

# What is a disease? Perspectives of the public, health professionals, and legislators

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**Objective:** To assess the perception of diseases and the willingness to use public tax revenue for their treatment among relevant stakeholders.

**Design:** A population-based, cross-sectional mailed survey.

**Setting:** Finland

**Participants:** 3 000 laypeople, 1 500 doctors, 1 500 nurses (randomly identified from the databases of the Finnish Population Register, the Finnish Medical Association and the Finnish Nurses Association), and all 200 parliament members.

**Main outcome measures:** Respondents' perspectives on a 5-point Likert scale on two claims on 60 states of being: "[This state of being] is a disease"; and "[This state of being] should be treated with public tax revenue".

**Results:** Of the 6 200 individuals approached, 3 280 (53%) responded. Of the 60 states of being,  $\geq$ 80% of respondents considered 12 to be diseases (Likert scale responses of "4" and "5") and five not to be diseases (Likert scale responses of "1" and "2"). There was considerable variability in most states, and great variability in ten ( $\geq$ 20% of respondents of all groups considered it a disease and  $\geq$ 20% rejected as a disease). Doctors were more inclined to consider states of being as diseases than laypeople; nurses and parliament members were intermediate (p<0.001), but all groups showed large variability. Responses to the two claims were very strongly correlated (r = 0.96 [95% CI: 0.94-0.98]; p<0.001).

Conclusions: There is large disagreement among the public, health professionals, and legislators regarding the classification of states of being as diseases and whether their management should be publicly funded. Understanding attitudinal differences can help to enlighten social discourse on a number of contentious public policy issues.

#### ARTICLE SUMMARY

#### **Article focus**

The concept of disease lies at the heart of medicine.

No study has addressed perceptions of all relevant stakeholders on what, across a wide range of conditions, should be classified as a disease.

# **Key messages**

Our survey found large differences in the views among Finnish laypeople, doctors, nurses and parliament members regarding whether states of being should be considered diseases and be managed through public revenue.

Although doctors were more inclined to consider states of being as diseases, disagreement was as evident among health professionals as in other groups.

Understanding peoples' attitudes about whether states of being should be considered diseases elucidates fundamental underlying attitudes and thus can enlighten social discourse regarding a number of contentious public policy issues.

# Strengths and limitations of this study

This is the first study to assess whether states of being should be considered diseases and should be managed through public revenue using representative sample of doctors, nurses, laypeople as well as legislators.

Our results from the Finnish population may be less generalizable to lower income countries and those with different social and cultural values.

# Introduction

Disease can refer to a combination of signs and symptoms, phenomena associated with a disorder of function or structure, or illness associated with a specific cause(s). There are, however, no universally accepted criteria for establishing "disease". The concept of disease is subject to social, cultural and economic influences that have varied over time. A 4 5 6

During the last decades, there has been a growing tendency to classify states of being as diseases.<sup>6</sup> <sup>7</sup> <sup>8</sup> <sup>9</sup> This evolution may facilitate patient-physician communication<sup>3</sup> <sup>4</sup> <sup>7</sup> and from a social and economic standpoint, it may increase willingness to use public money and thus equality in the distribution of limited resources.<sup>3</sup> <sup>10</sup> Possible disadvantages of labeling states of being as diseases include making relatively healthy individuals perceive themselves as 'sick', encouraging misguided attempts to 'treat' states that are part of the normal human condition, or lead to individuals being denied employment or insurance.<sup>3</sup> <sup>7</sup> <sup>11</sup> <sup>12</sup> <sup>13</sup>

Because of the importance of the issue, and the paucity of empirical evidence regarding peoples' views, we conducted a survey of the general public, doctors, nurses, and parliament members in Finland to determine the extent to which they considered 60 states of being disease and their attitudes toward using public funds for managing these states.

# The Finnish Disease (FIND) Survey study population

In 2010, we selected a random sample of 3 000 laypeople, 1 500 doctors, 1 500 nurses, and all the 200 members of the Parliament of Finland (MPs). We identified laypeople 18 to 75 years of age from the Finnish Population Register Centre, and doctors and nurses less than 65 years of age from the registers of the Finnish Medical Association and the Finnish Nurses Association. We excluded individuals who had died, emigrated, were deemed seriously disabled or who changed careers and would therefore no longer be members of their respective group (fig 1).

# **Survey**

Referring to the existing literature and the International Classification of Diseases (ICD-10),<sup>1 7 14 15</sup> we chose 60 states of being that we estimated to be familiar to the relevant stakeholders, some that everyone would consider a disease, some that none would consider a disease, and some that might elicit disagreement (fig A1 in appendix). We asked participants to respond to two claims: 1) "[This state of being] is a disease" (claim A) and 2) "[This state of being] should be treated with public tax revenue" (claim B) on a 5-point Likert scale ranging from *strongly disagree* to *strongly agree* (fig A1 in appendix). We elicited demographic information using questions from earlier surveys (table A1 in appendix). We pilot tested the questionnaire with 20 laypeople and 5 doctors, and made minor revisions on the basis of feedback.

We mailed the questionnaires in June 2010 and sent reminders in August and October 2010. We made pre-contacts with MPs by email and telephone. The ethics committee of the Pirkanmaa Hospital District in Finland granted exemption from ethical review (R11110). The reporting of the study conforms to the STROBE statement.<sup>16</sup>

#### Randomization and exclusion criteria

We randomized the 60 states of being into three blocks (1, 2 and 3; each containing 20 states). We created three versions of the questionnaire: version A consisted of blocks in the order 1-2-3, version B in the order 3-1-2 and version C in the order 2-3-1. Within each sample group (laypeople, doctors, nurses, and MPs), we randomized respondents to the three versions (fig 1).

To check comprehension of the questionnaire, we placed three states (myocardial infarction, pneumonia and breast cancer) likely to be considered as disease as the first state of being in each block. Respondents who did not agree to some extent or strongly agree to the statement "[This state of being] is a disease" (fig A1 in appendix) for any of these three were deemed unlikely to understand the questionnaire and excluded from the analyses (fig 1).

#### Statistical analysis

For each group (doctors, nurses, laypeople, and MPs), we calculated the proportion of states of being where respondents strongly agreed or agreed to some extent regarding the two claims. Using a Pearson Chi-square test on all possible pair-wise comparisons (altogether 6 comparisons for each state of being by claim), we evaluated the order of ratings of perception of disease and expenditure of public tax revenue claims across groups. We calculated the correlation between the proportions of individuals who either strongly agreed or agreed to some extent across states in the two claims. All other analyses were descriptive.

# Results

Of the 6 200 approached, 3 280 (53.2%) participated, of whom 36 proved ineligible (fig 1). Of the 3 244 eligible individuals who completed and understood the questionnaire, 3 246 (99.0%) provided response to at least 55 of the 60 states of being. Among respondents, the mean (standard deviation) age was: laypeople 49.5 (15.5), doctors 46.1 (10.7), nurses 44.9 (11.3) and MPs 54.4 (9.8). There were significantly more females among nurses (97.3%), and fewer among MPs (35.7%) compared to doctors (61.5%) and laypeople (57.3%). We found no significant differences in ratings or background characteristics between questionnaire versions and individuals responding at different response rounds. Table A1 in appendix presents the demographic data.

From the 60 states of being, 12 were perceived as diseases by  $\ge 80\%$  of respondents from all groups and five were perceived as not diseases by  $\ge 80\%$  (fig 2 and table 1). Doctors were most likely to consider states of being as diseases followed by nurses, MPs and laypeople (p<0.001 for all pairwise comparisons). For a large number of states, there was extreme disagreement regarding classification as a disease among all study groups (fig 2). In ten states,  $\ge 20\%$  of participants considered them diseases and  $\ge 20\%$  did not (table 1). There was a very strong correlation between responses to claims (r = 0.96 [95% confidence interval 0.94 to 0.98]; p<0.001; no differences between groups) (fig A2 in appendix).

#### **Discussion**

#### **Statement of principal findings**

Our survey found large differences in the views among laypeople, doctors, nurses and MPs in Finland regarding whether states of being should be considered diseases and should be managed through public revenue. Although physicians were more inclined to consider states of being as diseases, disagreement was as evident among health professionals as in other groups (fig 2 and table 1). In all groups, willingness to pay for treatment was very strongly correlated with the perception of disease.

# Strengths and limitations

The strengths of our study include a large sample of both health professionals and general population, an acceptable response rate, excellent completeness of questionnaires, and a large number of states of being that elicited a wide range of responses. Further, the sample proved representative of the target populations in terms of age and gender distribution, education, employment and marital status (table A1 in appendix). We found no trend in the perceptions or participants' characteristics by response round, reducing concern regarding selection bias.

The limitations of our study include concern that the strong correlation between the claims may be partly caused by the positioning of questions adjacent to one another in the questionnaire. Second, these results from the Finnish population may be less generalizable to lower income countries and those with different social and cultural values.

#### **Comparison with other studies**

Although some investigators have addressed patients' and health care providers' perceptions regarding the concept of disease in specific conditions, only one other study<sup>1</sup> has assessed

 perception of disease over a wide range of conditions. In keeping with our finding that physicians were slightly more likely than others to consider states of being as diseases, Campbell and coworkers<sup>1</sup> found no difference among non-medical faculty, secondary school students, academic internists and general practitioners on how they perceived illnesses due to infections, but found that doctors considered more non-infectious conditions to be diseases.

In another related investigation, the editorial board of the *BMJ* and its readers identified a list of almost 200 *non-diseases* (defined as "a human process or problem that some have defined as a medical condition but where people may have better outcomes if the problem or process was not defined in that way") including ageing, baldness, and boredom.<sup>7</sup> As in our survey, there was considerable variation in the states of being deemed 'non-diseases'.

# Meaning of the study: possible explanations and implications

The concept of "disease" lies at the heart of medicine,<sup>5</sup> 10 defining its domain and its role in public policy, including the range of conditions in which sufferers may be entitled to public funding for their treatment.<sup>17</sup> 18 19 20 Table 2 presents a taxonomy of states of being, exploring the relation between categorization - or not - as a disease, the implications for action, and potential negative consequences. The issues presented in table 2 are subjects of ongoing, often heated, debate.<sup>3</sup> 6 7 9 10 11 12 13 20 21 22 23 24 25 26 27 28 29 30 31 Our results provide insight into these debates: why they are so contentious is due at least in part to disparities in views on the fundamental nature of these states of being.

People tend to think of diseases as conditions for which individuals do not bear primary responsibility, afflictions of which the sufferer is at least to some extent a victim.<sup>32</sup> Thus, if we view addictions, as diseases (which substantial proportions of our respondents did, and

did not) we are inclined to look for solutions through harm reduction approaches and medical treatment, and to allocate public funding for these interventions.<sup>25</sup> <sup>31</sup> A non-disease perspective on addiction includes two alternatives: If we regard addiction as a moral failing, we are likely to demand personal responsibility for dealing with the problem, and institute punitive approaches for those who fail.<sup>23</sup> <sup>25</sup> Alternatively, we may see addiction as a social problem and seek social solutions such as poverty reduction.<sup>27</sup> The general unavailability of safe injection sites for drug users, despite evidence of benefit and eminent advocacy illustrates how these issues play out in public policy.<sup>29</sup> Our results suggest that the current contentious debate on social policy toward addiction could benefit not only from evidence regarding effectiveness of alternative policies, but a more profound understanding of the biology and sociology of addiction.

Viewing social anxiety disorder or fibromyalgia as specific biological problems may lead to overdiagnosis and medical overtreatment, and undertreatment with behavioral approaches.<sup>11</sup>
<sup>21 28</sup> On the other hand, seeing these conditions as socially mediated adjustment problem risks stigmatization and underuse of potentially effective medical treatment.<sup>11 21 28</sup> For other states of being, ongoing passionate debate has highlighted possible dangers in medicalizing conditions that might be considered normal problems of living.<sup>10 11 13 33</sup>

We found the association between considering a state of being a disease and readiness to fund treatment through public revenue very strong. If we consider obesity a disease, we might devote public funding to weight loss clinics. While this is true of very few jurisdictions, <sup>34</sup> most high income countries devote public funding to bariatric surgery for morbid obesity, a policy which – according to a Danish study<sup>32</sup> – many laypeople may question despite evidence suggesting it is highly cost-effective.

Advocates argue that placing a disease label on absence of sexual desire is a step forward to helping people, <sup>22</sup> while critics deem it a destructive medicalization of a normal part of living fostering problematic commercialization. <sup>24</sup> Similarly, creating new diagnostic terms, such as the concept "overactive bladder" may help to increase awareness of the symptoms and to simplify management but it may also cause problematic oversimplification leading to excessive use of ineffective treatment. <sup>4</sup> <sup>35</sup> <sup>36</sup>

This discussion can also be seen from more general perspective: essentialism versus nominalism. Essentialists regard diseases as causes of illness; the role of a physician, in this view, is to identify the cause and treat it appropriately.<sup>35</sup> Nominalists see diseases as constructs that humans create to bring order to a disorderly world.<sup>35</sup>

The concept of disease also helps us understand differing perspectives on patterns of behavior (table 2), such as homosexuality. The American Psychiatric Association labeled homosexuality as a disease until 1973, when it was removed from its diagnostic and statistical manual of mental disorders (DSM). However, it remained in the international classification of diseases (ICD) until 1992.<sup>37</sup> Western societies increasingly view homosexuality as a legitimate lifestyle choice; less than 5% of doctors and nurses, and less than 10% of laypeople and MPs in our survey considered homosexuality a disease. Our respondents likewise did not consider transsexualism a disease, contrary to the current ICD-10 classification.<sup>15</sup> As with addiction, there is another non-disease perspective on sexual orientation: that homosexuality represents a moral failing. Historically, Western societies have deemed homosexual acts criminal behavior. In many countries in the world, this continues to be the case.

#### **Conclusions**

In summary, the substantial disagreement we found in classifying of states of being as diseases, and the parallel disagreement regarding the legitimacy of public funding for those that warrant treatment, provides insight into the attitudes underlying a number of current high profile social debates. The finding suggests that a shared understanding of the biological and social determinants of health conditions and human behaviors could be very useful in helping to facilitate resolution of these debates.

**Table A1.** Characteristics of the study groups.

Fig A1. English translation of the questionnaire version A (excluding background

information questions).

Fig A2. Relation between claim A (concept of disease) and claim B (willingness to use public

tax revenue for treatment) in laypeople, doctors, nurses and parliament members. 'r'

represents the strength of the correlation between those who either strongly agreed or agreed

to some extent with claim A and claim B.

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Author contributions: KAOT, JSL and TLNJ conceptualized the study. KAOT and TLNJ

obtained funding. KAOT collected the data. KAOT and GHG developed the analysis plan

with JSL, SE and TLNJ. KAOT analyzed the data. All authors contributed to the

interpretation of the results. KAOT and GHG led the writing of the manuscript; all authors

contributed. All authors had full access to all the data and take responsibility for the integrity

and the accuracy of the data. All authors have approved the final version of the manuscript.

KAOT is the guarantor.

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Competing interest statement: "All authors have completed the Unified Competing Interest form atwww.icmje.org/coi\_disclosure.pdf (available on request from the corresponding author) and declare: KAOT, GHG, SE, and TLNJ declare no conflict of interest. JSL is a chief medical officer at the Insurance Medicine of State Treasury (Helsinki, Finland), which is a government agency that handles statutory employment pension, accident and indemnity insurances and insurance-related employer services of government agencies.

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**Ethical approval:** In accordance with the Finnish regulations on questionnaire surveys, the ethics committee of the Pirkanmaa Hospital District in Finland granted exemption from ethical review (R11110).

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**Table 1.** A) States of being perceived as a disease by at least 80% of respondents of all groups, B) states of being not perceived as a disease by at least 80% of respondents of all groups, and C) states of being perceived as a disease by at least 20% and not as a disease by at least another 20% of respondents of all groups (laypeople, doctors, nurses and parliament members).\*

A) Perceived as disease by more than 80% (res	ponse options "4" and "5")
Breast cancer	Schizophrenia
Prostate cancer	HIV/AIDS
Pneumonia	Malaria
Lung cancer	Adult-onset diabetes
Juvenile diabetes	Osteoporosis
Myocardial infarction	Autism
B) Not perceived as disease by more than 80%	(response options "1" and "2")
Wrinkles	Grief
Smoking	Homosexuality
Ageing	
C) More than 20% perceived as disease (response option) did not perceive as disease (response option)	
Pre-menstrual syndrome, PMS	Age-related muscle loss, sarcopenia
Erectile dysfunction	Female menopause
Gambling addiction	Malnutrition
Infertility	Eye refractive error, need for eyeglasses
Drug addiction	Lactose intolerance

**Table 2.** Implications of alternative viewpoints regarding accepting or rejecting states of being as diseases

Categories of states of being Examples	Disease?	Conceptualization	Implications for action	Potential negative consequences/ramifications		
Addictions or possible addictions	Yes	Biological health disorder	Harm reduction Public funding Medical treatment	Focus on individuals and treatments may cause social and moral aspects to be ignored <sup>6 26 27 30</sup>		
Alcoholism Drug addiction Gambling addiction Obesity	N	Lack of self-control Moral failing	Abstinence through individual choice and self-discipline Punitive management strategies	Stigma and discrimination, neglect of harm reduction, neglect of social causes, increased suffering for the population <sup>23 25 26 27 29 31</sup>		
Smoking	No	Preventive social solutions: income redistribution, poverty reduction, education, social marketing		Effective medical treatment underused <sup>25</sup> <sup>26</sup>		
Madical diamental management						
Medical diagnoses with uncertain biologic / psychosocial basis Chronic fatigue syndrome	Yes	Specific biological problem	Diagnose and treat, possibly with drugs	Overdiagnosis and overtreatment with drugs, undertreatment with behavioral approaches <sup>7</sup> 11 12 33		
Fibromyalgia Irritable bowel syndrome Panic disorder Personality disorder	No	Socially mediated adjustment problem	Behavioral therapy Modify environment	Patients may feel stigmatized Effective medical treatment may be underused <sup>7</sup> 12 21		
Diminished function or altered appearance, often age-related	Yes	Biological health disorder	Diagnose and treat, possibly with drugs Public funding	Overdiagnosis and overtreatment Medicalization of society, with increased self- perception of illness and poorer coping with suffering that is part of life <sup>7 11 12 13 21</sup>		
Age-related muscle loss Baldness Erectile dysfunction Lack of sexual desire	No	Normal consequence of living	Accept and adjust Responsibility on individual	Neglect of treatments that may reduce suffering and improve function <sup>7</sup> <sup>12</sup> <sup>21</sup>		

Homosexuality Obesity Smoking Transsexualism	No	T:0 . 1 . 1 .		
Transsextansm		Lifestyle choice	Respect person's choice	Permissive attitude encourages self-destructive or morally reprehensible behavior* <sup>26</sup> Underuse of effective treatment* <sup>32</sup>
	No	Moral failing	Abstinence/modification of behavior through individual choice/self-discipline Punitive strategies	Stigma and discrimination <sup>37</sup>
Syndromes or constellation of patterns of symptoms of unclear basis	Yes	Essentialist: specific biological disorder	Label all patients with specific category and treat uniformly	Failure to recognize diversity of illness, excessively uniform management, stifle research that could deepen understanding <sup>1 4 35</sup>
Attention deficit hyperactivity disorder Fibromyalgia Overactive urinary bladder Panic disorder	No	Nominalist: collection of symptoms, signs, behaviors, label of convenience	Acknowledge syndromes as convenient constructions, seek underlying causes, don't attempt to pigeon-hole unusual presentations	Acknowledgement of complexity may lead to inefficiency, paralysis <sup>1 4 35</sup>

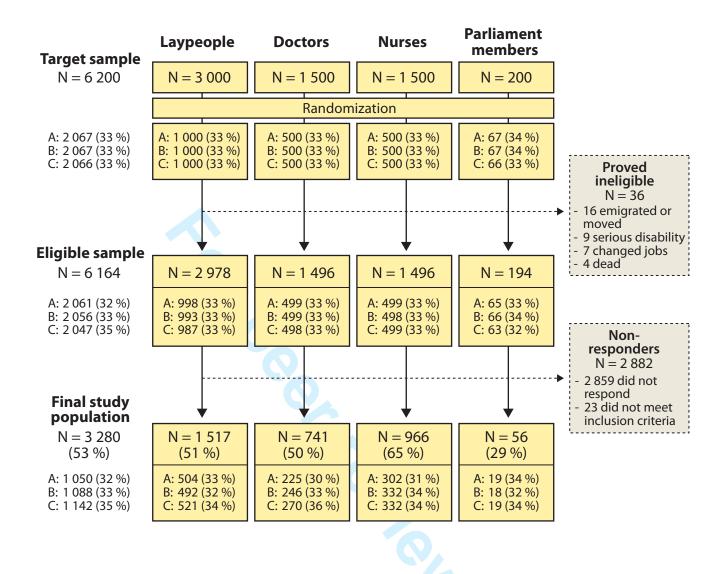
<sup>\*</sup> Negative consequences listed here refer particularly to smoking and obesity not to homosexuality and transsexualism

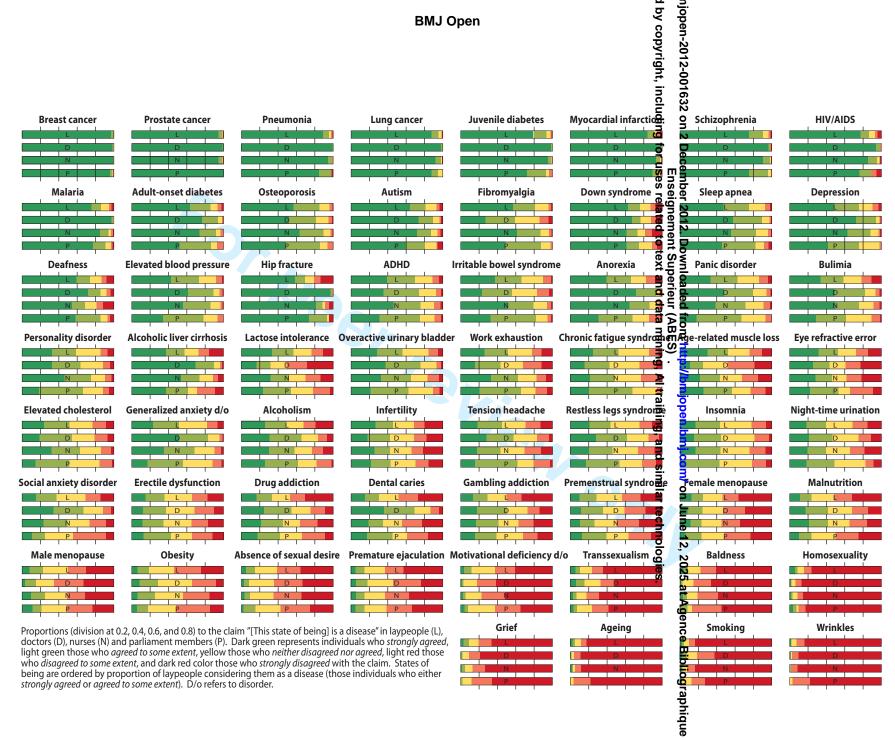
### Figure legends

Fig 1. Study flow.

**Fig 2.** Variation of perceptions in concept of disease among laypeople, doctors, nurses and parliament members.







**Supplementary Information (Web-only Appendix)** 

**Table A1.** Characteristics of the study groups.

**Fig A1.** English translation of the questionnaire version A (excluding background information questions).

**Fig A2.** Relation between claim A (concept of disease) and claim B (willingness to use public tax revenue for treatment) in laypeople, doctors, nurses and parliament members. 'r' represents the strength of the correlation between those who either *strongly agreed* or *agreed to some extent* with claim A and claim B.

**Table A1.** Characteristics of the study groups among the 3280 included participants.

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Table A1. Characterist	ics of the study g	groups among the 3280 inclu	uded participants	S.		njopen-2012-001632 on 2 ช by copyright, including	
Laypeople		Doctors		Nurses		<b>a</b> D	
N (% of females)	1517 (57.3)		741 (61.5)		966 (97.3)	ember Enseig	56 (35.7)
Age distribution	n (%)	Age distribution	n (%)	Age distribution	n (%)	TParticular and the second sec	n (%)
18-35	340 (22.4)	18-35	155 (20.9)	18-35	236 (24.5)	#188	2 (3.6)
36-55	542 (35.7)	36-55	411 (55.5)	36-55	523 (54.2)	<del>*                                   </del>	26 (46.4)
56-75	635 (41.9)	56-75	174 (23.5)	56-75	206 (21.3)	\$58.8	28 (50.0)
					` /	\$ 0 0 0	` '
Employment		Location of primary occupa	ation	Current employment sector		Displayment	T.
Employed	887 (58.5)	Hospital	337 (45.5)	Working at the public sector	739 (76.5)	<b>⊉E</b> poyed	56 (100)
Student	87 (5.7)	Health centre	161 (21.7)	Working for a private employer	124 (12.8)	<b>₫</b> Stu <b>t</b> ent	0 (0.0)
Unemployed	106 (7.0)	Occupational health care	67 (9.0)	Self-employed	23 (2.4)	Unemployed	0 (0.0)
Retired	430 (28.3)	Private clinic	74 (10.0)	Unemployed	29 (3.0)	<b>⊈</b> Ret <mark>∓e</mark> d	0 (0.0)
Insufficient information	7 (0.5)	Research or education	29 (3.9)	Insufficient information	51 (5.3)	Insufficient information	0 (0.0)
		Industry	4 (0.5)			# <u> </u>	
						<del>                                    </del>	
		Insufficient information	5 (0.7)			<u> </u>	
		Other  Not currently employed  Insufficient information	4 (0.5) 40 (5.4) 24 (3.2) 5 (0.7)		0/	n.bmj.com/ on June 12, 2025	

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Laypeople		Doctors		Nurses		© 3			
Education	n (%)	Specialization	n (%)	Primary task n (%)		Education	n (%)		
Elementary school	271 (17.9)	Not specialized	119 (16.1)	Registered nurse	622 (64.4)	###entary school	4 (7.1)		
Upper level of elementary	52 (3.4)	Resident	151 (20.4)	Public health nurse	40 (4.1)	The level of elementary	2 (3.6)		
Vocational school or equivalent	380 (25.0)	Medical specialist	465 (62.8)	Midwife	8 (0.8)	Sectional school or equivalent	3 (5.4)		
Upper secondary school	131 (8.6)	Insufficient information	6 (0.8)	Paramedic	5 (0.5)	<b>Ç</b> L∰per secondary school	3 (5.4)		
College	306 (20.2)			Head nurse or matron	118 (12.2)	(B) lege	11 (19.6)		
Polytechnic degree	144 (9.5)			Other work in health care	83 (8.6)	Polyechnic degree	3 (5.4)		
Academic degree	220 (14.5)			Working outside health care	29 (3.0)	A⊊a⊒emic degree	30 (53.6)		
Insufficient information	13 (0.9)			Not currently in working life	52 (5.4)	HE Gricient information	0 (0.0)		
				Insufficient information	9 (0.9)	d de			
						d fi			
Marital status		Academic training	0			ded car (ABm m Marital status			
Married	809 (53.3)	Licentiate in medicine (MD)	580 (78.3)			Marged	45 (80.4)		
Cohabiting	240 (15.8)	Doctorate in medicine (PhD)	96 (13.0)			Cohabiting	1 (1.8)		
Single	256 (16.9)	Adjunct professor	47 (6.3)			Singe	3 (5.4)		
Separated or divorced	126 (8.3)	Professor	12 (1.6)			Sepsated or divorced	5 (8.9)		
Widowed	74 (4.9)	Insufficient information	6 (0.8)			<b>∄</b> Wid <mark>⊈</mark> wed	2 (3.6)		
Insufficient information	12 (0.8)					Insu <b>c</b> ficient information	0 (0.0)		
						an j			
						ΨPoligical party			
						Cenge Party	14 (25.0)		
			1			Lef Alliance	6 (10.7)		
			1			Natanal Coalition Party	13 (23.2)		
			1			Social Democratic Party	13 (23.2)		
						Other parties	10 (17.9)		

The study sample is representative of the target populations. For more information, see 1) Laypeople: Peltonen M, Harald K, Männistöss, et al. The National FINRISK 2007 Study (in Finnish with English summary). Helsinki: National Public Health Institute, 2008. http://www.ktl.fi/attachments/suomi/julkaisut/julkaisusarja\_b/2008/2008b34.pdf (accessed Feb 1, 2012); 2) Doctors: Lääkärikysely 2009 [Statistics of the Finnish Medical Association] (in Finnish and Swedish). Helsinki, Finnish Medical Association, 2009 http://www.laakariliitto.fi/files/laakarikysely2009.pdf (accessed Feb 1, 2012); 3) Nurses: Statistics of the Finnish Nurses Association (in Finnish). Helsinki, Finnish Nurses Association, 2012. http://www.sairaanhoitajaliitto.fi/viestinta/tilastoja/ (accessed Feb 1, 2012); 4) Parliament members: Wikipedia. Pakiamentary elections 2007. Eduskuntavaalit 2007 (in Finnish). http://fi.wikipedia.org/wiki/Eduskuntavaalit\_2007 (accessed Feb 1, 2012).

Page 27 of 32 ATTENTION: This is an <u>opinion poll</u> to clarify the concept of disease. The purpose <u>is</u>

not to find out whether you have any of the states of being/diseases below.

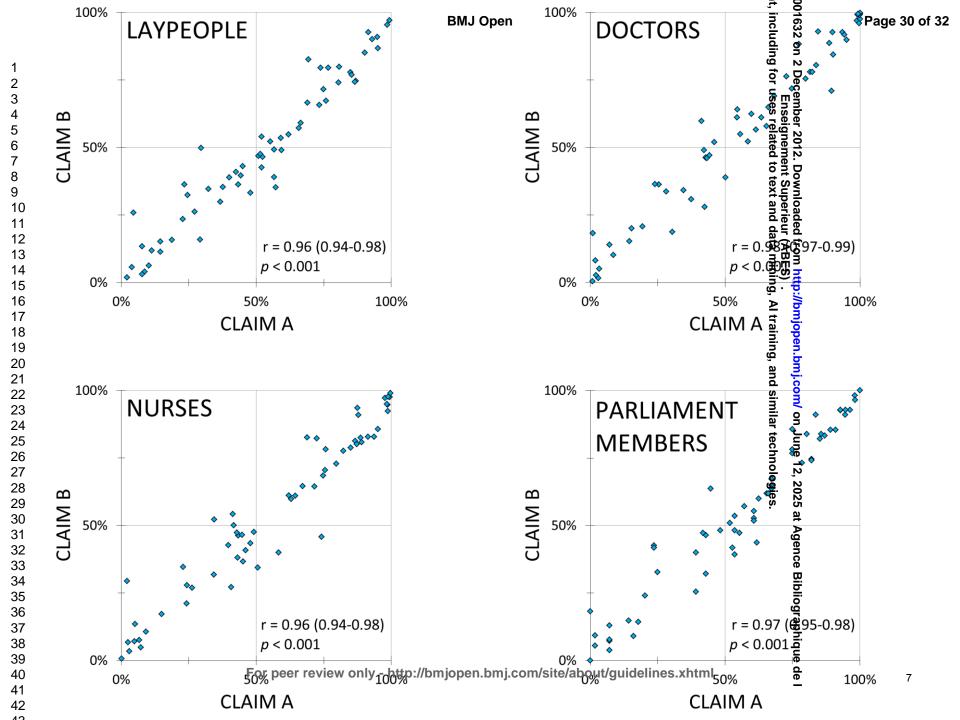
INSTRUCTIONS FOR FILLING OUT THE FORM: Please circle a number 1-5 that best describes your <u>opinion</u> (in both claims A and B).

- 1 = Strongly disagree
- 2 = Disagree to some extent
- 3 = Neither disagree nor agree
- 4 = Agree to some extent
- 5 = Strongly agree

		C	LAIM .	A			C	CLAIM	В		Prote
	"[This sta	ate of	being	g] is a	disease"	"[This state of being] should be treated with public tax revenue"					
	Strongly disagree				Strongly agree	Strongly Strongly disagree agree					
[Myocardial infarction]	1	2	3	4	5	1	2	3	4	5	ght, inc
[Chronic fatigue syndrome]	1	2	3	4	5	1	2	3	4	5	duding
[Baldness]	1	2	3	4	5	1	2	3	4	5	for us
[Absence of sexual desire]	1	2	3	4	5	1	2	3	4	5	nseign es rela
[Alcoholism]	1	2	3	4	5	1	2	3	4	5	ement ted to t
[Premenstrual syndrome, PMS]	1	2	3	4	5	1	2	3	4	5	Enseignement Superieur (ABES) Protected by copyright, including for uses related to text and data minii
[Panic disorder]	1	2	3	4	5	1	2	3	4	5	ur (AB data m
[Anorexia]	1	2	3	4	5	1	2	3	4	5	ining,
[Grief]	1	2	3	4	5	1	2	3	4	5	Al train
[Deafness]	1	2	3	4	5	1	2	3	4	5	BES) . mining, Al training, and similar tech
[Erectile dysfunction]	1	2	3	4	5	1	2	3	4	5	d simil
[Motivational deficiency disorder]	1	2	3	4	5	1	2	3	4	5	
[Osteoporosis]	1	2	3	4	5	1	2	3	4	5	nologies
[Gambling addiction]	1	2	3	4	5	1	2	3	4	5	Ş.
[Tension headache]	1	2	3	4	5	1	2	3	4	5	
[Work exhaustion, burnout]	1	2	3	4	5	1	2	3	4	5	
	Strongly disagree				Strongly agree	Strongly disagree				Strongly agree	

		C	LAIM	Α		CLAIM B				
	"[This sta	disease"	1			_	ould be evenue"			
	Strongly disagree				Strongly agree	Strongly disagree	WICH	public	taxi	Strongly agree
[HIV/AIDS]	1	2	3	4	5	1	2	3	4	5
[Infertility]	1	2	3	4	5	1	2	3	4	5
[Attention-deficit hyper- activity disorder, ADHD]	1	2	3	4	5	1	2	3	4	5
[Prostate cancer]	1	2	3	4	5	1	2	3	4	5
[Pneumonia]	1	2	3	4	5	1	2	3	4	5
[Insomnia]	1	2	3	4	5	1	2	3	4	5
[Obesity]	1	2	3	4	5	1	2	3	4	5
[Drug addiction]	1	2	3	4	5	1	2	3	4	5
[Male menopause]	1	2	3	4	5	1	2	3	4	5
[Ageing]	1	2	3	4	5	1	2	3	4	5
[Transsexualism]	1	2	3	4	5	1	2	3	4	5
[Alcoholic liver cirrhosis]	1	2	3	4	5	1	2	3	4	5
[Schizophrenia]	1	2	3	4	5	1	2	3	4	5
[Restless legs syndrome]	1	2	3	4	5	1	2	3	4	5
[Age-related muscle loss, sarcopenia]	1	2	3	4	5	1	2	3	4	5
[Adult-onset diabetes]	1	2	3	4	5	1	2	3	4	5
[Smoking]	1	2	3	4	5	1	2	3	4	5
[Autism]	1	2	3	4	5	1	2	3	4	5
[Night-time urination]	1	2	3	4	5	1	2	3	4	5
[Binge eating, bulimia]	1	2	3	4	5	1	2	3	4	5
[Generalized anxiety disorder]	1	2	3	4	5	1	2	3	4	5
[Sleep apnea, pauses in breathing during sleep]	1	2	3	4	5	1	2	3	4	5
	Strongly disagree				Strongly agree	Strongly disagree				Strongly agree

		C	LAIM	Α		CLAIM B					
	"[This sta	ate of	being	g] is a	disease"	"[This state of being] should be treated with public tax revenue"					
	Strongly disagree				Strongly agree	Strongly disagree	WILII	public	taxi	Strongly agree	
[Wrinkles]	1	2	3	4	5	1	2	3	4	5	
[Elevated cholesterol]	1	2	3	4	5	1	2	3	4	5	
[Breast cancer]	1	2	3	4	5	1	2	3	4	5	
[Fibromyalgia, chronic pain syndrome]	1	2	3	4	5	1	2	3	4	5	
[Elevated blood pressure]	1	2	3	4	5	1	2	3	4	5	
[Dental caries]	1	2	3	4	5	1	2	3	4	5	
[Lung cancer]	1	2	3	4	5	1	2	3	4	5	
[Female menopause]	1	2	3	4	5	1	2	3	4	5	
[Malnutrition]	1	2	3	4	5	1	2	3	4	5	
[Irritable bowel syndrome]	1	2	3	4	5	1	2	3	4	5	
[Homosexuality]	1	2	3	4	5	1	2	3	4	5	
[Eye refractive error, need for eyeglasses]	1	2	3	4	5	1	2	3	4	5	
[Lactose intolerance]	1	2	3	4	5	1	2	3	4	5	
[Down syndrome]	1	2	3	4	5	1	2	3	4	5	
[Personality disorder]	1	2	3	4	5	1	2	3	4	5	
[Overactive urinary bladder]	1	2	3	4	5	1	2	3	4	5	
[Depression]	1	2	3	4	5	1	2	3	4	5	
[Juvenile diabetes]	1	2	3	4	5	1	2	3	4	5	
[Malaria]	1	2	3	4	5	1	2	3	4	5	
[Social anxiety disorder]	1	2	3	4	5	1	2	3	4	5	
[Premature ejaculation]	1	2	3	4	5	1	2	3	4	5	
[Hip fracture]	1	2	3	4	5	1	2	3	4	5	
	Strongly disagree				Strongly agree	Strongly disagree				Strongly agree	



#### STROBE 2007 (v4) Statement—Checklist of items that should be included in reports of cross-sectional studies

Section/Topic	Item #	Recommendation	Reported on page #				
Title and abstract	1 (a) Indicate the study's design with a commonly used term in the title or the abstract		2				
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found					
Introduction							
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	4				
Objectives	3	State specific objectives, including any prespecified hypotheses	4				
Methods							
Study design	4	Present key elements of study design early in the paper	5-6				
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	5				
Participants	6	(a) Give the eligibility criteria, and the sources and methods of selection of participants	5-6, Figure 1				
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	5-6				
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	5				
Bias	9	Describe any efforts to address potential sources of bias	5-7				
Study size	10	Explain how the study size was arrived at					
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	5-6				
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding	6				
		(b) Describe any methods used to examine subgroups and interactions					
		(c) Explain how missing data were addressed	7				
		(d) If applicable, describe analytical methods taking account of sampling strategy					
		(e) Describe any sensitivity analyses					
Results							

Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility,	7, Figure 1
		confirmed eligible, included in the study, completing follow-up, and analysed	
		(b) Give reasons for non-participation at each stage	Figure 1
		(c) Consider use of a flow diagram	Figure 1
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential	Table A1
		confounders	
		(b) Indicate number of participants with missing data for each variable of interest	
Outcome data	15*	Report numbers of outcome events or summary measures	Figure 1, Table 1
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence	Figure 1
		interval). Make clear which confounders were adjusted for and why they were included	
		(b) Report category boundaries when continuous variables were categorized	
		(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	7
Discussion			
Key results	18	Summarise key results with reference to study objectives	8
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	8
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	9-11
Generalisability	21	Discuss the generalisability (external validity) of the study results	8
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on	14
		which the present article is based	

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Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

<sup>\*</sup>Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.



# What is a disease? Perspectives of the public, health professionals, and legislators

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What is a disease? Perspectives of the public, health professionals, and legislators

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**Objective:** To assess the perception of diseases and the willingness to use public tax revenue for their treatment among relevant stakeholders.

**Design:** A population-based, cross-sectional mailed survey.

**Setting:** Finland

**Participants:** 3 000 laypeople, 1 500 doctors, 1 500 nurses (randomly identified from the databases of the Finnish Population Register, the Finnish Medical Association and the Finnish Nurses Association), and all 200 parliament members.

**Main outcome measures:** Respondents' perspectives on a 5-point Likert scale on two claims on 60 states of being: "[This state of being] is a disease"; and "[This state of being] should be treated with public tax revenue".

**Results:** Of the 6 200 individuals approached, 3 280 (53%) responded. Of the 60 states of being,  $\geq$ 80% of respondents considered 12 to be diseases (Likert scale responses of "4" and "5") and five not to be diseases (Likert scale responses of "1" and "2"). There was considerable variability in most states, and great variability in ten ( $\geq$ 20% of respondents of all groups considered it a disease and  $\geq$ 20% rejected as a disease). Doctors were more inclined to consider states of being as diseases than laypeople; nurses and members were intermediate (p<0.001), but all groups showed large variability. Responses to the two claims were very strongly correlated (r = 0.96 [95% CI: 0.94-0.98]; p<0.001).

**Conclusions:** There is large disagreement among the public, health professionals, and legislators regarding the classification of states of being as diseases and whether their management should be publicly funded. Understanding attitudinal differences can help to enlighten social discourse on a number of contentious public policy issues.

# ARTICLE SUMMARY

#### **Article focus**

The concept of disease lies at the heart of medicine.

No study has addressed perceptions of all relevant stakeholders on what, across a wide range of conditions, should be classified as a disease.

# **Key messages**

Our survey found large differences in the views among Finnish laypeople, doctors, nurses and parliament members regarding whether states of being should be considered diseases and be managed through public revenue.

Although doctors were more inclined to consider states of being as diseases, disagreement was as evident among health professionals as in other groups.

Understanding peoples' attitudes about whether states of being should be considered diseases elucidates fundamental underlying attitudes and thus can inform social discourse regarding a number of contentious public policy issues.

# Strengths and limitations of this study

This is the first study to assess whether states of being should be considered diseases and should be managed through public revenue using representative sample of doctors, nurses, laypeople as well as legislators.

Our results from the Finnish population may be less generalizable to less affluent countries and countries with different social and cultural values.

# Introduction

Disease, and illness, are related concepts: patients suffer from "illnesses" and doctors diagnose and treat "diseases". Illnesses are experiences of discontinuities in states of being and perceived role performances; when diagnosed as diseases, they are presumed abnormalities in the function or structure of body systems. Disease can refer to a combination of signs and symptoms, phenomena associated with a disorder of function or structure, or illness associated with a specific cause(s). There are, however, no universally accepted criteria for establishing "disease". Indeed, the complexity of the concept of disease has led to the observation that it can be as difficult to define as beauty, truth or love.

The concept of disease is subject to social, cultural and economic influences that have varied over time: these influences have been particularly evident in the last two decades. <sup>457-9</sup> During this time, we have witnessed a growing tendency to classify states of being as diseases, a trend with important possible consequences, both positive and negative. <sup>810-13</sup> Possible positive consequences include facilitation of patient-physician communication <sup>4511</sup> and increased willingness to use public money and thus enhance equality in the distribution of limited resources. <sup>414</sup> Possible adverse consequences include making relatively healthy individuals perceive themselves as sick, encouraging misguided attempts to treat states that are part of the normal human condition, and individuals being denied employment or insurance. <sup>411 15-17</sup> Authors have also suggested that the disease label can be used as a social control mechanism, <sup>18-20</sup> which could be positive or negative on one's perspective. The extent to which health workers and the public have been influenced by these tendencies, and their current perceptions remains uncertain.

Because of the importance of the issue, and the paucity of empirical evidence regarding peoples' views, we conducted a survey of the general public, doctors, nurses, and parliament members in Finland to determine the extent to which they considered 60 states of being to be diseases and their attitudes toward using public funds for managing these states. We hypothesized that groups (laypeople, doctors, nurses, and parliament members) would vary in their conceptions of disease, and that there would also be large variation in conceptions of disease within groups. Furthermore, we hypothesized that there would be strong correlation between the conception of disease and the willingness to use public funds for its management.

# Methods

# The Finnish Disease (FIND) Survey study population

In 2010, we selected a random sample of 3 000 laypeople, 1 500 doctors, 1 500 nurses, and all the 200 members of the Parliament of Finland (MPs). We identified laypeople 18 to 75 years of age from the Finnish Population Register Centre, and doctors and nurses less than 65 years of age from the registers of the Finnish Medical Association and the Finnish Nurses Association. We excluded individuals who had died, emigrated, were deemed seriously disabled or who changed careers and would therefore no longer be members of their respective group (fig 1).

#### Survey

Referring to the existing literature and the International Classification of Diseases (ICD-10),<sup>2</sup> 11 21 22 we chose 60 states of being that we estimated to be familiar to the relevant stakeholders, some that everyone would consider a disease, some that none would consider a disease, and some that might elicit disagreement (fig A1 and fig A2 in the appendix). We asked participants to respond to two claims: 1) "[This state of being] is a disease" (claim A) and 2) "[This state of being] should be treated with public tax revenue" (claim B) on a 5-point Likert scale ranging from *strongly disagree* to *strongly agree* (fig A1 and fig A2 in appendix). We elicited demographic information using questions from earlier surveys (table A1 in the appendix). We pilot tested the questionnaire with 20 laypeople and 5 doctors, and made minor revisions on the basis of feedback.

We mailed the questionnaires in June 2010 and sent reminders in August and October 2010. We made pre-contacts with MPs by email and telephone. The ethics committee of the

Pirkanmaa Hospital District in Finland granted exemption from ethical review (R11110). The reporting of the study conforms to the STROBE statement.<sup>23</sup>

#### Randomization and exclusion criteria

Each participant received a questionnaire eliciting responses to 60 states of being. We randomized the 60 states of being into three blocks (1, 2 and 3; each containing 20 states). We created three versions of the questionnaire: version A consisted of blocks in the order 1-2-3, version B in the order 3-1-2 and version C in the order 2-3-1. Within each sample group (laypeople, doctors, nurses, and MPs), we randomized respondents to the three versions (fig 1).

To check comprehension of the questionnaire, we placed three states (myocardial infarction, pneumonia and breast cancer) likely to be considered as disease as the first state of being in each block. Respondents who did not *agree to some extent* or *strongly agree* to the statement "[This state of being] is a disease" (fig A1 and fig A2 in appendix) for *any* of these three were deemed unlikely to understand the questionnaire and excluded from the analyses (fig 1).

#### Statistical analysis

For each group (doctors, nurses, laypeople, and MPs), we calculated the proportion of states of being where respondents *strongly agreed* or *agreed to some extent* regarding the two claims. Using a Pearson Chi-square test on all possible pair-wise comparisons (altogether 6 comparisons for each state of being by claim), we evaluated the order of ratings of perception of disease and expenditure of public tax revenue claims across groups. We calculated the correlation between the proportions of individuals who either *strongly agreed* or *agreed to some extent* across states in the two claims. All other analyses were descriptive.

# **Results**

Of the 6 200 people approached, 3 280 (53.2%) participated, of whom 36 proved ineligible (fig 1). Of the 3 244 eligible individuals who completed and understood the questionnaire, 3 246 (99.0%) responded to at least 55 of the 60 states of being. Among respondents, the mean (standard deviation) age was: laypeople 49.5 (15.5), doctors 46.1 (10.7), nurses 44.9 (11.3) and MPs 54.4 (9.8). There were significantly more females among nurses (97.3%), and fewer among MPs (35.7%) compared to doctors (61.5%) or laypeople (57.3%) (p < 0.01 for all comparisons). We found no significant differences in ratings or background characteristics between questionnaire versions and individuals responding at different response rounds. Table A1 in the appendix presents the demographic data.

From the 60 states of being, 12 were perceived as diseases by  $\ge 80\%$  of respondents from all groups and five were perceived not to be diseases by  $\ge 80\%$  (fig 2 and table 1). Doctors were most likely to consider states of being as diseases followed by nurses, MPs and laypeople (p<0.001 for all pairwise comparisons). For a large number of states, there was extreme disagreement regarding classification as a disease among all study groups (fig 2). In ten states,  $\ge 20\%$  of participants considered them diseases and  $\ge 20\%$  did not (table 1). There was a very strong correlation between responses to claims (r = 0.96 [95% confidence interval 0.94 to 0.98]; p<0.001; no differences between groups) (fig A3 in the appendix).

# **Discussion**

# Statement of principal findings

Our survey found large discrepancies in the views among laypeople, doctors, nurses and MPs in Finland regarding whether states of being should be considered diseases and should be managed through public revenue. Although physicians were more inclined to consider states of being as diseases, disagreement was as evident among health professionals as in other groups (fig 2 and table 1). In all groups, willingness to pay for treatment from public funds was very strongly correlated with the perception of disease.

# Strengths and limitations

The strengths of our study include a large sample of both health care professionals and general population, an acceptable response rate, excellent completeness of questionnaires, and a large number of states of being that elicited a wide range of responses. Further, the sample proved representative of the target populations in terms of age and gender distribution, education, employment and marital status (for details, see table A1 in the appendix and its supplementary references). We found no trend in the perceptions or participants' characteristics by response round, reducing concern regarding selection bias.

The limitations of our study include concern that the strong correlation between the claims may be partly caused by the positioning of questions adjacent to one another in the questionnaire. Second, these results from the Finnish population may be less generalizable to less affluent countries and those with different social and cultural values. For instance, the high correlation between the disease label and the willingness to fund socially may be related to Finland's high level of social solidarity or what has been referred to as its status as a "welfare state" and may not be reproduced in other jurisdictions. Third, despite our attempt at

screening for misunderstanding in a pilot study, the impact of the exact wording we ultimately chose remains uncertain. In particular, it is possible that alternative framing of questions regarding whether states of being should be funded by public revenue would have elicited different results.<sup>24</sup>

# Comparison with other studies

Although some investigators have addressed patients' and health care providers' perceptions regarding the concept of disease and use of public funding in specific conditions, only one other study has assessed perceptions' on the concept of disease and none perceptions' on use of public funding over a wide range of conditions. In keeping with our finding that physicians were slightly more likely than others to consider states of being to be diseases, Campbell and coworkers found no difference among non-medical faculty, secondary school students, academic internists and general practitioners on how they perceived illnesses due to infections, but found that doctors considered more non-infectious conditions to be diseases.

In another related investigation, the editorial board of the *BMJ* and its readers identified a list of almost 200 *non-diseases* (defined as "a human process or problem that some have defined as a medical condition but where people may have better outcomes if the problem or process was not defined in that way") including ageing, baldness, and boredom. As in our survey, there was considerable variation in the states of being deemed 'non-diseases'.

#### Meaning of the study: possible explanations and implications

The concept of "disease" lies at the heart of medicine,<sup>7 14</sup> defining its domain and its role in public policy, including the range of conditions in which sufferers may be entitled to public funding for their treatment.<sup>29-31</sup> Building on earlier work,<sup>4 8 11 13-17 32-42</sup> table 2 presents a

taxonomy of states of being, exploring the relation between categorization - or not - as a disease, the implications for action, and potential negative consequences. The issues presented in table 2 are subjects of ongoing, often heated, debate. He is 13-17 32-42 Our results (i.e., large differences in views whether states of being should be considered diseases and should be managed through public revenue) provide insight into these debates: why they are so contentious is due at least in part to disparities in views on the fundamental nature of these states of being. Our study represents only the first steps in understanding the concept of "disease". Additional qualitative studies would be useful for obtaining further insight into interpretation of the findings.

As reflected in table 2, people tend to think of diseases as conditions for which individuals do not bear primary responsibility, afflictions of which the sufferer is at least to some extent a victim.<sup>28</sup> Thus, if we view addictions as diseases (which substantial proportions of our respondents did, and did not) we are inclined to look for solutions through harm reduction approaches and medical treatment, and to allocate public funding for these interventions.<sup>36 42</sup> Alternative views include viewing a condition as a moral failing, bad habit, or retribution for bad behavior (all related perspectives) or as a social problem (a quite different perspective).

For instance, a non-disease perspective on addiction includes two alternatives: If we regard addiction as a moral failing, we are likely to demand personal responsibility for dealing with the problem, and institute punitive approaches for those who fail (table 2).<sup>34</sup> Alternatively, we may see addiction as a social problem and seek social solutions such as poverty reduction.<sup>38</sup> The general unavailability of safe injection sites for drug users, despite evidence of benefit and eminent advocacy illustrates how these issues play out in public policy.<sup>40</sup> Our results suggest that the current contentious debate on social policy toward addiction could

benefit not only from evidence regarding the effectiveness of alternative policies, but a more profound understanding of the biology and sociology of addiction.

To take other examples from table 2 with potentially negative consequences of a disease perspective, viewing social anxiety disorder or fibromyalgia as specific biological problems may lead to overdiagnosis and medical overtreatment, and undertreatment with behavioral approaches. On the other hand, seeing these conditions as socially mediated adjustment problem risks stigmatization and underuse of potentially effective medical treatment. For other states of being, the ongoing passionate debate has highlighted possible dangers in medicalizing conditions that might be considered normal problems of living. At 15 17 25

We found the association between considering a state of being a disease and readiness to fund treatment through public revenue very strong. If we consider obesity a disease, we might devote public funding to weight loss clinics. While this is true of very few jurisdictions, 44 most high income countries devote public funding to bariatric surgery for morbid obesity, a policy which – according to a Danish study<sup>28</sup> – many laypeople may question despite evidence suggesting it is highly cost-effective.

Advocates argue that placing a disease label on absence of sexual desire is a step towards helping people,<sup>33</sup> while critics deem it a destructive medicalization of a normal part of living fostering problematic commercialization.<sup>35</sup> Similarly, creating new diagnostic terms, such as the concept "overactive bladder" may help to increase awareness of the symptoms and to simplify management, but it may also cause problematic oversimplification leading to excessive use of ineffective treatment.<sup>5 45 46</sup>

The concept of disease also helps us understand differing perspectives on patterns of behavior (table 2), such as homosexuality. The American Psychiatric Association labeled homosexuality as a disease until 1973, when it was removed from its diagnostic and statistical manual of mental disorders (DSM). However, it remained in the international classification of diseases (ICD) until 1992.<sup>47</sup> Western societies increasingly view homosexuality as a legitimate lifestyle choice; less than 5% of doctors and nurses, and less than 10% of laypeople and MPs in our survey considered homosexuality a disease. Our respondents likewise did not consider transsexualism a disease, contrary to the current ICD-10 classification.<sup>22</sup> As with addiction, there is another non-disease perspective on sexual orientation: that homosexuality represents a moral failing. Historically, Western societies have deemed homosexual acts criminal behavior. In many countries in the world this continues to be the case.

#### **Conclusions**

In summary, the substantial disagreement we found in classifying of states of being as diseases, and the parallel disagreement regarding the legitimacy of public funding for those that warrant treatment provides insight into the attitudes underlying a number of current high profile social debates. The finding suggests that a shared understanding of the biological and social determinants of health conditions and human behaviors could be very useful in helping to facilitate resolution of these debates.

# **Supplementary Information (Web-only Appendix)**

**Table A1.** Characteristics of the study groups.

**Fig A1.** English translation of the questionnaire version A (excluding background information questions).

**Fig A2.** Original (Finnish-language) questionnaire version A (excluding background information questions).

**Fig A3.** Relation between claim A (concept of disease) and claim B (willingness to use public tax revenue for treatment) in laypeople, doctors, nurses and parliament members. 'r' (with 95% confidence intervals) represents the strength of the correlation between those who either *strongly agreed* or *agreed to some extent* with claim A and claim B.

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Author contributions: KAOT, JSL and TLNJ conceptualized the study. KAOT and TLNJ obtained funding. KAOT collected the data. KAOT and GHG developed the analysis plan with JSL, SE and TLNJ. KAOT analyzed the data. All authors contributed to the interpretation of the results. KAOT and GHG led the writing of the manuscript; all authors contributed. All authors had full access to all the data and take responsibility for the integrity and the accuracy of the data. All authors have approved the final version of the manuscript. KAOT is the guarantor.

Competing interest statement: All authors have completed the Unified Competing Interest form at <a href="www.icmje.org/coi\_disclosure.pdf">www.icmje.org/coi\_disclosure.pdf</a> (available on request from the corresponding author) and declare: KAOT, GHG, SE, and TLNJ declare no conflict of interest. JSL is a chief medical officer at the Insurance Medicine of the State Treasury (Helsinki, Finland), which is a government agency that handles statutory employment pension, accident and

indemnity insurances and insurance-related employer services of government agencies.

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**Ethical approval:** In accordance with the Finnish regulations on questionnaire surveys, the ethics committee of the Pirkanmaa Hospital District in Finland granted exemption from ethical review (R11110).

**Data sharing:** Data is freely available at Dryad (<a href="http://datadryad.org/">http://datadryad.org/</a>).

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**Table 1.** A) States of being perceived as a disease by at least 80% of respondents of all groups, B) states of being not perceived as a disease by at least 80% of respondents of all groups, and C) states of being perceived as a disease by at least 20% and not as a disease by at least another 20% of respondents of all groups (laypeople, doctors, nurses and parliament members).\*

A) Perceived as disease by more than 80% (re-	sponse options "4" and "5")					
Breast cancer	Schizophrenia					
Prostate cancer	HIV/AIDS					
Pneumonia	Malaria					
Lung cancer	Adult-onset diabetes					
Juvenile diabetes	Osteoporosis					
Myocardial infarction	Autism					
B) Not perceived as disease by more than 80% Wrinkles Smoking	17					
Ageing						
C) More than 20% perceived as disease (response options "4" and "5") and at least another 20% did not perceive as disease (response options "1" and "2")						
Pre-menstrual syndrome, PMS	Age-related muscle loss, sarcopenia					
Erectile dysfunction	Female menopause					
Gambling addiction	Malnutrition					
Infertility	Eye refractive error, need for eyeglasses					
Drug addiction	Lactose intolerance					

**Table 2.** Implications of alternative viewpoints regarding accepting or rejecting states of being as diseases

Categories of states of being Examples	Disease?	Conceptualization	Implications for action	Potential negative consequences/ramifications
Addictions or possible addictions  Alcoholism  Drug addiction  Gambling addiction  Obesity  Smoking	Yes	Biological health disorder	Harm reduction Public funding Medical treatment	Focus on individuals and treatments may cause social and moral aspects to be ignored <sup>8 37 38 41</sup>
	No	Lack of self-control Moral failing	Abstinence through individual choice and self-discipline Punitive management strategies	Stigma and discrimination, neglect of harm reduction, neglect of social causes, increased suffering for the population <sup>34</sup> 36-38 40 42
		Social problem	Preventive social solutions: income redistribution, poverty reduction, education, social marketing	Effective medical treatment underused <sup>36 37</sup>
Medical diagnoses with uncertain biologic / psychosocial basis  Chronic fatigue syndrome Fibromyalgia Irritable bowel syndrome Panic disorder Personality disorder	Yes	Specific biological problem	Diagnose and treat, possibly with drugs	Overdiagnosis and overtreatment with drugs, undertreatment with behavioral approaches <sup>11 15 16 25</sup>
	No	Socially mediated adjustment problem	Behavioral therapy Modify environment	Patients may feel stigmatized Effective medical treatment may be underused <sup>11</sup> 16 43
Diminished function or altered appearance, often age-related  Age-related muscle loss Baldness Erectile dysfunction Lack of sexual desire	Yes	Biological health disorder	Diagnose and treat, possibly with drugs Public funding	Overdiagnosis and overtreatment Medicalization of society, with increased self- perception of illness and poorer coping with suffering that is part of life <sup>11</sup> 15-17 43
	No	Normal consequence of living	Accept and adjust Responsibility on individual	Neglect of treatments that may reduce suffering and improve function <sup>11</sup> 16 43

Patterns of behavior  Homosexuality Obesity Smoking Transsexualism	Yes	Biological health disorder	Diagnose and treat, possibly with drugs Negative social stigma	Adverse judgment and resulting stigma and discrimination <sup>47</sup>
	No	Lifestyle choice	Respect person's choice	Permissive attitude encourages self-destructive or morally reprehensible behavior* <sup>37</sup> Underuse of effective treatment* <sup>28</sup>
	No	Moral failing	Abstinence/modification of behavior through individual choice/self-discipline Punitive strategies	Stigma and discrimination <sup>47</sup>
Syndromes or constellation of patterns of symptoms of unclear basis	Yes	Essentialist: specific biological disorder	Label all patients with specific category and treat uniformly	Failure to recognize diversity of illness, excessively uniform management, stifle research that could deepen understanding <sup>2 5 45</sup>
Attention deficit hyperactivity disorder Fibromyalgia Overactive urinary bladder Panic disorder	No	Nominalist: collection of symptoms, signs, behaviors, label of convenience	Acknowledge syndromes as convenient constructions, seek underlying causes, don't attempt to pigeon-hole unusual presentations	Acknowledgement of complexity may lead to inefficiency, paralysis <sup>2 5 45</sup>

<sup>\*</sup> Negative consequences listed here refer particularly to smoking and obesity not to homosexuality and transsexualism

### Figure legends

# Fig 1. Study flow.

We randomized the 60 states of being into three blocks: version A consisted of three blocks (each consisting 20 states of being) in the order 1-2-3, version B in the order 3-1-2 and version C in the order 2-3-1.

**Fig 2.** Variation of perceptions in concept of disease among laypeople, doctors, nurses and members of parliament.

What is a disease? Perspectives of the public, health professionals, and legislators

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**Objective:** To assess the perception of diseases and the willingness to use public tax revenue for their treatment among relevant stakeholders.

**Design:** A population-based, cross-sectional mailed survey.

Setting: Finland

**Participants:** 3 000 laypeople, 1 500 doctors, 1 500 nurses (randomly identified from the databases of the Finnish Population Register, the Finnish Medical Association and the Finnish Nurses Association), and all 200 parliament members.

**Main outcome measures:** Respondents' perspectives on a 5-point Likert scale on two claims on 60 states of being: "[This state of being] is a disease"; and "[This state of being] should be treated with public tax revenue".

**Results:** Of the 6 200 individuals approached, 3 280 (53%) responded. Of the 60 states of being,  $\geq$ 80% of respondents considered 12 to be diseases (Likert scale responses of "4" and "5") and five not to be diseases (Likert scale responses of "1" and "2"). There was considerable variability in most states, and great variability in ten ( $\geq$ 20% of respondents of all groups considered it a disease and  $\geq$ 20% rejected as a disease). Doctors were more inclined to consider states of being as diseases than laypeople; nurses and members were intermediate (p<0.001), but all groups showed large variability. Responses to the two claims were very strongly correlated (r = 0.96 [95% CI: 0.94-0.98]; p<0.001).

**Conclusions:** There is large disagreement among the public, health professionals, and legislators regarding the classification of states of being as diseases and whether their management should be publicly funded. Understanding attitudinal differences can help to enlighten social discourse on a number of contentious public policy issues.

## **ARTICLE SUMMARY**

#### Article focus

The concept of disease lies at the heart of medicine.

No study has addressed perceptions of all relevant stakeholders on what, across a wide range of conditions, should be classified as a disease.

#### **Key messages**

Our survey found large differences in the views among Finnish laypeople, doctors, nurses and parliament members regarding whether states of being should be considered diseases and be managed through public revenue.

Although doctors were more inclined to consider states of being as diseases, disagreement was as evident among health professionals as in other groups.

Understanding peoples' attitudes about whether states of being should be considered diseases elucidates fundamental underlying attitudes and thus can enlighten inform social discourse regarding a number of contentious public policy issues.

#### Strengths and limitations of this study

This is the first study to assess whether states of being should be considered diseases and should be managed through public revenue using representative sample of doctors, nurses, laypeople as well as legislators.

Our results from the Finnish population may be less generalizable to lower less income <u>affluent</u> countries and those countries with different social and cultural values.

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#### Introduction

Disease, and illness, are related concepts: patients suffer from "illnesses" and doctors diagnose and treat "diseases". {{1875 Eisenberg,L. 1977;}} Illnesses are experiences of discontinuities in states of being and perceived role performances; when diagnosed as diseases, they are presumed abnormalities in the function or structure of body systems. Disease can refer to a combination of signs and symptoms, phenomena associated with a disorder of function or structure, or illness associated with a specific cause(s). {{647 Campbell,E.J. 1979;}} There are, however, no universally accepted criteria for establishing "disease". {{760 Wulff,H.R. 1999;725 Temple,L.K. 2001;646 Pearce,J.M. 2011;}} Indeed, the complexity of the concept of disease has led to the observation that it can be as difficult to define as beauty, truth or love. {{1874 McWhinney,I.R. 1987;}}

The concept of disease is subject to social, cultural and economic influences that have varied over time: these influences have been particularly evident in the last two decades. {{762 SEGUIN,C.A. 1946;726 Conrad,P. 1992;1872 Hinshaw,S.P. 2000;725 Temple,L.K. 2001;646 Pearce,J.M. 2011}}

During this timee last decades, we have witnessed there has been a growing tendency toclassify states of being as diseases, a trend with important possible consequences, both
positive and negative. {{726 Conrad,P. 1992;1873 Perry,B.L. 2011;651 Smith,R. 2002;727

Heath 2005;656 Moynihan,R. 2011;}} ThisPossible positive consequences include evolution
may facilitatione of patient-physician communication {{725 Temple,L.K. 2001;651 Smith,R.
2002;646 Pearce,J.M. 2011;}} and from a social and economic standpoint, it may increased

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willingness to use public money and thus <a href="enhance\_equality">enhance\_equality</a> in the distribution of limited resources. {{725 Temple,L.K. 2001;650 Scully,J.L. 2004;}}—PPossible <a href="disadvantagerse">disadvantagerse</a> consequences of labeling states of being as diseases—include making relatively healthy individuals perceive themselves as <a href="esick2">esick2</a>,—encouraging misguided attempts to <a href="etireat2">etreat2</a> states that are part of the normal human condition, <a href="mailto:ander lead to-individuals">ander lead to-individuals</a> being denied employment or insurance. {{725 Temple,L.K. 2001;651 Smith,R. 2002;91 Moynihan,R. 2002;759 Metzl,J.M. 2007;761 Kleinman,A. 2012}} <a href="mailto:Authors have also suggested that the disease label can be used as a social control mechanism,">etality (1881 Foucault 1973;1879 Conrad 1992;1880 Padamsee,T.J. 2011})</a> which could be positive or negative on one's perspective. The extent to which health workers and the public have been influenced by these tendencies, and their current perceptions remains uncertain.

Because of the importance of the issue, and the paucity of empirical evidence regarding peoples' views, we conducted a survey of the general public, doctors, nurses, and parliament members in Finland to determine the extent to which they considered 60 states of being to be diseases and their attitudes toward using public funds for managing these states. We hypothesized that groups (laypeople, doctors, nurses, and parliament members) would vary in their conceptions of disease, and that there would also be large variation in conceptions of disease within groups. Furthermore, we hypothesized that there would be strong correlation between the conception of disease and the willingness to use public funds for its management.

#### Methods

#### The Finnish Disease (FIND) Survey study population

In 2010, we selected a random sample of 3 000 laypeople, 1 500 doctors, 1 500 nurses, and all the 200 members of the Parliament of Finland (MPs). We identified laypeople 18 to 75 years of age from the Finnish Population Register Centre, and doctors and nurses less than 65 years of age from the registers of the Finnish Medical Association and the Finnish Nurses Association. We excluded individuals who had died, emigrated, were deemed seriously disabled or who changed careers and would therefore no longer be members of their respective group (fig 1).

#### Survey

Referring to the existing literature and the International Classification of Diseases (ICD-10),{{662 MEADOR 1965;647 Campbell,E.J. 1979;651 Smith,R. 2002;661 WHO 2010;}} we chose 60 states of being that we estimated to be familiar to the relevant stakeholders, some that everyone would consider a disease, some that none would consider a disease, and some that might elicit disagreement (fig A1 and fig A2 in the appendix). We asked participants to respond to two claims: 1) "[This state of being] is a disease" (claim A) and 2) "[This state of being] should be treated with public tax revenue" (claim B) on a 5-point Likert scale ranging from *strongly disagree* to *strongly agree* (fig A1 and fig A2 in appendix). We elicited demographic information using questions from earlier surveys (table A1 in the appendix). We pilot tested the questionnaire with 20 laypeople and 5 doctors, and made minor revisions on the basis of feedback.

We mailed the questionnaires in June 2010 and sent reminders in August and October 2010. We made pre-contacts with MPs by email and telephone. The ethics committee of the

Pirkanmaa Hospital District in Finland granted exemption from ethical review (R11110). The reporting of the study conforms to the STROBE statement. {{768 von Elm, E. 2007;}}

#### Randomization and exclusion criteria

Each participant received a questionnaire eliciting responses to 60 states of being. We randomized the 60 states of being into three blocks (1, 2 and 3; each containing 20 states). We created three versions of the questionnaire: version A consisted of blocks in the order 1-2-3, version B in the order 3-1-2 and version C in the order 2-3-1. Within each sample group (laypeople, doctors, nurses, and MPs), we randomized respondents to the three versions (fig 1).

To check comprehension of the questionnaire, we placed three states (myocardial infarction, pneumonia and breast cancer) likely to be considered as disease as the first state of being in each block. Respondents who did not *agree to some extent* or *strongly agree* to the statement "[This state of being] is a disease" (fig A1 and fig A2 in appendix) for *any* of these three were deemed unlikely to understand the questionnaire and excluded from the analyses (fig 1).

#### Statistical analysis

For each group (doctors, nurses, laypeople, and MPs), we calculated the proportion of states of being where respondents *strongly agreed* or *agreed to some extent* regarding the two claims. Using a Pearson Chi-square test on all possible pair-wise comparisons (altogether 6 comparisons for each state of being by claim), we evaluated the order of ratings of perception of disease and expenditure of public tax revenue claims across groups. We calculated the correlation between the proportions of individuals who either *strongly agreed* or *agreed to some extent* across states in the two claims. All other analyses were descriptive.

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Of the 6 200 people approached, 3 280 (53.2%) participated, of whom 36 proved ineligible (fig 1). Of the 3 244 eligible individuals who completed and understood the questionnaire, 3 246 (99.0%) provided responded to at least 55 of the 60 states of being. Among respondents, the mean (standard deviation) age was: laypeople 49.5 (15.5), doctors 46.1 (10.7), nurses 44.9 (11.3) and MPs 54.4 (9.8). There were significantly more females among nurses (97.3%), and fewer among MPs (35.7%) compared to doctors (61.5%) orand laypeople (57.3%) (p < 0.01) for all comparisons). We found no significant differences in ratings or background characteristics between questionnaire versions and individuals responding at different response rounds. Table A1 in the appendix presents the demographic data.

From the 60 states of being, 12 were perceived as diseases by  $\geq 80\%$  of respondents from all groups and five were perceived as not not to be diseases by  $\geq 80\%$  (fig 2 and table 1). Doctors were most likely to consider states of being as diseases followed by nurses, MPs and laypeople (p < 0.001 for all pairwise comparisons). For a large number of states, there was extreme disagreement regarding classification as a disease among all study groups (fig 2). In ten states,  $\geq 20\%$  of participants considered them diseases and  $\geq 20\%$  did not (table 1). There was a very strong correlation between responses to claims (r = 0.96 [95% confidence interval 0.94 to 0.98]; p < 0.001; no differences between groups) (fig A32 in the appendix).

#### **Discussion**

# Statement of principal findings

Our survey found large discrepancies fferences in the views among laypeople, doctors, nurses and MPs in Finland regarding whether states of being should be considered diseases and should be managed through public revenue. Although physicians were more inclined to consider states of being as diseases, disagreement was as evident among health professionals as in other groups (fig 2 and table 1). In all groups, willingness to pay for treatment from public funds was very strongly correlated with the perception of disease.

#### Strengths and limitations

The strengths of our study include a large sample of both health <u>care</u> professionals and general population, an acceptable response rate, excellent completeness of questionnaires, and a large number of states of being that elicited a wide range of responses. Further, the sample proved representative of the target populations in terms of age and gender distribution, education, employment and marital status (<u>for details, see table A1</u> in <u>the</u> appendix <u>and its supplementary references</u>). We found no trend in the perceptions or participants' characteristics by response round, reducing concern regarding selection bias.

The limitations of our study include concern that the strong correlation between the claims may be partly caused by the positioning of questions adjacent to one another in the questionnaire. Second, these results from the Finnish population may be less generalizable to lower incomeless affluent countries and those with different social and cultural values. For instance, the high correlation between the disease label and the willingness to fund socially may be related to Finland's high level of social solidarity or what has been referred to as its status as a "welfare state" and may not be reproduced in other jurisdictions. Third, despite our

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attempt at screening for misunderstanding in a pilot study, the impact of the exact wording we ultimately chose remains uncertain. In particular, it is possible that alternative framing of questions regarding whether states of being should be funded by public revenue would have elicited different results. {{1878 Akl,E.A. 2011;}}

#### Comparison with other studies

Although some investigators have addressed patients' and health care providers' perceptions regarding the concept of disease and use of public funding in specific conditions, \{\{765}\}

Jones, M.P. 2003; 1877 Tang, C.H. 2007; 1876 Perry, B.L. 2007; 767 Lund, T.B. 2011; \} only one other study \{\{647 Campbell, E.J. 1979\}\} has assessed perceptions' on the concept of disease \{\{647 Campbell, E.J. 1979\}\} and none perceptions' on use of public funding over a wide range of conditions. In keeping with our finding that physicians were slightly more likely than others to consider states of being to beas diseases, Campbell and coworkers-\{\{647 Campbell, E.J. 1979\}\} found no difference among non-medical faculty, secondary school students, academic internists and general practitioners on how they perceived illnesses due to infections, but found that doctors considered more non-infectious conditions to be diseases.

In another related investigation, the editorial board of the *BMJ* and its readers identified a list of almost 200 *non-diseases* (defined as "a human process or problem that some have defined as a medical condition but where people may have better outcomes if the problem or process was not defined in that way") including ageing, baldness, and boredom. {{651 Smith,R. 2002;}} As in our survey, there was considerable variation in the states of being deemed 'non-diseases'.

Meaning of the study: possible explanations and implications

The concept of "disease" lies at the heart of medicine, {{762 SEGUIN, C.A. 1946;650 Scully, J.L. 2004}} defining its domain and its role in public policy, including the range of conditions in which sufferers may be entitled to public funding for their treatment. {{733} Stronks, K. 1997;734 Gross C.P. 1999;737 Gillum 2011763 Hawkes, N. 2012; }} Building on earlier work, {{725 Temple, L.K. 2001;726 Conrad 1992;651 Smith, R. 2002; 656 Moynihan, R. 2011; 650 Scully, J.L. 2004; 91 Moynihan, R. 2002; 759 Metzl, J.M. 2007; 761 Kleinman, A. 2012;763 Hawkes, N. 2012770 Broom 1996;772 Basson, R. 2000; 764 Gandey, A. 2003;773 Moynihan, R. 2003;753 Hyman 2007;754 Madueme, H. 2007;756 Levy, N. 2007;1772 Henningsen, P. 2007;738 Anonymous 2011;732 Moscrop, A. 2011;758 McNeil 2011;}} \_Ftable 2 presents a taxonomy of states of being, exploring the relation between categorization - or not - as a disease, the implications for action, and potential negative consequences. The issues presented in table 2 are subjects of ongoing, often heated, debate. {{725 Temple, L.K. 2001;726 Conrad 1992;651 Smith, R. 2002; 656 Moynihan, R. 2011; 650 Scully, J.L. 2004; 91 Moynihan, R. 2002; 759 Metzl, J.M. 2007; 761 Kleinman, A. 2012;763 Hawkes, N. 2012770 Broom 1996;772 Basson, R. 2000; 764 Gandey, A. 2003;773 Moynihan, R. 2003;753 Hyman 2007;754 Madueme, H. 2007;756 Levy, N. 2007;1772 Henningsen, P. 2007; 738 Anonymous 2011; 732 Moscrop, A. 2011; 758 McNeil 2011; }} Our results (i.e., large differences in views whether states of being should be considered diseases and should be managed through public revenue) provide insight into these debates: why they are so contentious is due at least in part to disparities in views on the fundamental nature of these states of being. Our study represents only the first steps in understanding the concept of "disease". Additional qualitative studies would be useful for obtaining further insight into interpretation of the findings.

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As reflected in table 2, pPeople tend to think of diseases as conditions for which individuals do not bear primary responsibility, afflictions of which the sufferer is at least to some extent a victim. {{767 Lund, T.B. 2011;}} Thus, if we view addictions; as diseases (which substantial proportions of our respondents did, and did not) we are inclined to look for solutions through harm reduction approaches and medical treatment, and to allocate public funding for these interventions. {{753 Hyman 2007;758 McNeil 2011;}} Alternative views include viewing a condition as a moral failing, bad habit, or retribution for bad behavior (all related perspectives) or as a social problem (a quite different perspective).

For instance, aA non-disease perspective on addiction includes two alternatives: If we regard addiction as a moral failing, we are likely to demand personal responsibility for dealing with the problem, and institute punitive approaches for those who fail (table 2). {{764 Gandey,A. 2003;753 Hyman 2007;}} Alternatively, we may see addiction as a social problem and seek social solutions such as poverty reduction. {{756 Levy 2007;}} The general unavailability of safe injection sites for drug users, despite evidence of benefit and eminent advocacy illustrates how these issues play out in public policy. {{738 Anonymous 2011;}} Our results suggest that the current contentious debate on social policy toward addiction could benefit not only from evidence regarding the effectiveness of alternative policies, but a more profound understanding of the biology and sociology of addiction.

To take other examples from table 2 with potentially negative consequences of a disease perspective, vViewing social anxiety disorder or fibromyalgia as specific biological problems may lead to overdiagnosis and medical overtreatment, and undertreatment with behavioral approaches. {{770 Broom 1996;91 Moynihan,R. 2002;1772 Henningsen,P. 2007}} On the other hand, seeing these conditions as socially mediated adjustment problem risks

stigmatization and underuse of potentially effective medical treatment. {{770 Broom 1996;91 Moynihan,R. 2002;1772 Henningsen,P. 2007}} For other states of being, the ongoing passionate debate has highlighted possible dangers in medicalizing conditions that might be considered normal problems of living. {{765 Jones,M.P. 2003;650 Scully,J.L. 2004; 91 Moynihan,R. 2002;761 Kleinman,A. 2012;}}

We found the association between considering a state of being a disease and readiness to fund treatment through public revenue very strong. If we consider obesity a disease, we might devote public funding to weight loss clinics. While this is true of very few jurisdictions, {{766 Wharton,S. 2012;}} most high income countries devote public funding to bariatric surgery for morbid obesity, a policy which – according to a Danish study {{767 Lund,T.B. 2011;}} – many laypeople may question despite evidence suggesting it is highly cost-effective.

Advocates argue that placing a disease label on absence of sexual desire is a step forward towards helping people, {{772 Basson,R. 2000;}} while critics deem it a destructive medicalization of a normal part of living fostering problematic commercialization. {{773 Moynihan,R. 2003;}} Similarly, creating new diagnostic terms, such as the concept "overactive bladder" may help to increase awareness of the symptoms and to simplify management, but it may also cause problematic oversimplification leading to excessive use of ineffective treatment. {{649 Scadding,J.G. 1996;646 Pearce,J.M. 2011;771 Tikkinen,K.A. 2012;}}

This discussion can also be seen from a more general perspective: essentialism versus nominalism (table 2). Essentialists regard diseases as causes of illness; the role of a physician, in this view, is to identify the cause and treat it appropriately. {{649 Scadding, J.G. 1996;}}

Nominalists see diseases as constructs that humans create to bring order to a disorderly world. {{649 Scadding, J.G. 1996;}}

The concept of disease also helps us understand differing perspectives on patterns of behavior (table 2), such as homosexuality. The American Psychiatric Association labeled homosexuality as a disease until 1973, when it was removed from its diagnostic and statistical manual of mental disorders (DSM). However, it remained in the international classification of diseases (ICD) until 1992.{{739 King,M. 1999;}} Western societies increasingly view homosexuality as a legitimate lifestyle choice; less than 5% of doctors and nurses, and less than 10% of laypeople and MPs in our survey considered homosexuality a disease. Our respondents likewise did not consider transsexualism a disease, contrary to the current ICD-10 classification.{{661 WHO 2010;}} As with addiction, there is another non-disease perspective on sexual orientation: that homosexuality represents a moral failing. Historically, Western societies have deemed homosexual acts criminal behavior. In many countries in the world, this continues to be the case.

#### Conclusions

In summary, the substantial disagreement we found in classifying of states of being as diseases, and the parallel disagreement regarding the legitimacy of public funding for those that warrant treatment, provides insight into the attitudes underlying a number of current high profile social debates. The finding suggests that a shared understanding of the biological and social determinants of health conditions and human behaviors could be very useful in helping to facilitate resolution of these debates.

**Table A1.** Characteristics of the study groups.

**Fig A1.** English translation of the questionnaire version A (excluding background information questions).

**Fig A2.** Original (Finnish-language) questionnaire version A (excluding background information questions).

Fig A3. Relation between claim A (concept of disease) and claim B (willingness to use public tax revenue for treatment) in laypeople, doctors, nurses and parliament members. 'r' (with 95% confidence intervals) represents the strength of the correlation between those who either strongly agreed or agreed to some extent with claim A and claim B.

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Author contributions: KAOT, JSL and TLNJ conceptualized the study. KAOT and TLNJ obtained funding. KAOT collected the data. KAOT and GHG developed the analysis plan with JSL, SE and TLNJ. KAOT analyzed the data. All authors contributed to the interpretation of the results. KAOT and GHG led the writing of the manuscript; all authors contributed. All authors had full access to all the data and take responsibility for the integrity

and the accuracy of the data. All authors have approved the final version of the manuscript.

KAOT is the guarantor.

Competing interest statement: All authors have completed the Unified Competing Interest

form at www.icmje.org/coi disclosure.pdf (available on request from the corresponding

author) and declare: KAOT, GHG, SE, and TLNJ declare no conflict of interest. JSL is a

chief medical officer at the Insurance Medicine of the State Treasury (Helsinki, Finland),

which is a government agency that handles statutory employment pension, accident and

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Ethical approval: In accordance with the Finnish regulations on questionnaire surveys, the

ethics committee of the Pirkanmaa Hospital District in Finland granted exemption from

ethical review (R11110).

**Data sharing:** Data is freely available at Dryad (http://datadryad.org/).

**Table 1.** A) States of being perceived as a disease by at least 80% of respondents of all groups, B) states of being not perceived as a disease by at least 80% of respondents of all groups, and C) states of being perceived as a disease by at least 20% and not as a disease by at least another 20% of respondents of all groups (laypeople, doctors, nurses and parliament members).\*

A) Perceived as disease by more than 80	0% (response options "4" and "5")
Breast cancer	Schizophrenia
Prostate cancer	HIV/AIDS
Pneumonia	Malaria
Lung cancer	Adult-onset diabetes
Juvenile diabetes	Osteoporosis
Myocardial infarction	Autism
B) Not perceived as disease by more that	an 80% (response options "1" and "2")  Grief
WITIKIES	Gilei
Smoking	Homosexuality
Ageing	
C) More than 20% perceived as disease 20% did not perceive as disease (respon	e (response options "4" and "5") and at least another use options "1" and "2")
Pre-menstrual syndrome, PMS	Age-related muscle loss, sarcopenia
Erectile dysfunction	Female menopause
Gambling addiction	Malnutrition
Infertility	Eye refractive error, need for eyeglasses
Drug addiction	Lactose intolerance

Table 2. Implications of alternative viewpoints regarding accepting or rejecting states of being as diseases

Categories of states of being Examples	Disease?	Conceptualization	Implications for action	Potential negative consequences/ramifications				
Addictions or possible addictions	Yes	Biological health disorder	Harm reduction Public funding Medical treatment	Focus on individuals and treatments may cause social and moral aspects to be ignored {{726 Conrad 1992;754 Madueme,H. 2007;756 Levy,N. 2007;732 Moscrop,A. 2011;}}				
Alcoholism Drug addiction Gambling addiction Obesity	No	Lack of self-control Moral failing	Abstinence through individual choice and self-discipline Punitive management strategies	Stigma and discrimination, neglect of harm reduction, neglect of social causes, increased suffering for the population { {764 Gandey ,A. 2003;754 Madueme,H. 2007;753 Hyman,S.E.				
Smoking	NO	Social problem	Preventive social solutions: income redistribution, poverty reduction, education, social marketing	Effective medical treatment underused { {754 Madueme, H. 2007;753 Hyman, S.E. 2007;} }				
Medical diagnoses with uncertain biologic / psychosocial basis Chronic fatigue syndrome	Yes	Specific biological problem	Diagnose and treat, possibly with drugs	Overdiagnosis and overtreatment with drugs, undertreatment with behavioral approaches { 651 Smith, R. 2002; 765 Jones, M.P. 2003;91 Moynihan, R. 2002;759 Metzl, J.M. 2007} }				
Fibromyalgia Irritable bowel syndrome Panic disorder Personality disorder	No	Socially mediated adjustment problem	Behavioral therapy Modify environment	Patients may feel stigmatized Effective medical treatment may be underused { {770 Broom 1996;651 Smith,R. 2002;759 Metzl,J.M. 2007} }				
Diminished function or altered appearance, often age-related	Yes	Biological health disorder	Diagnose and treat, possibly with drugs Public funding	Overdiagnosis and overtreatment Medicalization of society, with increased self- perception of illness and poorer coping with suffering that is part of life{{770 Broom 1996;651 Smith,R.				
Age-related muscle loss Baldness Erectile dysfunction Lack of sexual desire	No	Normal consequence of living	Accept and adjust Responsibility on individual	Neglect of treatments that may reduce suffering and improve function { {770 Broom 1996;651 Smith,R. 2002;759 Metzl,J.M. 2007} }				
	1							

Patterns of behavior	Yes	Biological health disorder	Diagnose and treat, possibly with drugs Negative social stigma	Adverse judgment and resulting stigma and discrimination {{739 King,M. 1999;}}
Iomosexuality Desity Moking Transsexualism		Lifestyle choice	Respect person's choice	Permissive attitude encourages self-destructive or morally reprehensible behavior* {{ 754 Madueme, H. 2007;}} Underuse of effective treatment* {{ 767 Lund, T.B. 2011;}}
	No	Moral failing	Abstinence/modification of behavior through individual choice/self-discipline Punitive strategies	Stigma and discrimination {{739 King,M. 1999;}}
Syndromes or constellation of patterns of symptoms of unclear basis	Yes	Essentialist: specific biological disorder	Label all patients with specific category and treat uniformly	Failure to recognize diversity of illness, excessively uniform management, stifle research that could deepen understanding{{647 Campbell,E.J. 1979;649 Scadding,J.G. 1996;646 Pearce,J.M. 2011;}}
Attention deficit hyperactivity disorder Fibromyalgia Overactive urinary bladder Panic disorder	No	Nominalist: collection of symptoms, signs, behaviors, label of convenience	Acknowledge syndromes as convenient constructions, seek underlying causes, don't attempt to pigeon-hole unusual presentations	Acknowledgement of complexity may lead to inefficiency, paralysis { {647 Campbell,E.J. 1979;649 Scadding,J.G. 1996;646 Pearce,J.M. 2011;}}

Figure legends

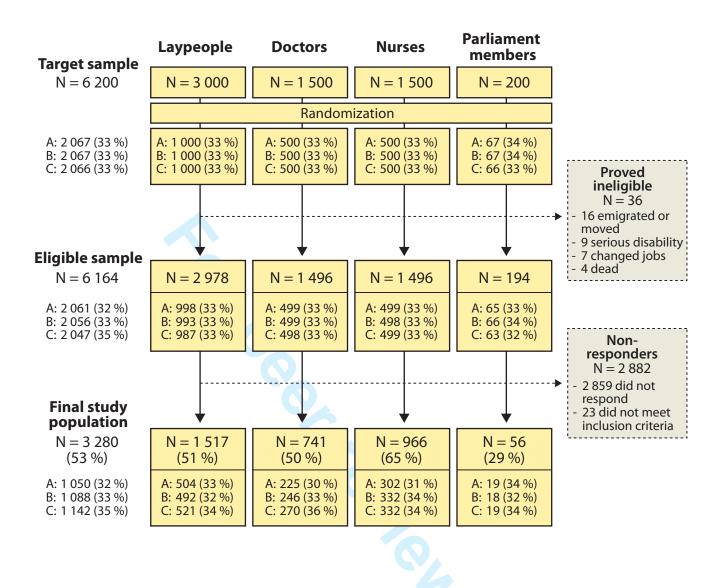
Fig 1. Study flow.

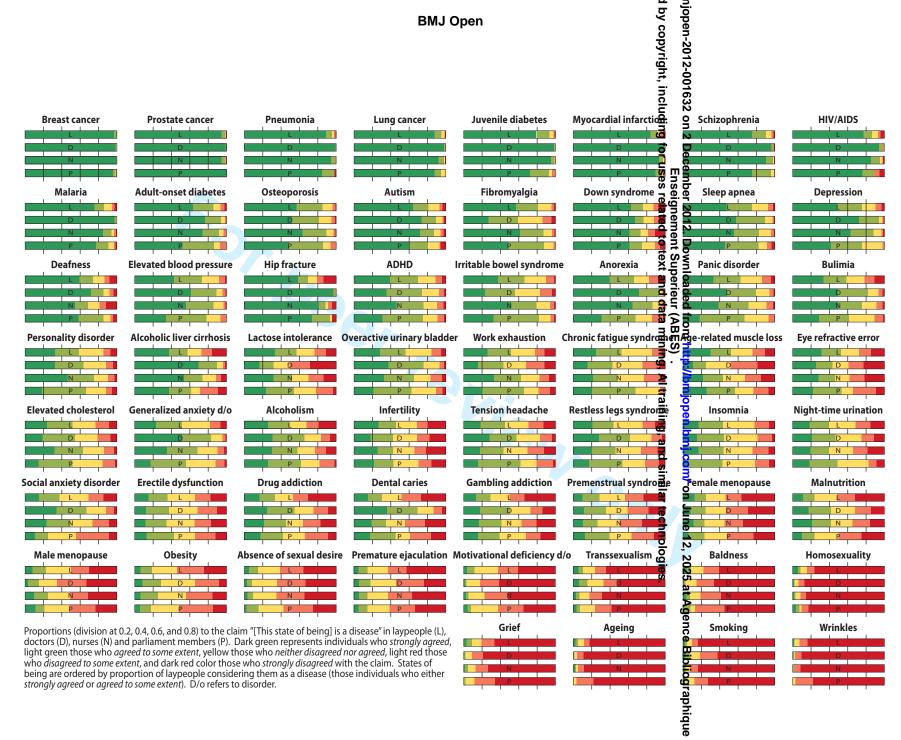
We randomized the 60 states of being into three blocks: version A consisted of three blocks (each consisting 20 states of being) in the order 1-2-3, version B in the order 3-1-2 and version C in the order 2-3-1.

**Fig 2.** Variation of perceptions in concept of disease among laypeople, doctors, nurses and parliament members of parliament.

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**Supplementary Information (Web-only Appendix)** 

**Table A1.** Characteristics of the study groups.

**Fig A1.** English translation of the questionnaire version A (excluding background information questions).

**Fig A2.** Original (Finnish-language) questionnaire version A (excluding background information questions).

**Fig A3.** Relation between claim A (concept of disease) and claim B (willingness to use public tax revenue for treatment) in laypeople, doctors, nurses and parliament members. 'r' represents the strength of the correlation between those who either *strongly agreed* or *agreed to some extent* with claim A and claim B.

**Table A1.** Characteristics of the study groups among the 3280 included participants.

Laypeople		Doctors		Nurses		Parliament members		
N (% of females)	1517 (57.3)		741 (61.5)		966 (97.3)		56 (35.7)	
Age distribution	n (%)	Age distribution	n (%)	Age distribution	n (%)	Age distribution	n (%)	
18-35	340 (22.4)	18-35	155 (20.9)	18-35	236 (24.5)	18-35	2 (3.6)	
36-55	542 (35.7)	36-55	411 (55.5)	36-55	523 (54.2)	36-55	26 (46.4)	
56-75	635 (41.9)	56-75	174 (23.5)	56-75	206 (21.3)	56-75	28 (50.0)	
Employment	I	Location of primary occupa	ation	Current employment sector		Employment		
Employed	887 (58.5)	Hospital	337 (45.5)	Working at the public sector	739 (76.5)	Employed	56 (100)	
Student	87 (5.7)	Health centre	161 (21.7)	Working for a private employer	124 (12.8)	Student	0 (0.0)	
Unemployed	106 (7.0)	Occupational health care	67 (9.0)	Self-employed	23 (2.4)	Unemployed	0 (0.0)	
Retired	430 (28.3)	Private clinic	74 (10.0)	Unemployed	29 (3.0)	Retired	0 (0.0)	
Insufficient information	7 (0.5)	Research or education	29 (3.9)	Insufficient information	51 (5.3)	Insufficient information	0 (0.0)	
		Industry	4 (0.5)					
		Other	40 (5.4)					
		Not currently employed	24 (3.2)					
		Insufficient information	5 (0.7)					

Laypeople		Doctors		Nurses		Parliament members	
Education	n (%)	Specialization	n (%)	Primary task	n (%)	Education	n (%)
Elementary school	271 (17.9)	Not specialized	119 (16.1)	Registered nurse	622 (64.4)	Elementary school	4 (7.1)
Upper level of elementary	52 (3.4)	Resident	151 (20.4)	Public health nurse	40 (4.1)	Upper level of elementary	2 (3.6)
Vocational school or equivalent	380 (25.0)	Medical specialist	465 (62.8)	Midwife	8 (0.8)	Vocational school or equivalent	3 (5.4)
Upper secondary school	131 (8.6)	Insufficient information	6 (0.8)	Paramedic	5 (0.5)	Upper secondary school	3 (5.4)
College	306 (20.2)			Head nurse or matron	118 (12.2)	College	11 (19.6)
Polytechnic degree	144 (9.5)			Other work in health care	83 (8.6)	Polytechnic degree	3 (5.4)
Academic degree	220 (14.5)			Working outside health care	29 (3.0)	Academic degree	30 (53.6)
Insufficient information	13 (0.9)			Not currently in working life	52 (5.4)	Insufficient information	0 (0.0)
		100		Insufficient information	9 (0.9)		
Marital status		Academic training	Q <sub>A</sub>			Marital status	
Married	809 (53.3)	Licentiate in medicine (MD)	580 (78.3)			Married	45 (80.4)
Cohabiting	240 (15.8)	Doctorate in medicine (PhD)	96 (13.0)			Cohabiting	1 (1.8)
Single	256 (16.9)	Adjunct professor	47 (6.3)			Single	3 (5.4)
Separated or divorced	126 (8.3)	Professor	12 (1.6)			Separated or divorced	5 (8.9)
Widowed	74 (4.9)	Insufficient information	6 (0.8)			Widowed	2 (3.6)
Insufficient information	12 (0.8)					Insufficient information	0 (0.0)
				6//	,	Political party	
						Centre Party	14 (25.0)
						Left Alliance	6 (10.7)
						National Coalition Party	13 (23.2)
			1			Social Democratic Party	13 (23.2)
						Other parties	10 (17.9)

The study sample is representative of the target populations. For more information, see 1) Laypeople: Peltonen M, Harald K, Männistö S, et al. The National FINRISK 2007 Study (in Finnish with English summary). Helsinki: National Public Health Institute, 2008. http://www.ktl.fi/attachments/suomi/julkaisut/julkaisusarja b/2008/2008b34.pdf (accessed Feb 1, 2012); 2) Doctors: Lääkärikysely 2009 [Statistics of the Finnish Medical Association] (in Finnish and Swedish). Helsinki, Finnish Medical Association, 2009 http://www.laakariliitto.fi/files/laakarikysely2009.pdf (accessed Feb 1, 2012); 3) Nurses: Statistics of the Finnish Nurses Association (in Finnish). Helsinki, Finnish Nurses Association, 2012. http://www.sairaanhoitajaliitto.fi/viestinta/tilastoja/ (accessed Feb 1, 2012); 4) Parliament members: Wikipedia. Parliamentary elections 2007. Eduskuntavaalit 2007 (in Finnish). http://fi.wikipedia.org/wiki/Eduskuntavaalit 2007 (accessed Feb 1, 2012).

Page 49 of TENTION: This is an <u>opinion poll</u> to clarify the concept of disease. The purpose <u>is</u>
not to find out whether you have any of the states of being/diseases below.

INSTRUCTIONS FOR FILLING OUT THE FORM: Please circle a number 1-5 that best describes your <u>opinion</u> (in both claims A and B).

1 = Strongly disagree

- 2 = Disagree to some extent
- 3 = Neither disagree nor agree
- 4 = Agree to some extent
- 5 = Strongly agree

		C	LAIM	A			С	LAIM	В			
	"[This sta	ite o	f being	] is a	disease"	"[This state of being] should be treated with public tax revenue'						
	Strongly disagree				Strongly agree	Strongly disagree				Strongly agree		
[Myocardial infarction]	1	2	3	4	5	1	2	3	4	5		
[Chronic fatigue syndrome]	1	2	3	4	5	1	2	3	4	5		
[Baldness]	1	2	3	4	5	1	2	3	4	5		
[Absence of sexual desire]	1	2	3	4	5	1	2	3	4	5		
[Alcoholism]	1	2	3	4	5	1	2	3	4	5		
[Premenstrual syndrome, PMS]	1	2	3	4	5	1	2	3	4	5		
[Panic disorder]	1	2	3	4	5	1	2	3	4	5		
[Anorexia]	1	2	3	4	5	1	2	3	4	5		
[Grief]	1	2	3	4	5	1	2	3	4	5		
[Deafness]	1	2	3	4	5	1	2	3	4	5		
[Erectile dysfunction]	1	2	3	4	5	1	2	3	4	5		
[Motivational deficiency disorder]	1	2	3	4	5	1	2	3	4	5		
[Osteoporosis]	1	2	3	4	5	1	2	3	4	5		
[Gambling addiction]	1	2	3	4	5	1	2	3	4	5		
[Tension headache]	1	2	3	4	5	1	2	3	4	5		
[Work exhaustion, burnout]	1	2	3	4	5	1	2	3	4	5		
	Strongly disagree				Strongly agree	Strongly disagree				Strongly agree		

		C	LAIM	Α		!	CLAIM B					
	"[This st	ate of	being	g] is a	disease"	· -				ould be evenue"		
	Strongly disagree				Strongly agree	Strongly disagree	т	, G. G. I.	, tax i	Strongly agree		
[HIV/AIDS]	1	2	3	4	5	1	2	3	4	5		
[Infertility]	1	2	3	4	5	1	2	3	4	5		
[Attention-deficit hyper- activity disorder, ADHD]	1	2	3	4	5	1	2	3	4	5		
[Prostate cancer]	1	2	3	4	5	1	2	3	4	5		
[Pneumonia]	1	2	3	4	5	1	2	3	4	5		
[Insomnia]	1	2	3	4	5	1	2	3	4	5		
[Obesity]	1	2	3	4	5	1	2	3	4	5		
[Drug addiction]	1	2	3	4	5	1	2	3	4	5		
[Male menopause]	1	2	3	4	5	1	2	3	4	5		
[Ageing]	1	2	3	4	5	1	2	3	4	5		
[Transsexualism]	1	2	3	4	5	1	2	3	4	5		
[Alcoholic liver cirrhosis]	1	2	3	4	5	1	2	3	4	5		
[Schizophrenia]	1	2	3	4	5	1	2	3	4	5		
[Restless legs syndrome]	1	2	3	4	5	1	2	3	4	5		
[Age-related muscle loss, sarcopenia]	1	2	3	4	5	1	2	3	4	5		
[Adult-onset diabetes]	1	2	3	4	5	1	2	3	4	5		
[Smoking]	1	2	3	4	5	1	2	3	4	5		
[Autism]	1	2	3	4	5	1	2	3	4	5		
[Night-time urination]	1	2	3	4	5	1	2	3	4	5		
[Binge eating, bulimia]	1	2	3	4	5	1	2	3	4	5		
[Generalized anxiety disorder]	1	2	3	4	5	1	2	3	4	5		
[Sleep apnea, pauses in breathing during sleep]	1	2	3	4	5	1	2	3	4	5		
	Strongly disagree				Strongly agree	Strongly disagree			St	trongly agree		

Page 51	of 70		С	LAHM.	<b>Р</b> Оре	n		C	LAIM	В	
		"[This sta	ate of	being	g] is a	disease"	"[This st				
1 2 3		Strongly disagree				Strongly agree	Strongly disagree	WILII	public	tax I	Strongly agree
4 5	[Wrinkles]	1	2	3	4	5	1	2	3	4	5
6 7 8	[Elevated cholesterol]	1	2	3	4	5	1	2	3	4	5
9 10	[Breast cancer]	1	2	3	4	5	1	2	3	4	5
11 12	[Fibromyalgia, chronic pain syndrome]	1	2	3	4	5	1	2	3	4	5
13 14 15	[Elevated blood pressure]	1	2	3	4	5	1	2	3	4	5
16 17	[Dental caries]	1	2	3	4	5	1	2	3	4	5
18 19	[Lung cancer]	1	2	3	4	5	1	2	3	4	5
20 21 22	[Female menopause]	1	2	3	4	5	1	2	3	4	5
23 24	[Malnutrition]	1	2	3	4	5	1	2	3	4	5
25 26 27	[Irritable bowel syndrome]	1	2	3	4	5	1	2	3	4	5
28 29	[Homosexuality]	1	2	3	4	5	1	2	3	4	5
30 31 32	[Eye refractive error, need for eyeglasses]	1	2	3	4	5	1	2	3	4	5
33 34	[Lactose intolerance]	1	2	3	4	5	1	2	3	4	5
35 36	[Down syndrome]	1	2	3	4	5	1	2	3	4	5
37 38 39	[Personality disorder]	1	2	3	4	5	1	2	3	4	5
40 41	[Overactive urinary bladder]	1	2	3	4	5	1	2	3	4	5
42 43	[Depression]	1	2	3	4	5	1	2	3	4	5
44 45 46	[Juvenile diabetes]	1	2	3	4	5	1	2	3	4	5
47 48	[Malaria]	1	2	3	4	5	1	2	3	4	5
49 50 51	[Social anxiety disorder]	1	2	3	4	5	1	2	3	4	5
51 52 53	[Premature ejaculation]	1	2	3	4	5	1	2	3	4	5
54 55	[Hip fracture]	1	2	3	4	5	1	2	3	4	5
56 57		Stronly disagree				Strongly agree	Strongly disagree			St	rongly agree

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HUOMIO: Tämä tutkimus on mielipidetutkimus, joka selvittää sairauden käsitettä. Tarkoituksena ei ole selvittää onko teillä jotakin alla olevista tiloista/sairauksista.

LOMAKKEEN TÄYTTÖOHJE: Ympyröikää molempiin väittämiin (A-väittämä ja Bväittämä) luku 1-5 väliltä, joka parhaiten kuvaa mielipidettänne.

- 1 = Täysin eri mieltä
- 2 = Jokseenkin eri mieltä
- 3 = Ei eri mieltä eikä samaa mieltä
- 4 = Jokseenkin samaa mieltä
- 5 = Täysin samaa mieltä

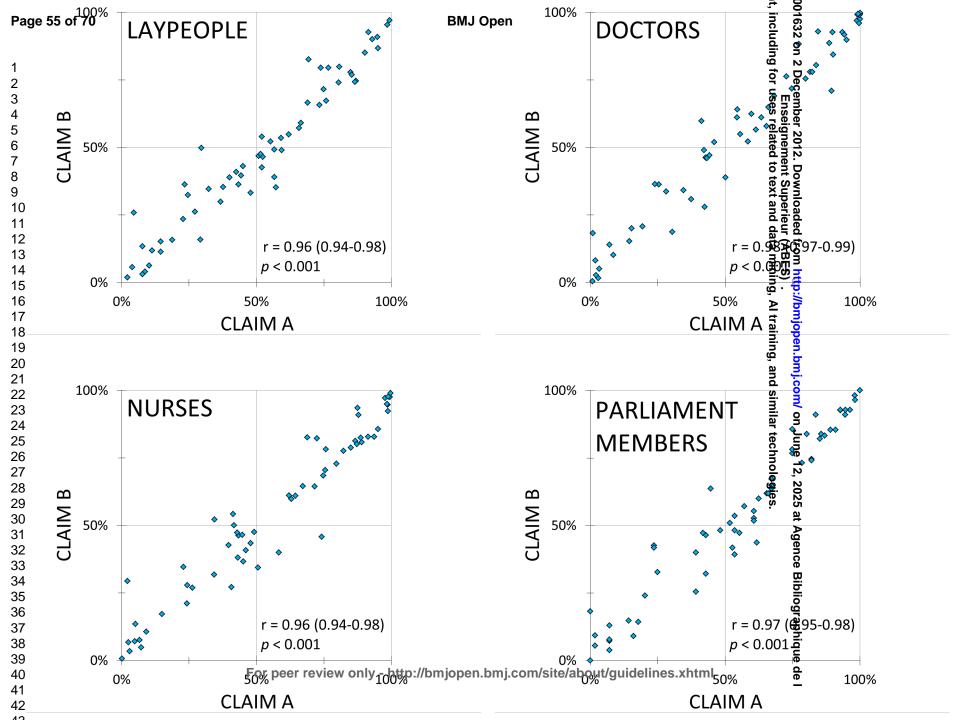
		A-V	ÄITTÄ	MÄ			B-V	ÄITTÄ	ÄМÄ		
	"[Тä		ila] on		aus"	"[Tämä tila] tulee hoitaa julkisin verovaroin"					
	Täysin eri mieltä				Täysin samaa mieltä	Täysin er mieltä	_			Γäysin samaa mieltä	
[Sydäninfarkti]	1	2	3	4	5	1	2	3	4	5	
[Krooninen väsymysoireyhtymä]	1	2	3	4	5	1	2	3	4	5	
[Kaljuuntuminen]	1	2	3	4	5	1	2	3	4	5	
[Seksuaalinen haluttomuus]	1	2	3	4	5	1	2	3	4	5	
[Alkoholismi]	1	2	3	4	5	1	2	3	4	5	
[Kuukautisia edeltävä oireyhtymä, PMS]	1	2	3	4	5	1	2	3	4	5	
[Paniikkihäiriö]	1	2	3	4	5	1	2	3	4	5	
[Anoreksia, laihuushäiriö]	1	2	3	4	5	1	2	3	4	5	
[Suru]	1	2	3	4	5	1	2	3	4	5	
[Kuurous]	1	2	3	4	5	1	2	3	4	5	
[Erektiohäiriö]	1	2	3	4	5	1	2	3	4	5	
[Motivaation puutos – oireyhtymä]	1	2	3	4	5	1	2	3	4	5	
[Osteoporoosi]	1	2	3	4	5	1	2	3	4	5	
[Peliriippuvuus]	1	2	3	4	5	1	2	3	4	5	
[Niskajännityspäänsärky]	1	2	3	4	5	1	2	3	4	5	
[Työuupumus, burn-out]	1	2	3	4	5	1	2	3	4	5	
	Täysin eri mieltä				Täysin samaa mieltä	Täysin er mieltä	i			Γäysin samaa mieltä	

		A-V	ÄITTÄ	МÄ		B-VÄITTÄMÄ					
	"[T	ämä t	ila] or	ı sair	aus"			ila] tul n verov			
	Täysin eri mieltä				Täysin samaa mieltä	Täysin eri mieltä	IKISI	n verov	varo	Täysin samaa mieltä	
[HIV/AIDS]	1	2	3	4	5	1	2	3	4	5	
[Lapsettomuus]	1	2	3	4	5	1	2	3	4	5	
[Tarkkaavaisuus- ja ylivilkkaushäiriö, ADHD]	1	2	3	4	5	1	2	3	4	5	
[Eturauhassyöpä]	1	2	3	4	5	1	2	3	4	5	
[Keuhkokuume]	1	2	3	4	5	1	2	3	4	5	
[Unettomuus]	1	2	3	4	5	1	2	3	4	5	
[Lihavuus]	1	2	3	4	5	1	2	3	4	5	
[Huumeriippuvuus]	1	2	3	4	5	1	2	3	4	5	
[Miehen vaihdevuodet, mieshormonin lasku]	1	2	3	4	5	1	2	3	4	5	
[Vanheneminen]	1	2	3	4	5	1	2	3	4	5	
[Transseksuaalisuus]	1	2	3	4	5	1	2	3	4	5	
[Alkoholimaksakirroosi]	1	2	3	4	5	1	2	3	4	5	
[Skitsofrenia]	1	2	3	4	5	1	2	3	4	5	
[Levottomat jalat - oireyhtymä]	1	2	3	4	5	1	2	3	4	5	
[Vanhuusiän lihaskato, sarkopenia]	1	2	3	4	5	1	2	3	4	5	
[Aikuistyypin diabetes]	1	2	3	4	5	1	2	3	4	5	
[Tupakointi]	1	2	3	4	5	1	2	3	4	5	
[Autismi]	1	2	3	4	5	1	2	3	4	5	
[Yövirtsaaminen]	1	2	3	4	5	1	2	3	4	5	
[Ahmimishäiriö, bulimia]	1	2	3	4	5	1	2	3	4	5	
[Yleistynyt ahdistuneisuushäiriö]	1	2	3	4	5	1	2	3	4	5	
[Uniapnea, unenaikaiset hengityskatkokset]	1	2	3	4	5	1	2	3	4	5	
	Täysin eri mieltä			•	Täysin samaa mieltä	Täysin eri mieltä				Täysin samaa mieltä	

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		A-\	/ÄITTÄ	MÄ			B-V	/ÄITTÄ	MÄ	
	"[Tä	imä t	tila] on	sair	aus"			ila] tul n verov		
	Täysin eri mieltä			-	Täysin samaa mieltä	Täysin eri mieltä				Täysin samaa mieltä
[lhon ryppyisyys]	1	2	3	4	5	1	2	3	4	5
[Kohonnut kolesteroli]	1	2	3	4	5	1	2	3	4	5
[Rintasyöpä]	1	2	3	4	5	1	2	3	4	5
[Fibromyalgia, krooninen kipuoireyhtymä]	1	2	3	4	5	1	2	3	4	5
[Kohonnut verenpaine]	1	2	3	4	5	1	2	3	4	5
[Hampaiden reikiintyminen]	1	2	3	4	5	1	2	3	4	5
[Keuhkosyöpä]	1	2	3	4	5	1	2	3	4	5
[Naisen vaihdevuodet]	1	2	3	4	5	1	2	3	4	5
[Aliravitsemus]	1	2	3	4	5	1	2	3	4	5
[Ärtyvä suoli -oireyhtymä]	1	2	3	4	5	1	2	3	4	5
[Homoseksuaalisuus]	1	2	3	4	5	1	2	3	4	5
[Silmien taittovirhe, silmälasien tarve]	1	2	3	4	5	1	2	3	4	5
[Laktoosi-intoleranssi]	1	2	3	4	5	1	2	3	4	5
[Downin syndrooma]	1	2	3	4	5	1	2	3	4	5
[Persoonallisuushäiriö]	1	2	3	4	5	1	2	3	4	5
[Yliaktiivinen virtsarakko]	1	2	3	4	5	1	2	3	4	5
[Masennus]	1	2	3	4	5	1	2	3	4	5
[Nuoruustyypin diabetes]	1	2	3	4	5	1	2	3	4	5
[Malaria]	1	2	3	4	5	1	2	3	4	5
[Sosiaalisten tilanteiden pelko]	1	2	3	4	5	1	2	3	4	5
[Ennenaikainen siemensyöksy]	1	2	3	4	5	1	2	3	4	5
[Lonkkamurtuma]	1	2	3	4	5	1	2	3	4	5
	Täysin eri mieltä			•	Täysin samaa mieltä	Täysin eri mieltä				Täysin samaa mieltä



# STROBE 2007 (v4) Statement—Checklist of items that should be included in reports of cross-sectional studies

Section/Topic	Item #	Recommendation	Reported on page #
Title and abstract	1	(a) Indicate the study's design with a commonly used term in the title or the abstract	2
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found	2
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	4-5
Objectives	3	State specific objectives, including any prespecified hypotheses	5
Methods			
Study design	4	Present key elements of study design early in the paper	6-7
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	6
Participants	6	(a) Give the eligibility criteria, and the sources and methods of selection of participants	6-7, Figure 1
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	6-7
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	6
Bias	9	Describe any efforts to address potential sources of bias	6-8
Study size	10	Explain how the study size was arrived at	
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	6-7
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding	7
		(b) Describe any methods used to examine subgroups and interactions	
		(c) Explain how missing data were addressed	8
		(d) If applicable, describe analytical methods taking account of sampling strategy	
		(e) Describe any sensitivity analyses	
Results			

Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility,	8, Figure 1
		confirmed eligible, included in the study, completing follow-up, and analysed	
		(b) Give reasons for non-participation at each stage	Figure 1
		(c) Consider use of a flow diagram	Figure 1
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential	Table A1
		confounders	
		(b) Indicate number of participants with missing data for each variable of interest	8
Outcome data	15*	Report numbers of outcome events or summary measures	Figure 1, Table 1
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence	Figure 2
		interval). Make clear which confounders were adjusted for and why they were included	
		(b) Report category boundaries when continuous variables were categorized	
		(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	8
Discussion			
Key results	18	Summarise key results with reference to study objectives	9
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	9
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	10-13
Generalisability	21	Discuss the generalisability (external validity) of the study results	9-10
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on	15
		which the present article is based	

<sup>\*</sup>Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

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**REVISION NOTES** 

Reviewer(s)' Comments to Author:

Reviewer: Ivar Sønbø Kristiansen

**University of Oslo** 

Reviewer #1 Comment #1:

"This paper aims to address important conceptual and policy issues. Based on a Finnish survey, the authors conclude that there is considerable disagreement when politicians, lay people and health professional are asked to consider whether 60 states are diseases or not and whether their they should be treated with public tax revenue."

**RESPONSE** 

Summarizing the manuscript, hence, no revision/comment needed.

#### Reviewer #1 Comment #2:

"In Table 2, however, they propose implications that go far beyond what their data would indicate."

#### **RESPONSE**

We created Table 2 as part of Discussion of the manuscript, not as part of Results. In contrast to Reviewer 1, Reviewer 2 states: "Table 2 is very interesting... This represents the crux of the theoretical and substantive implications, and I feel like they should be discussed more fully." Our view is exactly that of Reviewer 2, and so we have retained Table 2. To respond to the criticism, we have added the phrase "Building on earlier work, 48 11 13-17 32-42" to the sentence that introduces Table 2: "...table 2 presents a taxonomy of states of being, exploring the relation between categorization - or not - as a disease, the implications for action, and potential negative consequences". In addition, we have added "Our study represents only the first steps in understanding the concept of "disease". Additional qualitative studies would be useful for obtaining further insight into interpretation of the findings." to the end of the paragraph in which we discuss table 2 (page 10-11).

# Reviewer #1 Comment #3:

"Although the study aims to address important issues, it has several weaknesses:

1. The paper lacks a theoretical underpinning. The introduction does not present any introduction to concepts such as disease, illness, sickness, and related concepts. The authors do not develop any hypotheses or research questions but jumps directly to a simple survey based on 60 different states. It would be good to

have a statement from the authors about their own definition in order to better understand their discussion."

# **RESPONSE**

We thank the reviewer for these comments regarding the theoretical underpinning. In response, we have begun the manuscript with a clarification regarding the concepts of disease and illness as follows (page 4): "Disease, and illness, are related concepts: patients suffer from "illnesses" and doctors diagnose and treat "diseases". Illnesses are experiences of discontinuities in states of being and perceived role performances; when diagnosed as diseases, they are presumed abnormalities in the function or structure of body systems. Regarding definition, we have noted: "Indeed, the complexity of the concept of disease has led to the observation that it can be as difficult to define as beauty, truth or love. Given the challenges of the definition highlighted in this observation, and the changing nature of the definition and characterization of disease according to social, cultural, and economic influences that we have noted, we did not think it useful to provide a specific definition of disease.

We have described our hypotheses as follows (page 5): "We hypothesized that groups (laypeople, doctors, nurses, and parliament members) would vary in their conceptions of disease, and that there would also be large variation in conceptions of disease within groups. Furthermore, we hypothesized that there would be strong correlation between the conception of disease and the willingness to use public funds for its management."

#### Reviewer #1 Comment #4:

"2. English has more words than many other languages. In some languages
disease and illness may have the same translation. It would be good to have a brief statement about the
language issue, and the terms that were used in Finnish."

# **RESPONSE**

During the conception and design of the FIND Survey project, we acknowledged the concern raised by Reviewer #1. We regularly consulted linguistic expert Virginia Mattila (who has expertise both in Finnish and English languages, with special expertise in humanistic and medical English/Finnish) regarding the use of suitable/appropriate words. In Finnish language, we have similar if not identical words for *disease* and *illness* (in Finnish 'sairaus' and 'tauti'). Prompted by reviewer comments, we have included not only the translated questionnaire but also the original (Finnish-language) questionnaire as supplementary information (Fig A2 in Supplementary Information).

# Reviewer #1 Comment #5:

"3. Analysis of a concept such as illness may best be quided by researchers with a background in sociology, ethics or philosophy while the authors all seem to have a medical background. The list of references is taken almost entirely from medical journals."

#### **RESPONSE**

 We believe that our work should be judged on what we did and how we presented and reflected on the results rather than our background. We note, however, that we consulted (and acknowledged) individuals from other fields. While many of the references in our original manuscript were published in general medicine journals, nine references were from sociology (original reference numbers 6 and 21), ethics (original reference numbers 25, 26 and 27), psychology/psychiatry (original reference number 5), and general science (original reference numbers 3, 10 and 19) literature. We have added eight new primarily non-medical references (new references numbers: 9, 10, 18, 19, 20, 24, 26, 27).

#### Reviewer #1 Comment #6:

"4. Economists have studied preferences for funding of health care programs and medical treatment, and how such stated preferences may be influenced by wording and context. The authors seem to be unaware of this literature."

#### **RESPONSE**

We thank the reviewer for this very perceptive remark. We examined each of our claims (A and B) separately for wording and context. From the very beginning of this project, we acknowledged the importance of wording and framing, and, hence not only consulted a linguistic expert but also performed a pilot study in which we asked respondents regarding understanding, challenges and potential modifications to our questionnaire.

In the questionnaire, Claim A asks the participant for an opinion rather than a preference. We agree that Claim B assesses preferences, and may be influenced by framing (wording and context). A recent Cochrane review (Akl E, Oxman A, Herrin J, et al. Cochrane Database Syst Rev. 2011 Dec 7;(12):CD006777), evaluating the effect of framing of health information messages differently on health consumers' decisions, found that there may be a possibility of a framing effect under specific conditions. The authors, however, concluded that the quality of evidence was low to moderate and suggested that the framing of the question may have little to no consistent effect on health consumers' behavior. Hence, based on our survey results and earlier work, the impact of the exact wording we have chosen is speculative. We have included this as a potential limitation in our discussion section, and cited the paper by Akl and coworkers, as follows:

"Third, despite our attempt at screening for misunderstanding in a pilot study, the impact of the exact wording we ultimately chose remains uncertain. In particular, it is possible that alternative framing of

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questions regarding whether states of being should be funded by public revenue would have elicited different results.<sup>24</sup>" (pages 9 and 10)

#### Reviewer #1 Comment #7:

"5. The authors find considerable variation in responses to the questions about which states are diseases. It is unclear, however, whether this variation is caused by variation in responses is caused by varying definitions of the concept of disease or varying judgment of the presented states. It seems implausible that all responses have the same definition of the disease concept, and it is consequently impossible to infer whether the variation is causes by varying definitions or judgment. Additional qualitative studies are necessary to get insight into interpretation of the findings."

# **RESPONSE**

We agree that the exact explanation of the reasons for differences in whether or not states of being were characterized as diseases remains speculative and that qualitative studies could provide insight into this matter. In response, we have added sentences: "Our study represents only the first steps in understanding the concept of "disease". Additional qualitative studies would be useful for obtaining further insight into interpretation of the findings." to the discussion (page 11). We note, however, that the implications of the judgments, as characterized in table 2 and the associated text, are relevant irrespective of the exact reasons for those judgments.

#### **Reviewer #1 Comment #8:**

"6. The design of the study is unclear. Were each respondent presented with 20 or 60 states? A graph may ease the understanding of the design."

#### **RESPONSE**

In the original manuscript we wrote: "We randomized the 60 states of being into three blocks (1, 2 and 3; each containing 20 states). We created three versions of the questionnaire: version A consisted of blocks in the order 1-2-3, version B in the order 3-1-2 and version C in the order 2-3-1. Within each sample group (laypeople, doctors, nurses, and MPs), we randomized respondents to the three versions (fig 1)." We have now revised to text to address the concern expressed by Reviewer #1. To clarify, we have added a sentence to the beginning of the paragraph (page 7): "Each participant received a questionnaire eliciting responses to 60 states of being." In addition, we added a sentence to the legend of figure 1 (page 22): "We randomized the 60 states of being into three blocks (each block consisting of 20 states of being): version A had the blocks in the order 1-2-3, version B in the order 3-1-2 and version C in the order 2-3-1."

#### Reviewer #1 Comment #9:

"7. There is no analysis of predictors (age, sex, income, occupation, etc) of responses to the questions."

#### **RESPONSE**

We thank the reviewer for pointing out the issue of analyzing predictors. We did indeed assess the association of the predictors with the responses of the questions, but felt that the presentation of those analyses would complicate the paper and distract from the key message we seek to convey. If the editors believe it would be useful to expand the paper to include these analyses, we will be happy to do so.

# Reviewer #1 Comment #10:

"8. Apparently, the correlation between response to the question about disease and about funding is analysed with all 60 states together. It would be useful to see whether the correlation varies across states. If the correlation is equal for all 60 states, it raises the question whether the two questions in reality taps the same underlying latent variable."

#### **RESPONSE**

We calculated the correlation between the proportions of individuals who either strongly agreed (response option '5' on a Likert scale 1-5) or agreed to some extent (response option '4' on a Likert scale 1-5) across states in the two claims. As we had 60 states of being in our survey, we had 60 pairs for each study group (as shown in the original Figure A2 in appendix; Figure A3 in the revised appendix). Correlations of proportions were practically identical and very strong for each group (laypeople 0.96; doctors 0.98; nurses 0.96; members of parliament 0.97). However, correlation was not same for all 60 states as can be seen from the original figure A2 (current figure A3); there are some outliers. Nevertheless, the correlation is consistently high, and it is quite possible that the two questions tap the same underlying latent variable. This potential limitation was already discussed in our manuscript, as follows (page 9): "The limitations of our study include concern that the strong correlation between the claims may be partly caused by the positioning of questions adjacent to one another in the questionnaire." We have not further expanded on this issue.

#### Reviewer #1 Comment #11:

"9. The discussion goes far beyond what the authors' data would indicate. Table 2 presents a range of hypotheses that could be tested empirically in a survey, but seems to stem from the authors opinions and reading of papers. Several of the issues raised in the discussion are interesting, but would need a separate

paer with systematic review of the literature. Also, it would need a broader perspective then the medical one."

# **RESPONSE**

We thank the reviewer for pointing out these issues. We have addressed them in our responses to Reviewer #1 Comment #2 and Comment #5, as well as in our response to Reviewer #2 Comment #8.

Reviewer: Brea L. Perry

# **University of Kentucky**

#### Reviewer #2 Comment #1:

"This study examines lay and professional attitudes toward various conditions, determining the extent to which the public views them as diseases and believes that government funding should be devoted to treating them. They find substantial heterogeneity in labeling, with physicians most likely and laypeople least like to define conditions as diseases. Also, there is strong association between disease definition and willingness to devote public funds."

#### **RESPONSE**

Summarizing the manuscript, hence, no revision/comment needed.

# Reviewer #2 Comment #2:

"The large, population-based random sample is a strength of the study, as is the large number of conditions examined. I think that this paper could be strengthened with a few changes and additions."

#### **RESPONSE**

Summarizing the manuscript, hence, no revision/comment needed.

# Reviewer #2 Comment #3:

"The authors should do a bit more up front to contextualize the study. The reader needs to be convinced that this is important. What is the unique contribution? Also, it is not apparent until well into the discussion section that other research has been conducted on this topic. Even then, only one study is cited. There are a number of publications using U.S. General Social Survey data that examine lay definitions of mental illness and substance use disorders. The authors could also cite, at least for those "marginal" and more socially constructed conditions, increases in diagnosis and treatment patterns over time to demonstrate

medicalization. Likewise, the authors cite Conrad, but do not discuss medicalization as a form of social control."

# **RESPONSE**

Thank you for these highly relevant and insightful comments regarding literature relevant to the underlying issues. It is indeed true that there are a number of studies that have addressed perceptions regarding the concept of disease and use of public funding in specific conditions, but only one study assessed the perceptions of the concept of disease, and none assessed the perceptions of the use of public funding over a wide range of conditions.

We have now added more references to earlier studies (including a study using data from U.S. General Social Survey database) (page 10), which demonstrate a medicalization trend. In response to the request to do a bit more up front to contextualize the study, reflect on the unique contribution and commenting on medicalization as a social control, we have modified the second paragraph of the introduction as follows (page 4): "The concept of disease is subject to social, cultural and economic influences that have varied over time: these influences have been particularly evident in the last two decades. <sup>457-9</sup> During this time, we have witnessed a growing tendency to classify states of being as diseases, a trend with important possible consequences, both positive and negative. <sup>810-13</sup> Possible positive consequences include facilitation of patient-physician communication <sup>4511</sup> and increased willingness to use public money and thus enhance equality in the distribution of limited resources. <sup>414</sup> Possible adverse consequences include making relatively healthy individuals perceive themselves as sick, encouraging misguided attempts to treat states that are part of the normal human condition, and individuals being denied employment or insurance. <sup>411 15-17</sup> Authors have also suggested that the disease label can be used as a social control mechanism, <sup>18-20</sup> which could be positive or negative on one's perspective. The extent to which health workers and the public have been influenced by these tendencies, and their current perceptions remains uncertain."

#### Reviewer #2 Comment #4:

"I do not agree with the decision to exclude individuals who reported that myocardial infarction, pneumonia, or breast cancer were not diseases. Since the term "disease" was not defined for respondents, it is open to interpretation. Some people may think of pneumonia as an illness rather than a disease, with diseases being more long term. Alternatively, they may think of conditions as diseases only if they are infectious or life threatening. These may be individuals in the tail of your distribution, but I believe this is real heterogeneity. The authors did not exclude people who reported that baldness was definitely a disease, creating bias toward more medicalized perceptions."

#### **RESPONSE**

Thank you for your comment. The issue here is whether those 23 individuals properly understood the questions. To clarify, none of those excluded 23 individuals considered any of those three earlier mentioned conditions (breast cancer, myocardial infarction, pneumonia) as a disease. With regard to the issues the reviewer raises, breast cancer is a long-term condition, pneumonia is infectious, and all three may be life threatening. To further address the issue, we explored the responses of these 23 excluded individuals. These excluded respondents had typically not completed the questionnaire properly (see below).

ID	How did this excluded individual respond to the questionnaire?
1417	Answered background information questions but answered only 17 out of 60 claim A questions
1565	Answered background information questions but answered zero out of 60 claim A questions
1591	Answered background information questions but answered only 1 out of 60 claim A questions
1777	Answered background information questions but answered zero out of 60 claim A questions
1807	Answered most background information questions but answered zero out of 60 claim A questions
1901	Answered background information questions but answered six out of 60 claim A questions
1911	Answered all 60 claim A questions but considered none of them as a disease
2036	Answered all 60 claim A questions but considered only baldness as a disease
2147	Answered background information questions but answered only 2 out of 60 claim A questions
2167	Answered background information questions but answered zero out of 60 claim A questions
2515	Answered background information questions but answered 39 out of 60 claim A questions
2591	Answered all 60 claim A questions but considered only two out of 60 as a disease
2686	Answered all 60 claim A questions but did not consider any of our three 'diseases' as a disease
2725	Answered all 60 claim A questions but did not consider any of our three 'diseases' as a disease
2743	Answered all 60 claim A questions but considered none of them as a disease
2803	Answered '1' (definitely not a disease) for all our three 'diseases' but answered '5' (definitely a
	disease) for conditions usually not considered as a disease including grief, smoking and ageing
3244	Answered all 60 claim A questions but considered only eight out of 60 as a disease
3426	Answered some of 60 claim A questions and considered only one as a disease
3430	Answered all 60 claim A questions but considered none as a disease
3486	Answered all 60 claim A questions but considered only seven as a disease
4057	Answered most of 60 claim A questions but none of those we used as exclusion criteria
5317	Answered all 60 claim A questions but did not consider any of our three 'diseases' as a disease
7085	Answered all 60 claim A questions but considered only premature ejaculation, baldness, grief,
	ageing, transsexuality, smoking, wrinkles, malnutrition, homosexuality and female menopause as

BMJ Open: first published as 10.1136/bmjopen-2012-001632 on 2 December 2012. Downloaded from http://bmjopen.bmj.com/ on June 12, 2025 at Agence Bibliographique de I Enseignement Superieur (ABES) .
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 diseases

We continue to consider that exclusion is reasonable. If the editors disagree, we would be prepared to rerun all the analyses adding these 23 individuals. We note that this is such a small proportion that it will not materially affect the results. Thus, we did not perform any revision based on this comment.

#### Reviewer #2 Comment #5:

"How were the 60 conditions chosen?"

#### **RESPONSE**

In the Methods we write (page 6): "Referring to the existing literature and the International Classification of Diseases (ICD-10), 211 21 22 we chose 60 states of being that we estimated to be familiar to the relevant stakeholders, some that everyone would consider a disease, some that none would consider a disease, and some that might elicit disagreement (fig A1 and fig A2 in the appendix)." Testing a number of states of being was considered to be feasible by earlier research performed by Campbell et al (BMJ 1979). As they assessed perceptions on 38 conditions, we estimated that 60 states of being might be feasible. In the pilot study, we asked people whether we had too many states of being. Most participants thought that the number of states of being is appropriate. Hence, we maintained the chosen states of being. With respect to how these states of being were chosen, these sixty states of being were chosen by the authors by discussion (during conceptualization and design). When choosing and voting for which states of being to include, we considered a few items: 1) familiarity to laypeople and 2) a range of states that would be perceived as a disease by the majority, perceived not to be a disease by the majority, and those that would give rise to disagreement. We totally agree with the reviewer that this is a pivotal aspect of our survey, but simultaneously highlight that there may be no ideal way to choose states of being for this type of survey. We did not make any revisions based on this comment.

#### **Reviewer #2 Comment #6:**

"The authors note that the sample is representative, but we have no evidence of this. Did they conduct statistical comparisons to the Finnish population, for example? If so, the test statistics should be reported."

# **RESPONSE**

In the discussion of the manuscript, we wrote: "... the sample proved representative of the target populations in terms of age and gender distribution, education, employment and marital status (table A1 in appendix)." Table A1 is on the next two pages (in its original, non-revised form) of this response to reviewers document. We did not perform statistical tests but instead compared the estimates. Our sample

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was representative of the target populations in a number of ways. For instance, according to Statistics Finland, 7.6% of Finnish people were unemployed in 2010, corresponding well with 7.0% reported by our lay participants. Similarly, our sample proved to be representative in the distribution of members of the Parliament of Finland. In the Parliament of Finland, the distribution was as follows (by political party; FIND Survey respondents' proportions in parentheses): Centre Party 26% (25%), National Coalition Party 25% (23%), Social Democratic Party 23% (23%), Left Alliance 9% (11%), and other parties 19% (18%). In our survey, 78% of the doctors reported that 'Licentiate in medicine (MD)' is their highest academic (medical) degree while 21% reported also having a 'Doctorate in medicine (PhD)' degree (all 'Adjunct professors' or 'Professors' in Finland have doctorate (PhD)), and information was lacking from 1% of the doctors. According to the Finnish Medical Association (in 2010), the corresponding figures were very similar: 78% of Finnish doctors did not, and 22% did have a 'Doctorate in medicine (PhD)'. Finally, according to database of the Finnish Nurses Association, 21% were aged 35 or less, 64% aged 36-55, and 15% aged 55 or more. In our survey corresponding figures were 25%, 54%, and 21%. Furthermore, according to the Finnish Nurses Association 3% of nurses were men and 97% women, which is identical to the estimates in the FIND Survey (3% and 97%). Additionally, our sampling was based on representative databases: the Finnish Population Register (includes all citizens of Finland), the Finnish Medical Association, the Finnish Nurses' Association, and the Parliament of Finland. We revised text in the discussion. Revised text is as (page 9): "the sample proved representative of the target populations in terms of age and gender distribution, education, employment and marital status (for details, see table A1 in appendix and its supplementary references)".

**Table A1.** Characteristics of the study groups among the 3280 included participants.

N (% of females)         1517 (57.3)         741 (61.5)         966 (97.3)           Age distribution         n (%)         Age distribution         n (%)         Age distribution         n (%)           18-35         340 (22.4)         18-35         155 (20.9)         18-35         236 (24.5)           36-55         542 (35.7)         36-55         411 (55.5)         36-55         523 (54.2)           56-75         635 (41.9)         56-75         174 (23.5)         56-75         206 (21.3)           Employment         Location of primary occupation         Current employment sector           Employed         887 (58.5)         Hospital         337 (45.5)         Working at the public sector         739 (76.5)           Student         87 (5.7)         Health centre         161 (21.7)         Working for a private employer         124 (12.8)           Unemployed         106 (7.0)         Occupational health care         67 (9.0)         Self-employed         23 (2.4)           Retired         430 (28.3)         Private clinic         74 (10.0)         Unemployed         29 (3.0)           Insufficient information         7 (0.5)         Research or education         29 (3.9)         Insufficient information         51 (5.3)	Age distri  18-35  36-55  56-75  Employm  Employee	2 (3.6) 26 (46.4) 28 (50.0)  nent  d
18-35       340 (22.4)       18-35       155 (20.9)       18-35       236 (24.5)         36-55       542 (35.7)       36-55       411 (55.5)       36-55       523 (54.2)         56-75       635 (41.9)       56-75       174 (23.5)       56-75       206 (21.3)         Employment         Employded       887 (58.5)       Hospital       337 (45.5)       Working at the public sector       739 (76.5)         Student       87 (5.7)       Health centre       161 (21.7)       Working for a private employer       124 (12.8)         Unemployed       106 (7.0)       Occupational health care       67 (9.0)       Self-employed       23 (2.4)         Retired       430 (28.3)       Private clinic       74 (10.0)       Unemployed       29 (3.0)	18-35 18-35 19 36-55 19 56-75 Employm 10 Employed 10 Student	2 (3.6) 26 (46.4) 28 (50.0)  nent  d
36-55       542 (35.7)       36-55       411 (55.5)       36-55       523 (54.2)         56-75       635 (41.9)       56-75       174 (23.5)       56-75       206 (21.3)         Employment         Location of primary occupation         Employed       887 (58.5)       Hospital       337 (45.5)       Working at the public sector       739 (76.5)         Student       87 (5.7)       Health centre       161 (21.7)       Working for a private employer       124 (12.8)         Unemployed       106 (7.0)       Occupational health care       67 (9.0)       Self-employed       23 (2.4)         Retired       430 (28.3)       Private clinic       74 (10.0)       Unemployed       29 (3.0)	36-55 56-75 Employm 1) Employed 5) Student	26 (46.4) 28 (50.0)  ment  d
56-75         635 (41.9)         56-75         174 (23.5)         56-75         206 (21.3)           Employment         Current employment sector           Employed         887 (58.5)         Hospital         337 (45.5)         Working at the public sector         739 (76.5)           Student         87 (5.7)         Health centre         161 (21.7)         Working for a private employer         124 (12.8)           Unemployed         106 (7.0)         Occupational health care         67 (9.0)         Self-employed         23 (2.4)           Retired         430 (28.3)         Private clinic         74 (10.0)         Unemployed         29 (3.0)	Employm Employee Student	28 (50.0)  nent  d 56 (100) 0 (0.0)
Employment         Location of primary occupation         Current employment sector           Employed         887 (58.5)         Hospital         337 (45.5)         Working at the public sector         739 (76.5)           Student         87 (5.7)         Health centre         161 (21.7)         Working for a private employer         124 (12.8)           Unemployed         106 (7.0)         Occupational health care         67 (9.0)         Self-employed         23 (2.4)           Retired         430 (28.3)         Private clinic         74 (10.0)         Unemployed         29 (3.0)	Employm  Employed  Student	ment d 56 (100) 0 (0.0)
Employed         887 (58.5)         Hospital         337 (45.5)         Working at the public sector         739 (76.5)           Student         87 (5.7)         Health centre         161 (21.7)         Working for a private employer         124 (12.8)           Unemployed         106 (7.0)         Occupational health care         67 (9.0)         Self-employed         23 (2.4)           Retired         430 (28.3)         Private clinic         74 (10.0)         Unemployed         29 (3.0)	Employed Student	d 56 (100) 0 (0.0)
Student         87 (5.7)         Health centre         161 (21.7)         Working for a private employer         124 (12.8)           Unemployed         106 (7.0)         Occupational health care         67 (9.0)         Self-employed         23 (2.4)           Retired         430 (28.3)         Private clinic         74 (10.0)         Unemployed         29 (3.0)	Student	0 (0.0)
Unemployed         106 (7.0)         Occupational health care         67 (9.0)         Self-employed         23 (2.4)           Retired         430 (28.3)         Private clinic         74 (10.0)         Unemployed         29 (3.0)	<del></del>	
Retired         430 (28.3)         Private clinic         74 (10.0)         Unemployed         29 (3.0)	Unemploy	ved 0.(0.0)
		y cu 0.07
Insufficient information 7 (0.5) Records an advention 20 (3.0) Insufficient information 51 (5.3)	Retired	0 (0.0)
Insufficient information 7 (0.5) Research or education 29 (3.9) Insufficient information 51 (5.3)	Insufficie	ent information 0 (0.0)
Industry 4 (0.5)		
Other 40 (5.4)		
Not currently employed 24 (3.2)		
Insufficient information 5 (0.7)		
	7/	

Laypeople		Doctors		Nurses		Parliament members	
Education	n (%)	Specialization	n (%)	Primary task	n (%)	Education	n (%)
Elementary school	271 (17.9)	Not specialized	119 (16.1)	Registered nurse	622 (64.4)	Elementary school	4 (7.1)
Upper level of elementary	52 (3.4)	Resident	151 (20.4)	Public health nurse	40 (4.1)	Upper level of elementary	2 (3.6)
Vocational school or equivalent	380 (25.0)	Medical specialist	465 (62.8)	Midwife	8 (0.8)	Vocational school or equivalent	3 (5.4)
Upper secondary school	131 (8.6)	Insufficient information	6 (0.8)	Paramedic	5 (0.5)	Upper secondary school	3 (5.4)
College	306 (20.2)			Head nurse or matron	118 (12.2)	College	11 (19.6)
Polytechnic degree	144 (9.5)			Other work in health care	83 (8.6)	Polytechnic degree	3 (5.4)
Academic degree	220 (14.5)			Working outside health care	29 (3.0)	Academic degree	30 (53.6)
Insufficient information	13 (0.9)			Not currently in working life	52 (5.4)	Insufficient information	0 (0.0)
				Insufficient information	9 (0.9)		
Marital status		Academic training				Marital status	
Married	809 (53.3)	Licentiate in medicine (MD)	580 (78.3)			Married	45 (80.4)
Cohabiting	240 (15.8)	Doctorate in medicine (PhD)	96 (13.0)			Cohabiting	1 (1.8)
Single	256 (16.9)	Adjunct professor	47 (6.3)			Single	3 (5.4)
Separated or divorced	126 (8.3)	Professor	12 (1.6)			Separated or divorced	5 (8.9)
Widowed	74 (4.9)	Insufficient information	6 (0.8)			Widowed	2 (3.6)
Insufficient information	12 (0.8)					Insufficient information	0 (0.0)
				10/2		Political party	
						Centre Party	14 (25.0)
						Left Alliance	6 (10.7)
						National Coalition Party	13 (23.2)
						Social Democratic Party	13 (23.2)
						Other parties	10 (17.9)

The study sample is representative of the target populations. For more information, see 1) Laypeople: Peltonen M, Harald K, Männistö S, et al. The National FINRISK 2007 Study (in Finnish with English summary). Helsinki: National Public Health Institute, 2008.

http://www.ktl.fi/attachments/suomi/julkaisut/julkaisusarja b/2008/2008b34.pdf (accessed Feb 1, 2012); 2) Doctors: Lääkärikysely 2009 [Statistics of the Finnish Medical Association] (in Finnish and Swedish). Helsinki, Finnish Medical Association, 2009

http://www.laakariliitto.fi/files/laakarikysely2009.pdf (accessed Feb 1, 2012); 3) Nurses: Statistics of the Finnish Nurses Association (in Finnish). Helsinki, Finnish Nurses Association, 2012. http://www.sairaanhoitajaliitto.fi/viestinta/tilastoja/ (accessed Feb 1, 2012); 4) Parliament members: Wikipedia. Parliamentary elections 2007. Eduskuntavaalit 2007 (in Finnish). http://fi.wikipedia.org/wiki/Eduskuntavaalit 2007 (accessed Feb 1, 2012).

# Reviewer #2 Comment #7:

"Sometimes claims are made but are not substantiated with test statistics. For example, there were significantly more females among nurses. Please make sure these are presented in the text whenever patterns are presented."

#### **RESPONSE**

In the Results we wrote: "There were significantly more females among nurses (97.3%), and fewer among MPs (35.7%) compared to doctors (61.5%) and laypeople (57.3%)." We performed Chi square tests for significance but did not report them as we assumed that they may not be needed due to 1) very large differences in estimates (proportions), and 2) large sample size. Chi square test results (p values) for comparison of these groups are (when comparing the proportion of women in group): Laypeople vs. Doctors: p = 0.054; Laypeople vs. Nurses: p < 0.001; Laypeople vs. MPs: p = 0.001; Doctors vs. Nurses: p < 0.001; Doctors vs. MPs: p < 0.001; Nurses vs. MPs: p < 0.001. We revised the sentence as (page 8): "There were significantly more females among nurses (97.3%), and fewer among MPs (35.7%) compared to doctors (61.5%) or laypeople (57.3%) (p < 0.01 for all comparisons)."

#### Reviewer #2 Comment #8:

"Table 2 is very interesting, but I wonder why these ideas are not fleshed out sufficiently in the text. This represents the crux of the theoretical and substantive implications, and I feel like they should be discussed more fully. I would also like to see more discussion about the extremely strong correlation between disease definitions and public funding. These are remarkably highly correlated. Why might this be? Is there something unique about the welfare state or culture in Finland that explains this? I do not think the correlation would be this high in many other countries.

#### **RESPONSE**

Thank you for these remarks, particularly regarding table 2; as we agree that it represents the "crux of the theoretical and substantive implications". Prompted by this comment, we have now discussed table 2 more fully (pages 10-13). As for the high correlation between disease definition and public funding (claims A and B), we have already mentioned in the text that this may at least partly be attributable to the fact that the claims were placed side-by-side in the questionnaire (page 9). However, we agree that this could also be attributable to the welfare state model and/or values and preferences in the use of public money in Finland and have added this as another explanation as follows (page 9): "For instance, the high correlation between the disease label and the willingness to fund socially may be related to Finland's high level of social solidarity or what has been referred to as its status as a "welfare state" and may not be reproduced in other jurisdictions."



# What is a disease? Perspectives of the public, health professionals, and legislators

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 What is a disease? Perspectives of the public, health professionals, and legislators

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# Abstract

**Objective:** To assess the perception of diseases and the willingness to use public tax revenue for their treatment among relevant stakeholders.

**Design:** A population-based, cross-sectional mailed survey.

**Setting:** Finland

**Participants:** 3 000 laypeople, 1 500 doctors, 1 500 nurses (randomly identified from the databases of the Finnish Population Register, the Finnish Medical Association and the Finnish Nurses Association), and all 200 parliament members.

**Main outcome measures:** Respondents' perspectives on a 5-point Likert scale on two claims on 60 states of being: "[This state of being] is a disease"; and "[This state of being] should be treated with public tax revenue".

**Results:** Of the 6 200 individuals approached, 3 280 (53%) responded. Of the 60 states of being,  $\geq$ 80% of respondents considered 12 to be diseases (Likert scale responses of "4" and "5") and five not to be diseases (Likert scale responses of "1" and "2"). There was considerable variability in most states, and great variability in ten ( $\geq$ 20% of respondents of all groups considered it a disease and  $\geq$ 20% rejected as a disease). Doctors were more inclined to consider states of being as diseases than laypeople; nurses and members were intermediate (p<0.001), but all groups showed large variability. Responses to the two claims were very strongly correlated (r = 0.96 [95% CI: 0.94-0.98]; p<0.001).

**Conclusions:** There is large disagreement among the public, health professionals, and legislators regarding the classification of states of being as diseases and whether their management should be publicly funded. Understanding attitudinal differences can help to enlighten social discourse on a number of contentious public policy issues.

# **Article focus**

The concept of disease lies at the heart of medicine.

No study has addressed perceptions of all relevant stakeholders on what, across a wide range of conditions, should be classified as a disease.

# **Key messages**

Our survey found large differences in the views among Finnish laypeople, doctors, nurses and parliament members regarding whether states of being should be considered diseases and be managed through public revenue.

Although doctors were more inclined to consider states of being as diseases, disagreement was as evident among health professionals as in other groups.

Understanding peoples' attitudes about whether states of being should be considered diseases elucidates fundamental underlying attitudes and thus can inform social discourse regarding a number of contentious public policy issues.

# Strengths and limitations of this study

This is the first study to assess whether states of being should be considered diseases and should be managed through public revenue using a broad sample of doctors, nurses, laypeople as well as legislators.

Our results from the Finnish population may be less generalizable to less affluent countries and countries with different social and cultural values.

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### Introduction

Disease, and illness, are related concepts: patients suffer from "illnesses" and doctors diagnose and treat "diseases". Illnesses are experiences of discontinuities in states of being and perceived role performances; when diagnosed as diseases, they are presumed abnormalities in the function or structure of body systems. Disease can refer to a combination of signs and symptoms, phenomena associated with a disorder of function or structure, or illness associated with a specific cause(s). There are, however, no universally accepted criteria for establishing "disease". Indeed, the complexity of the concept of disease has led to the observation that it can be as difficult to define as beauty, truth or love.

The concept of disease is subject to social, cultural and economic influences that have varied over time: these influences have been particularly evident in the last two decades. 457-9 During this time, we have witnessed a growing tendency to classify states of being as diseases, a trend with important possible consequences, both positive and negative. 10-13 Possible positive consequences include facilitation of patient-physician communication 11 and increased willingness to use public money and thus enhance equality in the distribution of limited resources. 14 Possible adverse consequences include making relatively healthy individuals perceive themselves as sick, encouraging misguided attempts to treat states that are part of the normal human condition, and individuals being denied employment or insurance. 11 The extent to which health workers and the public have been influenced by these tendencies, and their current perceptions remains uncertain.

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Authors have also suggested that the disease label can be used as a social control mechanism. 18-20 The "sick role" theory suggests that illness disrupts normal social functioning, making the individual responsible for adhering to treatment regimes in order to maintain social productivity. 21-23 However, the relationship between the patient and the medical sphere exists within a socially constructed hierarchy wherein medical institutions ultimately hold the individual accountable for collective social problems. 19 21 23 When individual behavior deviates from pre-established social norms, it is not the individual, but the medical community that labels, diagnoses and treats aberrant behavior as a socially legitimated health condition. 19

No earlier study assessed perceptions' on use of public funding, and only one study<sup>2</sup> assessed perceptions' on the concept of disease over wider range of conditions. Campbell and coworkers found that doctors considered more non-infectious conditions to be diseases than laypeople.<sup>2</sup> Because of the importance of the issue, and the paucity of empirical evidence regarding peoples' views, we conducted a survey of the general public, doctors, nurses, and parliament members in Finland to determine the extent to which they considered 60 states of being to be diseases and their attitudes toward using public funds for managing these states. On the basis of differences in background, training, and life experience, and underlying attitudes, we hypothesized that groups (laypeople, doctors, nurses, and parliament members) would vary in their conceptions of disease, and that there would also be large variation in conceptions of disease within groups.

### Methods

# The Finnish Disease (FIND) Survey study population

In 2010, we selected a random sample of 3 000 laypeople, 1 500 doctors, 1 500 nurses, and all the 200 members of the Parliament of Finland (MPs). We identified laypeople 18 to 75 years of age from the Finnish Population Register Centre, and doctors and nurses less than 65 years of age from the registers of the Finnish Medical Association and the Finnish Nurses Association. We excluded individuals who had died, emigrated, were deemed seriously disabled or who changed careers and would therefore no longer be members of their respective group (fig 1).

### Survey

Referring to the existing literature and the International Classification of Diseases (ICD-10),<sup>2</sup> <sup>11</sup> <sup>24</sup> <sup>25</sup> we chose, through iterative discussion and consensus-building, 60 states of being that we considered familiar to the relevant stakeholders. We anticipated that everyone would consider some of these states a disease, none would consider some states a disease, and that some states might elicit disagreement (fig A1 and fig A2 in the appendix). We asked participants to respond to two claims: 1) "[This state of being] is a disease" (claim A) and 2) "[This state of being] should be treated with public tax revenue" (claim B) on a 5-point Likert scale ranging from *strongly disagree* to *strongly agree* (fig A1 and fig A2 in appendix). We elicited demographic information using questions from earlier surveys (table A1 in the appendix). We pilot tested the questionnaire with 20 laypeople and 5 doctors, and made minor revisions on the basis of feedback.

We mailed the questionnaires in June 2010 and sent reminders in August and October 2010. We made pre-contacts with MPs by email and telephone. The ethics committee of the

 Pirkanmaa Hospital District in Finland granted exemption from ethical review (R11110). The reporting of the study conforms to the STROBE statement.<sup>26</sup>

### Randomization and exclusion criteria

Each participant received a questionnaire eliciting responses to 60 states of being. We randomized the 60 states of being into three blocks (1, 2 and 3; each containing 20 states). We created three versions of the questionnaire: version A consisted of blocks in the order 1-2-3, version B in the order 3-1-2 and version C in the order 2-3-1. Within each sample group (laypeople, doctors, nurses, and MPs), we randomized respondents to the three versions (fig 1).

To check comprehension of the questionnaire, we placed three states (myocardial infarction, pneumonia and breast cancer) likely to be considered as disease as the first state of being in each block. Respondents who did not *agree to some extent* or *strongly agree* to the statement "[This state of being] is a disease" (fig A1 and fig A2 in appendix) for *any* of these three were deemed unlikely to understand the questionnaire and excluded from the analyses (fig 1).

### Statistical analysis

For each group (doctors, nurses, laypeople, and MPs), we calculated the proportion of states of being where respondents *strongly agreed* or *agreed to some extent* regarding the two claims. Using a Pearson Chi-square test on all possible pair-wise comparisons (altogether 6 comparisons for each state of being by claim), we evaluated the order of ratings of perception of disease and expenditure of public tax revenue claims across groups. We calculated the correlation between the proportions of individuals who either *strongly agreed* or *agreed to some extent* across states in the two claims. All other analyses were descriptive.

# **Results**

Of the 6 200 people approached, 3 280 (53.2%) participated, of whom 36 proved ineligible (fig 1). Of the 3 244 eligible individuals who completed and understood the questionnaire, 3 246 (99.0%) responded to at least 55 of the 60 states of being. Among respondents, the mean (standard deviation) age was: laypeople 49.5 (15.5), doctors 46.1 (10.7), nurses 44.9 (11.3) and MPs 54.4 (9.8). There were significantly more females among nurses (97.3%), and fewer among MPs (35.7%) compared to doctors (61.5%) or laypeople (57.3%) (p < 0.01 for all comparisons). We found no significant differences in ratings or background characteristics between questionnaire versions and individuals responding at different response rounds. Table A1 in the appendix presents the demographic data.

From the 60 states of being, 12 were perceived as diseases by  $\ge 80\%$  of respondents from all groups and five were perceived not to be diseases by  $\ge 80\%$  (fig 2 and table 1). Doctors were most likely to consider states of being as diseases followed by nurses, MPs and laypeople (p<0.001 for all pairwise comparisons). For a large number of states, there was extreme disagreement regarding classification as a disease among all study groups (fig 2). In ten states,  $\ge 20\%$  of participants considered them diseases and  $\ge 20\%$  did not (table 1). There was a very strong correlation between responses to claims (r = 0.96 [95% confidence interval 0.94 to 0.98]; p<0.001; no differences between groups) (fig A3 in the appendix).

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### **Discussion**

# Statement of principal findings

Our survey found large discrepancies in the views among laypeople, doctors, nurses and MPs in Finland regarding whether states of being should be considered diseases and should be managed through public revenue. Although physicians were more inclined to consider states of being as diseases, disagreement was as evident among health professionals as in other groups (fig 2 and table 1). In all groups, willingness to pay for treatment from public funds was very strongly correlated with the perception of disease.

### Strengths and limitations

The strengths of our study include a large sample of both health care professionals and general population, an acceptable response rate, excellent completeness of questionnaires, and a large number of states of being that elicited a wide range of responses. Further, the sample proved similar in its characteristics to the target populations in terms of age and gender distribution, education, employment and marital status (for details, see table A1 in the appendix and its supplementary references). We found no trend in the perceptions or participants' characteristics by response round, reducing concern regarding selection bias.

The limitations of our study include concern that the strong correlation between the claims may be partly caused by the positioning of questions adjacent to one another in the questionnaire. Second, these results from the Finnish population may be less generalizable to less affluent countries and those with different social and cultural values. For instance, the high correlation between the disease label and the willingness to fund socially may be related to Finland's high level of social solidarity. Finland is said to have a strong welfare state, and the high correlation between claims may not be reproduced in other jurisdictions. Third,

despite our attempt to address understanding and the potential impact of wording in a pilot study, there is a possibility that a framing effect (i.e., individuals reacting differently to a particular response depending on how the question is worded) may have occurred. There is evidence from various populations illustrating the impact of framing on decision-making and preferences.<sup>27-29</sup> In particular, this may have been an issue for our claim B, whether states of being should be funded by public revenue; an alternative framing of questions may have elicited different results.<sup>30</sup>

# Comparison with other studies

Some investigators have addressed patients' and health care providers' perceptions regarding the disease concept and use of public funding in specific conditions. However, no earlier study assessed perceptions' on use of public funding over wider range of conditions, and only one study assessed perceptions' of the disease concept. In keeping with our finding that physicians were slightly more likely than others to consider states of being to be diseases, Campbell and coworkers found no difference among non-medical faculty, secondary school students, academic internists and general practitioners on how they perceived illnesses due to infections, but found that doctors considered more non-infectious conditions to be diseases.

In another related investigation, the editorial board of the *BMJ* and its readers identified a list of almost 200 *non-diseases* (defined as "a human process or problem that some have defined as a medical condition but where people may have better outcomes if the problem or process was not defined in that way") including ageing, baldness, and boredom. As in our survey, there was considerable variation in the states of being deemed 'non-diseases'.

### Meaning of the study: possible explanations and implications

The concept of "disease" lies at the heart of medicine,<sup>7 14</sup> defining its domain and its role in public policy, including the range of conditions in which sufferers may be entitled to public funding for their treatment.<sup>35-37</sup> Building on earlier work,<sup>4 8 11 13-17 38-48</sup> table 2 presents a taxonomy of states of being, exploring the relation between categorization - or not - as a disease, the implications for action, and potential negative consequences. The issues presented in table 2 are subjects of ongoing, often heated, debate. Our results (i.e., large differences in views whether states of being should be considered diseases and should be managed through public revenue) provide insight into these debates: why they are so contentious is due at least in part to disparities in views on the fundamental nature of these states of being. Our study represents only the first steps in understanding the concept of "disease". Additional qualitative studies would be useful for obtaining further insight into interpretation of the findings.

As reflected in table 2, people tend to think of diseases as conditions for which individuals do not bear primary responsibility, afflictions of which the sufferer is at least to some extent a victim.<sup>34</sup> Thus, if we view addictions as diseases (which substantial proportions of our respondents did, and did not) we are inclined to look for solutions through harm reduction approaches and medical treatment, and to allocate public funding for these interventions.<sup>42 48</sup> Alternative views include viewing a condition as a moral failing, bad habit, or retribution for bad behavior (all related perspectives) or as a social problem (a quite different perspective).

For instance, a non-disease perspective on addiction includes two alternatives: If we regard addiction as a moral failing, we are likely to demand personal responsibility for dealing with the problem, and institute punitive approaches for those who fail (table 2).<sup>40 42</sup> Alternatively, we may see addiction as a social problem and seek social solutions such as poverty

reduction.<sup>44</sup> The general unavailability of safe injection sites for drug users, despite evidence of benefit and eminent advocacy illustrates how these issues play out in public policy.<sup>46</sup> Our results suggest that the current contentious debate on social policy toward addiction could benefit not only from evidence regarding the effectiveness of alternative policies, but a more profound understanding of the biology and sociology of addiction.

To take other examples from table 2 with potentially negative consequences of a disease perspective, viewing social anxiety disorder or fibromyalgia as specific biological problems may lead to overdiagnosis and medical overtreatment, and undertreatment with behavioral approaches. <sup>15 45 49</sup> On the other hand, seeing these conditions as socially mediated adjustment problem risks stigmatization and underuse of potentially effective medical treatment. <sup>15 45 49</sup> For other states of being, the ongoing passionate debate has highlighted possible dangers in medicalizing conditions that might be considered normal problems of living. <sup>14 15 17 31</sup>

We found the association between considering a state of being a disease and readiness to fund treatment through public revenue very strong. If we consider obesity a disease, we might devote public funding to weight loss clinics. While this is true of very few jurisdictions, <sup>50</sup> most high income countries devote public funding to bariatric surgery for morbid obesity, a policy which – according to a Danish study<sup>34</sup> – many laypeople may question despite evidence suggesting it is highly cost-effective.

Advocates argue that placing a disease label on absence of sexual desire is a step towards helping people,<sup>39</sup> while critics deem it a destructive medicalization of a normal part of living fostering problematic commercialization.<sup>41</sup> Similarly, creating new diagnostic terms, such as the concept "overactive bladder" may help to increase awareness of the symptoms and to

simplify management, but it may also cause problematic oversimplification leading to excessive use of ineffective treatment.<sup>5 51 52</sup>

This discussion can also be seen from a more general perspective: essentialism versus nominalism (table 2). Essentialists regard diseases as causes of illness; the role of a physician, in this view, is to identify the cause and treat it appropriately.<sup>51</sup> Nominalists see diseases as constructs that humans create to bring order to a disorderly world.<sup>51</sup>

The concept of disease also helps us understand differing perspectives on patterns of behavior (table 2), such as homosexuality. The American Psychiatric Association labeled homosexuality as a disease until 1973, when it was removed from its diagnostic and statistical manual of mental disorders (DSM). However, it remained in the international classification of diseases (ICD) until 1992.<sup>53</sup> Western societies increasingly view homosexuality as a legitimate lifestyle choice; less than 5% of doctors and nurses, and less than 10% of laypeople and MPs in our survey considered homosexuality a disease. Our respondents likewise did not consider transsexualism a disease, contrary to the current ICD-10 classification.<sup>25</sup> As with addiction, there is another non-disease perspective on sexual orientation: that homosexuality represents a moral failing. Historically, Western societies have deemed homosexual acts criminal behavior. In many countries in the world this continues to be the case.

### **Conclusions**

In summary, the substantial disagreement we found in classifying of states of being as diseases, and the parallel disagreement regarding the legitimacy of public funding for those that warrant treatment provides insight into the attitudes underlying a number of current high

profile social debates. The finding suggests that a shared understanding of the biological and social determinants of health conditions and human behaviors could be very useful in helping to facilitate resolution of these debates.



### **Supplementary Information (Web-only Appendix)**

**Table A1.** Characteristics of the study groups.

**Fig A1.** English translation of the questionnaire version A (excluding background information questions).

**Fig A2.** Original (Finnish-language) questionnaire version A (excluding background information questions).

**Fig A3.** Relation between claim A (concept of disease) and claim B (willingness to use public tax revenue for treatment) in laypeople, doctors, nurses and parliament members. 'r' (with 95% confidence intervals) represents the strength of the correlation between those who either *strongly agreed* or *agreed to some extent* with claim A and claim B.

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Author contributions: KAOT, JSL and TLNJ conceptualized the study. KAOT and TLNJ obtained funding. KAOT collected the data. KAOT and GHG developed the analysis plan with JSL, SE and TLNJ. KAOT analyzed the data. All authors contributed to the interpretation of the results. KAOT and GHG led the writing of the manuscript; all authors contributed. All authors had full access to all the data and take responsibility for the integrity and the accuracy of the data. All authors have approved the final version of the manuscript. KAOT is the guarantor.

Competing interest statement: All authors have completed the Unified Competing Interest form at <a href="www.icmje.org/coi\_disclosure.pdf">www.icmje.org/coi\_disclosure.pdf</a> (available on request from the corresponding author) and declare: KAOT, GHG, SE, and TLNJ declare no conflict of interest. JSL is a chief medical officer at the Insurance Medicine of the State Treasury (Helsinki, Finland), which is a government agency that handles statutory employment pension, accident and indemnity insurances and insurance-related employer services of government agencies.

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**Ethical approval:** In accordance with the Finnish regulations on questionnaire surveys, the ethics committee of the Pirkanmaa Hospital District in Finland granted exemption from ethical review (R11110).

**Data sharing:** Data is freely available at Dryad (<a href="http://datadryad.org/">http://datadryad.org/</a>).

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**Table 1.** A) States of being perceived as a disease by at least 80% of respondents of all groups, B) states of being not perceived as a disease by at least 80% of respondents of all groups, and C) states of being perceived as a disease by at least 20% and not as a disease by at least another 20% of respondents of all groups (laypeople, doctors, nurses and parliament members).\*

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ponse options "4" and "5")						
Schizophrenia						
HIV/AIDS						
Malaria						
Adult-onset diabetes						
Osteoporosis						
Autism						
B) Not perceived as disease by more than 80% (response options "1" and "2")  Wrinkles  Grief						
Homosexuality						
nse options "4" and "5") and at least another ons "1" and "2")						
· · · · · · · · · · · · · · · · · · ·						
ons "1" and "2")						
Age-related muscle loss, sarcopenia						
Age-related muscle loss, sarcopenia  Female menopause						

**Table 2.** Implications of alternative viewpoints regarding accepting or rejecting states of being as diseases

Categories of states of being Examples	Disease?	Conceptualization	Implications for action	Potential negative consequences/ramifications
Addictions or possible addictions  Alcoholism  Drug addiction  Gambling addiction  Obesity  Smoking	Yes	Biological health disorder	Harm reduction Public funding Medical treatment	Focus on individuals and treatments may cause social and moral aspects to be ignored <sup>8 43 44 47</sup>
	N	Lack of self-control Moral failing	Abstinence through individual choice and self-discipline Punitive management strategies	Stigma and discrimination, neglect of harm reduction, neglect of social causes, increased suffering for the population 40 42-44 46 48
	No	Social problem	Preventive social solutions: income redistribution, poverty reduction, education, social marketing	Effective medical treatment underused <sup>42 43</sup>
M.P. I.P				
Medical diagnoses with uncertain biologic / psychosocial basis  Chronic fatigue syndrome Fibromyalgia Irritable bowel syndrome Panic disorder Personality disorder	Yes	Specific biological problem	Diagnose and treat, possibly with drugs	Overdiagnosis and overtreatment with drugs, undertreatment with behavioral approaches <sup>11 15 16 31</sup>
	No	Socially mediated adjustment problem	Behavioral therapy Modify environment	Patients may feel stigmatized Effective medical treatment may be underused <sup>11 16 49</sup>
Diminished function or altered appearance, often age-related  Age-related muscle loss Baldness Erectile dysfunction Lack of sexual desire	Yes	Biological health disorder	Diagnose and treat, possibly with drugs Public funding	Overdiagnosis and overtreatment Medicalization of society, with increased self- perception of illness and poorer coping with suffering that is part of life <sup>11 15-17 49</sup>
	No	Normal consequence of living	Accept and adjust Responsibility on individual	Neglect of treatments that may reduce suffering and improve function <sup>11 16 49</sup>

Patterns of behavior  Homosexuality Obesity Smoking Transsexualism	Yes	Biological health disorder	Diagnose and treat, possibly with drugs Negative social stigma	Adverse judgment and resulting stigma and discrimination <sup>53</sup>
	No	Lifestyle choice	Respect person's choice	Permissive attitude encourages self-destructive or morally reprehensible behavior* <sup>43</sup> Underuse of effective treatment* <sup>34</sup>
	No	Moral failing	Abstinence/modification of behavior through individual choice/self-discipline Punitive strategies	Stigma and discrimination <sup>53</sup>
Syndromes or constellation of patterns of symptoms of unclear basis	Yes	Essentialist: specific biological disorder	Label all patients with specific category and treat uniformly	Failure to recognize diversity of illness, excessively uniform management, stifle research that could deepen understanding <sup>2 5 51</sup>
Attention deficit hyperactivity disorder Fibromyalgia Overactive urinary bladder Panic disorder	No	Nominalist: collection of symptoms, signs, behaviors, label of convenience	Acknowledge syndromes as convenient constructions, seek underlying causes, don't attempt to pigeon-hole unusual presentations	Acknowledgement of complexity may lead to inefficiency, paralysis <sup>2 5 51</sup>

<sup>\*</sup> Negative consequences listed here refer particularly to smoking and obesity not to homosexuality and transsexualism

### Figure legends

### **Fig 1.** Study flow.

We randomized the 60 states of being into three blocks: version A consisted of three blocks (each consisting 20 states of being) in the order 1-2-3, version B in the order 3-1-2 and version C in the order 2-3-1.

**Fig 2.** Variation of perceptions in concept of disease among laypeople, doctors, nurses and members of parliament.

What is a disease? Perspectives of the public, health professionals, and legislators

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**Objective:** To assess the perception of diseases and the willingness to use public tax revenue for their treatment among relevant stakeholders.

**Design:** A population-based, cross-sectional mailed survey.

**Setting:** Finland

**Participants:** 3 000 laypeople, 1 500 doctors, 1 500 nurses (randomly identified from the databases of the Finnish Population Register, the Finnish Medical Association and the Finnish Nurses Association), and all 200 parliament members.

**Main outcome measures:** Respondents' perspectives on a 5-point Likert scale on two claims on 60 states of being: "[This state of being] is a disease"; and "[This state of being] should be treated with public tax revenue".

**Results:** Of the 6 200 individuals approached, 3 280 (53%) responded. Of the 60 states of being,  $\geq$ 80% of respondents considered 12 to be diseases (Likert scale responses of "4" and "5") and five not to be diseases (Likert scale responses of "1" and "2"). There was considerable variability in most states, and great variability in ten ( $\geq$ 20% of respondents of all groups considered it a disease and  $\geq$ 20% rejected as a disease). Doctors were more inclined to consider states of being as diseases than laypeople; nurses and members were intermediate (p<0.001), but all groups showed large variability. Responses to the two claims were very strongly correlated (r = 0.96 [95% CI: 0.94-0.98]; p<0.001).

**Conclusions:** There is large disagreement among the public, health professionals, and legislators regarding the classification of states of being as diseases and whether their management should be publicly funded. Understanding attitudinal differences can help to enlighten social discourse on a number of contentious public policy issues.

### **Article focus**

The concept of disease lies at the heart of medicine.

No study has addressed perceptions of all relevant stakeholders on what, across a wide range of conditions, should be classified as a disease.

# **Key messages**

Our survey found large differences in the views among Finnish laypeople, doctors, nurses and parliament members regarding whether states of being should be considered diseases and be managed through public revenue.

Although doctors were more inclined to consider states of being as diseases, disagreement was as evident among health professionals as in other groups.

Understanding peoples' attitudes about whether states of being should be considered diseases elucidates fundamental underlying attitudes and thus can inform social discourse regarding a number of contentious public policy issues.

# Strengths and limitations of this study

This is the first study to assess whether states of being should be considered diseases and should be managed through public revenue using representative a broad sample of doctors, nurses, laypeople as well as legislators.

Our results from the Finnish population may be less generalizable to less affluent countries and countries with different social and cultural values.

### Introduction

Disease, and illness, are related concepts: patients suffer from "illnesses" and doctors diagnose and treat "diseases". Illnesses are experiences of discontinuities in states of being and perceived role performances; when diagnosed as diseases, they are presumed abnormalities in the function or structure of body systems. Disease can refer to a combination of signs and symptoms, phenomena associated with a disorder of function or structure, or illness associated with a specific cause(s). There are, however, no universally accepted criteria for establishing "disease". Indeed, the complexity of the concept of disease has led to the observation that it can be as difficult to define as beauty, truth or love.

The concept of disease is subject to social, cultural and economic influences that have varied over time: these influences have been particularly evident in the last two decades. <sup>457-9</sup> During this time, we have witnessed a growing tendency to classify states of being as diseases, a trend with important possible consequences, both positive and negative. <sup>8 10-13</sup> Possible positive consequences include facilitation of patient-physician communication <sup>4 5 11</sup> and increased willingness to use public money and thus enhance equality in the distribution of limited resources. <sup>4 14</sup> Possible adverse consequences include making relatively healthy individuals perceive themselves as sick, encouraging misguided attempts to treat states that are part of the normal human condition, and individuals being denied employment or insurance. <sup>4 11 15-17</sup> Authors have also suggested that the disease label can be used as a social control mechanism, <sup>18 20</sup> which could be positive or negative on one's perspective. The extent to which health workers and the public have been influenced by these tendencies, and their current perceptions remains uncertain.

Authors have also suggested that the disease label can be used as a social control mechanism. 18-20 The "sick role" theory suggests that illness disrupts normal social functioning, making the individual responsible for adhering to treatment regimes in order to maintain social productivity. 21-23 However, the relationship between the patient and the medical sphere exists within a socially constructed hierarchy wherein medical institutions ultimately hold the individual accountable for collective social problems. 19 21 23 When individual behavior deviates from pre-established social norms, it is not the individual, but the medical community that labels, diagnoses and treats aberrant behavior as a socially legitimated health condition. 19

No earlier study assessed perceptions' on use of public funding, and only one study<sup>2</sup> assessed perceptions' on the concept of disease over wider range of conditions. Campbell and coworkers found that doctors considered more non-infectious conditions to be diseases than laypeople.<sup>2</sup> Because of the importance of the issue, and the paucity of empirical evidence regarding peoples' views, we conducted a survey of the general public, doctors, nurses, and parliament members in Finland to determine the extent to which they considered 60 states of being to be diseases and their attitudes toward using public funds for managing these states. On the basis of differences in background, training, and life experience, and underlying attitudes, —wWe hypothesized that groups (laypeople, doctors, nurses, and parliament members) would vary in their conceptions of disease, and that there would also be large variation in conceptions of disease within groups. Furthermore, we hypothesized that there would be strong correlation between the conception of disease and the willingness to use public funds for its management.

# The Finnish Disease (FIND) Survey study population

In 2010, we selected a random sample of 3 000 laypeople, 1 500 doctors, 1 500 nurses, and all the 200 members of the Parliament of Finland (MPs). We identified laypeople 18 to 75 years of age from the Finnish Population Register Centre, and doctors and nurses less than 65 years of age from the registers of the Finnish Medical Association and the Finnish Nurses Association. We excluded individuals who had died, emigrated, were deemed seriously disabled or who changed careers and would therefore no longer be members of their respective group (fig 1).

### Survey

Referring to the existing literature and the International Classification of Diseases (ICD-10),<sup>2</sup> 11 241 252 we chose, through iterative discussion and consensus-building, 60 states of being that we estimated considered to be familiar to the relevant stakeholders. We anticipated, some that everyone would consider some of these states a disease, some that none would consider some states a disease, and that some that states might elicit disagreement (fig A1 and fig A2 in the appendix). We asked participants to respond to two claims: 1) "[This state of being] is a disease" (claim A) and 2) "[This state of being] should be treated with public tax revenue" (claim B) on a 5-point Likert scale ranging from *strongly disagree* to *strongly agree* (fig A1 and fig A2 in appendix). We elicited demographic information using questions from earlier surveys (table A1 in the appendix). We pilot tested the questionnaire with 20 laypeople and 5 doctors, and made minor revisions on the basis of feedback.

We mailed the questionnaires in June 2010 and sent reminders in August and October 2010. We made pre-contacts with MPs by email and telephone. The ethics committee of the Pirkanmaa Hospital District in Finland granted exemption from ethical review (R11110). The reporting of the study conforms to the STROBE statement.<sup>263</sup>

### Randomization and exclusion criteria

Each participant received a questionnaire eliciting responses to 60 states of being. We randomized the 60 states of being into three blocks (1, 2 and 3; each containing 20 states). We created three versions of the questionnaire: version A consisted of blocks in the order 1-2-3, version B in the order 3-1-2 and version C in the order 2-3-1. Within each sample group (laypeople, doctors, nurses, and MPs), we randomized respondents to the three versions (fig 1).

To check comprehension of the questionnaire, we placed three states (myocardial infarction, pneumonia and breast cancer) likely to be considered as disease as the first state of being in each block. Respondents who did not *agree to some extent* or *strongly agree* to the statement "[This state of being] is a disease" (fig A1 and fig A2 in appendix) for *any* of these three were deemed unlikely to understand the questionnaire and excluded from the analyses (fig 1).

### Statistical analysis

For each group (doctors, nurses, laypeople, and MPs), we calculated the proportion of states of being where respondents *strongly agreed* or *agreed to some extent* regarding the two claims. Using a Pearson Chi-square test on all possible pair-wise comparisons (altogether 6 comparisons for each state of being by claim), we evaluated the order of ratings of perception of disease and expenditure of public tax revenue claims across groups. We calculated the

correlation between the proportions of individuals who either *strongly agreed* or *agreed to some extent* across states in the two claims. All other analyses were descriptive.

### Results

Of the 6 200 people approached, 3 280 (53.2%) participated, of whom 36 proved ineligible (fig 1). Of the 3 244 eligible individuals who completed and understood the questionnaire, 3 246 (99.0%) responded to at least 55 of the 60 states of being. Among respondents, the mean (standard deviation) age was: laypeople 49.5 (15.5), doctors 46.1 (10.7), nurses 44.9 (11.3) and MPs 54.4 (9.8). There were significantly more females among nurses (97.3%), and fewer among MPs (35.7%) compared to doctors (61.5%) or laypeople (57.3%) (p < 0.01 for all comparisons). We found no significant differences in ratings or background characteristics between questionnaire versions and individuals responding at different response rounds. Table A1 in the appendix presents the demographic data.

From the 60 states of being, 12 were perceived as diseases by  $\geq 80\%$  of respondents from all groups and five were perceived not to be diseases by  $\geq 80\%$  (fig 2 and table 1). Doctors were most likely to consider states of being as diseases followed by nurses, MPs and laypeople (p<0.001 for all pairwise comparisons). For a large number of states, there was extreme disagreement regarding classification as a disease among all study groups (fig 2). In ten states,  $\geq 20\%$  of participants considered them diseases and  $\geq 20\%$  did not (table 1). There was a very strong correlation between responses to claims (r = 0.96 [95% confidence interval 0.94 to 0.98]; p<0.001; no differences between groups) (fig A3 in the appendix).

### **Discussion**

### Statement of principal findings

Our survey found large discrepancies in the views among laypeople, doctors, nurses and MPs in Finland regarding whether states of being should be considered diseases and should be managed through public revenue. Although physicians were more inclined to consider states of being as diseases, disagreement was as evident among health professionals as in other groups (fig 2 and table 1). In all groups, willingness to pay for treatment from public funds was very strongly correlated with the perception of disease.

# Strengths and limitations

The strengths of our study include a large sample of both health care professionals and general population, an acceptable response rate, excellent completeness of questionnaires, and a large number of states of being that elicited a wide range of responses. Further, the sample proved similar in its characteristics to representative of the target populations in terms of age and gender distribution, education, employment and marital status (for details, see table A1 in the appendix and its supplementary references). We found no trend in the perceptions or participants' characteristics by response round, reducing concern regarding selection bias.

The limitations of our study include concern that the strong correlation between the claims may be partly caused by the positioning of questions adjacent to one another in the questionnaire. Second, these results from the Finnish population may be less generalizable to less affluent countries and those with different social and cultural values. For instance, the high correlation between the disease label and the willingness to fund socially may be related to Finland's high level of social solidarity.—or—Finland is said to have a strong welfare

state what has been referred to as its status as a "welfare state",—and the high correlation between claims may not be reproduced in other jurisdictions. Third, despite our attempt ato screening for address misunderstanding and the potential impact of wording in a pilot study, there is a possibility that a framing effect (i.e., individuals reacting differently to a particular response depending on how the question is worded) may have occurred. There is evidence from various populations illustrating the impact of framing on decision-making and preferences of the exact wording we ultimately chose remains uncertain. In particular, this may have been an issue for our claim B, it is possible that alternative framing of questions regarding whether states of being should be funded by public revenue; an alternative framing of questions may would have elicited different results.

# Comparison with other studies

Although Some investigators have addressed patients' and health care providers' perceptions regarding the disease concept of disease and use of public funding in specific conditions. However, only one other study has assessed perceptions' on the concept of disease and no earlier study assessed perceptions' on use of public funding over wider range of conditions, and only one study assessed perceptions' of the disease concept. over a wide range of conditions. In keeping with our finding that physicians were slightly more likely than others to consider states of being to be diseases, Campbell and coworkers found no difference among non-medical faculty, secondary school students, academic internists and general practitioners on how they perceived illnesses due to infections, but found that doctors considered more non-infectious conditions to be diseases.

In another related investigation, the editorial board of the *BMJ* and its readers identified a list of almost 200 *non-diseases* (defined as "a human process or problem that some have defined

as a medical condition but where people may have better outcomes if the problem or process was not defined in that way") including ageing, baldness, and boredom. 11 As in our survey, there was considerable variation in the states of being deemed 'non-diseases'.

# Meaning of the study: possible explanations and implications

The concept of "disease" lies at the heart of medicine, 7 14 defining its domain and its role in public policy, including the range of conditions in which sufferers may be entitled to public funding for their treatment. 3529-374 Building on earlier work, 4 8 11 13-17 382-482 table 2 presents a taxonomy of states of being, exploring the relation between categorization - or not - as a disease, the implications for action, and potential negative consequences. The issues presented in table 2 are subjects of ongoing, often heated, debate. 4 8 11 13 17 32 42 Our results (i.e., large differences in views whether states of being should be considered diseases and should be managed through public revenue) provide insight into these debates: why they are so contentious is due at least in part to disparities in views on the fundamental nature of these states of being. Our study represents only the first steps in understanding the concept of "disease". Additional qualitative studies would be useful for obtaining further insight into interpretation of the findings.

As reflected in table 2, people tend to think of diseases as conditions for which individuals do not bear primary responsibility, afflictions of which the sufferer is at least to some extent a victim. 3428 Thus, if we view addictions as diseases (which substantial proportions of our respondents did, and did not) we are inclined to look for solutions through harm reduction approaches and medical treatment, and to allocate public funding for these interventions. 4236 <sup>482</sup> Alternative views include viewing a condition as a moral failing, bad habit, or retribution

for bad behavior (all related perspectives) or as a social problem (a quite different perspective).

For instance, a non-disease perspective on addiction includes two alternatives: If we regard addiction as a moral failing, we are likely to demand personal responsibility for dealing with the problem, and institute punitive approaches for those who fail (table 2). Alternatively, we may see addiction as a social problem and seek social solutions such as poverty reduction. The general unavailability of safe injection sites for drug users, despite evidence of benefit and eminent advocacy illustrates how these issues play out in public policy. Our results suggest that the current contentious debate on social policy toward addiction could benefit not only from evidence regarding the effectiveness of alternative policies, but a more profound understanding of the biology and sociology of addiction.

To take other examples from table 2 with potentially negative consequences of a disease perspective, viewing social anxiety disorder or fibromyalgia as specific biological problems may lead to overdiagnosis and medical overtreatment, and undertreatment with behavioral approaches. On the other hand, seeing these conditions as socially mediated adjustment problem risks stigmatization and underuse of potentially effective medical treatment. For other states of being, the ongoing passionate debate has highlighted possible dangers in medicalizing conditions that might be considered normal problems of living. A 15 17 3125

We found the association between considering a state of being a disease and readiness to fund treatment through public revenue very strong. If we consider obesity a disease, we might devote public funding to weight loss clinics. While this is true of very few jurisdictions, 5044

most high income countries devote public funding to bariatric surgery for morbid obesity, a policy which – according to a Danish study $\frac{3428}{}$  – many laypeople may question despite evidence suggesting it is highly cost-effective.

Advocates argue that placing a disease label on absence of sexual desire is a step towards helping people, <sup>393</sup> while critics deem it a destructive medicalization of a normal part of living fostering problematic commercialization. <sup>4135</sup> Similarly, creating new diagnostic terms, such as the concept "overactive bladder" may help to increase awareness of the symptoms and to simplify management, but it may also cause problematic oversimplification leading to excessive use of ineffective treatment. <sup>5451</sup> 5246

This discussion can also be seen from a more general perspective: essentialism versus nominalism (table 2). Essentialists regard diseases as causes of illness; the role of a physician, in this view, is to identify the cause and treat it appropriately. Nominalists see diseases as constructs that humans create to bring order to a disorderly world.

The concept of disease also helps us understand differing perspectives on patterns of behavior (table 2), such as homosexuality. The American Psychiatric Association labeled homosexuality as a disease until 1973, when it was removed from its diagnostic and statistical manual of mental disorders (DSM). However, it remained in the international classification of diseases (ICD) until 1992. Western societies increasingly view homosexuality as a legitimate lifestyle choice; less than 5% of doctors and nurses, and less than 10% of laypeople and MPs in our survey considered homosexuality a disease. Our respondents likewise did not consider transsexualism a disease, contrary to the current ICD-10 classification. As with addiction, there is another non-disease perspective on sexual

orientation: that homosexuality represents a moral failing. Historically, Western societies have deemed homosexual acts criminal behavior. In many countries in the world this continues to be the case.

### **Conclusions**

In summary, the substantial disagreement we found in classifying of states of being as diseases, and the parallel disagreement regarding the legitimacy of public funding for those that warrant treatment provides insight into the attitudes underlying a number of current high profile social debates. The finding suggests that a shared understanding of the biological and social determinants of health conditions and human behaviors could be very useful in helping to facilitate resolution of these debates.

**Table A1.** Characteristics of the study groups.

Fig A1. English translation of the questionnaire version A (excluding background

information questions).

Fig A2. Original (Finnish-language) questionnaire version A (excluding background

information questions).

Fig A3. Relation between claim A (concept of disease) and claim B (willingness to use public

tax revenue for treatment) in laypeople, doctors, nurses and parliament members. 'r' (with

95% confidence intervals) represents the strength of the correlation between those who either

strongly agreed or agreed to some extent with claim A and claim B.

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Author contributions: KAOT, JSL and TLNJ conceptualized the study. KAOT and TLNJ

obtained funding. KAOT collected the data. KAOT and GHG developed the analysis plan

with JSL, SE and TLNJ. KAOT analyzed the data. All authors contributed to the

interpretation of the results. KAOT and GHG led the writing of the manuscript; all authors

contributed. All authors had full access to all the data and take responsibility for the integrity

and the accuracy of the data. All authors have approved the final version of the manuscript.

KAOT is the guarantor.

Competing interest statement: All authors have completed the Unified Competing Interest form at <a href="www.icmje.org/coi\_disclosure.pdf">www.icmje.org/coi\_disclosure.pdf</a> (available on request from the corresponding author) and declare: KAOT, GHG, SE, and TLNJ declare no conflict of interest. JSL is a chief medical officer at the Insurance Medicine of the State Treasury (Helsinki, Finland), which is a government agency that handles statutory employment pension, accident and indemnity insurances and insurance-related employer services of government agencies.

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**Ethical approval:** In accordance with the Finnish regulations on questionnaire surveys, the ethics committee of the Pirkanmaa Hospital District in Finland granted exemption from ethical review (R11110).

**Data sharing:** Data is freely available at Dryad (http://datadryad.org/).

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**Table 1.** A) States of being perceived as a disease by at least 80% of respondents of all groups, B) states of being not perceived as a disease by at least 80% of respondents of all groups, and C) states of being perceived as a disease by at least 20% and not as a disease by at least another 20% of respondents of all groups (laypeople, doctors, nurses and parliament members).\*

A) Perceived as disease by more than 80% (re	sponse options "4" and "5")								
Breast cancer	Schizophrenia								
Prostate cancer	HIV/AIDS								
Pneumonia	Malaria								
Lung cancer	Adult-onset diabetes								
Juvenile diabetes	Osteoporosis								
Myocardial infarction	Autism								
B) Not perceived as disease by more than 80% Wrinkles Smoking									
Ageing									
C) More than 20% perceived as disease (respo 20% did not perceive as disease (response opti									
Pre-menstrual syndrome, PMS	Age-related muscle loss, sarcopenia								
Erectile dysfunction	Female menopause								
Gambling addiction	Malnutrition								
Infertility	Eye refractive error, need for eyeglasses								
Drug addiction	Lactose intolerance								

Table 2. Implications of alternative viewpoints regarding accepting or rejecting states of being as diseases

Categories of states of being Examples	Disease?	Conceptualization	Implications for action	Potential negative consequences/ramifications
 Addictions or possible addictions	Yes	Biological health disorder	Harm reduction Public funding Medical treatment	Focus on individuals and treatments may cause social and moral aspects to be ignored <sup>8</sup> 437 4438 474
Alcoholism Drug addiction Gambling addiction Obesity	No	Lack of self-control Moral failing	Abstinence through individual choice and self-discipline Punitive management strategies	Stigma and discrimination, neglect of harm reduction, neglect of social causes, increased suffering for the population 340 4236-4438 460 482
Smoking	NO	Social problem	Preventive social solutions: income redistribution, poverty reduction, education, social marketing	Effective medical treatment underused 4236 437
Medical diagnoses with uncertain biologic / psychosocial basis  Chronic fatigue syndrome	Yes	Specific biological problem	Diagnose and treat, possibly with drugs	Overdiagnosis and overtreatment with drugs, undertreatment with behavioral approaches <sup>11 15 16 3125</sup>
Fibromyalgia Irritable bowel syndrome Panic disorder Personality disorder	No	Socially mediated adjustment problem	Behavioral therapy Modify environment	Patients may feel stigmatized Effective medical treatment may be underused <sup>11 16 493</sup>
Diminished function or altered appearance, often age-related	Yes	Biological health disorder	Diagnose and treat, possibly with drugs Public funding	Overdiagnosis and overtreatment Medicalization of society, with increased self- perception of illness and poorer coping with suffering that is part of life <sup>11</sup> 15-17 423
Age-related muscle loss Baldness Erectile dysfunction Lack of sexual desire	No	Normal consequence of living	Accept and adjust Responsibility on individual	Neglect of treatments that may reduce suffering and improve function <sup>11</sup> 16 493

   Patterns of behavior	Yes	Biological health disorder	Diagnose and treat, possibly with drugs Negative social stigma	Adverse judgment and resulting stigma and discrimination 5347
Homosexuality Obesity Smoking Transsexualism	No	Lifestyle choice	Respect person's choice	Permissive attitude encourages self-destructive or morally reprehensible behavior* 4437 Underuse of effective treatment* 3428
	No	Moral failing	Abstinence/modification of behavior through individual choice/self-discipline Punitive strategies	Stigma and discrimination 5347
Syndromes or constellation of patterns of symptoms of unclear basis	Yes	Essentialist: specific biological disorder	Label all patients with specific category and treat uniformly	Failure to recognize diversity of illness, excessively uniform management, stifle research that could deepen understanding <sup>2 5 451</sup>
Attention deficit hyperactivity disorder Fibromyalgia Overactive urinary bladder Panic disorder	No	Nominalist: collection of symptoms, signs, behaviors, label of convenience	Acknowledge syndromes as convenient constructions, seek underlying causes, don't attempt to pigeon-hole unusual presentations	Acknowledgement of complexity may lead to inefficiency, paralysis <sup>2 5 45</sup>

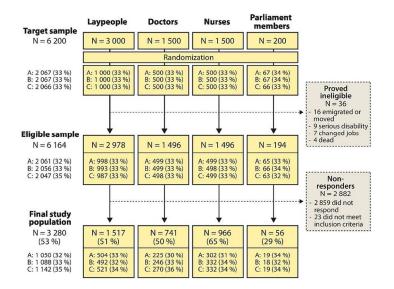
<sup>\*</sup> Negative consequences listed here refer particularly to smoking and obesity not to homosexuality and transsexualism

## Figure legends

## Fig 1. Study flow.

We randomized the 60 states of being into three blocks: version A consisted of three blocks (each consisting 20 states of being) in the order 1-2-3, version B in the order 3-1-2 and version C in the order 2-3-1.

**Fig 2.** Variation of perceptions in concept of disease among laypeople, doctors, nurses and members of parliament.



Study flow 90x127mm (300 x 300 DPI)

BMJ Open: first published as 10.1136/bmjopen-2012-001632 on 2 December 2012. Downloaded from http://bmjopen.bmj.com/ on June 12, 2025 at Agence Bibliographique de l Enseignement Superieur (ABES)

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Variation of perceptions in concept of disease among laypeople, doctors, nurses and parliament members.  $127 \times 90 \text{mm} (300 \times 300 \text{ DPI})$ 

**Supplementary Information (Web-only Appendix)** 

**Table A1.** Characteristics of the study groups.

**Fig A1.** English translation of the questionnaire version A (excluding background information questions).

**Fig A2.** Original (Finnish-language) questionnaire version A (excluding background information questions).

**Fig A3.** Relation between claim A (concept of disease) and claim B (willingness to use public tax revenue for treatment) in laypeople, doctors, nurses and parliament members. 'r' (with 95% confidence intervals in parentheses) represents the strength of the correlation between those who either *strongly* agreed or agreed to some extent with claim A and claim B.

**Table A1.** Characteristics of the study groups among the 3280 included participants.

Laypeople		Doctors		Nurses		njopen-2012-001632 on 2 Decembers	
N (% of females)	1517 (57.3)		741 (61.5)		966 (97.3)	ambe Ense	56 (35.7)
						High 20	
Age distribution	n (%)	Age distribution	n (%)	Age distribution	n (%)	Paragrament members  Paragrame	n (%)
18-35	340 (22.4)	18-35	155 (20.9)	18-35	236 (24.5)	\$180 S	2 (3.6)
36-55	542 (35.7)	36-55	411 (55.5)	36-55	523 (54.2)	<u> </u>	26 (46.4)
56-75	635 (41.9)	56-75	174 (23.5)	56-75	206 (21.3)	#5 <u>8</u> .8	28 (50.0)
						led eur	
Employment		Location of primary occupa	ntion	Current employment sector		Disposed	
Employed	887 (58.5)	Hospital	337 (45.5)	Working at the public sector	739 (76.5)	⊒ Foo proyed	56 (100)
Student	87 (5.7)	Health centre	161 (21.7)	Working for a private employer	124 (12.8)	<b>₫</b> Stu <mark>te</mark> nt	0 (0.0)
Unemployed	106 (7.0)	Occupational health care	67 (9.0)	Self-employed	23 (2.4)	Unemployed	0 (0.0)
Retired	430 (28.3)	Private clinic	74 (10.0)	Unemployed	29 (3.0)	Retired.	0 (0.0)
Insufficient information	7 (0.5)	Research or education	29 (3.9)	Insufficient information	51 (5.3)	Insufficient information	0 (0.0)
		Industry	4 (0.5)			<del>j</del>	
		Other	40 (5.4)			9, bm	
		Not currently employed	24 (3.2)			<b>3 1 3 3 3 3 3 3 3 3 3 3</b>	
		Insufficient information	5 (0.7)			simi	
				njopen.bmj.com/site/about		on June 12, 2025 at Agence Har technologies.	

of 60				BMJ Open		njopen-2012-001633ament members	
Laypeople		Doctors		Nurses		T A B A B A B A B A B A B A B A B A B A	
Education	n (%)	Specialization	n (%)	Primary task	n (%)	Education	n (%)
Elementary school	271 (17.9)	Not specialized	119 (16.1)	Registered nurse	622 (64.4)	d Eleindentary school	4 (7.1)
Upper level of elementary	52 (3.4)	Resident	151 (20.4)	Public health nurse	40 (4.1)	of Lapper level of elementary	2 (3.6)
Vocational school or equivalent	380 (25.0)	Medical specialist	465 (62.8)	Midwife	8 (0.8)		3 (5.4)
Upper secondary school	131 (8.6)	Insufficient information	6 (0.8)	Paramedic	5 (0.5)	secondary school	3 (5.4)
College	306 (20.2)		, ,	Head nurse or matron	118 (12.2)	<b>2</b> (3) Re	11 (19.6)
Polytechnic degree	144 (9.5)			Other work in health care	83 (8.6)	TP3lytechnic degree	3 (5.4)
Academic degree	220 (14.5)			Working outside health care	29 (3.0)	A Pagemic degree	30 (53.6)
Insufficient information	13 (0.9)			Not currently in working life	52 (5.4)	Fixed information	0 (0.0)
				Insufficient information	9 (0.9)	and each	
Marital status		Academic training				specification of the control of the	
Married	809 (53.3)	Licentiate in medicine (MD)	580 (78.3)			1 3 W 3	45 (80.4)
Cohabiting	240 (15.8)	Doctorate in medicine (PhD)	96 (13.0)			Cohobiting	1 (1.8)
Single	256 (16.9)	Adjunct professor	47 (6.3)			Single	3 (5.4)
Separated or divorced	126 (8.3)	Professor	12 (1.6)			Separated or divorced	5 (8.9)
Widowed	74 (4.9)	Insufficient information	6 (0.8)			Wiewed	2 (3.6)
Insufficient information	12 (0.8)	insurrecent information	0 (0.0)			<b>5</b> Insufficient information	0 (0.0)
	` '					<del>9</del> 9	
				- N		Political party	
						Centre Party	14 (25.0)
						Lef Alliance	6 (10.7)
						Natenal Coalition Party	13 (23.2)
						Socol Democratic Party	13 (23.2)
						Othes parties	10 (17.9)

The study sample is representative of the target populations. For more information, see 1) Laypeople: Peltonen M, Harald K, Männistögs, et al. The National FINRISK 2007 Study (in Finnish with English summary). Helsinki: National Public Health Institute, 2008. http://www.ktl.fi/attachments/suomi/julkaisut/julka 1, 2012); 2) Doctors: Lääkärikysely 2009 [Statistics of the Finnish Medical Association] (in Finnish and Swedish). Helsinki, Finnish Medical Association, 2009 http://www.laakariliitto.fi/files/laakarikysely2009.pdf (accessed Feb 1, 2012); 3) Nurses: Statistics of the Finnish Nurses Association ( Finnish). Helsinki, Finnish Nurses Association, 2012. http://www.sairaanhoitajaliitto.fi/viestinta/tilastoja/ (accessed Feb 1, 2012); 4) Parliament members: Wikipedia. Parliamentary elections 2007. Eduskuntavaalit 2007 (in Finnish). http://fi.wikipedia.org/wiki/Eduskuntavaalit\_2007 (accessed Feb 1, 2012).

ATTENTION: This is an <u>opinion poll</u> to clarify the concept of disease. The purpose is not to find out whether you have any of the states of being/diseases below.

INSTRUCTIONS FOR FILLING OUT THE FORM: Please circle a number 1-5 that best describes your <u>opinion</u> (in both claims A and B).

- 1 = Strongly disagree
- 2 = Disagree to some extent
- 3 = Neither disagree nor agree
- 4 = Agree to some extent
- 5 = Strongly agree

		C	LAIM	A			(	CLAIM	В		Prote
	"[This sta	ate of	being	g] is a	disease"	1			_	ould be evenue"	cted by
	Strongly disagree				Strongly agree	Strongly disagree				Strongly agree	copyri
[Myocardial infarction]	1	2	3	4	5	1	2	3	4	5	ght, inc
[Chronic fatigue syndrome]	1	2	3	4	5	1	2	3	4	5	duding
[Baldness]	1	2	3	4	5	1	2	3	4	5	for us
[Absence of sexual desire]	1	2	3	4	5	1	2	3	4	5	nseign es relat
[Alcoholism]	1	2	3	4	5	1	2	3	4	5	ement ted to t
[Premenstrual syndrome, PMS]	1	2	3	4	5	1	2	3	4	5	Enseignement Superieur (ABES) Protected by copyright, including for uses related to text and data minir
[Panic disorder]	1	2	3	4	5	1	2	3	4	5	ur (AB data m
[Anorexia]	1	2	3	4	5	1	2	3	4	5	nining,
[Grief]	1	2	3	4	5	1	2	3	4	5	Al train
[Deafness]	1	2	3	4	5	1	2	3	4	5	BES) . mining, Al training, and similar tech
[Erectile dysfunction]	1	2	3	4	5	1	2	3	4	5	d simil
[Motivational deficiency disorder]	1	2	3	4	5	1	2	3	4	5	
[Osteoporosis]	1	2	3	4	5	1	2	3	4	5	nologies
[Gambling addiction]	1	2	3	4	5	1	2	3	4	5	Š
[Tension headache]	1	2	3	4	5	1	2	3	4	5	
[Work exhaustion, burnout]	1	2	3	4	5	1	2	3	4	5	
	Strongly disagree				Strongly agree	Strongly disagree				Strongly agree	

		C	LAIM	Α		CLAIM B					
		ate of	being	g] is a	disease"	treated			_		
	Strongly disagree				Strongly agree	Strongly disagree				Strongly agree	
[HIV/AIDS]	1	2	3	4	5	1	2	3	4	5	
[Infertility]	1	2	3	4	5	1	2	3	4	5	
[Attention-deficit hyper- activity disorder, ADHD]	1	2	3	4	5	1	2	3	4	5	
[Prostate cancer]	1	2	3	4	5	1	2	3	4	5	Pro
[Pneumonia]	1	2	3	4	5	1	2	3	4	5	tected
[Insomnia]	1	2	3	4	5	1	2	3	4	5	ьу сор
[Obesity]	1	2	3	4	5	1	2	3	4	5	Enseignement Superie Protected by copyright, including for uses related to text and
[Drug addiction]	1	2	3	4	5	1	2	3	4	5	includi
[Male menopause]	1	2	3	4	5	1	2	3	4	5	ng for ι
[Ageing]	1	2	3	4	5	1	2	3	4	5	Enseig Ises re
[Transsexualism]	1	2	3	4	5	1	2	3	4	5	nemen lated to
[Alcoholic liver cirrhosis]	1	2	3	4	5	1	2	3	4	5	t Super text ar
[Schizophrenia]	1	2	3	4	5	1	2	3	4	5	
[Restless legs syndrome]	1	2	3	4	5	1	2	3	4	5	BES) mining
[Age-related muscle loss, sarcopenia]	1	2	3	4	5	1	2	3	4	5	, Al tra
[Adult-onset diabetes]	1	2	3	4	5	1	2	3	4	5	ining, a
[Smoking]	1	2	3	4	5	1	2	3	4	5	ınd sim
[Autism]	1	2	3	4	5	1	2	3	4	5	ilar tec
[Night-time urination]	1	2	3	4	5	1	2	3	4	5	ur (ABES) . data mining, Al training, and similar technologies.
[Binge eating, bulimia]	1	2	3	4	5	1	2	3	4	5	ies.
[Generalized anxiety disorder]	1	2	3	4	5	1	2	3	4	5	
[Sleep apnea, pauses in breathing during sleep]	1	2	3	4	5	1	2	3	4	5	
	Strongly disagree				Strongly agree	Strongly disagree			S	trongly agre	e

		C	CLAEMI	Pope	<del>!</del> n	CLAIM B Page					of 60
	"[This st	ate of	f being	ː] is a	a disease"	!				nould be revenue"	
	Strongly disagree				Strongly agree	Strongly disagree	/VICI	public	taxi	Strongly agree	
[Wrinkles]	1	2	3	4	5	1	2	3	4	5	_
[Elevated cholesterol]	1	2	3	4	5	1	2	3	4	5	
[Breast cancer]	1	2	3	4	5	1	2	3	4	5	•
[Fibromyalgia, chronic pain syndrome]	1	2	3	4	5	1	2	3	4	5	
[Elevated blood pressure]	1	2	3	4	5	1	2	3	4	5	Prote
[Dental caries]	1	2	3	4	5	1	2	3	4	5	cted b
[Lung cancer]	1	2	3	4	5	1	2	3	4	5	у соруг
[Female menopause]	1	2	3	4	5	1	2	3	4	5	right, in
[Malnutrition]	1	2	3	4	5	1	2	3	4	5	cludin
[Irritable bowel syndrome]	1	2	3	4	5	1	2	3	4	5	g for us
[Homosexuality]	1	2	3	4	5	1	2	3	4	5	nseign es rela
[Eye refractive error, need for eyeglasses]	1	2	3	4	5	1	2	3	4	5	Enseignement Su Protected by copyright, including for uses related to tex
[Lactose intolerance]	1	2	3	4	5	1	2	3	4	5	Superie ext and
[Down syndrome]	1	2	3	4	5	1	2	3	4	5	uperieur (ABES). ct and data mining, Al training, and similar technologies.
[Personality disorder]	1	2	3	4	5	1	2	3	4	5	es) . nining,
[Overactive urinary bladder]	1	2	3	4	5	1	2	3	4	5	Al train
[Depression]	1	2	3	4	5	1	2	3	4	5	iing, an
[Juvenile diabetes]	1	2	3	4	5	1	2	3	4	5	d simil
[Malaria]	1	2	3	4	5	1	2	3	4	5	ar tech
[Social anxiety disorder]	1	2	3	4	5	1	2	3	4	5	nologie
[Premature ejaculation]	1	2	3	4	5	1	2	3	4	5	S.
[Hip fracture]	1	2	3	4	5	1	2	3	4	5	
	Stronly				Strongly	Strongly			S	Strongly agree	e

agree

disagree

disagree

HUOMIO: Tämä tutkimus on mielipidetutkimus, joka selvittää sairauden käsitettä. Tarkoituksena ei ole selvittää onko teillä jotakin alla olevista tiloista/sairauksista.

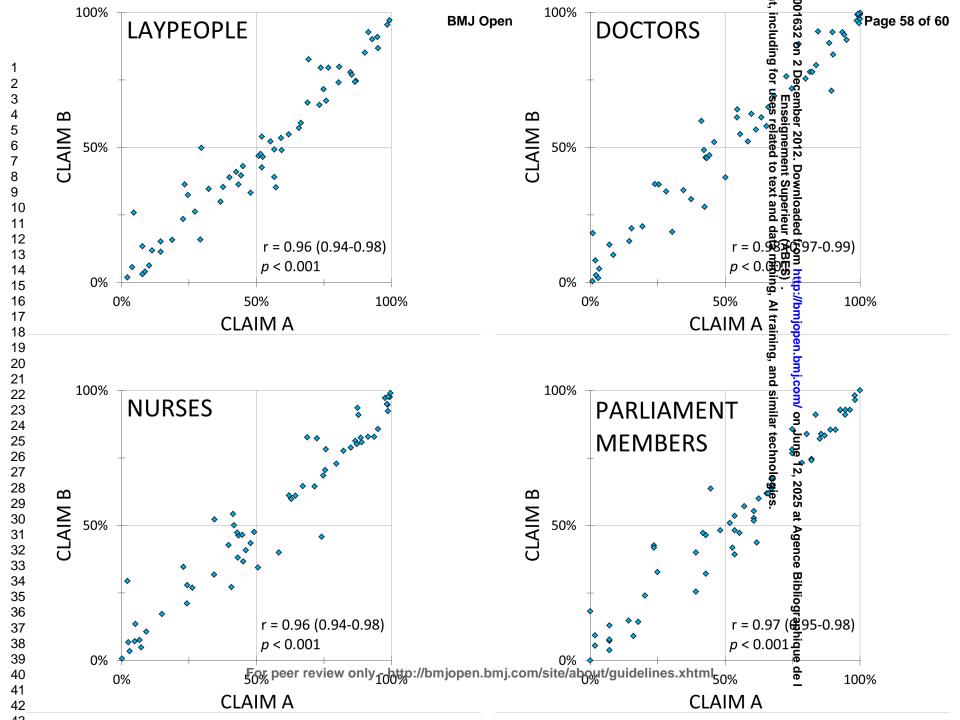
LOMAKKEEN TÄYTTÖOHJE: Ympyröikää molempiin väittämiin (A-väittämä ja Bväittämä) luku 1-5 väliltä, joka parhaiten kuvaa mielipidettänne.

- 1 = Täysin eri mieltä
- 2 = Jokseenkin eri mieltä
- 3 = Ei eri mieltä eikä samaa mieltä
- 4 = Jokseenkin samaa mieltä
- 5 = Täysin samaa mieltä

		A-VÄ	İITTÄI	ΜÄ		B-VÄITTÄMÄ							
	"[Tä	mä til	a] on	saira	us"	_		ila] tul n verov		oitaa n"	ted by		
	Täysin eri mieltä			Tä	äysin samaa mieltä	Täysin eri mieltä				Täysin samaa mieltä	copyri		
[Sydäninfarkti]	1	2	3	4	5	1	2	3	4	5	ght, in		
[Krooninen väsymysoireyhtymä]	1	2	3	4	5	1	2	3	4	5	cluding		
[Kaljuuntuminen]	1	2	3	4	5	1	2	3	4	5	for us		
[Seksuaalinen haluttomuus]	1	2	3	4	5	1	2	3	4	5	nseigne es relat		
[Alkoholismi]	1	2	3	4	5	1	2	3	4	5	ed to t		
[Kuukautisia edeltävä oireyhtymä, PMS]	1	2	3	4	5	1	2	3	4	5	Protected by copyright, including for uses related to text and data minit		
[Paniikkihäiriö]	1	2	3	4	5	1	2	3	4	5	ur (ABI data m		
[Anoreksia, laihuushäiriö]	1	2	3	4	5	1	2	3	4	5	ES) . iining, ,		
[Suru]	1	2	3	4	5	1	2	3	4	5	AI train		
[Kuurous]	1	2	3	4	5	1	2	3	4	5	ing, and		
[Erektiohäiriö]	1	2	3	4	5	1	2	3	4	5	d simil		
[Motivaation puutos – oireyhtymä]	1	2	3	4	5	1	2	3	4	5	BES) . mining, Al training, and similar technologies		
[Osteoporoosi]	1	2	3	4	5	1	2	3	4	5	nologie		
[Peliriippuvuus]	1	2	3	4	5	1	2	3	4	5	Š		
[Niskajännityspäänsärky]	1	2	3	4	5	1	2	3	4	5			
[Työuupumus, burn-out]	1	2	3	4	5	1	2	3	4	5			
	Täysin eri mieltä			Tä	äysin samaa mieltä	Täysin eri mieltä				Täysin samaa mieltä			

		ÄITTÄ	MÄ	B-VÄITTÄMÄ						
	"[Tä	mä t	ila] on	saira	aus"			ila] tul		
	Täysin eri mieltä			Т	äysin samaa mieltä	Täysin eri mieltä	IKISII	ı vero		Täysin samaa mieltä
[HIV/AIDS]	1	2	3	4	5	1	2	3	4	5
[Lapsettomuus]	1	2	3	4	5	1	2	3	4	5
[Tarkkaavaisuus- ja ylivilkkaushäiriö, ADHD]	1	2	3	4	5	1	2	3	4	5
[Eturauhassyöpä]	1	2	3	4	5	1	2	3	4	5
[Keuhkokuume]	1	2	3	4	5	1	2	3	4	5
[Unettomuus]	1	2	3	4	5	1	2	3	4	5
[Lihavuus]	1	2	3	4	5	1	2	3	4	5
[Huumeriippuvuus]	1	2	3	4	5	1	2	3	4	5
[Miehen vaihdevuodet, mieshormonin lasku]	1	2	3	4	5	1	2	3	4	5
[Vanheneminen]	1	2	3	4	5	1	2	3	4	5
[Transseksuaalisuus]	1	2	3	4	5	1	2	3	4	5
[Alkoholimaksakirroosi]	1	2	3	4	5	1	2	3	4	5
[Skitsofrenia]	1	2	3	4	5	1	2	3	4	5
[Levottomat jalat - oireyhtymä]	1	2	3	4	5	1	2	3	4	5
[Vanhuusiän lihaskato, sarkopenia]	1	2	3	4	5	1	2	3	4	5
[Aikuistyypin diabetes]	1	2	3	4	5	1	2	3	4	5
[Tupakointi]	1	2	3	4	5	1	2	3	4	5
[Autismi]	1	2	3	4	5	1	2	3	4	5
[Yövirtsaaminen]	1	2	3	4	5	1	2	3	4	5
[Ahmimishäiriö, bulimia]	1	2	3	4	5	1	2	3	4	5
[Yleistynyt ahdistuneisuushäiriö]	1	2	3	4	5	1	2	3	4	5
[Uniapnea, unenaikaiset hengityskatkokset]	1	2	3	4	5	1	2	3	4	5
	Täysin eri mieltä			T	äysin samaa mieltä	Täysin eri mieltä			7	äysin samaa mieltä

		A-V	MÄ			B-\	/ÄITTÄ	ΜÄ		
	"[Tä	imä ti	ila] on	sair	aus"	_		ila] tul n verov		
	Täysin eri mieltä			-	Täysin samaa mieltä	Täysin eri mieltä				Täysin samaa mieltä
[lhon ryppyisyys]	1	2	3	4	5	1	2	3	4	5
[Kohonnut kolesteroli]	1	2	3	4	5	1	2	3	4	5
[Rintasyöpä]	1	2	3	4	5	1	2	3	4	5
[Fibromyalgia, krooninen kipuoireyhtymä]	1	2	3	4	5	1	2	3	4	5
[Kohonnut verenpaine]	1	2	3	4	5	1	2	3	4	5
[Hampaiden reikiintyminen]	1	2	3	4	5	1	2	3	4	5
[Keuhkosyöpä]	1	2	3	4	5	1	2	3	4	5
[Naisen vaihdevuodet]	1	2	3	4	5	1	2	3	4	5
[Aliravitsemus]	1	2	3	4	5	1	2	3	4	5
[Ärtyvä suoli -oireyhtymä]	1	2	3	4	5	1	2	3	4	5
[Homoseksuaalisuus]	1	2	3	4	5	1	2	3	4	5
[Silmien taittovirhe, silmälasien tarve]	1	2	3	4	5	1	2	3	4	5
[Laktoosi-intoleranssi]	1	2	3	4	5	1	2	3	4	5
[Downin syndrooma]	1	2	3	4	5	1	2	3	4	5
[Persoonallisuushäiriö]	1	2	3	4	5	1	2	3	4	5
[Yliaktiivinen virtsarakko]	1	2	3	4	5	1	2	3	4	5
[Masennus]	1	2	3	4	5	1	2	3	4	5
[Nuoruustyypin diabetes]	1	2	3	4	5	1	2	3	4	5
[Malaria]	1	2	3	4	5	1	2	3	4	5
[Sosiaalisten tilanteiden pelko]	1	2	3	4	5	1	2	3	4	5
[Ennenaikainen siemensyöksy]	1	2	3	4	5	1	2	3	4	5
[Lonkkamurtuma]	1	2	3	4	5	1	2	3	4	5
	Täysin eri mieltä			•	Täysin samaa mieltä	Täysin eri mieltä				Täysin samaa mieltä



## STROBE 2007 (v4) Statement—Checklist of items that should be included in reports of cross-sectional studies

Section/Topic	Item #	Recommendation	Reported on page #
Title and abstract	1	(a) Indicate the study's design with a commonly used term in the title or the abstract	2
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found	2
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	4-5
Objectives	3	State specific objectives, including any prespecified hypotheses	5
Methods			
Study design	4	Present key elements of study design early in the paper	6-7
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	6
Participants	6	(a) Give the eligibility criteria, and the sources and methods of selection of participants	6-7, Figure 1
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	6-7
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	6
Bias	9	Describe any efforts to address potential sources of bias	6-8
Study size	10	Explain how the study size was arrived at	
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	6-7
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding	7
		(b) Describe any methods used to examine subgroups and interactions	
		(c) Explain how missing data were addressed	8
		(d) If applicable, describe analytical methods taking account of sampling strategy	
		(e) Describe any sensitivity analyses	
Results			

Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility,	8, Figure 1
		confirmed eligible, included in the study, completing follow-up, and analysed	
		(b) Give reasons for non-participation at each stage	Figure 1
		(c) Consider use of a flow diagram	Figure 1
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential	Table A1
		confounders	
		(b) Indicate number of participants with missing data for each variable of interest	8
Outcome data	15*	Report numbers of outcome events or summary measures	Figure 1, Table 1
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence	Figure 2
		interval). Make clear which confounders were adjusted for and why they were included	
		(b) Report category boundaries when continuous variables were categorized	
		(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	8
Discussion			
Key results	18	Summarise key results with reference to study objectives	9
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and	9
		magnitude of any potential bias	
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from	10-13
		similar studies, and other relevant evidence	
Generalisability	21	Discuss the generalisability (external validity) of the study results	9-10
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on	16
		which the present article is based	

<sup>\*</sup>Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.