perhaps	no	no	no	no	no	no	no	no	no
a medical or dental treatment <sup>3</sup>	6/0	2/7	1/6	1/17	0/8	0/18	6/0	8/0	8/0	0/18	6/0	0/8
Dimension 4: lack of not	rmative int	egration										
14. I give to good causes <sup>3</sup>	perhaps 1/8	perhaps 1/5	no 0/5	no 1/15	yes 6/8	perhaps 1/5	yes 3/7	yes 7/15	no 0/8	yes 2/5	perhaps 1/7	no 0/15
15. I sometimes do	perhaps	ves	ou	ou	ves	ves	ves	ves	ou	perhaps	perhaps	ou
something for my neighbours <sup>3</sup>	1/8	3/6	0/5	0/15	3/8	2/6	3/7	5/17	8/0	1/6	1/7	1/16
16. I put glass items in	no	perhaps	no	no	perhaps	perhaps	no	perhaps	no	perhaps	no	ou
the glass recycling bin <sup>3</sup>	0/8	2/7	0/5	1/15	1/9	1/8	L/0	2/15	6/0	1/8	L/0	0/15
17. Work is just a way of	yes 7/6	yes 7/5	yes 2/5	perhaps	100 10/6	perhaps	perhaps	perhaps	no 0/5	x 2/0	0/6	no 0/16
Legend: no = no reason fi a different connotatic information (less than and yes = yes, there n	or concern on than inte 15 observat nay be a rea	i.e. 0-10% inded (con ions); perh ason for cc	of the res ceptual ev naps= perh ncern: >=	spondents ridence) or aps, there 30% met t	did not ur mentione is some re- he criteric	nderstand ed cultural ason for co	the wordi ly specifi oncern: 10	ng or forr c context )-30% of t	nulation (( (contextue he respone	semantic e el evidenc dents met t	e). $x = in$ the above	reported sufficient criterion;
Cell colour: Jellow – pour	innal unrear		SS-cultural	Valuity, g		unreat tot	une cross-	cultural va	alluity; uit	le – gener	аг vалuлу	Issue.
		-	· co · · ·	.1								

\* The Dutch version of the SEI-HS can be found in S3 Appendix. <sup>1</sup> Loneliness scale De Jong & Gierveld [23].<sup>2</sup> Dutch Public Health Monitor [21].<sup>3</sup> SCP Social excusion index [20].<sup>4</sup> Social Cohesion and Trust scale [22].

version of the SEI-H sion and Trust

level. The content of items 1-5 was derived from literature, life histories and interviews and judged by researchers and students [44]. Item 11 stems from a validated scale [45] that was translated into Dutch with back translation into English [22]. As far as we could establish, these items were not pre-tested among persons from disadvantaged social groups and/or low education or income.

Despite the fact that the Normative Integration items were pretested with lowincome and low-education participants, several issues with semantic and conceptual validity were encountered. The concept of normative integration touches on the moral underclass discourse, one of three models of social exclusion identified by Levitas [46]. The discourse focuses on the behavioural and attitudinal characteristics of the excluded and their imputed deficiencies. The Normative Integration scale developed by the SCP [20] reflects a fairly narrow spectrum of behaviours and attitudes that are relatively common in the general Dutch population. Our study showed that high scores on lack of normative integration do not necessarily reflect a lack of social commitment or anomie, but may reflect an inability to comply. For example, not helping your neighbours because you are handicapped yourself or not donating to good causes because you are in serious debt. One could argue that concept and social group are coming together here and that the failure to comply with given norms and values is part and parcel of the exclusion itself. From this point of view, the validity of the Normative Integration scale need not be jeopardised. High scores on the Normative Integration scale reflect high social exclusion, even though the interpretation of the concept and context may differ between respondents. Further research in the nonexcluded group could shed more light on this issue.

A strong point of our study is the use of a sequential explanatory mixed methods design for validation purposes. This approach is not very common. Usually, qualitative research precedes quantitative validation and not vice versa [47]. Although uncommon, the approach has been used before. For example, Morren et al.[48] interviewed respondents with deviant response style behaviour and Carlier et al.[49] approached groups with high levels of non-response. In our case, the design allowed us to address reliability and validity issues that were uncovered in the quantitative survey. It also allowed to confirm the ability of the social exclusion index to identify a diverse group of socially excluded persons including perpetrators of domestic violence, persons leading very isolated lives, victims of violent incidents such as armed robbery or rape, people with drug addiction or aggression disorder, and someone just released from detention.

There are some limitations to our study. The first limitation is related to the low response rate of the PHM especially among non-Western immigrant groups. Although the Public Health Services employed a large range of measures to increase participation of difficult to reach groups, a certain degree of selection bias e.g. for better integrated and educated immigrants, is inevitable. The great diversity within the qualitative research group gave us, however, confidence in the representativeness of the research outcomes. Another limitation is that the research was conducted only in urban areas.

Lastly, we classified the persons in our research based on their country of birth and that of their parents. This classification does not necessarily define their individual identity or represent meaningful social categories [50]. Gender, age, occupation, ethnic identity and educational level, may be more relevant in certain contexts than migration background. As more detailed knowledge becomes available, it becomes more difficult to make statements about immigrant groups in general [51].

# CONCLUSIONS

The results of this study support the cross-cultural validity of the SEI-HS in three major non-Western immigrant groups in the Netherlands. The findings suggest that the large differences in SE found between native Dutch and non-Western immigrant groups are real and not due to measurement bias. This raises serious concerns about the social inclusion of non-Western immigrants in the four largest cities in the Netherlands and its potential effect on health and wellbeing. Policy measures to reduce SE are urgently needed as well as more research into the mechanisms and risk factors of SE among immigrant groups and pathways to more social inclusion.

Further research is necessary to examine the content validity of the normative integration dimension of the SEI-HS and rephrasing semantically problematic items. The interviews showed that the lived experience of socially excluded people may differ from the majority population. In general, it is advisable to involve people in adverse social circumstances in the development of health related measures.

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# SUPPORTING INFORMATION

S1 Tables A-C. Differential item functioning in SEI-HS items with respect to migrant background, A: Surinamese, B: Moroccan and C Turkish versus native Dutch

S2 Table. Factor loadings items SEI-HS in adults of Surinamese, Moroccan and Turkish origin compared to the reference values in the general Dutch population

S3 Appendix. Dutch version of the SEI-HS

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#### Fatima

In een rijtjeswoning in Utrecht woont Fatima (63) met haar man Houssein. Het interview vindt plaats in het Berbers. Fatima zit onrustig op het puntje van de bank. De achterdeur en ramen staan open. Sinds het overlijden van haar eerste man, 25 jaar geleden, heeft Fatima last van paniek-aanvallen. '*Dan krijg ik het gevoel dat ik een gevangene ben in mijn eigen huid en moet ik naar buiten.*' Dit heeft een grote impact op hun leven.

Buren zijn behulpzaam, familieleden helpen waar dat kan, maar de situatie lijkt uitzichtloos. Hulp van een psycholoog is niet aan de orde. Fatima's angst voor afgesloten ruimten speelt een rol. 'N*ee nee nee ik ga niet naar die kantoortjes waar ze heen gaan. Ik ga niet.*' Maar Fatima heeft ook geen idee waar zij terecht kan en hoe er te komen.

Financieel redden ze het net, maar geld om spullen te vervangen hebben Fatima en Houssein niet. 'Het matras van mijn bed doe ik extra deken onder zodat ik geen last krijg van mij zij. Een matras is al gauw 125 euro en dat is veel.' Onderzoeker: 'Spreekt u een beetje Nederlands?' Fatima: 'Nee helemaal niet, als ik Nederlands sprak had ik tenminste niks om over te huilen. We willen het graag leren maar het lukt niet, het gaat mijn hoofd niet meer in.'

Gebaseerd op interviews voor Sociaal Uitgesloten in de grote stad, van Bergen et al. 2014.

The cumulation of ill health and low agency in socially excluded city dwellers in the Netherlands: how to better identify high-risk/high-need population segments with public health survey data

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# ABSTRACT

**Background.** Population segmentation and risk stratification are important strategies for allocating resources in public health, health care and social care. Social exclusion, which is defined as the cumulation of disadvantages in social, economic, cultural and political domains, is associated with an increased risk of health problems, low agency, and as a consequence, a higher need for health and social care. The aim of this study is to test social exclusion against traditional social stratifiers to identify high-risk/high-need population segments.

**Methods.** We used data from 33,285 adults from the 2016 Public Health Monitor of four major cities in the Netherlands. To identify at-risk populations for cardiovascular risk, cancer, low self-rated health, anxiety and depression symptoms, and low personal control, we compared relative risks (RR) and population attributable fractions (PAF) for social exclusion, which was measured with the Social Exclusion Index for Health Surveys (SEI-HS), and four traditional social stratifiers, namely, education, income, labour market position and migration background.

**Results.** The analyses showed significant associations of social exclusion with all the health indicators and personal control. Particular strong RRs were found for anxiety and depression symptoms (7.95) and low personal control (6.36), with corresponding PAFs of 42% and 35%, respectively. Social exclusion was significantly better at identifying population segments with high anxiety and depression symptoms and low personal control than were the four traditional stratifiers, while the two approaches were similar at identifying other health problems. The combination of social exclusion with a low labour market position (19.5% of the adult population) captured 67% of the prevalence of anxiety and depression symptoms and 60% of the prevalence of low personal control, as well as substantial proportions of the other health indicators.

**Conclusions.** This study shows that the SEI-HS is a powerful tool for identifying high-risk/high-need population segments in which not only ill health is concentrated, as is the case with traditional social stratifiers, but also a high prevalence of anxiety and depression symptoms and low personal control are present, in addition to an accumulation of social problems. These findings have implications for health care practice, public health and social interventions in large cities.

# INTRODUCTION

Changes in society and demographic trends are putting pressure on our health care system [1]. The ageing population is leading to an increase in multiple morbidities [2], while improved medical treatment is expanding the lifespan of individuals with these health conditions [3]. Over the coming years, health care expenditures in the Netherlands are expected to grow twice as fast as the economy [3]. Households in which social and medical problems accumulate bring in numerous professionals— often too late—and this puts pressure on municipal finances [3]. It is therefore more important than ever to deploy resources in health care, public health and social care in such a manner that the greatest health gains can be made. To help understand the needs of the population so that governances and services can be better planned and delivered, population segmentation and risk stratification are essential steps.

In Western countries, a strong socioeconomic gradient in health has been observed. Health appears to progressively increase with socioeconomic position [4] and to decrease with higher societal inequality [5]. Traditionally, education, income and profession are used as indicators for socioeconomic status [6], but other social stratifiers have also been used. The World Health Organization summarises the 8 stratifiers that are the most frequently assessed in health inequality monitoring, namely, place of residence (rural, urban, etc.), race or ethnicity, occupation, gender, religion, education, socioeconomic status and social capital or resources (PROGRESS) [7]. We expected that social exclusion (SE) would also be a good or even better candidate than these traditional social factors to describe and analyse the social stratification of health.

According to the World Health Organization (WHO), SE is rooted in an interplay of dynamic processes at the individual, household, community, country, and global levels. These processes are driven by unequal power relationships and lead to a cumulation of deprivations in the economic, social, cultural and political domains [8, 9]. There is ample evidence that SE impacts health and that, vice versa, ill health exacerbates social exclusion [10]. Mediation and moderation effects may also be in place [11-13]. In fact, health is so intricately linked to SE that it is considered by some as part and parcel of the concept itself [14]

In this paper, we explored SE as a promising stratifier for both health and low agency. Agency refers herein to the human capability to influence one's functioning and the course of events by one's actions [15]. According to Link and Phelan [16], differential access to resources such as knowledge, money, power, prestige and beneficial social connections is an important, or even the most important, reason why interventions to improve health are consistently less effective in low versus high socioeconomic groups. So-called "high agent" interventions do not work for low socioeconomic groups because participants must use their personal resources or "agency" to benefit [17-19]. Population interventions that require individuals to use a low level of agency, for example, food manufacturers reducing the salt content of bread, smoke-free public places and so-called "nudge" interventions, are likely to be most effective and

equitable [17]. At the core of SE lies the inability of persons to participate fully in society and make full use of the benefits that society offers. SE reinforces feelings of powerlessness, alienation, demoralization and lack of self-esteem [20, 21]. We therefore expected that SE may also be a good candidate to describe and analyse the social stratification of low agency.

To validly measure SE in routine public health monitoring, we previously developed the Social Exclusion Index for Health Surveys (SEI-HS) [22]. The measurement of SE in public health research is still in its infancy, and a generally accepted valid measure has not yet been developed [9]. Limitations related to earlier measures include a limited focus on only one aspect of SE, a lack of conceptual justification of indicator choice, a lack of measurement validation, undue length and unsuitability for monitoring in the general population [21]. The SEI-HS measures SE as a multidimensional concept involving cumulative disadvantages in the social, economic, cultural and political domains. It is based on extensive theoretical and empirical research [23, 24] and has been validated for the general population, as well as for the major non-Western immigrant groups in the Netherlands [25].

The aim of this study was to compare SE, as measured with the SEI-HS, with traditional social stratifiers as identifiers for high-risk/high-need population segments. We explored SE as a stratifier for health and low agency that potentially captures the information of most of the known stratifiers in a single measure. Our hypotheses were as follows:

- 1) SE is a stronger social stratifier than the commonly used social factors of education, income, labour market position and migration background.
- 2) SE is more strongly associated with low agency than the four abovementioned social factors.
- 3) Combining SE with one of the social factors will not improve its stratifying ability (as SE is the stronger social stratifier).

A social stratifier is considered to be stronger if it identifies strata with a larger health divide. The relative size of the health divide is measured by the relative risk (RR), and the absolute size is measured by the population attributable fraction (PAF). In epidemiology, the RR is the ratio of two risk estimates, and it is a statistic of choice for the comparison of risks between groups, as it is intuitively meaningful [26]<sup>3</sup>. The PAF estimates the proportion of the health problem that can be attributed to, or that is

<sup>&</sup>lt;sup>3</sup> While the frequently used odds ratio (OR) is an algebraic transformation of probabilities, the relative risk is intuitively more meaningful. To give an example: suppose that 30% of men and 10% of women in a given population have diabetes. The OR of men compared to women in this population is 3.9, which is calculated as (0.3/0.7)/(0.1/0.9). The RR of men compared to women is 3.0, which means that diabetes is 3-times as common in men than in women. The latter result is easy to grasp, while the first is quite abstract and difficult to explain to policy makers and practitioners. In practice, the OR is often interpreted as a RR. This is acceptable when the outcome is rare (<10%) as the value of OR will not be too different from that of RR. However, as the prevalence increases, the two ratios diverge, and the OR will tend to exaggerate the strength of the association [26]. Hence, we have a preference for the use of RRs in this study.

associated with, a particular risk factor, and thus represents the maximum health effect that can be achieved if the risk factor could be eliminated. We compared the RR and PAF of the stratifiers to identify at-risk populations for cardiovascular risk (diabetes, high blood pressure, smoking, obesity and inactivity), cancer, low self-rated health, anxiety and depression symptoms and low personal control, and we explored whether SE captures in a single measure the information that is normally obtained by the four abovementioned social factors. Data from the 2016 Public Health Monitor from four major cities in the Netherlands were used to test the hypotheses.

## **METHODS**

### **Data collection**

The data in this study were collected by the Public Health Services of Amsterdam, Rotterdam, The Hague and Utrecht as part of the Public Health Monitor questionnaire 2016. The population sizes of the four cities ranged from 835 thousand in Amsterdam to 630 thousand, 520 thousand and 340 thousand in Rotterdam, The Hague and Utrecht, respectively. In each city, a stratified sample was drawn from the adult population aged  $\geq$  19 in non- institutionalised households based on neighbourhood and age category. Subjects were sent an invitation letter and up to three reminders by mail. The average response rate to the survey was 33.2%. Statistics Netherlands (CBS) enriched the monitoring data with administrative information regarding migration background, standardised household income and household composition.

#### Measures

#### Dependent variables

- <u>Health.</u> The following measures were included:
  - cardiovascular disease (CVD) risk factors: self-reported general practitioner (GP) diagnosis of diabetes; self-reported GP diagnosis of high blood pressure; current smoking; obesity (BMI 30 or higher based on self-reported height and weight); and inactivity (not meeting the daily recommended 30 minutes of moderate intensive physical activity on any day of the week).
  - cancer: self-reported GP diagnoses of cancer;
  - anxiety and/or depression symptoms: score 30 or higher on the 10-item Kessler Psychological Distress Scale (K10) versus score < 30 [27];</li>
  - self-rated health: fair or poor versus good or very good.
- <u>Agency</u>. The 7-item Pearlin Mastery Scale was used to measure the extent to which an individual regards his or her life chances as being under his or her personal control rather than fatalistically ruled: low (<20) versus high (>=20) personal control.

#### Independent variables

- <u>Social exclusion.</u> Social exclusion (SE) was measured with the Social Exclusion Index for Health Surveys (SEI-HS) [22]. The index consists of 17 items that measure four dimensions of SE: 1) social (limited social participation), 2) economic (material deprivation), 3) political (inadequate access to basic social rights) and 4) cultural (lack of normative integration). The scores were dichotomised into 1) moderate to strong exclusion and 2) some or no exclusion. As the cut-off point, we used the 95th percentile score in the 2012 Dutch adult population [22].
- <u>Social stratifiers.</u> The following four social factors were included:
  - educational level: highest completed education (self-report) low, i.e., no schooling or elementary schooling versus low-middle, middle and high schooling;
  - household income: standardised disposable annual household income after payment of income tax and social contributions lower than or equal to €16,100 versus higher<sup>4</sup>;
  - labour market position: self-reported status low, i.e., unemployed, disabled for work and/or on social assistance, versus "other", i.e., paid labour, retired, housewife/man and/or student; and
  - migration background: mother and/or father born in a non-Western country versus born in the Netherlands and/or other Western countries (source: Statistics Netherlands).

#### General characteristics.

The following measures were included: sex, age and household composition. Age was treated as a continuous variable. Household composition was divided into four categories: family with children (i.e., living with partner, parent(s) and/or other adult(s) with children), family without children (ditto without children), single parent family and living alone.

### Statistics

First, we described the demographic composition, health, level of personal control and social stratification of the study population. To account for the complex sampling design and selective non-response, sample weights were calculated by Statistics Netherlands based on a linear model with 9 sociodemographic variables and their interaction terms [28]. For each of the measures, weighted descriptive statistics (percentages or means with standard deviations) were computed, and for the demographic measures, unweighted statistics were also computed.

 $<sup>^4</sup>$  €16,100 corresponds to the lowest income quintile in the Netherlands (source: Statistics Netherlands).

Second, we estimated the relative risk with a 95% confidence interval (CI) for each health indicator and personal control by SE, education, income, labour market position and migration background. Complex samples cross tabs with relative risk tests were used. Herein, the RR represents the probability of a health indicator or personal control being present in the exposed group ( $P_{SE+}$  or  $P_{SF+}$ ) divided by the probability in the non-exposed group ( $P_{SE-}$  or  $P_{SF}$ -), in which SE is social exclusion and SF is one of the social factors; + is present and – is not present. An RR between 3 and 8 was considered strong, that between 1.8 and 3.0 was considered moderate and that between 1.4 and 1.8 was considered modest [26].

Third, we calculated the population attributable fractions from the RRs and the prevalences of SE and social factors (SF) with the following formulas:

$$PAF_{SE} = P_{SE^+} * (RR_{SE} - 1)/(P_{SE^+} * (RR_{SE} - 1) + 1).$$
$$PAF_{SE} = P_{SE^+} * (RR_{SF} - 1)/(P_{SE^+} * (RR_{SE} - 1) + 1).$$

PAFs and RRs were also calculated for the four dimensions of SE: limited social participation, material deprivation, inadequate access to basic social rights and lack of normative integration.

Finally, we calculated the overlap between SE and the four social factors, explored the contribution of SE to the stratifying power of the social factors and investigated the added value of combining SE with one of the social factors in terms of higher RRs and PAFs. Significance was assumed if there was no overlap between the 95% CIs.

### RESULTS

#### **General characteristics**

The sample consisted of 18,401 women (55.3%) and 14,884 men (44.7%), with a mean age of 57.1 years (SD 17.7) (Table 1). Almost half of the respondents lived with a partner and no children (46.4%), and over one-third (34.5%) lived alone. In the weighted sample, the mean age was lower, i.e., 44.9 years (SD 17.5), and the proportion living with partners and no children was lower (42.9%), as was the proportion living alone (22.7%). Weighted data were used in all subsequent analyses.

	% / me	an (SD)	
	Unweighted	Weighted #	
DEMOGRAPHICS			
Female (%)	55.3	51.1	
Mean age (sd)	57.1 (17.7)	44.9 (17.5)	
Household composition (%)			
Family with children <sup>1)</sup>	13.8	21.7	
Family without children <sup>2)</sup>	46.4	42.9	
Single parent	5.3	7.4	
Living alone	34.5	22.7	

Table 1. General characteristics of the study sample, Public Health Monitor 2016 (N=33,285)

# Sampling weights were calculated by Statistics Netherlands based on a linear model with 9 sociodemographic variables and their interaction terms [28].

1) Living with partner, parent(s) and/or other adult(s) with children; 2) ditto, without children.

#### Prevalence of health indicators, personal control, SE and social factors

Smoking was the most prevalent CVD risk factor, as one in four adults reported smoking (25.6%). Self-rated fair or poor health (SRH) was reported by 27.3%. We found a low score for personal control in 11.9% of the adult population and a low score for anxiety and depression symptoms in 9.4% of the population. (Table 2).

 Table 2. Prevalence of health indicators and personal control (weighted #)

	%
CVD risk factors	
Diabetes	7.0
High blood pressure	14.1
Current smoking	25.6
Obesity (BMI 30 or higher)	13.4
Inactivity	9.3
Cancer	2.8
Self-rated health fair or poor	27.3
Anxiety and depression symptoms	9.4
Low personal control	11.9

# Sampling weights were calculated by Statistics Netherlands based on a linear model with 9 sociodemographic variables and their interaction terms [28].

One in ten adults were moderately to strongly socially excluded (10.3%); 9.0% reported a low educational level; 14.1% reported being unemployed, disabled for work, living on social assistance and without a paid job, and 31.8% of the adult population had a non-Western migration background. In the cities of Rotterdam and The Hague, these percentages were generally higher than those in Amsterdam and Utrecht. Only income showed a different pattern, with the highest rates of low income

being found in Amsterdam and Rotterdam (Table 3).

		<b>D</b> 44 <b>J</b>	The	<b>.</b>	TOTAL
	Amster-dam	Rotter-dam	Hague	Utrecht	TOTAL
SOCIAL EXCLUSION					
SEI-HS index					
Moderate to strong	8.1	12.0	13.8	7.1	10.3
Some or no	91.9	88.0	86.2	92.9	89.7
SOCIAL RISK FACTORS					
Educational level (self-reported) @					
Low	7.4	11.9	9.5	6.9	9.0
Not low	92.6	88.1	90.5	93.1	91.0
Standardised annual household					
income					
Low: < 16,100 euro	26.0	25.4	22.1	23.8	24.7
Not low	74.0	74.6	77.9	76.2	75.3
Labour market position					
Low: unemployed, disabled, on social assistance	12.8	16.7	15.5	10.3	14.1
Not low	87.2	83.3	84.5	89.7	85.9
Migration background					
Native Dutch	49.5	52.3	48.7	68.7	52.9
Western migration background	18.2	12.1	17.0	11.2	15.3
Non-Western migration background	32.2	35.6	34.3	20.1	31.8

Table 3. Prevalence of social exclusion and other social factors by city (weighted percentages#)

# Sampling weights were calculated by Statistics Netherlands based on a linear model with 9 sociodemographic variables and their interaction terms [28].

- <sup>@</sup> Low: no or elementary schooling (PO); Not low: general secondary education, primary vocational education (MAVO, LBO); higher secondary education, secondary vocational training (HAVO, VWO, MBO); higher professional education and university (HBO, WO).
- <sup>8</sup> For this question, multiple answers were possible. The answers were categorised hierarchically with "> 20 hrs/week paid labour" first, followed by "1-20 hrs/week paid labour" and "retired". Those who checked "I am unemployed/job-seeking", "I am disabled for work" or "I am on social assistance" and did not check one of the former three categories were classified as "unemployed, disabled, on social assistance". The remaining respondents who checked "I am housewife/man" or "I am studying" were classified as "housewife/man" or subsequently classified as low, and the remaining categories were classified as not low.

#### Performance of SE as social stratifier

The RRs and PAFs for SE are listed in Table 4, columns 2 and 3, respectively. All relationships were significant at  $\alpha = 0.05$ . The strength of the associations, however, varied considerably between health indicators. The RR was lowest for cancer (1.31) and highest for inactivity (3.29) and anxiety and depression symptoms (7.95). The PAF for cancer was 3.1%, and that for inactivity and anxiety and depression symptoms was 19.0 % and 41.6%, respectively. The RR for low personal control was 6.36, with

a PAF of 35.5%. This outcome signifies that socially excluded adults have a 6.36-fold higher chance of experiencing low personal control than non-excluded adults and that a hypothetical reduction of 35% in the prevalence of low personal control could be achieved if the socially excluded segment of the population were to have the same level of personal control as the rest of the population. An overview of RRs and PAFs is given in Figures 1a and 2a.



- Figure 1. Relative risks of SE and four social factors, single (Panel a) and combined with SE (Panel b).
- Panel 1a. First orange dot: adults with low education had a 3.8 times higher risk of diabetes than other adults. Last orange dot: adults with low education had a 3.2 times higher risk of low personal control than other adults.
- Panel 1b. First orange dot: adults with low education and/or SE had a 3.2 higher risk of diabetes than other adults. Last orange dot: adults with low education and/or SE had a 5.9 times higher risk of low personal control than other adults.



Figure 2. Population attributable fractions of SE and four social factors, single (Panel a) and combined with SE (Panel b).

- Panel 2a. First orange dot: if adults with low education would have the same risk of diabetes as other adults, the prevalence of diabetes would be reduced by 20%. Last orange dot: if adults with low education would have the same risk of low personal control as other adults, the prevalence of low personal control would be reduced by 27%.
- Panel 2b. First orange dot: if adults with low education and/or SE would have the same risk of diabetes as other adults, the prevalence of diabetes would be reduced with 16%. Last orange dot: if adults with low education and/or SE would have the same risk of low personal control as other adults, the prevalence of low personal control would be reduced by 45%.

#### Performance of other social factors

Table 4 columns 4 to 11 present the RRs and PAFs for each combination of social factors and health indicators. Low educational level showed a strong RR for diabetes (3.83) and moderate RRs for all other health indicators except current smoking, which was not significant. Low labour market position showed strong RRs for inactivity (3.11), low SRH (3.04) and anxiety and depression symptoms (5.79) and moderate RRs for diabetes and obesity. We did not find strong RRs in relation to low household income and non-Western migration background. Moderate RRs were found for inactivity, low SRH and anxiety and depression symptoms by non-Western migration background. The RRs for low personal control were strong for low education (3.17) and low labour market position (4.66) and moderate for low income and non-Western migration background. The PAFs showed a similar pattern.

#### SE compared with other social factors

Figure 1a confirms that SE had much higher RRs for anxiety and depression symptoms and low personal control than did the four social factors (see also Table 4). These higher RRs resulted in higher PAFs for anxiety and depression symptoms and low personal control (Figure 2a). The RRs of SE were also higher than the RR for smoking by low education; the RRs for diabetes, high blood pressure, obesity, cancer and low SRH by low income; and the RRs for high blood pressure, smoking and cancer by non-Western migration background. The RRs of SE were lower than the RRs for diabetes and high blood pressure by low education. In all other cases, the RRs of SE were not significantly different from those of the other four stratifiers (Figure 1a, Table 4).

#### **Dimensions of SE**

The RRs of the four dimension scales of the SEI-HS were found to be significant at  $\alpha$ =0.05 for all health indicators and low personal control, with two exceptions. Only the RRs of the cultural and political dimensions (inadequate access to basic social rights and lack of normative integration) for cancer were not significant. The social and economic dimensions (limited social participation and material deprivation) tended

to show somewhat higher RRs than those for the political and cultural dimensions, especially for anxiety and depression symptoms and low personal control. The RRs and PAFs are shown in Table A1 (Additional file 1).

### Overlap SE and social factors and combined effect

To test the third hypothesis, we examined the overlap between the social factors and SE and the added value of combining SE with one of the social factors. Over one-third of adults with a low labour market position were socially excluded (34.1%). Moderate to strong social exclusion was also found in at least one in five adults with low education (25.7%), low household income (21.5%) or non-Western migration background (20.7%). Therefore, the overlap with SE was considerable, yet the social factors identified mainly non-excluded population groups (66-79%) (Table A2, Additional file 1).

Figure 3 (and Table A3 Additional file 1) shows that for many health indicators, the RRs were lower in the non-excluded group than in the excluded group. The reference category here consisted of those who were not socially excluded and had no SF present (SE-SF- group). The reference value was set to 1. Figures 3a-d show that, especially for anxiety and depression symptoms and low personal control, the differences between the RRs were high. Respondents with low education and SE had an RR of 10.53 for anxiety and depression symptoms, while respondents with low education who were not socially excluded had an RR of 2.58, all of whom were compared to the non-exposed group (SE-SF- group) (Figure 3a). For low labour market positions, the RRs of anxiety and depression symptoms were 15.02 when combined with SE and 5.17 when not (Figure 3c). A large part of the stratifying power of low education and low labour market position is thus associated with SE. The same pattern can be seen for other health indicators and social factors, with a few exceptions; the  $\triangle RRs$ of cancer, obesity and high blood pressure by low education and low labour market position and the  $\triangle RR$  of diabetes by low education were not significantly higher with SE than without SE (Table A3 Additional file 1). In all other combinations, the RRs were significantly higher for the SF+SE+ group than for the SF+SE-group. It should be noted, however, that although the RRs in the SF+SE-group were generally lower, most of the RRs were significantly higher than 1 (31 out of 36) and would in other studies, with less pronounced results, be seen as relevant (Table A3 Additional file 1).

As shown in Table 5 and Figures 1b and 2b, we investigated the potential contribution of the social factors to the stratifying power of SE. The panels show for each combination of SE and the social factors the RRs (1b) and PAFs (2b) for ill health and low personal control. The blue diamonds represent the RRs and PAFs of SE alone. In only three cases did the combination of SE with one of the social actors yield a higher RR than that of SE alone. The RRs for diabetes and high blood pressure increased when SE was combined with of low education. This was to be expected, as we saw in Figure 1a that the RRs of low education were significantly higher for diabetes and

	Social exc. (10.3%	lusion )*	Low educati	on (9.0%)*	Low househ (24.7)	old income %)*	Low labour m position (14.)	tarket 1%)*	Non-Western background	migration (31.8%)*
	RR	PAF	RR	PAF	RR	PAF	RR P/	٨F	RR	PAF
CVD risk factors										
♦ Diabetes	2.25	11.33	3.83↑	20.27	1.43 [	9.66	2.12 13	.65	2.06	25.30
	(1.96-2.57)		(3.42-4.28)		(1.27-1.61)		(1.86-2.42)		(1.87-2.28)	
High blood pressure	1.63	6.09	2.37↑	10.96	<i>1.03</i> L	0.64	1.66 8.3	53	1.12 [	3.63
)	(1.47-1.81)		(2.17-2.59)		(0.94-1.12)		(1.51-1.83)		(1.03-1.21)	
♦ Current smoking	1.58	5.64	0.98 [	-0.22	1.41	9.27	1.51 6.	73	<i>1.02</i> ↓	0.57
)	(1.46—1.71)		(0.88 - 1.08)		(1.32 - 1.51)		(1.40-1.63)		(0.95-1.09)	
◆ Obesity	1.92	8.60	2.45↑	11.57	1.34 (	7.71	2.05 12	.85	1.68	17.72
	(1.72 - 2.14)		(2.22-2.71)		(1.22 - 1.47)		(1.85-2.26)		(1.54-1.82)	
◆ Inactivity	3.29	18.99	2.71	13.33	1.86 ↓	17.54	3.11 22	.97	2.48 (	32.01
•	(2.92-3.70)		(2.40 - 3.06)		(1.66-2.08)		(2.78 - 3.50)		(2.24-2.74)	
Cancer	1.31	3.11	1.90	7.46	0.82 ↓	-4.75	1.56 7.	30	0.55 ↓	-16.68
	(1.02 - 1.69)		(1.53-2.36)		(0.66-1.02)		(1.24 - 1.96)		(0.44-0.69)	
Low self-rated health	2.83	15.83	2.71	13.33	1.71 ↓	14.87	3.04 22	.31	1.82 (	20.73
	(2.69-2.99)		(2.57 - 2.85)		(1.62 - 1.80)		(2.89 - 3.19)		(1.73 - 1.92)	
Anxiety /depression	7.95	41.60	2.79 [	13.87	2.46 (	26.52	5.79 ( 40	.33	2.69 (	34.93
4 5	(7.19-8.78)		(2.48 - 3.14)		(2.21-2.75)		(5.22-6.43)		(2.42-2.98)	
Low personal control	6.36	35.49	3.17 ↓	16.34	2.08 ↓	20.98	<b>4.66</b> ↓ 34	.06	2.08 ↓	25.67
1	(5.87 - 6.91)		(2.88-3.50)		(1.89-2.28)		(4.28-5.09)		(1.91 - 2.28)	

Table 4. Relative risk (95% CI) and population attributable fraction for SE and social factors<sup>#  $\alpha$ </sup>

\* weighted prevalence, population 19 years and older, 04, 2010. # In italic if not significant at  $\alpha = 0.05$  and bold if RR strong, i.e., between 3 and 8 [26]. & L RR is significantly lower than the RR of SE, i.e., no overlap of 95% CIs, f RR is significantly higher than the RR of SE

6



Figure 3. Relative risk by social factor SF, without and with SE, compared to the non-exposed group (SF-SE- group)

high blood pressure than the RRs of SE alone. Additionally, the RR for poor SRH increased when SE was combined with a low labour market position (Figure 2a). In all other cases, combining SE with one of the four social factors resulted in equal or lower RRs (Table 5).

The PAFs were all substantially higher than those for SE alone, as shown in Figure 2b. For example, the RR and PAF for anxiety and depression symptoms by SE combined with low labour market position were 8.54 and 59.45, respectively, while those by SE alone were 7.95 and 41.60, respectively. This combination appears to be the most promising combination for population segmentation. Together, these two stratifiers, SE and low labour market position, identified 67.2% of the prevalence of anxiety and depression symptoms and 60.4% of the prevalence of low personal control in the adult population of the four study cities (Table 6). Worth mentioning are also the PAFs of inactivity (30.93), low SRH (29.71), diabetes (19.58), obesity (17.57) and high blood pressure (11.49) in this population segment (Table 5).

	SE (10.3	*(%)	<i>SE</i> + <i>low ed</i> 1 (16.7%)	ucation )*	SE + low hou income (29.	usehold 0%)*	SE + low la market pos (19.4%)	bour ition *	SE + no Western mig background (	n- gration 34.8%)*
	RR	PAF	RR	PAF	RR	PAF	RR	PAF	RR	PAF
CVD risk factors										
<ul> <li>◆ Diabetes</li> </ul>	2.25 (1.96-2.57)	11.33	<b>3.22</b> ↑ (2.89-3.58)	27.07	1.70↓ (1.52-1.89)	16.83	2.25 (2.01-2.53)	19.58	2.24 (2.03-2.47)	30.14
<ul> <li>High blood pressure</li> </ul>	1.63 (1.47-1.81)	60.9	2.03↑ (1.87-2.20)	14.69	$1.16\downarrow$ (1.07-1.26)	4.41	1.67 (1.53-1.82)	11.49	$1.21 \downarrow (1.12-1.30)$	6.76
<ul> <li>Current smoking</li> </ul>	1.58 (1.46-1.71)	5.64	1.32 ↓ (1.23-1.42)	5.15	1.52 (1.42-1.61)	13.01	1.53 (1.43-1.63)	9.31	$1.16 \downarrow (1.09-1.24)$	5.28
◆ Obesity	1.92 (1.72-2.14)	8.60	2.31 (2.12-2.52)	18.00	$1.54 \downarrow$ (1.41-1.68)	13.60	2.10 (1.92-2.29)	17.57	1.82 (1.68-1.98)	22.29
◆ Inactivity	<b>3.29</b> (2.92-3.70)	18.99	<b>3.30</b> (2.96-3.67)	27.80	2.28 ↓ (2.05-2.54)	27.11	<b>3.30</b> (2.96-3.68)	30.93	2.98 (2.69-3.30)	40.83
Cancer	1.31 (1.02-1.69)	3.11	1.64 (1.36-1.98)	9.74	0.95 (0.79-1.15)	-1.41	1.48 (1.22-1.81)	8.60	0.75 ↓ (0.61-0.90)	-9.92
Low self-rated health	2.83 (2.69-2.99)	15.83	<b>3.11</b> (2.96-3.27)	26.14	2.11 ↓ (2.00-2.22)	24.30	<b>3.18</b> ↑ (3.02-3.34)	29.71	2.20↓ (2.08-2.31)	29.40
Anxiety /depression	<b>7.95</b> (7.19-8.78)	41.60	<b>6.44</b> ↓ (5.78-7.18)	47.67	<b>4.68</b> ↓ (4.17-5.25)	51.63	<b>8.54</b> (7.63-9.57)	59.45	<b>4.60</b> ↓ (4.10-5.17)	55.66
Low personal control	<b>6.36</b> (5.87-6.91)	35.49	<b>5.92</b> (5.44-6.45)	45.20	<b>3.61</b> ↓ (3.31-3.95)	43.09	<b>6.42</b> (5.89-6.99)	51.30	<b>3.31</b> ↓ (3.03-3.61)	44.56
* Weighted prevalences. p	onulation 19 ve	sars and c	lder G4 2016							

Table 5. Relative risk (95% CI) and population attributable fraction for combinations of SE and social factors  $^{\#\&}$ 

ighted prevalences, population 19 years and older, G4, 2016.

& L RR is significantly lower than the RR of SE alone, i.e., no overlap of 95% CIs,  $\uparrow$  RR is significantly higher than the RR of SE alone. # In *italic* if <u>not</u> significant at  $\alpha = 0.05$  and **bold** if RR strong, i.e., between 3 and 8 [26].

Cumulation of ill health and low agency

6

	SE sea	gment	SE+low lab segr	our market nent
	Prevalence	Proportion	Prevalence	Proportion
CVD risk factors				
Diabetes	13.8	20.2	12.3	35.0
High blood pressure	21.4	15.5	20.3	28.4
Current smoking	38.2	15.3	35.5	26.9
Obesity (BMI 30 or higher)	23.5	17.6	23.0	33.0
Inactivity	24.3	26.6	20.3	43.8
Cancer	3.6	12.8	3.7	26.1
Self-rated health fair or poor	64.4	24.4	59.3	43.3
Anxiety and depression symptoms	42.4	47.5	31.5	67.2
Low personal control	48.6	41.7	35.5	60.4

Table 6	Prevalence and	l proportion	of ill	health	and	personal	control	by	population	segment
	(%'s, weighted	1 <i>#</i> ).						2		e e

# Sampling weights were calculated by Statistics Netherlands based on a linear model with 9 sociodemographic variables and their interaction terms [28].

<sup>@</sup> The proportion of the population with the condition in question, that falls within this segment. For example row 1 Diabetes: of the 174,134 socially excluded adults 24,030 or 13.8% reported diabetes. The socially excluded population segment thus accounted for 20.2% of all 118,965 diabetes cases (24,030/118,965).

# DISCUSSION

Our first hypothesis, i.e., that SE is a stronger social stratifier than the commonly used social factors of education, income, labour market position and migration background, was confirmed for all four stratifiers in relation to anxiety and depression symptoms and for low household income and non-Western migration background in relation to the other health indicators. The second hypothesis, i.e., that SE is more strongly associated with low agency than the four social factors was also confirmed. The differences found for low personal control (as an indicator of low agency) were substantial. The third hypothesis, i.e., that combining SE with one of the social factors would not improve its stratifying ability, was confirmed in terms of RRs but not in terms of PAFs.

The study showed a remarkable 7.9-fold higher chance of experiencing anxiety and depression symptoms in socially excluded persons in urban areas of the Netherlands compared to individuals who were not socially excluded, which was significantly higher than that found for low education, low income, low labour market position and non-Western migration background. One might suspect overlapping symptoms between SE and anxiety and depression symptoms, but this was not found to be the case. SE and anxiety and depression are theoretically distinct concepts. Both

were measured with validated instruments, namely, the SEI-HS for SE [22] and the Kessler-10 scale for anxiety and depression symptoms [27], respectively. The items of the scales reflect the different underlying concepts. The SEI-HS items ask, for example, about having enough money to heat one's home, missing the pleasure of the company of others, satisfaction with one's housing, giving money to good causes, etc., while the K10 scale items specifically ask about feeling tired, hopeless, restless, depressed, nervous, worthless, etc. There are no overlapping items.

The K10 scale was originally developed to measure psychological distress, which is a common underlying factor in severe mental illness, in the general population [27] and has since been used to screen for anxiety and, in particular, depression [29, 30]. A high score on the K10 scale may indicate the presence of an anxiety or a depressive disorder, as well as a response to a specific stressor or demand [31]. Persons in a situation of social exclusion are, by definition, facing multiple problems in different domains of life, including economic and social domains and the lack of access to basic social rights. The emotional, cognitive and psychophysiological manifestations measured with the K10 scale may thus be a reaction to the situation that socially excluded people are generally in [31], as well as the result of prolonged exposure to chronic stressors in the form of depression, generalised anxiety and other psychological disorders [32, 33]. This may explain some of the associations found in this study.

In addition to differential exposure to stress, differences in coping mechanisms and resources may also influence the risk of psychosocial distress. SE citizens are exposed to more stressors, such as financial debts, loneliness, poor housing conditions and other social problems, and their coping mechanisms are also less effective than those of their counterparts. That is why the confirmation of the second hypothesis is crucial. People with a higher level of personal control may appraise themselves as being capable of coping with or controlling problems in their life and therefore may be less physiologically impacted by stressful events and ongoing situations [34, 35]. As they are more likely to view their health as controllable, they might exercise healthier behaviour and the better management of their health [35]. As almost 50 percent of the socially excluded citizens in the four Dutch cities reported low personal control, compared to 5.2% in the rest of the city population, this finding has implications for health care practice, public health interventions and social care in these cities.

Regarding physical disorders (diabetes, high blood pressure, obesity), lifestyle factors (smoking, inactivity) and low SRH, the first hypothesis was confirmed for low household income and non-Western migration background but not for low education and low labour market position. Low education (no or elementary schooling) and low labour market position (unemployed, disabled for work and/or on social assistance) appeared to be stronger social stratifiers in this population than were low income (lowest quintile disposable household income) and non-Western migration background. In the Netherlands, educational level is commonly used as the standard indicator of socioeconomic status in health research [36]. Our analyses showed that neither the less

educated nor the other three social groups are homogeneous. We identified segments within these groups as those with higher and lower risks of ill health related to SE. Educational level, income and occupational status are good predictors of differences in (perceived) health but are not necessarily also the explanatory factors or the direction of solution [37]. Dutch health policies are now mainly aimed at compensating for a lack of knowledge through information, strengthening individual skills and promoting healthy behaviours, which is not enough to reduce health inequities [37].

The third hypothesis was confirmed only in terms of RRs. As SE is the strongest stratifier, combining SE with one of the four social factors did not lead to an increase in RRs. PAF is dependent not only on RR but also on the prevalence of exposure in the population. The proportion of people with SE and/or, for example, low education (16.7%) or low labour market position (19.4%) is of course higher than with SE alone (10.3%). The choice of whether to target a small group with a high RR or a larger population segment with a lower RR will depend on policy goals, opportunities and political values [38]. In-depth analyses per city can provide guidance here. From a population health perspective, one should consider the potential impact on those with different levels of risk for disease within a population, including those in underrepresented or underserved groups [39].

### Implications for policy, practice and research

We see a number of ways in which health care practice, public health interventions and social care services could be adapted to realise health gains for this population segment based on disease patterns and characteristics that influence the interaction with health and care services.

The first direction is taking agency into account in health care, public health and social care. In health care, a tailor-made and pro-active approach informed by data [40] could make a difference for persons with low agency, as could patient-centred care [41]. A promising development is DIABLEND, which is an integrated approach utilised in two deprived neighbourhoods in The Hague for personalised lifestyle optimisation in people with type-2 diabetes [42]. In public health, the focus for this group should be on the development and implementation of interventions that require little agency and explicitly enhance self-esteem and effective coping mechanisms [17, 43, 44] and increase social support as an important contributor to feelings of personal autonomy [45]. Good examples here are the Amsterdam Healthy Weight Programme that promotes a healthy food environment in which the healthy choice becomes the easy choice [46] and the municipality of Utrecht facilitating local support groups working together on building self-confidence, self-determination, healthy social relationships, meaningful roles and skills [47]. In social care too, agency should not be taken for granted. Pathways to Empowerment (Krachtwerk) is a good example, of a programme that is successfully applied in social and women's shelters in the G4. This programme aims to improve the quality of the daily lives of persons who experience loss of control in their lives by focusing on their strengths and stimulating their personal agency, participation in society, and self-direction in life [48].

A second direction is addressing the convergence of health and social problems in this population segment. Cross-domain working is still in its infancy and in practice, it is hard to get off the ground [3]. The Dutch programme "The Right Care in the Right Place" sets an example by advocating a different perspective on sickness and health, with more focus on what people need to be able to function and less on what the care system has to offer, starting with people's capabilities, vitality, resilience and wishes [3]. A good example is the introduction of Powerful Basic Care (Krachtige Basiszorg) within deprived areas in the G4 [49]. In social care, more attention should be given to health and health promotion.

A third direction is paying more attention to upstream policies at the meso and macro levels. SE is not just an individual problem. Lack of social cohesion, discrimination and stigma, deprived neighbourhoods, complex bureaucratic procedures, individualization, high demands on people's self-reliance and lagging social benefits are all factors that affect SE and health. The issue we should pursue is how to ensure that people who are on social benefits, and those we are unemployed or disabled and cannot work, can participate fully in our society; i.e., how do we make our institutions inclusive and build up self-respect and agency instead of distorting these capabilities? A good example here is the application of scientific evidence, e.g., on Mobility Mentoring®, to create stress-sensitive services within the municipality of Utrecht [47]. Room for future social experiments and comparative research is needed.

The fourth and last direction is not forgetting those who have already fallen through the cracks of society, i.e., the homeless, people living in protected and sheltered housing, detainees and undocumented immigrants, all of whom did not participate in this research. It is important to incorporate these groups in regular health care, prevention and social policies to prevent further exclusion.

#### **Strengths and limitations**

This study has some major strengths and limitations. The strong points include the use of a large representative sample, the inclusion of all major lifestyle and health outcomes in terms of mortality and morbidity and the employment of validated instruments to measure social exclusion, anxiety and depression symptoms and personal control. The limitations are as follows. First, as in any cross-sectional study, no causal relations could be examined. The PAFs calculated in this study are largely theoretical and do not necessarily hold in practice. The PAFs herein represent the proportional reduction in overall morbidity or unhealthy behaviour that would occur if the lowest social stratum would experience the same rate as the rest of the population. No rigorous statistical testing took place, as this was not considered relevant for the purpose of the research and the exploratory nature of the study. In addition, confounding has not been taken into account. Our goal was to identify population segments with high levels of ill health and low personal control in a given context. In a different social context, a comparable study could lead to different results. We expect, based on additional

analyses per city that are not shown herein but are available from the authors, that the results could be generalised to urban areas with similar socioeconomic characteristics. To allow for future generalizations, factors at the meso and macro levels should be included, such as urbanicity, neighbourhood characteristics, welfare and social policies. In this study, we treated SE, education, income, labour market position and migration background as micro-level characteristics of individuals, while these factors also reflect the underlying social and economic structure. Another limitation of this study is that persons without a fixed address and those living in institutions were not included in the Public Health Monitor, which could have led to an underestimation of the RRs and PAFs. A final limitation is that most health indicators were self-reported. Self-reported measures are prone to social desirability bias and recall bias. There are no concrete indications for differences between social groups in the magnitude or direction of these biases, but it cannot be ruled out.

# CONCLUSIONS

This study shows that the SEI-HS is a powerful tool for identifying high-risk/highneed population segments in which not only ill health is concentrated, as is the case with traditional social stratifiers, but also an extremely high prevalence of anxiety and depression symptoms and low personal control are present, in addition to an accumulation of multiple problems in different domains of life. The combination of SE with a low labour market position captured the largest part of the prevalence of anxiety and depression symptoms (67%) and low personal control (60%) in 19.5% of the population, as well as a substantial portion of other risk factors and negative health outcomes. Significant health gains are likely to be achieved by tailoring health care practice, public health interventions and social care to the needs and capacities of this socially excluded and low labour market group. More in-depth analysis of PHM data is recommended at the local level to sharpen the local profile of the socially excluded population segments per city. In general, more qualitative research, comparative studies and experiments are needed regarding the impact and interaction of meso- and macro-level factors on the triangle formed by SE, health and low agency.

# LIST OF ABBREVIATIONS

BMI:	body mass index
CI:	confidence interval
CVD:	cardiovascular disease
GP:	general practitioner
K10:	10-item Kessler psychological distress scale
PAF:	population attributable fraction
PROGRESS:	place of residence, race or ethnicity, occupation, gender, religion education, socioeconomic status and social capital or resources
RR:	relative risk

SD:	standard deviation
SE:	social exclusion
SEI-HS:	Social Exclusion Index for Health Surveys
SF:	social factor
SRH:	self-rated health
WHO:	World Health Organization

## GLOSSARY

Social exclusion

The cumulation of disadvantages in social, economic, cultural and political domains. - A person is socially excluded if he/she cannot participate fully in society and make use of the benefits that society offers.

Social Exclusion Index for Health Surveys (SEI-HS)

Validated instrument to measure the multidimensional concept of social exclusion.

Agency

The human capability to influence one's functioning and the course of events by one's actions.

Personal control

The extent to which an individual regards his or her life chances as being under his or her personal control rather than fatalistically ruled.

Relative risk (RR)

The risk of a certain event (disease, risk factor, etc.) in one group compared to the risk of the same event in another group.

#### Population attributable fraction (PAF)

The proportion of the health problem that can be attributed to, or that is associated with, a particular risk factor.

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## SUPPLEMENTARY MATERIALS

Table A1. Relative risk (95% CI) and PAF for four dimensions of social exclusion.

- Table A2. Overlap between social exclusion and four social factors (weighted percentages).
- Table A3. Relative risks (95% CI) for social factors with and without SE and differential effects.

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#### Roy

In een portiekwoning in Den Haag woont de Nederlands-Surinaamse Roy (43). Roy woont hier nu tweeënhalf jaar, maar zijn woning is nog niet echt ingericht (en schoon). De muren zijn niet geverfd of behangen en meubels staan her en der verspreid. Roy heeft een aantal ongelukken gehad en is voor 50% afgekeurd. Hij werkt 5 dagen in de week. Als hij thuis komt, is hij moe. Hij zou graag overwerken of zwaarder werk doen, om meer te verdienen, maar dat lukt niet door pijn en stress. Roy voetbalt graag. Ook dat lukt niet meer, door de pijn, maar ook vanwege de kosten. '*Kijk ze zeggen je hebt geld, maar het gaat allemaal weg aan vaste lasten. Wat heb je over? Daarom kan ik niet sporten. Ik kan ook niets geven als ik naar een verjaardag ga. Medicijnen betaalt mijn dochter.*'

Roy is bezig een ander huis te zoeken. Hij heeft het niet naar de zin in de buurt. '*Ik heb met bijna* niemand *contact, ik praat ook met niemand.*' Bij de buren komt geregeld politie aan de deur, in verband met overlast en vandalisme. Onlangs heeft nog iemand zijn auto bekrast.

Onderzoeker: 'Wat zou er nodig zijn voor u om uw leven te veranderen?' Roy: 'Kijk, als je een beetje geld hebt, ga je uit, sporten, ga je voetbal kijken, op vakantie, noem maar op. Dat moet allemaal met geld.'

Gebaseerd op interviews voor Sociaal Uitgesloten in de grote stad, van Bergen et al. 2014.

## **Chapter 7**

Summary and general discussion

## SUMMARY AND MAIN FINDINGS

The main aim of this dissertation is to develop a reliable and valid instrument to measure the multidimensional concept of social exclusion (SE) in public health surveys, more specifically as embedded in the Public Health Monitor conducted by the GGDs in the Netherlands. This can facilitate the systematic identification of population groups at high risk for ill health so that resources for public health can be used more efficiently and effectively and health inequalities can be addressed with appropriate health and social policies.

We started in Chapter 1 with the observation that although SE appears to be a promising concept to help with understanding and tackling health inequalities, the concept has been ill defined in health research, a generally accepted measure was lacking, and the evidence base was not well developed. In the current project, we took significant steps towards improving the knowledge base: we carried out a systematic review on the association between SE and health (Chapter 2), we constructed and validated a multidimensional measure for SE, the Social Exclusion Index for Health Surveys (SEI-HS) (Chapters 3, 4 and 5), and we explored a possible application of the SEI-HS in public health (Chapter 6).

In chapter 2, we described a systematic review of the evidence base for the association between social exclusion or social inclusion (SI) and health in EU and OECD countries. Six hypotheses were evaluated, i.e., that high SE/low SI is associated with (i) adverse mental health outcomes, (ii) adverse physical health outcomes and (iii) adverse general health outcomes in both (a) the general population and (b) populations at high risk of SE. We operationalised SE as the accumulation of deprivations in four dimensions, i.e., social, economic, political and cultural [1] and SI as the accumulation of involvement in these dimensions. Twenty-two observational studies were included in the review, both using a multidimensional operationalisation of SE or SI and testing the relationship between SE/SI and one or more health outcomes. In the general population, our study confirmed the association between SE/SI and mental and general health but not physical health. In groups at high risk of SE, we found clear confirmation for an association between SE/SI and mental health but not general health, the evidence was inconclusive, both in the general population and in groups at high risk of SE.

In chapter 3, we explored whether the multidimensional concept of SE could be validly approximated with items available in the Public Health Monitors (PHM) of the four major cities in the Netherlands: Amsterdam, Rotterdam, The Hague and Utrecht (G4). The Netherlands Institute for Social Research (SCP) social exclusion index of Hoff & Vrooman [2, 3] was used as the gold standard. This 15-item instrument measures the overall degree of SE in a single index score as well as scores on four dimensions of SE: 1) Limited social participation, 2) Material deprivation, 3) Inadequate access to basic social rights, and 4) Lack of normative integration. Analyses were performed

on data from the 2008 PHM, which was completed by 20,877 adults. As the content of the questionnaires differed among cities, three different indices were constructed using nonlinear canonical correlation analysis. The psychometric properties of the constructed indices were adequate to good. The content validity, however, was only moderate. Our study showed that a measure for social exclusion could be constructed with available health questionnaires. Recommendations were made to enhance content validity by adding extra items from the SCP social exclusion index to the PHM.

In chapter 4, we followed the recommendations made in the previous chapter. Nineteen of the 26 GGDs, covering over 70% of the Dutch population, included extra SCP items on material deprivation, access to basic social rights and normative integration in their 2012 PHM. Data from 258,928 respondents aged 19 years or older were thus obtained. The dataset was randomly divided in half: a development sample and a validation sample. Nonlinear canonical correlation analysis in the development sample produced an overall index and four dimension scales, the SEI-HS, containing 9 PHM items and 8 SCP items. The internal consistency, internal structure and construct validity were satisfactory to good and in line with the original SCP social exclusion index, and the content validity was good. Replication of the SEI-HS in the validation sample confirmed its generalisability. Both index and dimension scores were trichotomised into 'moderate to strong', 'some' and 'no' exclusion based on the 95th and 90th percentiles in the Dutch adult population to facilitate their application in public health monitoring and policy. The SEI-HS enables researchers to take the next step in advancing our much needed knowledge on SE and health.

In chapter 5, we presented the results of a cross-cultural validation study of the SEI-HS. In the four cities, Amsterdam, Rotterdam, The Hague and Utrecht, particularly high levels of SE were found among non-Western immigrant groups, e.g., 20%, 21% and 29% of adults of Surinamese, Moroccan and Turkish origin, respectively, were found to have moderate to strong SE; only 4% of adults of native Dutch origin were found to have the same. A sequential explanatory mixed methods design was used to explore the possible cultural bias of the SEI-HS. Data from the 2012 PHM were used to evaluate the structural validity and differential item functioning of the SEI-HS in three major immigrant groups in the G4. For each SEI-HS item, semantic, conceptual and contextual connotations were compared between the three immigrant groups and native Dutch based on semi-structured interviews with 11 Surinamese, 9 Moroccan, 10 Turkish and 22 Dutch respondents with high scores on the SEI-HS. Confirmatory factor analysis corroborated the 4-factor structure of the SEI-HS in all three immigrant groups, and no substantial differential item functioning was found for migration background. The interviews uncovered some methodological shortcomings, but these did not substantially impact the excess of social exclusion observed in the immigrant groups. Our study confirmed the cross-cultural validity of the SEI-HS in three major immigrant groups in the Netherlands. The high levels of SE among non-Western immigrants in the G4 proved to be real and not a methodological artefact. Our conclusion was that policy measures to enhance social inclusion and reduce exclusion are urgently needed.

Finally, in chapter 6, we explored possible applications of the SEI-HS. We tested the SE, measured with the SEI-HS, against four traditional social stratifiers (low education, low income, low labour market position and non-Western migration background) in terms of their ability to identify high-risk/high need population segments. We compared the relative risks (RR) and (hypothetical) population attributable fractions (PAF) for cardiovascular risk, cancer, low self-rated health, anxiety and depression symptoms, and low personal control and studied their overlap and their combined effect. Data from the G4 PHM 2016 were used for this study (N=33,285).

The analyses showed significant associations of SE with all health indicators and personal control, with particularly strong RRs for anxiety and depression symptoms (7.95) and low personal control (6.36). The corresponding PAFs were 42% and 35%, respectively. The SEI-HS was significantly better at identifying population segments with anxiety and depression symptoms and low personal control than the four traditional stratifiers were and performed equally well in identifying other health problems. The combination of SE and low labour market position proved to be most impactful: this population segment accounted for 67% of all adults exhibiting anxiety and depression symptoms and 60% of all those exhibiting low personal control, as well as substantial proportions of the other health indicators, while making up only 19.5% of the adult population in the G4. These findings have implications for health care practice, public health and social interventions in large cities.

### **GENERAL DISCUSSION**

To date, there has not been a generally accepted measure of SE in national and international public health research and monitoring. This dissertation presents the construction and validation of a short index for SE suitable for embedding in the Dutch PHM. The SEI-HS makes use of items that are already present in the PHM, i.e., on loneliness, social capital, financial situation and housing. The number of additional items to be included is thus limited, and by preventing overlap, respondent acceptance is not jeopardised. The psychometric measurement properties of the SEI-HS were found to be satisfactory to good, although there is still some room for improvement in one of the four dimension scales, i.e., the Normative Integration scale (Chapter 3).

In this dissertation, we show evidence for the association between high SE/low SI and adverse mental health outcomes (Chapter 2). Where other researchers became stuck in a forest of divergent ideas, a lack of definitions and different ways of measuring SE, by delineating the concept of SE, we were able to synthesise the existing evidence on the relation between SE and health. The findings from our own research confirm the association between SE and adverse mental health and strengthen the plausibility of the association between SE and adverse physical health, i.e., with severe functional limitations (Chapters 3 and 4) and diabetes, high blood pressure, obesity and cancer (Chapter 6).

An important outcome of this dissertation is the utility of the SEI-HS for identifying high-risk/high-need population segments (Chapter 6). As we had hoped for at the start of this study, measuring SE can thus help identify and quantify at-risk groups and gain better insight into their characteristics and health risks. This information is important for guiding public health policy and resource allocation. Embedding the SEI-HS in the PHM is a good choice, as data on SE can now be collected every four years, analysed by GGD epidemiologists, and presented and discussed with local policymakers. Some municipalities, such as Delft, use the SEI-HS in their municipal (omnibus) survey that takes place every two years.

The findings of this dissertation are also relevant outside of the Netherlands. Although the main focus of this dissertation was on Dutch local health monitoring and policy, we firmly positioned our research in a broader international context, with particular reference to the theoretical framework of the World Health Organization (WHO) on the social determinants of health [4] and the definition of SE developed by the WHO Social Exclusion Knowledge Network [1, 5]. This work bridges social sciences and health research, which we further enhanced by publishing only in open access journals indexed in PubMed. The articles in this dissertation are regularly cited by health researchers from countries all over the world, such as the United Kingdom [6], Spain [7], Finland [8], Croatia [9], Switzerland [10], Czech Republic [11], Ukraine [12], Cameroon [13], Brazil [14], Hong Kong [15], the United States [16] and Lebanon [17]. In particular, reference is made to the use of nonlinear canonical correlation analysis, to the results of our systematic review, and the definition, operationalisation and measurement of SE.

### STRENGHTS AND LIMITATIONS

#### Strengths

A major strength of this dissertation is that we were able to build on many years of theoretical and empirical research conducted by the SCP. We adopted its definition and operationalisation of SE and used the SCP social exclusion index of Hoff & Vrooman [2, 3], as the standard for measuring SE in the Dutch adult population.

Another strong point of this study is that we had three large datasets at our disposal: 2008 PHM data for the G4 (N=20,877), 2012 PHM data for 19 GGDs nationwide (N=258,928) and 2016 PHM data for the G4 (N=33,285). Not only were we able to adapt and improve the SE index based on 2008 data in the 2012 dataset, but our results were also stable and reliable, likely replicable not due to coincidence or p-hacking [18]. The use of nonlinear canonical correlation analysis for the construction of the SEI-HS is a strong point as well. In comparison with, for example, factor analysis, nonlinear canonical correlation analysis yields scales with fewer items and a broader scope, resulting in a more concise measure with higher content validity [2].

### Limitations

In this study, we faced several limitations. First, the current state of the relevant research did not allow us to quantify the strength of the association between SE and specific health outcomes. The method we used in chapter 2 to summarise the evidence is based on P-values. P-values give an indication of the compatibility of the data with the null hypothesis of each manuscript but not of the effect size or the importance of the results. Due to the great diversity in health outcomes, we classified them into broader groups: mental health, physical health and general health. The classification was not always straightforward, particularly not for general health.

Second, we have to mention potential bias due to selection in the studies in chapters 4, 5, 6 and 7. Persons without a fixed address or living in an institutional setting were a priori excluded from the sample. This group is estimated at approximately 0.2% and 1.6-1.8%, respectively, of the Dutch adult population (CBS Statline). As these tend to be vulnerable people with a high risk of SE, such as people experiencing homelessness, incarcerated people and frail, older people, this may lead to an underestimation of the prevalence of SE in the population. Selective non-response is another potential source of bias. In the Netherlands, the response rates in survey research are low and have decreased over time [19, 20]. Despite the use of strategies to reduce non-response rates concentrated on hard-to-reach groups and despite oversampling in deprived neighbourhoods and weighting to adjust for non-response bias, the possibility of some bias cannot be ruled out. The PHM is no exception: average response rates in the G4 declined from 50% in 2008 to 33% in 2016. Again, the tendency is towards an underestimation of the SE prevalence rates.

Third, the classification of the SEI-HS index and dimension scores into categories involved a certain degree of arbitrariness. SE is a continuous phenomenon with no natural boundaries between being excluded or not or between some, moderate and strong exclusion. The main reason for classifying the SEI-HS was to enhance its applicability in public health policy. Policymakers require clear and simple data, and continuous scale scores will not do. We opted for the use of 85th and 95th percentile values in the Dutch adult population as cut-off scores. These fit the right-skewed distribution of the index and dimension scores, with the largest part of the population having low scores, a small part having very high scores, and a modest group in the middle. Our choice is also in line with the cut-off point of 1 SD above the mean used by Gijsbers [21] to define social exclusion.

Fourth, widespread research across the Netherlands allowed us to extend the generalisability of the SEI-HS to the whole Dutch adult population, both urban and rural, but the generalisability to populations in other countries may be limited. The items of the SEI-HS measure aspects of SE in the Dutch context. Bottle banks, for example, are unknown in large parts of Turkey, and in southern countries such as India, the item "I have enough money to heat my home" is irrelevant. In low- and middle-income countries, items such as access to electricity, pipe water and sewerage as well

as the presence of dirt floors, overcrowding and illiteracy may be more pertinent for SE [22]. In high-income countries, a single adjustment of the items and a re-scaling of weights and factor loadings may be required. The method used in chapter 4 can accomplish this.

### IMPLICATIONS FOR PUBLIC HEALTH MONITORING

Now that there is a reliable and valid SE measure available for use in the local PHM conducted every four years, the next challenge will be to increase the utilisation of the SE data in local public health policy. A recent study among GGD epidemiologists and local policymakers identified three main barriers to the utilisation of SEI-HS data in local public health policy: 1) the abstractness of the concept of SE, 2) difficulty in translating the SEI-HS results into policy actions and 3) the limited reach of the SEI-HS [23].

#### Barrier 1: Abstractness of the concept of SE: a storytelling approach

The first barrier to the research application mentioned by GGD epidemiologists and local policymakers is the abstractness of the SE concept. Local policymakers indicate that they find the SE concept vague, broad and difficult to interpret. Epidemiologists find it difficult to make the results tangible for policymakers.

## 'It is an abstract concept. Municipalities in our region, if they read something like that, they think: "What is that, what can we do with it?' [GGD policy advisor] [23]

The current research focused primarily on the delineation of the concept of SE, its reliable and valid measurement and the systematic mapping of the scientific evidence base. As a consequence, the language we used in this research was abstract, the findings were interpreted cautiously, and particular emphasis was placed on limitations and possible pitfalls. We think the time has come to shift the focus from methodological and conceptual discussions to the people affected by social exclusion using a storytelling approach.

Behind the abstract figures on SE lies the often-harsh reality of people experiencing social exclusion and its consequences in everyday life. As Taket et al. [24] state, 'the concept of social exclusion attempts to help us make sense out of the lived experience arising from multiple deprivations and inequities experienced by people', and the concept should certainly not obscure this reality. According to the WHO Social Exclusion Knowledge Network, the complexity of the nature and impact of exclusionary processes can only be adequately 'represented' by using both quantitative and qualitative data – through indicators and stories [5]. Cairney et al. state that successful engagement in 'evidence-based policymaking' requires pragmatism, the combination of scientific evidence and governance principles, and persuasion to

translate complex evidence into simple stories [25]. This last step, translation into simple stories, has been missing until now.

The interviews with socially excluded citizens in Utrecht, Amsterdam and The Hague presented in Chapter 6 painted a picture of the daily lives and aspirations of people, the problems they are facing, how they are dealing with these problems and what support they need (Chapter 6). It is in the lived experience of people that theory becomes tangible and concrete. As one of the professionals pointed out in response to the interview results:

#### 'This is certainly recognisable. We see these people every day'. [26, 27]

#### Barrier 2: Translation of results into local public health policy: a larger policy story

The second barrier to the research application mentioned by GGD epidemiologists and local policymakers is the difficulty of translating the SEI-HS results into policy actions. Translating epidemiological data into public health policy is generally complicated. Regarding public health in the Netherlands, De Goede et al. explained this by the complexity of the local policy process, in which the knowledge, opinions, and interests of multiple actors have to be taken into account, and epidemiological findings cannot be transformed directly into action [28]. For a broad concept as SE, this is all the more true:

## 'The domains are sometimes that kind of broad, that it is difficult for municipalities to take concrete measures on the basis of the index.' [GGD epidemiologist] [23]

Another complicating factor is that to tackle SE and its impact on health, an integrated approach<sup>5</sup> is required in which the public health sector collaborates with other local policy sectors. Involving the appropriate policy sectors, e.g., housing, spatial planning, education, work, participation and income, and welfare, in the local public health policy dialogue is, however, difficult to achieve [29].

## 'If you really want to have an effect, then the presentation of the SE results should be given at different tables inside a municipality.' [GGD epidemiologist] [23]

Some GGDs solve this problem by translating the SE results into terms more aligned with current local policies, such as loneliness and poverty. However, what gets lost in this approach is the essence of SE – its multidimensionality, accumulative character and clustering of problems.

De Goede et al. [28] suggest that given the complexity of the policy process, it is probably better not to focus too much on the use of epidemiological data for

<sup>&</sup>lt;sup>5</sup> Outside the Netherlands this approach is more commonly known as Health in All Policies [29].

concrete policy actions (instrumental use) but to aim for higher awareness and better understanding of the provided epidemiological results (conceptual use):

'Ultimately, if the conceptual use of research is high during the policy process and applies to multiple policy actors, this can eventually lead to more instrumental use.' [28]

However, instrumental use should not be the measure of success [30]. Epidemiological knowledge contributes to the improvement of the policy process if findings are taken into account and discussed, whether it leads to policy changes or not [30]. We recommend presenting a larger policy story of SE, aiming at a deeper understanding, rather than piecemeal approaches. The SCP SE framework presented in Chapter 1 can serve as an example here. In our experience, this model is well understood by professionals and policymakers and leads to insightful discussions on meso and macro risk factors that enhance individual problems and vulnerabilities and to ideas about how to tackle these [26, 27].

#### Barrier 3: Limited reach of the SEI-HS: additional research

GGD epidemiologists play an important role in deciding whether to include the SEI-HS in the PHM [23]. The fact that the SEI-HS does not measure SE in high-risk population groups, such as people experiencing homelessness or living in institutions and undocumented immigrants, is perceived as a major barrier to its use by some GGD epidemiologists [23]. As such, this barrier is not due to the SEI-HS itself but to the exclusion of the mentioned groups from the PHM and applies equally to other health and social problems that are common among these groups, such as loneliness [31] and poverty [32, 33]. The people most affected are not included in the PHM or in population surveys in general and are usually excluded from mainstream policy as well. It is therefore important to supplement the PHM with additional research on high-risk groups, with, for example, register-based research [34], population estimates [35], on-site research [32, 33] or peer research [36].

This does not mean that the PHM does not provide valuable information. The qualitative interviews with socially excluded citizens in Utrecht, Amsterdam and The Hague showed that the PHM reached a diverse group of vulnerable people with non-institutional addresses, including persons leading very isolated lives, victims of violent incidents such as armed robbery or rape, people with drug addiction or aggression disorders, perpetrators of domestic violence, and people who have just been released from prison (Chapter 6). These are important target groups for public health policy and policies to prevent homelessness. Thanks to the SEI-HS, these otherwise invisible groups do not remain completely out of sight.

'With the PHM, we do not reach the real vulnerable citizens, but the outcome measures visualise an image of the size of the group that is possibly vulnerable and can become vulnerable more easily [GGD epidemiologist].'[23]

## **IMPLICATIONS FOR FUTURE RESEARCH**

Based on this dissertation, some potential directions for future research on SE and health are outlined below.

First, the large amount of SE data that are collected as part of PHM are currently underutilised. In 2020, the SEI-HS was administered for the third time in the G4 and a number of other GGD areas. Large amounts of data are thus available to help identify risk groups, assess relations with health outcomes, compare cities and rural areas, identify (syndemic) clusters and monitor developments over time. Until now, data analysis by GGDs has been limited to descriptive reports of the number and characteristics of socially excluded persons per municipality or neighbourhood [23]. It would be useful to develop a joint research agenda for in-depth analyses, for example, in the context of the Academic Collaborative Centre for Public Health G4 USER, and to share the outcomes.

Second, a new round of qualitative interviews with PHM respondents with a high score on the SEI-HS and focus groups with professionals would be useful. The interviews and focus groups described here were conducted in 2014, just before the introduction of the social neighbourhood teams in January 2015. The interviews portrayed a diverse group of people, but despite their diversity, they all faced similar problems, such as an inability to solve certain problems on their own and inadequate care utilisation. A new round of interviews can shed light on the situation of socially excluded citizens in 2022 and on the role of the social neighbourhood teams in reaching these underserved groups.

Third, it would be worthwhile to investigate whether the SEI-HS data can be made available as microdata by Statistics Netherlands, as part of the PHM dataset (GEMON) or via the CBS respondent number included in the GGD data files. This would offer opportunities to combine SE and PHM data with information from other databases, such as prescription reimbursement data, hospital admission and diagnosis data and mortality data [37], employment and social security data [38] and Dutch census data [39]. Data linkage allows one to follow developments over time and investigate, for example, the risk of a downward spiral of disadvantage into unemployment, poverty, family breakdown, deteriorating health, and homelessness, as described in the literature [40, 41]. An additional advantage is that SE data would become accessible to third parties, which could lead to wider use of the data.

Last, regarding the application of the findings at an individual level, in clinical practice, for example, an SE index could be developed on the basis of the available registration data and possibly supplemented with a short questionnaire. A data infrastructure such as that of the 'Healthy and Happy The Hague' initiative may offer opportunities here [42].

## IMPLICATIONS FOR POLICY AND PRACTICE

In Chapter 6, we have showed a serious accumulation of ill health, social problems and low agency in a relatively small urban population segment. Although more research can be done on this issue, these results emphasise the importance of paying attention to this group in health care practice, public health interventions and social care services. At the core of SE lies the inability of persons to participate fully in society and make full use of the benefits that society offers. SE reinforces feelings of powerlessness, alienation, demoralisation and a lack of self-esteem [43, 44]. Policymakers must take these factors into account when formulating policies, and professionals must do so when providing care and support. In Chapter 6, some examples were given of services in the G4 that take agency into account. We mention here stress-sensitive municipal services in Utrecht that are based on the principles of Mobility Mentoring® [45]; the Powerful Basic Care approach (Krachtige Basiszorg), which aims at a collaborative response by primary and social care givers to the health needs of patients in deprived areas in the G4, [46]; and Pathways to Empowerment (Krachtwerk), a programme for a wide range of people who, temporarily or more permanently, experience a loss of control in their lives and are confronted with an accumulation of risk factors for social exclusion [47]. Another example is the involvement of peer support workers to make care and assistance more accessible and foster people's self-management [26]. We hope these examples will inspire others to pursue similar goals.

### FINALLY

In this research, we took significant steps towards improving the knowledge base on the relation between SE and health. We largely confirmed the hypotheses derived from theory and practice that SE is associated with poor mental and general health. With the construction of the SEI-HS, there is now a reliable and valid instrument available to GGDs for measuring SE in the adult population, including the main non-Western migrant groups. As we hoped at the start of the study, the SEI-HS identifies a high-risk/high-need population segment in which social problems, low agency and ill health coincide. These findings can be used to guide public health policy and resource allocation. In particular, the high prevalence of low agency is an important factor to consider in choosing, designing and implementing interventions and services.

To increase the utilisation of the SEI-HS data in local public health policymaking, we suggest combining quantitative data with qualitative data on the lived experience of socially excluded people, giving a human face to an abstract concept, and interpreting the results in a broader contextual perspective. SE is not just an individual problem. A lack of social cohesion as well as discrimination and stigma, deprived neighbourhoods, complex bureaucratic procedures, individualization, high demands on people's self-reliance and lagging social benefits are all factors that affect SE and health. We further suggest that public health monitoring incorporate other methods in addition to the PHM to reach those who otherwise remain excluded from the picture. No one method is sufficient by itself. As one of the G4 policymakers put it:

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'Even though policy is not made one-to-one with these results, keep measuring social exclusion. The combination with other data contributes to a more complete image for complex problems in vulnerable groups [policymaker G4].' [23]

Last, we want to encourage researchers to use the wealth of data on SE collected by the GGDs and, where applicable, to combine this with other data sources.

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#### Stacey

Stacey (31) woont in een benedenwoning in de Haagse Schilderswijk. Haar grote passies zijn lezen en reizen. Als er aanbiedingen zijn, trekt ze er met de trein op uit. Maastricht is haar favoriete bestemming. 'Even een andere omgeving. Even andere mensen om je heen.'

Stacey heeft een hersenbloeding gehad en kon daardoor haar HBO opleiding niet afmaken en niet werken. 'Mijn leeftijdsgenoten hebben gewoon een vaste baan, huisje, boompje, beestje. Mijn leven speelt zich af in het ziekenhuis en in dat wereldje. En dat is vrij eenzaam. En een moeilijk bestaan.'

Sinds zij op haar zesde vanuit Suriname naar Nederland kwam, woont Stacey al in de Schilderswijk. '*Ik weet niet hoe het in andere buurten is, maar dit is geen beste buurt, laten we eerlijk zijn.*' Haar huis is klein en het sanitair, de leidingen en stopcontacten zijn dringend aan vervanging toe. Verhuizen zit er voor haar niet in. '*Omdat ik moeite heb met plekken herkennen. Van punt a naar punt b gaan dat lukt me niet in mijn eentje. In een vreemde wijk.*'

Stacey heeft weinig verwachtingen voor de toekomst. Zij leeft met de dag. 'Twee jaar geleden is er weer een nieuwe tumor ontdekt. Dus ik ben daar een beetje huiverig voor.'

Gebaseerd op interviews voor Sociaal Uitgesloten in de grote stad, van Bergen et al. 2014.

# **Supplementary material**

## **SUPPLEMENTARY MATERIAL CHAPTER 2**

### Supplementary file 1: Literature search strategy details

The following databases were searched:

PubMed (to 1 January 2018), EMBASE (to 1 January 2018) and CINAHL (to 1 January 2018).

Search terms :

PubMed	social exclusion [tiab] OR social inclusion [tiab]
EMBASE	'social exclusion'/exp OR (social NEXT/1 exclusion):ab,ti OR (social NEXT/1 inclusion):ab,ti
CINAHL	(TI 'social exclusion' OR AB 'social exclusion') OR (TI 'social inclusion' OR AB 'social inclusion')

# Supplementary file 2: CASP risk of bias tool for cross-sectional studies

#### CASP Critical Appraisal Skills Programme

11 questions to help you make sense of descriptive/cross-sectional studies How to use this appraisal tool

Three broad issues need to be considered when appraising the report of a descriptive/ cross-sectional study (e.g., a study that collects data on individuals at one time point using a survey or review of medical charts):

- Are the results of the study valid?
- What are the results?
- Will the results help locally?

The 11 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is "yes", it is worth proceeding with the remaining questions. You are asked to record a "yes", "no" or "can't tell" to most of the questions. A number of italicized prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided. These questions are adapted from Guyatt GH, Sackett DL, and Cook DJ, Users' guides to the medical literature. II. How to use an article about therapy or prevention. *JAMA* 1993; 270 (21): 2598-2601 and *JAMA* 1994; 271(1): 59-63 © Milton Keynes Primary Care Trust 2002. All rights reserved.

### **Screening Questions**

1. Did the study address a clearly focused issue? Yes Can't tell No

HINT: A question can be focused in terms of:

- *the population(s) studied*
- the health measure(s) studied (e.g., risk factor, preventive behavior, outcome)

2. Did the authors use an appropriate method Yes Can't tell No to answer their question?

HINT: Consider

- Is a descriptive/cross-sectional study an appropriate way of answering the question?
- *Did it address the study question?*

### **Detailed Questions**

3. Were the subjects recruited in an acceptable way?	les	Can't tell	No
<ul> <li>HINT: We are looking for selection bias which migh compromise the generalizability of the findings:</li> <li>Was the sample representative of a defined population.</li> <li>Was everybody included who should have been</li> </ul>	t ılation includ	? ed?	
4. Were the measures accurately measured to reduce bias?	Yes	Can't tell	No
<ul> <li>HINT: We are looking for measurement or classifica</li> <li>Did they use subjective or objective measurement</li> <li>Do the measures truly reflect what you want the (have they been validated)?</li> </ul>	tion bi nts? m to	as:	
5. Were the data collected in a way that addressed the research issue?	Yes	Can't tell	No
<ul> <li>Consider:</li> <li>if the setting for data collection was justified</li> <li>if it is clear how data were collected (e.g., interview, questionnaire, chart review)</li> <li>if the researcher has justified the methods chose</li> <li>if the researcher has made the methods explicit (e.g. for interview method, is there an indicatio of how interviews were conducted?)</li> </ul>	en n		
6. Did the study have enough participants to minimize the play of chance?	Yes	Can't tell	No
<ul> <li>Consider:</li> <li>if the result is precise enough to make a decision</li> <li>if there is a power calculation. This will estimat how many subjects are needed to produce a reliable estimate of the measure(s) of interest.</li> </ul>	n Te		
7. How are the results presented and what is the m ain result?	Yes	Can't tell	No
Consider:			

• *if, for example, the results are presented as a proportion of people experiencing an outcome,*  such as risks, or as a measurement, such as mean or median differences, or as survival curves and hazards

- how large this size of result is and how meaningful it is
- how you would sum up the bottom-line result of the trail in one sentence

8. Was the data analysis sufficiently rigorous? Yes Can't tell No Consider: if there is an in-depth description of the analysis process if sufficient data are presented to support the findings 9. Is there a clear statement of findings? Yes Can't tell No Consider: if the findings are explicit if there is adequate discussion of the evidence both for and against the researchers' arguments if the researcher have discussed the credibility of their findings if the findings are discussed in relation to the original research auestions 10. Can the results be applied to the local Yes Can't tell No population? HINT: Consider whether The subjects covered in the study could be sufficiently different from Your population to cause concern. *Your local setting is likely to differ much from that of the study* 11. How valuable is the research? write comments here

Consider:

- *if the researcher discusses the contribution the study makes to existing knowledge (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature?)*
- *if the researchers have discussed whether or how the findings can be transferred to other population*

### Supplementary file 3: CASP risk of bias tool for cohort studies

#### 12 questions to help you make sense of cohort studies

#### How to use this appraisal tool

Three broad issues need to be considered when appraising a cohort study:

- Are the results of the study valid? (Section A)
  What are the results? (Section B)
- Will the results help locally? (Section B)

The 12 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is "yes", it is worth proceeding with the remaining questions. There is some degree of overlap between the questions, you are asked to record a "yes", "no" or "can't tell" to most of the questions. A number of italicized prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

These checklists were designed to be used as educational tools as part of a workshop setting.

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(A) Are the results of th	ne study valid
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#### **Screening Questions**

1. Did the study address a clearly focused issue?	Yes	Can't tell	No
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HINT: A question can be focused in terms of:

- *the population studied*
- the risk factors studied
- the outcomes considered
- *Is it clear whether the study tried to detect a beneficial or harmful effect?*

#### 2. Was the cohort recruited in an acceptable way? Yes Can't tell No

*HINT: Look for selection bias which might compromise the generalisibility of the findings:* 

- Was the cohort representative of a defined population?
- *Was there something special about the cohort?*
- Was everybody included who should have been included?

#### Is it worth continuing?

## **3. Was the exposure accurately measured to** Yes Can't tell No **minimise bias**?

HINT: Look for measurement or classification bias:

- Did they use subjective or objective measurements?
- Do the measurements truly reflect what you want them to (have they been validated)?
- Were all the subjects classified into exposure groups using the same procedure

## **4. Was the outcome accurately measured to** Yes Can't tell No **minimise bias**?

HINT: Look for measurement or classification bias:

- Did they use subjective or objective measurements?
- Do the measures truly reflect what you want them to (have they been validated)?
- Has a reliable system been established for detecting all the cases (for measuring disease occurrence)?
- Were the measurement methods similar in the different groups?
- Were the subjects and/or the outcome assessor blinded to exposure (does this matter)?

## **5. (a) Have the authors identified all important** Yes Can't tell No **confounding factors?**

List the ones you think might be important, that the author missed.

## (b) Have they taken account of the confounding Yes Can't tell No factors in the design and/or analysis?

*HINT:* Look for restriction in design, and techniques e.g. modelling, stratified-, regression-, or sensitivity analysis to correct, control or adjust for confounding factors

- 6. (a) Was the follow up of subjects complete enough? Yes Can't tell No
  - (b) Was the follow up of subjects long enough? Yes Can't tell No

HINT: Consider

• The good or bad effects should have had long enough to reveal themselves

- The persons that are lost to follow-up may have different outcomes than those available for assessment
- In an open or dynamic cohort, was there anything special about the outcome of the people leaving, or the exposure of the people entering the cohort?

#### (B) What are the result?

#### 7. What are the results of this study? Yes Can't tell

HINT: Consider

- What are the bottom line results?
- Have they reported the rate or the proportion between the exposed/ unexposed, the ratio/the rate difference?
- How strong is the association between exposure and outcome (RR,)?
- What is the absolute risk reduction (ARR)?

#### 8. How precise are the results?

HINT: Look for the range of the confidence intervals, if given.

#### 9. Do you believe the results?

Yes Can't tell

No

No

#### HINT: Consider

- Big effect is hard to ignore!
- Can it be due to bias, chance or confounding?
- Are the design and methods of this study sufficiently flawed to make the results unreliable?
- Bradford Hills criteria (e.g. time sequence, dose-response gradient, biological plausibility, consistency)

#### (C) Will the results help locally?

#### **10. Can the results be applied to the local population?** Yes Can't tell No

#### HINT: Consider whether

- *A cohort study was the appropriate method to answer this question*
- The subjects covered in this study could be sufficiently different from your population to cause concern
- Your local setting is likely to differ much from that of the study
- You can quantify the local benefits and harms

## **11. Do the results of this study fit with other** Yes Can't tell No **available evidence?**

#### 12. What are the implications of this study for practice?

#### HINT: Consider

- One observational study rarely provides sufficiently robust evidence to recommend changes to clinical practice or within health policy decision making
- For certain questions observational studies provide the only evidence
- Recommendations from observational studies are always stronger when supported by other evidence

# Supplementary file 4: Details about the specific methodological limitations.

1, No theoretical motivation of the concept SE/SI. Limitation is present if the paper does not a. refer to SE literature and/or theories; b. provide a definition of SE/SI; and/or c. include a motivated choice of SE/SI measurement. Absence of theoretical motivation and conceptual underpinning may lead to confusion of what precisely is being measured [12].

2, Data set not originally designed to measure SE/SI. Limitation is present if the study is based on secondary data only, including register and case notes data.

3, Not all dimensions of SE/SI measured. Limitation is present if only two or three of the four dimensions of SE are measured.

4, No composite measure SE/SI. Limitation is present if the study measures indicators across a number of dimensions without aggregation into a composite measure (index / scale or total score / latent variable). 4" Limitation is partly present if aggregation does not include all dimensions measured.

5, No existing SE/SI measure. Limitation is present if the study did not use a questionnaire designed specifically to measure SE/SI, and researchers choose their own indicators, ex post or ex ante. Limitation is partly present if validated measures were used for the dimensions of SE or a measure was constructed and (partly) validated.

6, Testing of association SE/SI -health was not a stated objective. Limitation is present if the study did not set out to test the association between SE/SI and a health-related measure, but included SE/SI or health as a confounding or mediating factor.

7, No adjustment for demographic and other potential confounding factors. Limitation is present if potential confounding was not examined. Limitation is partly present if potential confounding was examined by demographic variables but not by other factors OR potential confounding was examined by other potential confounding factors but not by demographic variables. Gender, age, ethnicity, country of birth, marital status, household composition and geographic area were classified as demographic factors. Income, education, occupation and employment were categorised as 'other factors'.

### **Supplementary file 5:**

**Tables S1a-S3b** Description of observational studies on the association between SE/SI and mental health in the general population (S1a) and in high risk groups (S1b); physical health in the general population (S2a) and in high risk groups (S2b); and general health in the general population (S3a) and in high risk groups (S3b).

## Table S1a: Description of observational studies on the association between SE/SI and mental health in the general population

Study	Setting	Population	Sample size	Indicators SE/SI *	Health measure **	Statistical analysis
Retrospecti	ve cohort stu	dy		-		
Sacker et al. [46]	UK	General population, 65 years or older	4,312	SP: social exclusion index <sup>a)</sup> Measured in wave 3.	MH1: Transition in psychological distress between wave 1 and 2 <sup>b)</sup>	Linear regression
			4,244	-	MH2: Psychological distress (wave 4) b)	Logistic regression
Cross-sectio	onal study	1				1
Bayram et al. [34]	Turkey	General population, 18- 80 years	2,493	S: social participation (9) E: material deprivation (8) P1: access to institutions (5) P2: access to adequate housing and safe environment (8) C: cultural normative integration (5 items) <sup>d</sup>	MH: psychological health (WHOQOL- BREF)	Structural equation modeling
Halleröd & Larsson [47]	Sweden	General population 16-74 years	4,941	S: loneliness E1: deprivation of goods/ services (36); E2: cash margin P1: crowded housing (4); P2: disorganised area (4); P3: worried by crime; P4: victimisation crime; P5: victimisation violence C1: voting; C2: politically active	MH: anxiety (occurrence, over the previous two weeks, of anxiety, worry or anguish)	Bivariate correlation
Honey et al. [37]	Australia	General population, 15-29 years	3,392	S: social support (10) E: financial hardship (7) <sup>e)</sup>	MH: mental health <sup>f)</sup>	Linear regression
Van de Beek et al. [38]	Netherlands	Dutch Moroccan visitors of online community,18 years or older <sup>i)</sup>	267	S:social support (3) P: perceived discrimination (9) <sup>j)</sup>	MH1: depressive symptoms <sup>k)</sup> MH2: psychotic experiences <sup>k)</sup>	Hierarchical linear regression

Confounding, match-ing & stratification** etc.	Results per indicator***	Correlations and effect estimates per indicator \$	Combined result \$\$	Methodological limitations #	Study quality ##
 Confounder: gender, age. age <sup>2</sup> , ethnicity, migrant, marital status, job status, educational level, social class, region and (transitions in) SAH and LLTI. <sup>c)</sup> Mediator/moderator: rural vs urban; car access, mobile phone ownership, internet use	Effect on SP Transition from: -Low to high: + -High to low : ns -Stable high : + + SP	Effect MH1 on SP (wave 3)         MH1 $\beta$ (95% CI)         -Stable low is reference         -Low=>high       0.28 (0.01-0.54) ^         -Stable high       0.91 (0.64-1.18) ^^         ^ p<.05; ^^ p<.01	+	235	+
 phone ownership, internet use					
Other factors in model: physical health, environment, social relations. Not in model: P1 C.	+ S P2 ns E P1 C	MH⇔S: B=-0.77 MH⇔P2: B=-0.58 (Model fit criteria: RMSEA<0.05; GFI>0.90 & CFI>0.90)	+/0	4 7"	+
	+ S E1 E2 P1 P2 P3 P4 P5 C1 ns C2 (p<.001)	Kendall tau b S:0.23; E1:0.20; E2:0.18; P1:0.05; P2:0.09; P3:0.16; P4:0.05; P5:0.11; C1:0.09	+	24567	+
Stratified by gender. Covariate: D=disability other	+ S E <sup>g</sup> ) ♀	D*S: p < .05; D*E: p < .05; S*E: p < .05; D*S* E: p < .05	+	1 2 3 4 5" 6	+
 than mental health	+ S E <sup>g)</sup>	D*S: p < .05; D*E: p < .05; S*E: p < .05; D*S* E: p < .05	+	1 2 3 4 5" 6	
Adj for gender, age, migrant status and education	+ S ns P S*P	S: β=-0.339 p<.001	+	1 3 4 5" 7"	+
	+ S P	S: B=-0.154 p<.05 P: B=-0.197 p<.01			

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Study	Setting	Population	Sample size	Indicators SE/SI *	Health measure **	Statistical analysis
Richter & Hoffmann [48]	Switzerland	General population 18-64 for men / 63 for women	14,969	S1: living alone; S2 living without a partner; S3 no person to talk to; S4 attendance of social events; S5 feeling lonely; S6 social support (3) E: low income	MH1: severe mental illness or disability <sup>h)</sup>	Logistic regression
					MH2: common mental illness <sup>h)</sup>	1

- \* S= social dimension; E=economic dimension; P=political dimension; C=cultural dimension; between brackets the number of items (if more than 1). A group of letters e.g. EP or SEP indicates an aggregate measure based on the listed dimensions.
- \*\* MH=mental health.
- \*\*\* Code for results: + hypothesis confirmed i.e. high SE/low SI associated with adverse health outcome; ns no significant association; hypothesis rejected i.e. low SE/high SI associated with adverse health outcome; +? high SE/low SI combined with adverse health, but no statistical testing; na=not applicable. C/C = Case/Control.
- \$ P-value <.05 unless stated otherwise. OR's and HR's are given with the 95% confidence interval between brackets. SD=standard deviation. Adj=adjusted for potential confounders.
- \$\$ Code for results: + 0 see \*\*\*; +/0 hypothesis confirmed for 30-70% of SE/SI indicators and the remaining 70-30% not significant; x no statistical testing or no associations reported.
- # Specific methodological limitations: Limitations: 1, no theoretical motivation of the concept SE/SI; 2, data set not originally designed to measure SE/SI; 3, not all dimensions of SE/SI measured; 4, no composite measure SE/ SI; 5, no existing SE/SI measure; 6, testing of association SE/SI -H was not a stated objective; 7, no adjustment for demographic and other potential confounding factors; ", limitation partly present. For more details please see Supplementary file 4.
- ## General study quality was appraised with the CASP=Critical Appraisal Skills Programme tool for cohort studies (Supplementary file 2) or cross-sectional studies (Supplementary file 3).
- a) A social exclusion index was constructed with three underlying domains; S1=Civic participation (4 items e.g. participation in cultural, sports and leisure activities), S2=Social relations and resources (5 items e.g. living alone, no close friendship) and P= Service provision and access (5 items e.g. poor quality of local medical facilities).
- b) Psychological distress was measured with the 12 item General Health Questionnaire (GHQ).
- c) SAH=self-assessed health. LLTI=limiting long-term illness/disability. Transitions in SAH and LLTI were entered in the regression model with MH1 as independent variable and SP as dependent variable.
- d) Jehoel Gijsbers & Vrooman [35].

Confounding, match-ing & stratification** etc.	Results per indicator***	Correlations and effect estimates per indicator \$	Combined result \$\$	Methodological limitations #	Study quality ##
Adj for gender and age	+ S1-6 E	OR (95% CI) S1 4.47 (3.26-6.97) S2 4.19 (3.04-5.75) S3 5.31 (3.40-8.00) S4 3.98 (2.92-5.46)) S5 17.64 (12.62-24.48) S6 5.28 (3.81-7.28) E 4.10 (2.98-5.64) No illness is reference group	+	23457"	+
	+ S1-6 E	OR (95% CI) S1 2.17 (1.82-2.57) S2 1.95 (1.67-2.27) S3 1.66 (1.17-2.28) S4 1.22 (1.05-1.41) S5 5.31 (4.29-6.54) S6 1.78(1.46-2.16) E 1.28 (1.07-1.51) No illness is reference group			

- e) Dichotomous sum scores based on a median split (S) and "1 or more" versus "none" (E). Original sources Henderson et al. (1978) and Marshall & Barnett (1993). For references please see Honey et al. [37].
- f) Mental health was measured with the SF36 mental health scale. This scale consists of 5 questions on symptoms of depression, anxiety and positive mental health and is used for identifying common mental disorders.
- g) The association between disability and MH was moderated by both financial hardship and social support. Under conditions of low SE (= high social support & no financial hardship) there were no differences in MH between people with and without disabilities. Under conditions of low social support there was an enhanced risk of MH problems and the effect was stronger for people with disabilities. The combination of two factors contributing to SE strengthens the effect on MH.
- h) The analysis involved 171 people with severe mental illness (MH1), 299 people with severe physical illness PH1, 841 people with common mental illness (MH2) and 13,957 people without these illnesses. In Table S1a only results for MH1 and MH2 are presented (N=14,969). MH1 = being treated for a mental health problem and receiving a disability pension; MH2 = being treated for a mental health problem and not receiving a disability pension; No illness = not being treated for a mental health problem and receiving a disability pension; No illness = not being treated for a mental health problem and not receiving a disability pension. The results for PH1 are presented in TableS2a.
- i) Marokko.nl: a popular website, which is regularly visited by 70% of all young Moroccan-Dutch people.
- j) The study included three social exclusion variables: Social support measured with the Oslo Social Support Questionnaire; Perceived discrimination measured with the Every Day Discrimination Scale; and Social Defeat measured with the Defeat Scale. The Defeat scale contains 16 statements, which describe how feel about themselves e.g. successful, powerless or one of life's losers and does not correspond to our multidimensional definition of SE. In this table we only present the results for Social support and Perceived discrimination.
- k) Measures used: Depressive symptoms: Kessler Psychological Distress Scale 10 (K10); Psychotic experiences: Prodromal Questionnaire-16 (PQ-16).

## Table S1b: Description of observational studies on the association between SE/SI and mental health in high risk groups

Reference	Setting	Population	Sample size	Indicators SE/ SI *	Health measure **	Statistical analysis
Case control stu	idy	1	1	1	I	1
Flores et al. [42]	Spain	Adult men from various risk settings	105	S: family contact E: income level P: habitual domicile C: source of income (legal, illegal, work) SEPC: excluded on all 4 dimensions	Outcome MH: personality features by DSM- III (9 scales)	Mann-Whitney U Test comparing case groups with control (no AIDS, no drug addiction, no SE)
Todd et al. [49]	England	Clients of Mental Health Services (MHS) and Drug & Alcohol Services (DAS)	590	Outcome: S: isolation E: employment P1: homelessness (2) P2: education C: contact with criminal justice system (4)	MH: comorbidity of psychiatric and substance misuse disorders	Conditional logit model
Webber & Huxley [39]	England	Persons assessed for compulsory hospitalization	300	S: social support E1: income, E2: employment P1: insecure housing; P2: education; P3: neighbourhood deprivation <sup>a)</sup> SEP: 3 or more indicators above mean	Outcome: MH: emergency compulsory hospitalization MH: compulsory hospitalization	Uni and multivariate logistic regression
<b>Cross-sectional</b>	study			l		
Choi et al. [40]	South Korea	Torture survivors	206	S: exclusion by family and a cquaintances and not being able to reveal torture experiences (5) P: no support or help by government / institutions (1) SP: average rating on 6 items <sup>b</sup>	Post-traumatic stress disorder <sup>e)</sup> Depression Anxiety Hostility Somatisation Interpersonal sensitivity	Hierarchical regression analysis

Confounding, matching & stratification etc.	Results per indicator***	Correlations and effect estimates per indicator \$	Combined result \$\$	Methodological limitations #	Study quality ##
		1			
Case 1: AIDS + drug addiction + SE	+ SEPC 8 scales ns SEPC narcistic	Z-values ranged from -4.533 to -2.795	+	57	+
Case 2: drug addiction + SE	+ SEPC 8 scales ns SEPC narcistic	Z-values ranged from -5.852 to -2.714	+		
Case 3: SE	+ SEPC 6 scales ns SEPC histronic, ns SEPC antisocial ns SEPC aggressive- sadistic	Z-values ranged from -5.955 to -2.758	+/0		
C/C: MH=yes/no Matched on gender, age; type of substance (DAS clients only)	MHS clients: + S E P1 C ns P2	SE factor present vs not present: OR (95% CI) S:1.85 (1.20-2.83) E:0.36 (0.21-0.59) P1: 4.51 (2.25-9.04) and 3.40 (1.53-7.54) C: OR's ranging from 3.17 (1.34–7.49) to 10.05 (4.32–23.4)	+	145	+
	DAS clients: ns S E P C		0		
C/C: MH:=yes/other assessment outcome Stratified sample by geographic area and assessment outcome.	+ S S ns E P <sup>a</sup> SEP	S: OR=2.16 (1.22-3.83) S: OR <sub>adj</sub> =2.04 (1.12-3.71)	0 (SEP)	1 2 3 5"	+
Adj for ethnicity, bi-polar disorder and present risk	+ P1 SEP ns P1 <sub>adj</sub> SEP ns S E1 E2 P2 P3	P1: OR=1.72 (1.05-2.79) SEP: OR=2.01 (1.22-3.31)	0 (SEP <sub>adj</sub> )		
Co-variates: sex, age, education, psychological	+ SP	SP: β=0.310 p<.001	+	1 3 5"	+
preparedness, perceived	+ SP	SP: β=0.227 p<.05			
torture <sup>d)</sup> , other traumatic	+ SP	SP: β=0.297 p<.01			
experience and time since the	+ SP	SP: β=0.318 p<.01			
first torture event, perceived	+ SP	SP: β=0.296 p<.001			
related to torture and post torture stressors <sup>d)</sup>	0 SP				

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Reference	Setting	Population	Sample size	Indicators SE/ SI *	Health measure **	Statistical analysis
Cole et al. [36]	USA	Patients publicly funded substance abuse treatment	787	E: economic hardship P: perceived discrimination e) SSS = subjective social standing	Outcome: MH: Perceived stress	Multivariate linear regression
Fakhoury & Priebe [52] <sup>d)</sup>	England	Patients Assertive Outreach team	580	S: living alone P: street homelessness, C1: history of arrests, C2: physical violence	Outcome: MH1: Alcohol abuse and dependency MH2: Drug abuse and dependency	Multiple regression
Killaspy et al. [33]	England	Adults with psychosis	67	Outcome: S: social integration (T1:15/ T2:27 items) E1: consumption (7/8 items) E2: productivity (1/5 items)	MH1: Development of psychosis	Paired t-test (ΔT2-T1)
				P: access to services (2/4 items) C: political engagement (3/3 items) <sup>g)</sup>	MH2: current symptoms MH3: QoL MH4: unmet needs	ANCOVA
Maia et al. [55]	Portugal	Patients with HIV	371	EP: index based on 6 indicators <sup>in</sup> S1: Relationship with family S2: Social support	MH: symptoms of depression <sup>j)</sup>	Hierarchical linear regression
March et al. [50]	9 European countries	Drug users in public places	1,879	E: occupation P: housing in last year C: been in prison	MH: Intravenous drug use:	Hierarchical logistic regression
O'Brien et al. [51]	Cananda	Adults in HIV treatment	913	E: income, difficulty with housing costs, employment (5) P: housing situation and belonging in the neighbourhood (3) EP: latent variable based on E and P indicators	MH: mental symptoms & impairments (57)	Structural equation modeling

Confounding, matching & stratification etc.	Results per indicator***	Correlations and effect estimates per indicator \$	Combined result \$\$	Methodological limitations #	Study quality ##
Gender, age employment, health, substance abuse, social support, self and personal control,	+ E P	E: $\beta_{adj} = .182; p < .001$ P: $\beta_{adj}^{adj} = .139; p < .001$ SSS: $\beta_{adj} =324; p < .001$	+	3 4 5"	+
Gender, age, ethnicity, employment, marital status, new client, contact with other mental health services, previous (compulsory) hospitalisation, clinical diagnose, acts of parasuicide	+ S C1 C2 ns P + P C2 ns S C1	S: OR 2.30 (1.33, 3.99) C1: OR 2.14 (1.10, 4.17) C2: OR 1.87 (1.02, 3.44) P: OR 3.79 (1.37, 10.49) C2 OR 3.89 (2.27, 6.68)	+/0	12345	+
	+ $\Delta S \Delta E2$ ns $\Delta E1 \Delta P \Delta C^{g}$	Mean (SD) P value S: T1 33.2 (7.8) T2: 27.9 (6.4) p<001 E2: T1 5,4 (4.4) T2: 2.6 (1.5) p<.001	+/0	4	+
Covariates gender, age, marital status, ethnicity, education, accommodation, institutional, forensic and disease history	$\begin{array}{l} \Delta S \\ + \ MH3 \\ ns \ MH2 \ MH4 \\ \Delta E2 \\ ns \ MH2 \ MH3 \ MH4 \ ^{h)} \end{array}$	ΔS MH3: b <sub>adj</sub> =-3.0 (-6.0-0.0) P=.048	na		
Gender, age, adverse experiences index, health and disease indicators <sup>k)</sup>	+ EP S1 S2	$\begin{array}{llllllllllllllllllllllllllllllllllll$	+	1 3 4" 5	+
Gender, age, country, age of first use cocaine/heroin, drug treatment	+ E P C	Injectors versus non-injectors: E: $OR_{adj} = 1.38 (1.06-1.81)$ P: $OR_{adj} = 1.57 (1.17-2.12)$ C: $OR_{adj} = 1.32 (1.02-1.70)$	+	1345	+
Other factors in model: physical symptoms & impairments, daily functioning	+ EP	Physical symptoms MH SI, B=0.427 Significance level 0.05	+	2357"	+
For footnotes \* \*\* \*\*\* \$ \$\$ # ## see Table S1a.

- a) Based upon the Index of Multiple Deprivation (IMD) which includes 38 indicators on income, employment, health & disability, education, skills & training, barriers to housing & services, living environments and crime. (Department for Communities and Local Government. 2007. The index of multiple deprivation. London: The National Archives, DCLG.)
- b) Internal consistency (Cronbach's alpha) of the six items on social exclusion was .816.
- c) Post-traumatic stress disorder was assessed by the Korean version of the Impact of Event Scale-Revised. Other complex post-traumatic symptoms i.e. Depression, Anxiety, Hostility, Somatisation and Interpersonal sensitivity, were assessed by related subscales of the Symptom Checklist 90-Revised-Korean version.
- d) Types of torture were constructed using principal axis factor analysis and included physical torture, psychological torture and torture of deprivation. Post-torture psychosocial stressors were assessed by the Exposure to Psychosocial Stressor Scale designed specifically to assess the presence and perceived distress of stressors in the context of Korea and included probation, socio-economic repression and social exclusion. Social exclusion is reported here separately.
- e) Economic hardship was assessed with a modified measure of ability to meet expenses and food insecurity in the 1996 Survey of Income and Program Participation (SIPP; She and Livermore, 2007). Perceived discrimination: Kessler et al., 1999; Subjective social standing: Adler et al., 2000, p. 587. For references please see Cole et al. [36].
- f) The study of Fakhoury and Priebe is a prospective cohort study. The data in this review, however, come from a cross-sectional analysis. Hence, the classification as a cross-sectional design.
- g) SE is measured with the SInQUE [32] which is designed as a structured interview for use in people with mental health problems. The questionnaire is in two parts: the first part relates to the year prior to the first psychiatric admission (T1) and the second part relates to the current situation (T2).

- h) Two of the five SI domains (S and E2) showed a significant change in SInQUE scores between the development of a psychotic illness (T1) and currently (T2). The change in social integration (ΔS) was significantly associated with QoL(MH3) and not with current symptoms (MH2) and unmet needs (MH4).
- i) Index of social exclusion: sum of the level of needs with regard to 1. employment, 2. sources of income, 3. housing conditions (14 items), 4. support needs for nutrition, 5. money and 6. instrumental care providers in case of need (items). Sum score varying between 0 and 6.
- j) Depressive symptoms were measured with a reduced version of the Questionnaire for identification of the psychosocial needs of people living with HIV, Maia et al., 2014, based on six symptoms (thoughts of ending life, feeling lonely, feeling sad, not interested in anything, feeling hopeless about the future, and without hope for the future).
- k) Time since diagnosis of HIV, source of infection, marital infection, health status and daily concerns with health.

# Table S2a: Description of observational studies on the association between SE/SI and physical health in the general population

Reference	Setting	Population	Sample size	Indicators SE/SI *	Health measure**	Statistical analysis
Prospective c	ohort study	y				
Saito et al. [43]	Japan	General population, 65 years or older	13,310	S: social isolation and/or social inactivity E: relative poverty ES: excluded on S and E	<b>Outcome</b> : PH: mortality	Cox's proportional hazard model
Case control s	study					
Waterstone et al. [44]	England	General population: women who delivered in maternity units	2,938	SEPC: 1 or more indicators present, out of list of 13 SE indicators <sup>a)</sup>	Outcome: PH: severe obstetric morbidity PH: severe PET PH: severe haemorrhage PH: severe sepsis PH: uterine rupture	Multivariate logistic regression
Cross-section	al study			1	1	n
Bayram et al. [34]	Turkey	General population, 18-80 years	2,493	S: social participation (9) E: material deprivation (8) P1: access to institutions (5) P2: access to adequate housing and safe environment (8) C: cultural normative integration (5 items) <sup>b)</sup>	PH: physical health (WHOQOL- BREF)	Structural equation modeling
Halleröd & Larsson [47]	Sweden	General population 16-74 years	4,941	S: loneliness E1: deprivation of goods/services (36); E2: cash margin P1: crowded housing (4); P2: disorganised area (4); P3: worried by crime; P4: victimisation crime; P5: victimisation violence C1: voting; C2: politically active	PH1: obesity PH2: headache PH3: sleeplessness	Bivariate correlation

Confounding, match-ing & stratification etc.	Results per indicator***	Correlations and effect estimates per indicator \$	Combined result \$\$	Methodological limitations #	Study quality ##
<u></u>					
Adj for age, marital status, education,	$\begin{array}{c} + & S & ES \\ ns & E \end{array} \qquad \qquad$	S: HR <sub>adj</sub> 1.46 (1.03-2.09) ES: HR <sub>adj</sub> 1.73 (1.03-2.90)	+	235	+
and/or impairment,	ns S E ES 💍	X	0	235	
1	1				
C/C: PH=yes/no Matched on maternity unit Adj. for age, race,	+ SEPC	SEPC: OR <sub>adj</sub> =2.64;(1.69 – 4.11)	+	2 5	+
general medical and	+ SEPC	SEPC: OR <sub>adi</sub> =1.99;(1.07 - 3.72)	+		
course of pregnancy,	+ SEPC	SEPC: OR <sub>adi</sub> =2.91;(1.76 – 4.82)	+		
course of pregnancy, conditions at booking,	ns SEPC	X	0		
	ns SEPC	X	0		
Other factors in model: psychological health, environment and social relations. Not in model: C P1	+ S ns E P1-2 C	PH⇔S: β=-0.40 Significance level not mentioned	0	4 7"	+
	+ E1 E2 P3 P4 ns S P1 P2 P5 C1 C2 (p<0.001)	Kendall tau b: E1:0.13; E2:0.10; P3:0.03; P4:- 0.03	+/0	24567	+
	+ S E1 E2 P1 P2 P3 P4 P5 C1 C2 ns (p<0.001)	S:0.10; E1:0.13; E2:0.13; P1:0.05; P2:0.07; P3:0.06; P4:0.04; P5:0.06; C1:0.06; C2:-0.04	+		
	+ S E1 E2 P2 P3 P5 C1 ns P1 P4 C2 (p<0.001)	S:0.13; E1:0.15; E2:0.12; P2:0.10; P3:0.13; P5:0.09; C1:0.06	+		

Reference	Setting	Population	Sample size	Indicators SE/SI *	Health measure**	Statistical analysis
Richter & Hoffmann [48]	Switzerland	General population 18-64 for men / 63 for women	14,256 c)	S1: living alone; S2 living without a partner; S3 no person to talk to; S4 attendance of social events; S5 feeling lonely; S6 social support (3) E1: low income	PH: physical illness or disability <sup>e)</sup>	Logistic regression

- \* S= social dimension; E=economic dimension; P=political dimension; C=cultural dimension; between brackets the number of items (if more than 1). A group of letters e.g. EP or SEP indicates an aggregate measure based on the listed dimensions.
- \*\* PH=physical health. QoL=quality of life. PET=pre-eclamptic conditions including HELPP syndrome and eclampsia.
- \*\*\* Code for results: + hypothesis confirmed i.e. high SE/low SI associated with adverse health outcome; ns no significant association; hypothesis rejected i.e. low SE/high Si associated with adverse health outcome; +? high SE/low SI combined with adverse health, but no statistical testing. C/C = Case/Control.
- \$ P-value <.05 unless stated otherwise. OR's and HR's are given with the 95% confidence interval between brackets. Adj=adjusted for potential confounders.
- \$\$ Code for results: + 0 see \*\*\*; +/0 hypothesis confirmed for 30-70% of SE/SI indicators and the remaining 70-30% not significant; x no statistical testing or no associations reported.
- # Specific methodological limitations: Limitations: 1, no theoretical motivation of the concept SE/SI; 2, data set not originally designed to measure SE/SI; 3, not all dimensions of SE/SI measured; 4, no composite measure SE/SI; 5, no existing SE/SI measure; 6, testing of association SE/SI -H was not a stated objective; 7, no adjustment for demographic and other potential confounding factors; ", limitation partly present. For more details please see Supplementary file 4.
- ## General study quality was appraised with the CASP=Critical Appraisal Skills Programme tool for cohort studies (Supplementary file 2) or cross-sectional studies (Supplementary file 3).
- a) SE indicators: S − 1, partner abroad of unsupported. E 2. on income support. P − 3, poor housing. C 4, concealed pregnancy; 5, age <16 years; 6, previous minor/child in local authority or state care; 7, in trouble with the law; 8, unbooked; 9, unwanted pregnancy; 10, currently or previously in foster care; 11, care order being considered on potential child; 12, social worker involved; and 13, drug or alcohol dependency.</p>
- b) Jehoel Gijsbers & Vrooman [35].

Confounding, match-ing & stratification etc.	Results per indicator***	Correlations and effect estimates per indicator \$	Combined result \$\$	Methodological limitations #	Study quality ##
Adj for gender and age	+ S1-6 E	OR         (95% CI)           S1         2.68 (2.08-3.54)           S2         3.94 (3.08-5.02)           S3         3.18 (2.13-4.59)           S4         2.89 (2.29-3.64)           S5         6.54 (4.67-8.99)           S6         3.00 (2.28-3.90)           E         3.65 (2.84-4.47)           No illness is reference group	+	2 3 4 5 7"	+

c) The analysis involved 299 people with severe physical illness PH, 171 people with severe mental illness (MH1), 841 people with common mental illness (MH2) and 13,957 people without these illnesses. In Table S2a only results for PH are presented (N=14,256). PH = not being treated for a mental health problem and receiving a disability pension; MH1 = being treated for a mental health problem and receiving a disability pension; MH2 = being treated

 Table S2b: Description of observational studies on the association between SE/SI and physical health in high risk groups

For footnotes see Table S2a.

Reference	Setting	Population	Sample size	Indicators SE/SI *	Health measure**
O'Brien et al. [51]	Cananda	Adults in HIV treatment	913	E: income, difficulty with housing costs, employment (5) P: housing situation and belonging in the neighbourhood (3) EP: latent variable based on E and P indicators	PH1: physical symptoms & impairments (26) PH2: daily functioning (17)

 Table S3a: Description of observational studies on the association between SE/SI and general health in the general population

Reference	Setting	Population	Sample size	Indicators SE/SI *	Health measure**				
Prospective cohort study									
Bryngelson [41]	Sweden	General population, 18-55 years	3,144	Outcome: S: no close friends and/or single/ unmarried E: no cash margin C: not voting ES, EC: excluded on E&S, E&C	GH: long-term sickness absence				
Gannon & Nolan [53]	Ireland	General adult population	2,727	Outcome: S: evening out in last 2 week E1: household income	GH: disability onset				
				E2: risk of poverty	GH: persistent disability				

Statistical analysis	Confounding, match-ing & stratification etc.	Results per indicator***	Correlations and effect estimates per indicator \$	Combined result \$\$	Methodological limitations #	Study quality ##
Structural equation modeling	Mental symptoms & impairments (MH)	PH1 PH2: + EP	PH1 SI, B=-0.230 PH1 PH2 SI, B=0.239 PH1 MH SI, B=0.427 Significance level 0.05	+	235 7"	+

Statistical analysis	Confounding, match-ing & stratification etc.	Results per indicator***	Correlations and effect estimates per indicator \$	Combined result \$\$	Methodological limitations #	Study quality ##
Logistic regression analysis	Adj for age and social exclusion situation at T1	+ E ES $\varphi$ ns S C EC $\varphi$	E: $OR_{adj} = 1.81 (1.21-2.70)$ ES: $OR_{adj} = 10.08 (1.82-55.73)$ E: $OR_{adj} = 4.08 (2.42-6.86)$	+/0	2 3 4" 5 7" 2 3 4"	+
 Probit model (stand. regr. coeff)	Adj for gender, age, education and household composition	+ S E1 E2 + S E1 E2	S: $\beta_{adj} = 0.135$ E1: $\beta_{adj} = -0.217$ ; E2: $\beta_{adj} = 0.054$ . S: $\beta_{adj} = -0.135$ E1: $\beta_{adj} = -0.256$ ; E2: $\beta_{adj} = 0.040$	+	3 4 5	+

Reference	Setting	Population	Sample size	Indicators SE/SI *	Health measure**
Retrospective	cohort st	tudy			
Sacker et al. [46]	UK	General population, 65 years or older	4,321	SP: social exclusion index based on three dimensions: S1 = Civic participation (4), S2 = Social relations and resources (5) P = Service provision and access (5) <sup>a)</sup> Measured in wave 3.	GH1: transition in SAH (wave 1=>2) <sup>b)</sup>
					GH2: transition in LLTI (wave 1=>2) <sup>b)</sup>
					GH3: SAH (wave 4)
Cross-section	al study				
United &	Granda	C an anal	4.041	S. log aligned	CII. alarania diana a di
Larsson [47]	Sweden	population 16- 74 years	4,941	5: toneliness E1: deprivation of goods/services (36); E2: cash margin P1: crowded housing (4); P2: disorganised area (4); P3: worried by crime; P4: victimisation crime; P5: victimisation violence C1: voting; C2: politically active	GH: chronic disease <sup>(i)</sup>
Urbanos- Garrido [54]	Spain	General population, 16 and over	25,498	<ul> <li>S1: face contacts with family</li> <li>S2: face contacts with friends</li> <li>S3: non-face contacts with family</li> <li>S4: non-face contacts with friends</li> <li>S5: voluntary work</li> <li>E1: financial deprivation (10)</li> <li>E2: no dental treatment due to financial</li> <li>problems</li> <li>P1: housing deprivation (9)</li> </ul>	GH: SAH GH: chronic disease <sup>e)</sup> GH: limitations <sup>e)</sup>
·					

Statistical analysis	Confounding, match-ing & stratification etc.	Results per indicator***	Correlations and effect estimates per indicator \$	Combined result \$\$	Methodological limitations #	Study quality ##
 Linear regression	Adj for gender, age. age <sup>2</sup> , ethnicity, migrant, marital status, job status, educational level, social class, region and (transitions in) SAH and LLTI. Mediator/ moderator: rural vs urban; car access, mobile phone ownership, internet use	Effect on SP (wave 3) -Good=>poor: + -Poor=>good: + -Stable poor: + Effect on SP (wave 3) -Good=>poor: ns -Poor=>good: ns -Stable poor: +	Effect on SP (wave 3) e <sup>0</sup> GH1         β (95% CI)           -Stable good is reference           -Good=>poor         0.76 (0.49-1.02) ^^^           1.02) ^^^         -           -Poor=>good         0.61 (0.32-0.90) ^^           -Stable poor         0.95 (0.72-1.18) ^^           Effect on SP (wave 3) e <sup>0</sup> GH2         β (95% CI)           -Stable no LLTI is reference         -         Stable LLTI         0.22 (0.02-0.42) ^	+	235	+
 Logistic regression		+ SP + SP	Effect on GH3 (wave 4) SP: OR <sub>adj</sub> =1.15 (1.09-1.21) Effect on GH4 (wave 4) SP: OR <sub>adj</sub> =1.07 (1.02-1.12)			
Bivariate correlation		+ S E1 E2 P2 P3 ns P1 P4 P5 C1 C2 (p<0.001)	Kendall tau b: S:0.06; E1:0.07; E2:0.08; P2:0.05; P3:0.12	+/0	245 67	+
 Concentration index: % contribution to health inequality	Other factors in model: gender, age, education, employment, urbanicity, region, deprivation	+ S2 S4 E1 E2 P ns S1 S3 S5 + S1 S2 S3 S4 E1 E2 P ns S5 + S2 S3 S4 E1 E2 P ns S1 S5	S2 3.87%; S4 2.58%; E1: 29.85%, E2:2.61%, P: 8.56% S1 0.23%; S2 3.68%; S3 0.23%; S4 4.05%; E1: 29.73%, E2:3.74%, P: 7.17% S2 4.40%; S3 0.11% S4 4.43%; E1: 32.56%, E2:4.02%, P: 8.01%	+	3 4 5	+

- \* S= social dimension; E=economic dimension; P=political dimension; C=cultural dimension; between brackets the number of items (if more than 1). A group of letters e.g. ES or EC indicates an aggregate measure based on the listed dimensions.
- \*\* GH=general health. SAH=self-assessed health.
- \*\*\* Code for results: + hypothesis confirmed i.e. high SE/low SI associated with adverse health outcome; ns no significant association; - hypothesis rejected i.e. low SE/high SI associated with adverse health outcome; +? high SE/low SI combined with adverse health, but no statistical testing; na=not applicable.
- \$ P-value <.05 unless stated otherwise. OR's and HR's are given with the 95% confidence interval between brackets. Adj=adjusted for potential confounders.
- \$\$ Code for results: + 0 see \*\*\*; +/0 hypothesis confirmed for 30-70% of SE/SI indicators and the remaining 70-30% not significant; x no statistical testing or no associations reported.
- # Specific methodological limitations: Limitations: 1, no theoretical motivation of the concept SE/SI; 2, data set not originally designed to measure SE/SI; 3, not all dimensions of SE/SI measured; 4, no composite measure SE/SI; 5, no existing SE/SI measure; 6, testing of association SE/SI -H was not a stated objective; 7, no adjustment for demographic and other potential confounding factors; ", limitation partly present. For more details please see Supplementary file 4.

**Table S3b:** Description of observational studies on the association between SE/SI and general health in high risk groups

For footnotes see Table S3a.

Reference	Setting	Population	Sample size	Indicators SE/ SI *	Health measure**	Statistical analysis	
<b>Cross-sectional</b>	study						
Johner et al. [55]	Canada	Single mothers, 18-59 years	375	S1: social support; S2: social network diversity; S3: social network density; S4: sense of control; E: education	GH: SAH	Hierarchical logistic regression	

- ## General study quality was appraised with the CASP=Critical Appraisal Skills Programme tool for cohort studies (Supplementary file 2) or cross-sectional studies (Supplementary file 3).
- a) A social exclusion index was constructed with three underlying dimensions; P= Service provision and access (5 items e.g. poor quality of local medical facilities), S1=Civic participation (4 items e.g. participation in cultural, sports and leisure activities) and S2=Social relations and resources (5 items e.g. living alone, no close friendship).
- b) SAH=self-assessed health (excellent, very good, good vs fair or poor). LLTI=limiting long-term illness/ disability present (yes/no). Transitions in SAH and LLTI were entered in the regression model with MH1 as independent variable and SP as dependent variable.

c) ^ p<0.05, ^^^ p<0.001.

- d) Chronic disease was measured with a single question asking if the respondent suffered from any longstanding illness or handicap that negatively impacts on his/her ability to work or perform daily activities.
- e) Chronic disease was measured with a single question asking if any chronic disease, disability or condition was present (yes/no). Limitations was measured with a single question on the presence of any kind of limitations in daily activity (intense or not) due to health problems in the preceding six months (yes/no).

Confounding, match-ing & stratification etc.	Results per indicator***	Correlations and effect estimates per indicator \$	Combined result \$\$	Methodological limitations #	Study quality ##
Stratified by social assistance receipt. Adj. for income, age, aboriginal identity, children under 6 and disability.	On social assistance: + S4 ns S1 S2 S3 E Not on social assistance: + S1 S4 ns S2 S3 E	S4: $\beta_{adj}$ = .250 p=.004 S1: $\beta_{adj}$ = .278 p=.001; S4: $\beta_{adj}$ = .170 p=.042	0	3 4 5       3 4 5	+

### **SUPPLEMENTARY MATERIAL CHAPTER 3**

Figure S1. Centroid plots Index1: Quadrants I and II (A); Quadrants III and IV (B).



Figure S1A. Centroid plots Index1: Quadrants I and II.



#### **Dimension 1: social exclusion**

#### Figure S1B. Centroid plots Index3: Quadrants III and IV.

The Figures S1 A and B show the centroid plots generated by a two dimensional Overals analysis on the Amsterdam dataset. Blue are centroids of variables in the set 'Lack of social participation'; red are centroids of variables in the set 'Material deprivation'. The scales vary between figures. Although two dimensions are shown here, only dimension 1 is relevant as it represents the social exclusion domain. Dimension 2 is added for visual mapping of the constructed space. For the sake of clarity, only lowest and highest variable values are displayed.

As shown in Figures S1 A and B, all negative outcomes (difficult getting by; often feeling rejected; missing the pleasure of the company of others; etc) are clustered in quadrants I and II, while the positive outcomes are all clustered in the quadrants III and IV. The centroid plots thus show that the variables separate well groups of objects that are socially excluded (quadrants I and II) from those not socially excluded (quadrants III and IV).



#### Figure S2. Centroid plots Index2: Quadrants I and II (A); Quadrants III and IV (B).



Figure S2B. Centroid plots Index2: Quadrants III and IV.

The figures S2 A and B show the centroid plots generated by a two dimensional Overals analysis on the Rotterdam / The Hague dataset. Blue are centroids of variables in the set 'Lack of social participation'; red are centroids of variables in the set 'Material deprivation' and green are centroids of variables in the set 'Limited access to basic social rights'. The scales vary between figures. Although two dimensions are shown here, only dimension 1 is relevant as it represents the social exclusion domain. Dimension 2 is added for visual mapping of the constructed space. For the sake of clarity, only lowest and highest variable values are displayed. As shown in Figures S2 A and B, all negative outcomes (difficult getting by; often feeling rejected; missing having people around; etc) are clustered in quadrants I and II, while the positive outcomes are all clustered in the quadrants III and IV. The centroid plots thus show that the variables separate well groups of objects that are socially excluded (quadrants I and II) from those not socially excluded (quadrants III and IV).





Figure S3A. Centroid plots Index3: Quadrants I and II.



Figure S3B. Centroid plots Index3: Quadrants III and IV.

The figures S3 A and B show the centroid plots generated by a two dimensional Overals analysis on the Utrecht dataset. Blue are centroids of variables in the set 'Lack of social participation'; red are centroids of variables in the set 'Material deprivation' and green are centroids of variables in the set 'Limited access to basic social rights'. The scales vary between figures.

Although two dimensions are shown here, only dimension 1 is relevant as it represents the social exclusion domain. Dimension 2 is added for visual mapping of the constructed space. For the sake of clarity, only lowest and highest variable values are displayed. As shown in Figures S2 A and B, all negative outcomes (difficult getting by; often feeling rejected; limited contact with neighbours; etc) are clustered in quadrants I and II, while the positive outcomes are all clustered in the quadrants III and IV. The centroid plots thus show that the variables separate well groups of objects that are socially excluded (quadrants I and II) from those not socially excluded (quadrants III and IV).

### **SUPPLEMENTARY MATERIAL CHAPTER 4**

Additional file 1. Category quantifications SEI-HS items dimension (limited) Social Participation.



The figure shows for each item of the dimension (limited) Social Participation the relationship between the original category and the quantification resulting from the canonical correlation analysis. Categories indicating little or no social exclusion received the lowest quantifications and categories indicating high levels of social exclusion received the highest values. The category quantifications were used to calculate the Social Participation scale score by multiplying them with their item weights (Table 3); and adding up the results.

## Additional file 2. Category quantifications SEI-HS items dimension (inadequate access to basic) Social Rights.



The above figure shows for each item of the dimension (inadequate access to basic) Social Rights the relationship between the original category and the quantification resulting from the canonical correlation analysis. Categories indicating little or no social exclusion received the lowest quantifications and categories indicating high levels of social exclusion received the highest values. The category quantifications were used to calculate the Social Rights scale score by multiplying them with their item weights (Table 3); and adding up the results.



## Additional file 3. Category quantifications SEI-HS items dimension (lack of) Normative Integration.

The above figure shows for each item of the dimension (lack of) Normative Integration the relationship between the original category and the quantification resulting from the canonical correlation analysis. Categories indicating little or no social exclusion received the lowest quantifications and categories indicating high levels of social exclusion received the highest values. The category quantifications were used to calculate the Normative Integration scale score by multiplying them with their item weights (Table 3); and adding up the results.

SUPPLEMENTARY MATE	RIAL (	CHAP	TER 5						
S1A Table. Differential item functioning in SE	I-HS items	with resp	ect to migra	nt background	, Surinamese v	ersus na	tive Dutch.	* * *	
	Total DIF		Uniform <b>D</b>	OIF			Non-unifo	rm DIF	Type of DIF
Surinamese versus native Dutch	<i>P</i> Value M3 vs M1	$\Delta R^2$ M3-M1	<i>P</i> Value M2 vs M1	% difference in $\beta_{_{11}(M2-M1)}$	% difference in $\beta_{12 \text{ (M2-M1)}}$	$\Delta R^2$ M2-M1	<i>P</i> Value M3 vs M2	$\Delta R^2$ M3-M2	* * *
<b>Dimension 1: Limited social participation</b>									
1. I experience a general sense of emptiness	0.003	0.003	0.003	-1.4%	-0.9%	0.002	0.031	0.001	None
2. There is always someone I can talk to about my day-to-day problems	0.000	0.007	0.000	-3.1%	-2.2%	0.006	0.050	0.001	Not subst.
3. There are plenty of people I can lean on when I have problems	0.002	0.003	0.000	-1.9%	-1.5%	0.002	0.573	0.001	Not subst.
4. I miss the pleasure of the company of others	0.016	0.002	0.019	-1.2%	-0.8%	0.001	0.087	0.001	None
5. I often feel rejected	0.065	0.001	0.028	-1.1%	-0.7%	0.001	0.299	0.000	None
6. Little contact with neighbours and people in the street	0.162	0.001	0.412	-0.5%	-0.4%	0.000	0.107	0.001	None
Dimension 2: material deprivation									
7. Had difficulty past year getting by on the household income	0.000	0.008	0.000	-3.2%	-1.9%	0.004	0.000	0.004	Not subst.
8. I have enough money to heat my home	0.002	0.006	0.000	-4.7%	-0.9%	0.005	0.266	0.001	Not subst.
9. I have enough money for club memberships	0.000	0.004	0.000	-4.0%	-2.8%	0.005	0.000	0.005	Not subst.
10. I have enough money to visit others	0.019	0.002	0.005	-2.1%	-2.0%	0.002	0.375	0.000	None
Dimension 3: inadequate access to basic soci	ial rights								
11. People in this neighbourhood generally do not get along with each other	0.000	0.010	0.000	-2.8%	-2.3%	0.009	0.023	0.001	Not subst.
12. Degree of satisfaction with housing	0.993	0.000	0.971	0.0%	0.0%	0.000	0.955	0.000	None
13. I didn't receive a medical or dental treatment	0.035	0.004	0.025	-2.7%	-2.6%	0.002	0.164	0.002	None

Dimension 4: lack of normative integrati	0U								
14. I give to good causes	0.001	0.001	0.550	0.3%	0.3%	0.000	0.000	0.001	Not subst.
15. I sometimes do something for my neighbours	0.000	0.011	0.000	-2.5%	-2.2%	0.010	0.172	0.001	Not subst.
16. I put glass items in the bottle bank	0.000	0.005	0.001	-1.7%	-1.9%	0.002	0.000	0.003	Not subst.
17. Work is just a way of earning money	0.000	0.009	0.000	-3.2%	-7.3%	0.008	0.004	0.001	Not subst.
		•						:	

\*Model 1:  $Y = \beta_0 + \beta_1 M$ ; Model 2:  $Y = \beta_0 + \beta_1 M + \beta_2 G$ ; Model 3 :  $Y = \beta_0 + \beta_1 M + \beta_2 G + \beta_3 M^* G$ . Y=item, M=matching variabele=dimensions scale en G=grouping variable=Surinames vs native Dutch.

\*\*Results in bold if the following criteria for DIF were met: P value < 0.002 (Bonferroni corrected) [39], % difference in  $\beta > 10\%$  [39], Nagelkerke pseudo  $R^2 \Delta >= 0.035$  [40].

\*\*\*None: P value total DIF  $\geq 0.002$ ; Not substantial: P value total DIF  $< 0.002 \& \Delta R^2 (M3-MI) < 0.035$ .

S1B Table. Differential item functioning in	SEI-HS item	s with re	spect to mig	grant backgrou	ınd, Moroccan	versus n	ative Dutch.	* *	
	Total DIF		Uniform ]	DIF			Non-unifor	m DIF	Type of DIF
Moroccan versus native Dutch	<i>P</i> Value M3 vs M1	$\Delta R^2$ M3-M1	<i>P</i> Value M2 vs M1	% difference in $\beta_{11 (M2-M1)}$	% difference in $\beta_{12(M2-M1)}$	$\Delta R^2$ M2-M1	<i>P</i> Value M3 vs M2	$\Delta R^2$ M3-M2	* * *
<b>Dimension 1: Limited social participation</b>									
1. I experience a general sense of emptiness	0.009	0.002	0.235	-0.7%	-0.4%	0.000	0.006	0.002	None
2. There is always someone I can talk to about my day-to-day problems	0.000	0.005	0.000	-2.6%	-1.6%	0.005	0.628	0.000	Not subst.
3. There are plenty of people I can lean on when I have problems	0.000	-0.001	0.000	-0.5%	-2.2%	-0.002	0.179	0.001	Not subst.
4. I miss the pleasure of the company of others	0.000	0.004	0.000	-1.8%	-1.0%	0.003	0.030	0.001	Not subst.
5. I often feel rejected	0.445	0.000	0.685	0.2%	0.1%	0.000	0.286	0.000	None
6. Little contact with neighbours and people in the street	0.340	0.001	0.086	1.1%	1.1%	0.001	0.816	0.000	None
<b>Dimension 2: material deprivation</b>									
7. Had difficulty past year getting by on the household income	0.000	0.003	0.026	-1.3%	-1.1%	0.001	0.000	0.002	Not subst.
8. I have enough money to heat my home	0.000	0.024	0.000	-7.2%	-8.4%	0.023	0.307	0.001	Not subst.
9. I have enough money for club memberships	0.000	0.026	0.000	-4.3%	-3.2%	0.021	0.000	0.005	Not subst.
10. I have enough money to visit others	1.000	0.000	1.000	0.0%	0.3%	0.000	1.000	0.000	None
Dimension 3: inadequate access to basic s	ocial rights								
11. People in this neighbourhood generally do not get along with each other	0.000	0.008	0.110	1.4%	0.9%	0.000	0.000	0.008	Not subst.
12. Degree of satisfaction with housing	0.000	0.011	0.000	-3.1%	-2.6%	0.008	0.000	0.003	Not subst.
13. I didn't receive a medical or dental treatment	0.346	0.002	0.560	-1.2%	-0.9%	0.000	0.227	0.002	None

17.1 EIVC W 5000 Cuuses	X	0.4%	0 30%	0 000	0.815	0000	None
	000.0	0/+.0	0/ 0.0	0.000	0.010	0.000	TINUTO
15. I sometimes do something for my	101 0						
neighbours 0.401 0.000 0.404	0.404	-0.3%	-0.2%	0.000	0.336	0.000	None
	0000	0 407	. 10/		1000	0000	
10.1 put glass items in the bottle bank 0.000 0.01/ 0.000	0.000	-2.4%	-2.1%	CI0.0	0.004	0.002	Not subst.
17 Work is just a way of earning money 0 000 0 005 0 078	0.078	~0 L U-	~0 U~	0000	0.000	0.005	Not enhet
1/. WOIR is Just a way of carining money v.vvv 0.000 0.078	0/0.0	-0.1.0-	-0.2/0	0.000	0.000	0.000	John Subst.

G=grouping variable=Moroccan vs native Dutch.

\*\*Results in bold if the following criteria for DIF were met: P value < 0.002 (Bonferroni corrected) [39], % difference in  $\beta > 10\%$  [39], Nagelkerke pseudo  $R^2 \Delta >= 0.035$  [40].

\*\*\*None: P value total DIF >= 0.002; Not substantial: P value total DIF < 0.002 &  $\Delta R^2$  (M3-M1) < 0.035.

	Total DIF		Uniform D	IF			Non-unifor	m DIF	Type of DIF
Turkish versus native Dutch	<i>P</i> Value M3 vs M1	$\Delta R^2$ M3-M1	<i>P</i> Value M2 vs M1	% difference in $\beta_{11(M2-M1)}$	% difference in $\beta_{12 (M2-M1)}$	$\Delta R^2$ M2-M1	<i>P</i> Value M3 vs M2	$\Delta R^2$ M3-M2	* *
<b>Dimension 1: Limited social participat</b>	tion								
1. I experience a general sense of emptiness	0.000	0.016	0.000	-4.2%	-3.1%	0.016	0.079	0.000	Not subst.
2. There is always someone I can talk to about my day-to-day problems	0.000	0.004	0.000	-3.4%	-2.6%	0.003	0.234	0.001	Not subst.
3. There are plenty of people I can lean on when I have problems	0.000	0.009	0.000	-4.2%	-3.3%	0.006	0.001	0.003	Not subst.
4. I miss the pleasure of the company of others	0.000	0.017	0.000	-4.4%	-3.4%	0.017	0.583	0.000	Not subst.
5. I often feel rejected	0.001	0.003	0.000	-2.1%	-1.6%	0.003	0.790	0.000	Not subst.
6. Little contact with neighbours and people in the street	0.000	0.003	0.000	4.0%	4.5%	0.003	0.103	0.000	Not subst.
<b>Dimension 2: material deprivation</b>									
$\overline{7}$ . Had difficulty past year getting by on the household income	0.000	0.006	0.000	-3.5%	-3.3%	0.006	0.182	0.000	Not subst.
8. I have enough money to heat my home	0.000	0.014	0.000	-6.1%	-8.0%	0.013	0.274	0.001	Not subst.
9. I have enough money for club memberships	0.000	0.021	0.000	-4.7%	-4.6%	0.017	0.000	0.004	Not subst.
10. I have enough money to visit others	1.000	0.000	1.000	-0.9%	4.6%	0.000	1.000	0.000	None
<b>Dimension 3: inadequate access to bas</b>	alc social rig	hts							
11. People in this neighbourhood generally do not get along with each other	0.000	0.003	0.033	-1.5%	-0.9%	0.000	0.000	0.003	Not subst.
12. Degree of satisfaction with housing	0.000	0.002	0.641	0.2%	0.2%	0.000	0.000	0.002	Not subst.

S1C Table. Differential item functioning in SEI-HS items with respect to migrant background, Turkish versus native Dutch. \*\*\*

13. I didn't receive a medical or dental treatment	0.000	0.030	0.000	-11.9%	-10.4%	0.028	0.058	0.002	Not subst.
<b>Dimension 4: lack of normative integr</b>	ation								
14. I give to good causes	0.000	0.007	0.000	2.2%	2.6%	0.006	0.087	0.001	Not subst.
15. I sometimes do something for my neighbours	0.183	0.001	0.112	-0.3%	-0.4%	0.001	0.313	0.000	None
16. I put glass items in the bottle bank	0.000	0.023	0.000	-1.2%	-2.2%	0.020	0.000	0.003	Not subst.
17. Work is just a way of earning money	0.000	0.014	0.000	-1.5%	-4.1%	0.010	0.000	0.004	Not subst.
*Model 1: $Y = \beta_0 + \beta_1 M$ ; Model 2: $Y = \beta$	$_{0} + \beta_{1}M +$	$\beta_2 G; Mod$	lel 3 : Y = [	$\beta_0 + \beta_1 M + \beta_2 G$	$G + \beta_3 M^* G. Y$	=item, M=r	natching va	ariabele=di	mensions scale

\*\*Results in bold if the following criteria for DIF were met: P value < 0.002 (Bonferroni corrected) [39], % difference in  $\beta$  > 10% [39], Nagelkerke pseudo R2  $\Delta$  >= 0.035 [40]. en G=grouping variable=Turkish vs native Dutch.

\*\*\*None: P value total DIF  $\geq 0.002$ ; Not substantial: P value total DIF  $< 0.002 \& \Delta R^2$  (M3-M1) < 0.035.

	Surinan	nese	Morocc	an	Turkish		Reference
Dimension	1: Limite	d social pa	rticipation	1			
Item 1	0.773	.000	0.734	.000	0.825	.000	0.769
Item 2	0.497	.000	0.481	.000	0.551	.000	0.504
Item 3	0.561	.000	0.570	.000	0.558	.000	0.479
Item 4	0.780	.000	0.727	.000	0.789	.000	0.769
Item 5	0.770	.000	0.752	.000	0.718	.000	0.689
Item 6	0.151	.000	0.304	.000	0.217	.000	0.258
Dimension 2	2: materia	al depriva	tion				
Item 7	0.650	.000	0.596	.000	0.628	.000	0.588
Item 8	0.546	.000	0.591	.000	0.594	.000	0.519
Item 9	0.723	.000	0.567	.000	0.603	.000	0.720
Item 10	0.767	.000	0.722	.000	0.680	.000	0.679
Dimension 3	3: inadeq	uate acces	s to basic s	ocial righ	ts		
Item 11	0.380	.000	0.384	.000	0.312	.000	0.435
Item 12	0.393	.000	0.440	.000	0.495	.000	0.436
Item 13	0.252	.000	0.262	.000	0.149	.000	0.233
Dimension 4	4: lack of	normativ	e integratio	on			
Item 14	0.440	.000	0.453	.000	0.487	.000	0.414
Item 15	0.379	.000	0.528	.000	0.578	.000	0.332
Item 16	0.229	.000	0.257	.000	0.241	.000	0.336
Item 17	0.191	.000	0.097	.052	-0.046	.299	0.298

S2 Table. Factor loadings items SEI-HS in adults of Surinamese, Moroccan and Turkish origin compared to the reference values in the general Dutch population  $^{\#}$ 

# Confirmatory Factor Analysis in SPSS AMOS

### **S3** Appendix. Dutch version of the SEI-HS

Dimensie 1: Onvoldoende sociale participatie

Er volgen nu enkele uitspraken. Wilt u van elk van de volgende uitspraken aangeven in hoeverre die op u, zoals u de laatste tijd bent, van toepassing is?

Kru	is op iedere regel uw antwoord aan *	ja	min of meer	nee
a.	Er is altijd wel iemand in mijn omgeving bij wie ik met mijn dagelijkse probleempjes terecht kan.			
b.	Ik ervaar een leegte om mij heen.			
c.	Er zijn genoeg mensen op wie ik in geval van narigheid kan terugvallen.			
d.	Ik mis gezelligheid om mij heen.			
e.	Vaak voel ik me in de steek gelaten.			

Hoe vaak hebt u contact met buren of mensen die bij u in de straat wonen?

- minstens 1 keer in de week
- 3 keer per maand
- 2 keer per maand

- 1 keer per maand
- minder dan 1 keer per maand
- zelden of nooit

### Dimensie 2: Materiële deprivatie

Heeft uw huishouden meestal voldoende geld om de volgende dingen te doen?

		ja	nee
a.	uw huis goed verwarmen		
b.	lidmaatschap van sportclub of vereniging betalen		
c.	bij vrienden of familie op visite gaan		

Heeft u de afgelopen 12 maanden moeite gehad om van het inkomen van uw huishouden rond te komen?

Nee, geen enkele moeite 

Nee, geen moeite, maar ik moet wel opletten op mijn uitgaven

- Ja, enige moeite
- Ja, grote moeite

<u>Dimensie 3:</u> Onvoldoende toegang tot sociale grondrechten & <u>Dimensie 4:</u> Onvoldoende normatieve integratie

Hieronder wordt een aantal stellingen gegeven. Wilt u aangeven in hoeverre u het eens bent met deze stellingen?

Krui	s op iedere regel uw antwoord aan.	hele ee	maal ens	bee ee	etje ns	niet ni one	eens/ iet ens	bee one	etje ens	heler one	naal ens
a.	De mensen in mijn buurt kunnen in het algemeen slecht met elkaar opschieten.	C		Ľ		۵		C			]
b.	Werken is slechts een manier om geld verdienen.			C		[		C			]
Heet 12 n tand deze	ft u of iemand in uw huishouden de <b>afge</b> naanden een medische behandeling of heelkundige behandeling nodig gehad, n niet ontvangen?	<b>lopei</b> naar	n		ja nee	•					
Wat	geldt voor u?										
Ik ge	eef geld aan goede doelen				ja nee						
Ik do	be af en toe iets voor de buren				ja nee						
Ik bı	reng glas naar de glasbak				ja, a ja, s nee	altijd soms , noo	it				
Ное	e tevreden bent u met uw woning?	1	2 □	3	4 □	5 □	6 □	7 □	8	9 □	10 □
	Druk dit uit in een rapportcijfer van 1 tot en met 10, 1=zeer ontevreden, 10=zeer tevreden										

>>> De vragen mogen verspreid in de vragenlijst geplaatst worden, bij voorkeur in samenhang met vergelijkbare onderwerpen.

$\begin{array}{c c c c c c c c c c c c c c c c c c c $	RR         8.9%)*           PAF         RR         PAF         PAF           (8.9%)*         18.02         11.155         3.01         (2.28-3.99)         18.02           6.88         2.35         (2.05-2.70)         12.10         12.10           4.03         1.93         (1.74-2.15)         8.33           3.43         1.57         1.45-1.71)         5.12	basic social rights (10.0%)* RR P <sub>1</sub> 1.28 (0.93-1.75) 2	integration	ve
(9.67%)*       PAF       RR       PAF       RR         R       PAF       R       PAF       RR         CVD and risk factors       (3.9%)*       PAF       R         CVD and risk factors       (3.9%)       11.1       (3.9%)       18.02       1.2         • High blood       1.41       (1.26-1.58)       4.03       1.93       (1.74-2.15)       8.33       1.2         • High blood       1.41       (1.26-1.58)       4.03       1.93       (1.44-1.10)       1.14         • Current smoking       1.51       (1.24-1.48)       3.43       1.57       (1.45-1.71)       5.13       2.16       (1.46-1.77)       5.13       2.14       (1.24-1.48)       3.43       1.57       (1.46-1.71)       5.13       2.16       (1.46-2.1.71)       5.13	(8.9%)**           PAF         RR         PAF         PAF </th <th>R (10.0%)* RR P. 1.28 (0.93-1.75) 2</th> <th></th> <th>+1/05 01/</th>	R (10.0%)* RR P. 1.28 (0.93-1.75) 2		+1/05 01/
RR         PAF         RR         PAF         RR           CVD and risk factors         2.18 (1.65-2.89)         11.55 <b>3.01</b> (2.28-3.99)         18.02         1.2           • Ubibleod         1.71 (1.46-1.99)         6.88         2.35 (2.05-2.70)         12.10         1.4           • High blood         1.41 (1.26-1.58)         4.03         1.93 (1.74-2.15)         8.33         1.2           • The smoking         1.35 (1.24-1.48)         3.43         1.57 (1.45-1.71)         5.12         1.4           • Obesity         1.53 (1.36-1.72)         5.13         2.16 (1.94-2.41)         10.39         1.5           • Obesity         1.53 (1.36-1.72)         5.13         2.16 (1.94-2.41)         10.39         1.5           • Obesity         1.53 (1.36-1.72)         5.13         2.16 (1.94-2.41)         10.39         1.5           • Obesity         1.53 (1.36-1.72)         5.13         2.16 (1.94-2.41)         10.39         1.5           • Obesity         1.51 (1.15-1.99)         4.97         1.35 (1.04-1.77)         3.14         1.1           • Obesity         2.41 (2.28-2.56)         13.79         2.84 (2.69-3.00)         16.44         2.1	PAF         RR         PAF         I           11.55 <b>3.01</b> (2.28-3.99)         18.02           6.88         2.35 (2.05-2.70)         12.10           4.03         1.93 (1.74-2.15)         8.33           3.43         1.57 (1.45-1.71)         5.12	RR P2 1.28 (0.93-1.75) 2	$(8.0\%)^{*}$	$(10.3\%)^{*}$
CVD and risk factors            • CVD and risk factors             • CVD 2.18 (1.65-2.89) 11.55 3.01 (2.28-3.99) 18.02 1.2             • Diabetes 1.71 (1.46-1.99) 6.88 2.35 (2.05-2.70) 12.10 1.4             • High blood 1.41 (1.26-1.58) 4.03 1.93 (1.74-2.15) 8.33 1.2             • Dressure 1.35 (1.24-1.48) 3.43 1.57 (1.45-1.71) 5.12 1.4             • Obesity 1.53 (1.36-1.72) 5.13 2.16 (1.94-2.41) 10.39 1.5             • Obesity 2.80 (2.46-3.18) 17.52 3.03 (2.66-3.45) 18.19 2.0             • Inactivity 2.80 (2.46-3.18) 17.52 3.03 (2.66-3.45) 18.19 2.0             • Current substitue 1.51 (1.15-1.99) 4.97 1.35 (1.04-1.77) 3.14 1.1             • Low self-rated 2.41 (2.28-2.56) 13.79 2.84 (2.69-3.00) 16.44 2.1	11.55 <b>3.01</b> (2.28-3.99)         18.02           6.88         2.35 (2.05-2.70)         12.10           4.03         1.93 (1.74-2.15)         8.33           3.43         1.57 (1.45-1.71)         5.12	1.28 (0.93-1.75) 2	AF RR	PAF RR PAF
• CVD       2.18 (1.65-2.89)       11.55 <b>3.01</b> (2.28-3.99)       18.02       1.2         • Diabetes       1.71 (1.46-1.99)       6.88       2.35 (2.05-2.70)       12.10       1.4         • High blood       1.41 (1.26-1.58)       4.03       1.93 (1.74-2.15)       8.33       1.2         • Pressure       1.41 (1.26-1.58)       4.03       1.93 (1.74-2.15)       8.33       1.2         • Current smoking       1.35 (1.24-1.48)       3.43       1.57 (1.45-1.71)       5.12       1.4         • Obesity       1.53 (1.26-1.72)       5.13       2.16 (1.94-2.41)       10.39       1.5         • Obesity       1.53 (1.36-1.72)       5.13       2.16 (1.94-2.41)       10.39       1.5         • Obesity       1.53 (1.36-1.72)       5.13       2.16 (1.94-2.41)       10.39       1.5         • Obesity       1.53 (1.36-1.79)       4.97       1.35 (1.04-1.77)       3.14       1.1         Cancer       1.51 (1.15-1.99)       4.97       1.35 (1.04-1.77)       3.14       1.1         Low self-rated       2.41 (2.28-2.56)       13.79       2.84 (2.69-3.00)       16.44       2.1	11.55 <b>3.01</b> (2.28-3.99)         18.02           6.88         2.35         (2.05-2.70)         12.10           4.03         1.93         (1.74-2.15)         8.33           3.43         1.57         1.45         1.51	1.28 (0.93-1.75) 2		
◆ Diabetes       1.71 (1.46-1.99)       6.88       2.35 (2.05-2.70)       12.10       1.4         ◆ High blood       1.41 (1.26-1.58)       4.03       1.93 (1.74-2.15)       8.33       1.2         pressure       • Current smoking       1.35 (1.24-1.48)       3.43       1.57 (1.45-1.71)       5.12       1.4         • Current smoking       1.35 (1.24-1.48)       3.43       1.57 (1.45-1.71)       5.12       1.4         • Obesity       1.53 (1.36-1.72)       5.13       2.16 (1.94-2.41)       10.39       1.5         • Obesity       1.53 (1.36-1.72)       5.13       2.16 (1.94-2.41)       10.39       1.5         • Obesity       1.53 (1.36-1.72)       5.13       2.16 (1.94-2.41)       10.39       1.5         • Inactivity       2.80 (2.46-3.18)       17.52 <b>3.03</b> (2.66-3.45)       18.19       2.0         Cancer       1.51 (1.15-1.99)       4.97       1.35 (1.04-1.77)       3.14       1.1         Low self-rated       2.41 (2.28-2.56)       13.79       2.84 (2.69-3.00)       16.44       2.1	6.88         2.35 (2.05-2.70)         12.10           4.03         1.93 (1.74-2.15)         8.33           3.43         1.57 (1.45-1.71)         5.17		.78 1.47 ((1.11-1.94)	4.00 2.58 (1.95-3.41) 13.93
<ul> <li>High blood</li> <li>1.41 (1.26-1.58)</li> <li>4.03</li> <li>1.93 (1.74-2.15)</li> <li>8.33</li> <li>1.2 pressure</li> <li>Current smoking</li> <li>1.53 (1.24-1.48)</li> <li>3.43</li> <li>1.57 (1.45-1.71)</li> <li>5.12</li> <li>1.4</li> <li>Obesity</li> <li>1.53 (1.36-1.72)</li> <li>5.13</li> <li>2.16 (1.94-2.41)</li> <li>10.39</li> <li>1.5</li> <li>I.53 (1.36-1.72)</li> <li>5.13</li> <li>2.16 (1.94-2.41)</li> <li>10.39</li> <li>1.5</li> <li>Cancer</li> <li>1.51 (1.15-1.99)</li> <li>4.97</li> <li>1.35 (1.04-1.77)</li> <li>3.14</li> <li>1.1</li> <li>Low self-rated</li> <li>2.41 (2.28-2.56)</li> <li>13.79</li> <li>2.84 (2.69-3.00)</li> <li>16.44</li> <li>2.1</li> </ul>	4.03         1.93         (1.74-2.15)         8.33           3.43         1.577         1.45-1         71         5.12	1.4/(1.20-1./3) 4	.74 1.50 (1.28-1.75)	4.28 2.25 (1.96-2.57) 11.33
<ul> <li>Current smoking 1.35 (1.24-1.48) 3.43 1.57 (1.45-1.71) 5.12 1.4</li> <li>Obesity 1.53 (1.36-1.72) 5.13 2.16 (1.94-2.41) 10.39 1.5</li> <li>Inactivity 2.80 (2.46-3.18) 17.52 3.03 (2.66-3.45) 18.19 2.0</li> <li>Cancer 1.51 (1.15-1.99) 4.97 1.35 (1.04-1.77) 3.14 1.1</li> <li>Low self-rated 2.41 (2.28-2.56) 13.79 2.84 (2.69-3.00) 16.44 2.1</li> </ul>	3 43 1 57 (1 45-1 71) 5 1 2	1.23 (1.09-1.39) 2	.31 1.21 (1.07-1.36)	1.76 1.63 (1.47-1.81) 6.09
<ul> <li>Obesity 1.53 (1.36-1.72) 5.13 2.16 (1.94-2.41) 10.39 1.5</li> <li>Inactivity 2.80 (2.46-3.18) 17.52 3.03 (2.66-3.45) 18.19 2.0</li> <li>Cancer 1.51 (1.15-1.99) 4.97 1.35 (1.04-1.77) 3.14 1.1.</li> <li>Low self-rated 2.41 (2.28-2.56) 13.79 2.84 (2.69-3.00) 16.44 2.1</li> </ul>		1.44 (1.32-1.56) 4	.36 1.39 (1.27-1.52)	3.38 1.58 (1.46-1.71) 5.64
<ul> <li>◆ Inactivity 2.80 (2.46-3.18) 17.52 3.03 (2.66-3.45) 18.19 2.0</li> <li>Cancer 1.51 (1.15-1.99) 4.97 1.35 (1.04-1.77) 3.14 1.1</li> <li>Low self-rated 2.41 (2.28-2.56) 13.79 2.84 (2.69-3.00) 16.44 2.1</li> <li>Auxiety /</li> </ul>	5.13 2.16 (1.94-2.41) 10.39	1.57 (1.39-1.77) 5	.67 1.46 (1.29-2.51)	3.97 1.92 (1.72-2.14) 8.60
Cancer 1.51 (1.15-1.99) 4.97 1.35 (1.04-1.77) 3.14 1.1 Low self-rated 2.41 (2.28-2.56) 13.79 2.84 (2.69-3.00) 16.44 2.1 health	17.52 <b>3.03</b> (2.66-3.45) 18.19	2.02 (1.75-2.33) 1(	0.19 2.20 (1.92-2.51)	10.32 <b>3.29</b> (1.92-3.70) 18.99
Low self-rated 2.41 (2.28-2.56) 13.79 2.84 (2.69-3.00) 16.44 2.1 health	4.97 1.35 (1.04-1.77) 3.14	1.13 (0.87-1.46) 1	.28 1.22 (0.90-1.65)	1.86 1.31 (1.02-1.69) 3.11
Anvietu /	13.79 2.84 (2.69-3.00) 16.44	2.10 (1.98-2.24) 11	.04 1.59 (1.48-1.72)	5.10 2.83 (1.69-2.99) 15.83
depression 5.38 (4.94-5.86) 42.72 5.01 (4.59-5.48) 35.89 3.3	42.72 <b>5.01</b> (4.59-5.48) 35.89	<b>3.31</b> (3.00-3.65) 23	3.10 2.33 (2.08-2.62)	11.46 <b>7.95</b> (7.19-8.78) 41.60
Low personal <b>6.70</b> (6.05-7.42) 55.62 <b>5.95</b> (5.36-6.60) 44.27 <b>3.8</b> control	<b>55.62 5.95</b> (5.36-6.60) 44.27	<b>3.81</b> (3.40-4.27) 28	3.09 2.77 (2.43-3.16)	15.21 <b>6.36</b> (5.87-6.91) 35.49

Table A1. Relative risk (95% CI) and PAF for four dimensions of social exclusion

SUPPLEMENTARY MATERIAL CHAPTER 6

\* Weighted prevalence, population 19 years and older, G4, 2016.

# In italic if RR not significant at  $\alpha = 0.05$  and **bold** it RR strong, i.e., between 3 and 8 [26].

	Low educa	tion	Low he	ousehold i	нсоте	Low labc	our marke	t position	Non-И l	Vestern mig backgroun	gration d
Ž	o Yes	Total	No	Yes	Total	No	Yes	Total	No	Yes	Total
83.	3 6.6	89.8	71.0	19.0	90.0	80.6	9.3	89.8	65.2	24.6	89.7
7.0	9 2.3	10.2	4.8	5.2	10.0	5.4	4.8	10.2	3.8	6.4	10.3
91.	1 8.9	100.0	75.8	24.2	100.0	85.9	14.1	100.0	69.0	31.0	100.0
8	7 25.7		6.4	21.5		6.2	34.1		5.6	20.7	
l											

Table A2. Overlap between social exclusion and four social factors (weighted percentages)

	$RR_{SF+SE+}$	RR <sub>SF+SE-</sub>	$\Delta(RR_{SF+SE+,}RR_{SF+SE-})$
Low education			
CVD risk factors			
♦ Diabetes	4.93 (4.07-5.97)	3.97 (3.49-4.52)	0.96 .
♦ High blood pressure	2.84 (2.45-3.30)	2.36 (2.13-2.62)	0.48 .
♦ Current smoking	1.35 (1.15-1.59)	0.93 (0.81-1.06)	0.42↓
♦ Obesity	2.82 (2.37-3.35)	2.62 (2.33-2.94)	0.20.
♦ Inactivity	5.07 (4.24-6.07)	2.62 (2.26-3.04)	2.45 ↓
Cancer	1.89 (1.21-2.98)	1.96 (1.53-2.50)	-0.06 .
Low Self-Rated Health	4.09 (3.82-4.39)	2.89 (2.71-3.09)	1.20↓
Anxiety/depression symptoms	10.53 (9.14-12.13)	2.58 (2.16-3.08)	7.95↓
Low personal control	9.13(8.12-10.27)	3.35 (2.91-3.85)	5.78↓
Low household income			
CVD risk factors			-
♦ Diabetes	2.56 (2.13-3.08)	1.31 (1.13-1.51)	1.26↓
♦ High blood pressure	1.64 (1.42-1.90)	0.91 (0.82-1.02)	0.73↓
♦ Current smoking	1.80 (1.62-2.01)	1.41 (1.30-1.52)	0.40↓
♦ Obesity	2.03 (1.75-2.36)	1.27 (1.13-1.42)	0.76↓
♦ Inactivity	4.43 (3.82-5.14)	1.52 (1.31-1.76)	2.91↓
Cancer	1.13 (0.77-1.65)	0.78 (0,60-1.01)	0.35 .
Low Self-Rated Health	3.45 (3.23-3.67)	1.53 (1.42-1.64)	1.92↓
Anxiety/depression symptoms	10.35 (9.10-11.76)	1.99 (1.69-2.34)	8.36↓
Low personal control	7.71 (6.95-8.54)	1.66 (1.45-1.90)	6.05↓
Low labour market positi	on		
CVD risk factors			
♦ Diabetes	2.87 (2.37-3.49)	1.99 (1.68-2.35)	0.89↓
♦ High blood pressure	2.01 (1.74-2.33)	1.57 (1.39-1.78)	0.44 .
♦ Current smoking	1.92 (1.73-2.12)	1.37 (1.25-1.51)	0.55↓
♦ Obesity	2.42 (2.08-2.81)	2.04 (1.80-2.29)	0.38.
♦ Inactivity	4.98 (4.29-5.79)	2.71 (2.33-3.15)	2.28 ↓
Cancer	1.65 (1.13-2.42)	1.52 (1.16-2.01)	0.13.
Low self-Rated Health	4.30 (4.06-4.55)	2.88 (2.70-3.08)	1.42 ↓
Anxiety/depression symptoms	15.02 (13.29-16.97)	5.17 (4.42-6.06)	9.84↓
Low personal control	10.67 (9.69-11.74)	4.10 (3.60-4.66)	6.57↓

Table A3. Relative risks (95% CI) for social factors with and without SE and differential effects  $_{\#s}$ 

### Table A3 - continued

	RR <sub>SF+SE+</sub>	RR <sub>SF+SE-</sub>	$\Delta(RR_{SF+SE+,}RR_{SF+SE-})$	
Non-Western migration background				
CVD risk factors				
♦ Diabetes	3.21 (2.72-3.80)	1.99\(1.76-2.23)	1.23 ↓	
<ul> <li>High blood pressure</li> </ul>	1.67 (1.46-1.91)	1.03 (0.93-1.13)	0.64 ↓	
<ul> <li>Current smoking</li> </ul>	1.37 (1.23-1.54)	0.99 (0.91-1.07)	0.39↓	
♦ Obesity	2.30 (1.97-2.65)	1.65 (1.49-1.82)	0.65↓	
♦ Inactivity	4.88 (4.21-5.65)	2.36 (2.09-2.67)	2.52↓	
Cancer	0.68 (0.45-1.05)	0.57 (0.44-0.74)	0.11.	
Low self-Rated Health	3.44 (3.22-3.67)	1.70 (1.59-1.82)	1.73↓	
Anxiety/depression symptoms	10.95 (9.64-12.44)	2.16 (1.85-2.52)	8.79↓	
Low personal control	7.52 (6.79-8.32)	1.60 (1.41-1.82)	5.91↓	

# In italic if RR <u>not</u> significant at  $\alpha = 0.05$  and **bold** it RR strong i.e. between 3 and 8 [26].

&  $\downarrow$  RR<sub>SF+SE</sub>- is significantly lower than RR<sub>SF+SE+</sub>, i.e., there is no overlap between the 95% CIs.

### Gerard

In Amsterdam, op de 10e verdieping van een nieuwbouwflat, woont de 53-jarige Gerard. Gerard werkte ruim dertig jaar als internationaal vrachtwagenchauffeur. Twee jaar geleden is hij vanwege gezondheidsproblemen afgekeurd. Nu zit hij thuis, kijkt tv of speelt spelletjes op de computer, en om een uur of twee of drie rookt hij zijn eerste jointje. Gerard heeft een turbulent leven achter de rug. Op zijn 17e overleefde hij op het nippertje een steekpartij. Sindsdien is hij op zijn hoede en houdt mensen op een afstand. Na een pijnlijke scheiding en een breuk met zijn familie is hij op zichzelf aangewezen. Vrienden heeft hij niet maar mist hij wel. '*Gewoon vrienden hebben, met wie je kan praten, waarmee je kan lachen'*.

De laatste maanden ligt Gerard vaak wakker. Hij heeft schulden en dreigt uit zijn flat gezet te worden. De schulden zijn ontstaan in de periode na zijn scheiding. '*Ik was een beetje de weg kwijt, ben gevlucht in de drank en drugs, cocaïne, LSD,...*' Een eerder schuld-saneringstraject maakte hij niet af. '*Ik voelde me eigen te gecontroleerd. Nu moet ik wel doorzetten want als ik nu niet doorzet word ik uit de flat gezet.*'

Gerards toekomstdromen: schuldenvrij zijn, in zijn mooie flat blijven wonen, wat meer geld om leuke dingen te doen en misschien een nieuwe liefde.

Gebaseerd op interviews voor Sociaal Uitgesloten in de grote stad, van Bergen et al. 2014.

## Nederlandse samenvatting (Summary in Dutch)

Dankwoord

List of publications

About the author

## Nederlandse samenvatting (Summary in Dutch)

Dit proefschrift gaat over het meten van sociale uitsluiting in gezondheidsonderzoek. Sociale uitsluiting verwijst naar het onvermogen van mensen om volledig deel te nemen aan de maatschappij waarin zij leven. De Wereldgezondheidsorganisatie (WHO) ziet sociale uitsluiting als een veelbelovend concept om gezondheidsongelijkheden te begrijpen en aan te pakken. Een wetenschappelijke benadering van sociale uitsluiting vereist een duidelijke definitie en een operationalisering die nauw aansluit bij het onderliggende concept. In gezondheidsonderzoek is het concept sociale uitsluiting echter niet of nauwelijks gedefinieerd, een algemeen aanvaard meetinstrument ontbreekt en de wetenschappelijke basis is niet goed ontwikkeld. Dit staat de opbouw van kennis rondom sociale uitsluiting en gezondheid in de weg.

Sociale uitsluiting is allereerst een politiek concept, waarmee groepen aangeduid worden aan de rand of op de bodem van de maatschappij: burgers die vervreemd zijn, niet voldoen aan de normen van de samenleving, geen toegang hebben tot publieke diensten en burgerrechten of leven in armoede. Sociale wetenschappers zien sociale uitsluiting als een multidimensionaal fenomeen waarbinnen meerdere dimensies worden onderscheiden zowel sociaal, economisch, politiek (grondrechten) als cultureel (normen en waarden). In dit proefschrift sluiten we aan bij deze benadering van sociale uitsluiting als multidimensionaal concept.

Het hoofddoel van dit proefschrift is het ontwikkelen van een betrouwbaar en valide instrument om het multidimensionale concept van sociale uitsluiting in gezondheidsonderzoek te meten.

We richten ons in dit onderzoek specifiek op de ontwikkeling van een meetinstrument dat gebruikt kan worden in de Gezondheidsmonitor Volwassenen en Ouderen (GM). Dit is een grootschalig representatief vragenlijstonderzoek dat elke vier jaar door GGD-en wordt uitgevoerd in opdracht van gemeenten en als onderdeel van hun wettelijke taak om de gezondheidstoestand van de bevolking te monitoren. De resultaten van de GM worden gebruikt bij het formuleren van lokaal en regionaal volksgezondheidsbeleid. De GM vragenlijst bevat vragen over gezondheid en gezondheidsdeterminanten leefstijl, sociale situatie en fysieke omgeving. De doelgroep is de algemene bevolking van 19 jaar en ouder.

In **hoofdstuk 2** van dit proefschrift beschrijven we allereerst een systematische review naar de relatie tussen sociale uitsluiting (SU) of sociale insluiting (SI) en gezondheid in EU- en OESO-landen<sup>6</sup>. De relatie tussen SU en gezondheid is theoretisch goed onderbouwd, er is ook veel onderzoek naar gedaan, maar systematisch empirisch bewijs ontbrak. Pogingen van onderzoekers om de relatie tussen sociale

<sup>&</sup>lt;sup>6</sup> Organisatie voor Economische Samenwerking en Ontwikkeling, een samenwerkingsverband bestaande uit 38 overwegend welvarende landen met een markteconomie die worden geregeerd op basis van democratische beginselen en respect voor de mensenrechten.

uitsluiting en gezondheid systematisch in kaart te brengen strandden op de grote variatie in gebruikte concepten en operationalisering van SU. Om dit obstakel te omzeilen, beperkten we ons onderzoek tot slechts één concept en operationalisering

van SU en SI. We operationaliseerden SU als de accumulatie van tekorten op sociaal, economisch, politiek en cultureel gebied en SI als de mate van participatie op deze dimensies. Studies die slechts één dimensie van SU hanteerden of een andere invulling aan het concept gaven, werden geëxcludeerd. Om de homogeniteit verder te verhogen, maakten we onderscheid tussen vaak grote algemene populatiestudies en kleinere studies in specifieke groepen, meestal met een hoog risico op SU. We formuleerden zes hypothesen namelijk dat hoge SU/lage SI geassocieerd is met (i) ongunstige geestelijke gezondheidsuitkomsten, (ii) ongunstige lichamelijke gezondheidsuitkomsten en (iii) ongunstige algemene gezondheidsuitkomsten in (a) de algemene bevolking en in (b) populaties met een hoog risico op sociale uitsluiting. Algemene gezondheid omvatte onder andere ervaren gezondheid, aanwezigheid van minimaal één chronische ziekte en belemmerd zijn in de dagelijks bezigheden door gezondheidsproblemen. Van de 4.032 geselecteerde studies voldeden 22 studies aan de inclusiecriteria. Deze studies waren allen observationeel van aard. De studies in de algemene bevolking bevestigden de associatie tussen hoge SU/lage SI en ongunstige geestelijke en algemene gezondheid, maar niet met lichamelijke gezondheid. In groepen met een hoog risico op sociale uitsluiting zoals patiënten in de verslavingszorg, GGZ outreach programma's en in dwangopname, alleenstaande moeders in de bijstand en personen met HIV, vonden we een duidelijke bevestiging voor de associatie tussen hoge SU/lage SI en ongunstige geestelijke gezondheid. Het aantal studies naar de associatie tussen SU/SI en lichamelijke gezondheid of algemene gezondheid in hoog risicogroepen was te klein om uitspraken te kunnen doen.

In **hoofdstuk 3** onderzochten we of het multidimensionale concept van sociale uitsluiting valide kan worden benaderd met items die beschikbaar zijn in de gezondheidsmonitors van de vier grote steden: Amsterdam, Rotterdam, Den Haag en Utrecht (G4). We kozen de sociale-uitsluitingsindex van Hoff & Vrooman van het SCP als gouden standaard (hier verder SCP-index genoemd). Sociale uitsluiting wordt door het SCP gedefinieerd als de accumulatie van tekorten op vier dimensies: 1) onvoldoende sociale participatie; 2) materiële deprivatie; 3) onvoldoende toegang tot sociale grondrechten; en 4) onvoldoende normatieve integratie. GGD-en vonden de SCP-index, met 15 items, te lang om op te nemen in hun GM. De vrije ruimte in de vragenlijsten is beperkt en er is een felle concurrentie tussen onderwerpen. Bovendien is er een grote overlap tussen de SCP-index met onderwerpen in de GM, zoals eenzaamheid, sociaal kapitaal, financiële situatie en huisvesting. Deze laatste observatie vormde de aanleiding om te verkennen of en in hoeverre sociale uitsluiting met items uit de GM gemeten kan worden. Voor dit onderzoek gebruikten we data van de GM 2008 (N=20.877). Omdat de inhoud van de vragenlijsten tussen steden verschilde, werden met behulp van niet-lineaire canonieke correlatieanalyse
(OVERALS) drie verschillende indices geconstrueerd. De psychometrische eigenschappen van de geconstrueerde indices bleken voldoende tot goed, maar de inhoudsvaliditeit was matig. De dimensie 'onvoldoende normatieve integratie' kon niet gemeten worden, omdat er in de GM geen relevante items beschikbaar waren. Ook ontbraken items over toegang tot gezondheidszorg en basale goederen en diensten. Om de inhoudsvaliditeit te verbeteren zouden aan de GM extra items uit de SCP-index toegevoegd kunnen worden.

In **hoofdstuk** 4 hebben we de aanbevelingen uit het hoofdstuk 3 opgevolgd. Negentien van de 26 GGD-en namen extra items op in de GM 2012. Dit waren items uit de SCP-index over materiële deprivatie, toegang tot sociale grondrechten en normatieve integratie. In totaal werden gegevens verkregen van 258.928 respondenten van 19 jaar en ouder. We splitsten de dataset willekeurig in tweeën, in een ontwikkel sample en een validatie sample. In de ontwikkel sample werd met niet-lineaire canonieke correlatieanalyse een index geconstrueerd en vier dimensieschalen. Deze index, de Social Exclusion Index for Health Surveys (SEI-HS) was opgebouwd uit 9 items die al onderdeel uitmaakten van de GM en 8 extra SCP-items. De interne consistentie, interne structuur en constructvaliditeit van de SEI-HS bleken voldoende tot goed en in lijn met de oorspronkelijke SCP-index. Ook de inhoudsvaliditeit was goed: alle vier dimensies konden adequaat gemeten worden. Replicatie van de SEI-HS in de validatie sample bevestigde de generaliseerbaarheid van de SEI-HS. Om toepassing in public health monitoring en beleid te faciliteren, zijn de indexen dimensiescores ingedeeld in drie categorieën: 'matig tot sterk', 'enigszins' en 'niet of nauwelijks' uitsluiting. Als drempelwaarden voor de overgang van 'matig tot sterk' naar 'enigszins' en van 'enigszins naar 'niet of nauwelijks' uitgesloten is gekozen voor resp. de 95<sup>e</sup> en 85<sup>e</sup> percentiel in de Nederlandse bevolking. Met de SEI-HS hebben onderzoekers een valide, betrouwbaar en efficiënt instrument in handen waarmee sociale uitsluiting in de bevolking structureel gemeten kan worden. Hiermee kan een volgende stap gezet worden in de kennisopbouw over sociale uitsluiting en gezondheid. De SEI-HS is niet alleen toepasbaar in de Gezondheidsmonitor, maar is ook elders in andere settings inzetbaar, zoals in de gemeentelijke Omnibus enquêtes en onderzoek in risicopopulaties.

**Hoofdstuk 5** beschrijft de resultaten van een cross-culturele validatie studie. In de vier steden, Amsterdam, Rotterdam, Den Haag en Utrecht, liet de SEI-HS zeer hoge niveaus van sociale uitsluiting zien bij niet-westers allochtone groepen. Meer dan één op de vijf volwassenen met een Surinaamse, Marokkaanse of Turkse migratieachtergrond werd op basis van de SEI-HS score geclassificeerd als matig tot sterk sociaal uitgesloten (resp. 20%, 21% en 29%), terwijl dit aandeel onder volwassenen met een Nederlandse achtergrond slechts 4% was. Dit riep vragen op over de cross-culturele validiteit van de SEI-HS. Een mixed methods onderzoek met een sequentieel verklarend design werd ingezet om mogelijke culturele bias van de SEI-HS in de drie grootste immigrantengroepen in de G4 te onderzoeken. We gebruikten GM 2012 data om differentiële item werking en de structurele validiteit van de SEI-HS te onderzoeken. Aanvullend werden semi-gestructureerde interviews gehouden met 11 Surinaamse, 9 Marokkaanse, 10 Turkse en 22 Nederlandse respondenten met een hoge score op de SEI-HS. Tijdens de interviews zijn de items van de SEI-HS nogmaals voorgelegd en werd doorgevraagd naar de achtergrond en betekenis van de gegeven antwoorden. Voor elk item van de SEI-HS analyseerden we vervolgens de verschillen in semantische, conceptuele en contextuele connotaties tussen de drie immigrantengroepen en autochtone Nederlanders. We vonden geen substantiële differentiële item werking voor migratieachtergrond en de confirmatory factor analyses bevestigden de 4-factorstructuur van de SEI-HS in alle drie immigrantengroepen. De interviews brachten enkele methodologische tekortkomingen aan het licht, maar deze hadden geen wezenlijke invloed op de overmaat aan sociale uitsluiting die werd waargenomen bij de immigrantengroepen. Deze studie bevestigt de cross-culturele validiteit van de SEI-HS in drie grote immigrantengroepen in Nederland. De hoge niveaus van sociale uitsluiting onder mensen met een niet-westerse migratieachtergrond in de G4 blijken reëel te zijn en geen methodologisch artefact. Beleidsmaatregelen om sociale inclusie te versterken en uitsluiting terug te dringen zijn dringend nodig zijn.

In **hoofdstuk 6** beschrijven we een eerste toepassing van de SEI-HS. Met de steeds verder stijgende zorguitgaven in Nederland neemt de urgentie toe om beschikbare middelen daar in te zetten waar de grootste gezondheidswinst te behalen is. We verwachtten op basis van theorie en eerder onderzoek dat sociale uitsluiting gepaard gaat met meer gezondheidsproblemen en ook met een verminderd vermogen het eigen functioneren en de loop van gebeurtenissen te beïnvloeden. In deze studie onderzochten we of de SEI-HS een goede 'stratifier' is om een bevolkingssegment met veel gezondheidsproblemen en lage regie over het eigen leven in beeld te brengen. We vergeleken de SEI-HS met vier andere, vaak gebruikte, sociale stratifiers: zeer laag onderwijsniveau, laag inkomen, lage arbeidsmarktpositie en nietwesterse migratieachtergrond. We berekenden voor elke stratifier de relatieve risico's (RR) en (hypothetische) populatie-attributieve fracties (PAF) voor cardiovasculaire risicofactoren, kanker, minder dan goed ervaren gezondheid, ernstige angst- en depressieklachten en lage regie over het eigen leven. We gebruikten hiervoor GM 2016 data van de vier grote steden (N=33.285). De analyses lieten significante associaties zien tussen SU (gemeten met de SEI-HS) en de gezondheidsindicatoren en lage regie eigen leven. Met name de relatieve risico's voor angst- en depressieklachten (7,95) en lage regie eigen leven waren bijzonder hoog (6,36). Sociaal uitgesloten volwassenen in de G4 hadden 7,95 keer meer kans om ernstige angst- en depressieklachten te hebben en 6,36 keer meer kans een lage regie eigen leven te ervaren dan niet-uitgesloten volwassenen. De PAFs waren resp. 42% voor angst- en depressieklachten en 35% voor lage regie eigen leven. Dat betekent dat een vermindering van 42% in de prevalentie van ernstige angst- en depressieklachten bereikt zou kunnen worden als in het sociaal uitgesloten deel van de bevolking hetzelfde percentage angst- en depressieklachten zou voorkomen als in de rest van de bevolking. Voor lage regie eigen leven was de potentiële gezondheidswinst 35%. De vergelijking met de meer gangbare sociale stratifiers liet zien dat de SEI-HS significant beter presteerde in het identificeren van bevolkingssegmenten met angst- en depressieklachten en lage regie eigen leven en even goed presteerde bij het identificeren van andere gezondheidsproblemen. Ook zagen we dat laag opgeleide volwassenen mét sociale uitsluiting een vier keer hogere kans hadden op angst- en depressieklachten dan laag opgeleide volwassenen die niet sociaal uitgesloten zijn en bijna drie keer hogere kans op lage regie eigen leven. Ditzelfde patroon zagen we terug bij laag inkomen, lagere arbeidsmarktpositie en niet-westerse migratieachtergrond. De bevindingen van dit onderzoek hebben implicaties voor de gezondheidszorg, de publieke gezondheid en sociale domein in de grote steden. Vooral de hoge prevalentie van lage regie eigen leven is een belangrijke factor om rekening mee te houden bij het kiezen, ontwerpen en implementeren van interventies en diensten, zoals interventies en diensten die weinig eigen regie vereisen, het gevoel van eigenwaarde verhogen en effectieve coping-mechanismen stimuleren.

**Hoofdstuk** 7 van dit proefschrift vat de belangrijkste bevindingen samen, reflecteert op de beperkingen en sterke punten van het onderzoek en bespreekt implicaties voor lokale volksgezondsmonitoring en toekomstig onderzoek, beleid en praktijk.

In dit proefschrift brachten we op een systematische wijze de evidence base van de associatie tussen SU en gezondheid in beeld, we ontwikkelden een meetinstrument voor sociale uitsluiting en verkenden een eerste toepassing van dit meetinstrument in volksgezondheidsmonitoring. De resultaten waren beloftevol. De verwachte samenhang tussen hoge SU/lage SI en ongunstige gezondheidsindicatoren werd bevestigd. Met de constructie van de SEI-HS is nu een betrouwbaar, valide en efficiënt instrument beschikbaar voor GGD-en waarmee sociale uitsluiting in de volwassen bevolking periodiek gemeten kan worden, inclusief bij de belangrijkste niet-westerse migrantengroepen. De verkenning liet zien dat de SEI-HS een 'high-risk/high-need' bevolkingssegment in beeld brengt waarin sociale problemen, een minder goede gezondheid en weinig regie over het eigen leven samenkomen. Deze resultaten ondersteunen de WHO visie van sociale uitsluiting als beloftevol concept om gezondheidsachterstanden in kaart te brengen en aan te pakken.

Dit onderzoek kent ook beperkingen. Met bevolkingsenquêtes worden de meest uitgesloten burgers niet bereikt, zoals degenen die dakloos zijn of ongedocumenteerd. Andere onderzoeksmethoden zijn aangewezen om sociale uitsluiting in deze groepen in kaart te brengen.

De vertaling van monitoringsresultaten naar lokaal beleid is een aandachtspunt. Beleidsmedewerkers vinden het concept sociale uitsluiting abstract, breed en moeilijk te vertalen naar beleidsmaatregelen. De definitie en het meten van sociale uitsluiting mag dan abstract zijn, achter deze abstractie gaat vaak een harde realiteit schuil van mensen die de gevolgen van sociale uitsluiting dagelijks in hun leven ervaren. Met kwalitatief onderzoek en storytelling kunnen de abstracte cijfers tastbaar en concreet gemaakt worden. Sociale uitsluiting is inderdaad een breed concept. De problemen die met sociale uitsluiting te maken hebben zijn niet enkelvoudig maar meervoudig, op meerdere niveaus, van micro tot macro, en hangen onderling samen. Een integrale aanpak is daarom nodig waarin partijen in de publieke gezondheid samenwerken met andere sectoren zoals huisvesting, ruimtelijke ordening, onderwijs, werk, participatie en inkomen, en sociale domein. In veel gemeenten is dit nog een uitdaging. Het gebruik van monitorresultaten in beleid betreft overigens niet alleen de vertaling naar concrete beleidsmaatregels (instrumenteel gebruik) maar ook het creëren van meer bewustzijn en een beter begrip van de resultaten (conceptueel gebruik. Of, zoals een van de G4-beleidsmakers het verwoordde:

'Ook al wordt met deze resultaten niet één-op-één beleid gemaakt, blijf sociale uitsluiting meten. De combinatie met andere data draagt bij aan een completer beeld van complexe problemen bij kwetsbare groepen' [beleidsmedewerker G4].

Met dit onderzoek hebben we belangrijke eerste stappen gezet om de kennisbasis over sociale uitsluiting en gezondheid te verbeteren. We nodigen onderzoekers uit om gebruik te maken van de schat aan data over sociale uitsluiting die GGD-en verzamelden. Er liggen nu data van GM2012, GM2016 en GM2020 waarmee de omvang en kenmerken van risicogroepen in kaart gebracht kunnen worden, relaties met gezondheidsindicatoren onderzocht, (syndemische) clusters geïdentificeerd en ontwikkelingen in de tijd gevolgd. Ook het combineren met andere databronnen, bijvoorbeeld in de CBS micro-omgeving, is het overwegen waard.

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## About the author

Addi van Bergen was born on April 7th 1958 in Wouw, the Netherlands. After graduating from secondary school (VWO) in 1976, she studied Mathematics at the Technical University Delft (BSc, 1982) and Human Nutrition at the Wageningen University (MSc, 1988).

After working as associate researcher for the Wageningen University Marketing and Consumer Behaviour Group in Senegal and nutrition coordinator for Médecins Sans Frontières (MSF) Holland in Sudan, she returned to the Netherlands at the end of 1992. She worked for Dutch Interchurch Aid on the acquisition and organization of large scale emergency food aid and rehabilitation programs with local NGO's and government agencies in the Horn of Africa and the funding and monitoring of small scale food security and nutrition improvement projects.

In 2001 she made a career switch and commenced working as an epidemiologist at the GG&GD Utrecht (later Public Health Department of the municipality of Utrecht). In this position she carried out research on a wide variety of public health subjects ranging from ethnic health differences to school absenteeism and informal care support.

In 2007 she became responsible for public mental health monitoring and research. She developed a new model for monitoring socially vulnerable persons and, with her team, set up a homeless monitor and monitor alcohol and drugs. When the Academic Collaborative Centre G4 USER was launched in 2010 she joined the PMH monitoring group led by prof. dr. Bert van Hemert and prof. dr. Judith Wolf. It was here that the idea arose to develop a validated measure for social exclusion, which ultimately resulted in this thesis.

From 2016 to 2018 she carried out a number of studies for the GGD Amsterdam including an evaluation of experiments to increase the participation of citizens with a great distance to the labour market. Currently she works at the GGD Hollands Midden as public health researcher and coordinator of the Academic Collaborative Centre Public Health Northern part of South-Holland.

Addi is living with her partner Gerard Agterberg, they have two sons, Miguel and Ole, an amazing daughter in law, Manon, and an always happy dog Belle.

