

# Do social norms play a role in explaining involvement in medical decision-making?

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**Background:** Patients' involvement in medical decision-making is crucial to provide good quality of care that is respectful of, and responsive to, patients' preferences, needs and values. Whether people want to be involved in medical decision-making is associated with individual patient characteristics, and health status. However, the observation of differences in whether people want to be involved does not in itself provide an explanation. Insight is necessary into mechanisms that explain people's involvement. This study aims to examine one mechanism, namely social norms. We make a distinction between subjective norms, that is doing what others think one ought to do, and descriptive norms, doing what others do. We focus on self-reported involvement in medical decision-making. **Methods:** A questionnaire was sent to members of the Dutch Health Care Consumer Panel in May 2015 (response 46%;  $N=974$ ). A regression model was used to estimate the relationship between socio-demographics, social norms and involvement in medical decision-making. **Results:** In line with our hypotheses, we observed that the more conservative social norms are, the less people are involved in medical decision-making. The effects for both types of norms were comparable. **Conclusion:** This study indicates that social norms play a role as a mechanism to explain involvement in medical decision-making. Our study offers a first insight into the possibility that the decision to be involved in medical decision-making is not as individual as it at first seems; someone's social context also plays a role. Strategies aimed at emphasizing patient involvement have to address this social context.

## Introduction

One aspect of good quality of care is regarded as providing care that is respectful of, and responsive to, an individual patient's preferences, needs and values.<sup>1</sup> This implicitly requires that patients are involved in decisions about their health.<sup>2</sup> In the past decades, a shift has been observed from a paternalistic, or conservative, decision-making approach, adhering to the status quo where physicians play a dominant role, towards new approaches to decision-making incorporating a larger role for patients.<sup>3,4</sup> One approach that promotes patient involvement, and respects patient autonomy, is shared decision-making.<sup>5</sup> As Elwyn et al. (2010: 971)<sup>5</sup> say 'shared decision-making is an approach where clinicians and patients make decisions together using the best available evidence'.

A systematic review by Chewning et al. (2012)<sup>6</sup> shows that most patients want to participate in medical decision-making. The number of patients that want to be involved in such decision-making, as well as those actually involved, has increased over time.<sup>6,7</sup> On the other hand, it is known that some categories of patients want to leave the decision to their physician.<sup>8,9</sup> Whether patients want to be involved in medical decision-making is associated with individual patient characteristics, e.g. socio-demographics, and health status.<sup>6,10–12</sup> Women, younger people and higher educated people want to be involved more often in the decision-making process.<sup>10,12</sup> Conflicting results, however, are observed about whether patients with severe illness want to be involved in taking such decisions.<sup>12</sup> However, the observation of differences in whether categories of patients want to be involved in medical decision-making does not in itself provide an explanation. Insight is necessary into the mechanisms that explain why patients are actively involved in medical decision-making.

One of the possible mechanisms that might explain why people are actively involved in such decision-making is someone's social context, as this influences individual behaviour.<sup>13</sup> Someone's social

context influences behaviour through the existence of norms (p. 241). Social norms specify what actions are regarded by a group of people as normal, and what actions are regarded as deviant<sup>14</sup> (p. 242). Two types of social norms that are recognized in the literature are: (i) subjective norms, and (ii) descriptive norms.<sup>15</sup> 'Subjective' norms refer to the perception of what most people approve or disapprove of, that is doing what others think one ought to do.<sup>15</sup> It is concerned with perceived social pressure, the person's potential to gain approval or not from others for engaging in a behaviour.<sup>16</sup> 'Descriptive' norms refer to how others act in similar situations that is doing what others do.<sup>15</sup> The actions of others provide information that people may use in deciding what to do themselves.<sup>16</sup>

We ask in this study: 'How are social norms related to patient involvement in medical decision-making?' The focus of this study is on self-reported involvement in such decision-making. We hypothesize that the more a person thinks that, according to significant others, he or she should leave the decision to the physician, the less a person is involved in medical decision-making ('subjective' norm hypothesis). We also hypothesize that the more a person thinks that significant others leave the decision to the physician, the less a person is involved in medical decision-making ('descriptive' norm hypothesis).

## Methods

### Setting

Data were collected from the Dutch Health Care Consumer Panel, which aims to measure opinions on, and knowledge of, health care as well as the expectations of, and experiences with, health care among a cross-section of the Dutch population (see for more detailed information<sup>17</sup>). The Consumer Panel is a so-called access panel. An access panel consists of a large number of people who have agreed to answer questions on a regular basis. Many of the

**Table 1** Questions used to measure involvement in medical decision-making, the subjective norm and the descriptive norm

Questions	Answer categories
<p><b>Involvement in medical decision-making</b></p> <p>How often do you think that your doctor make the decisions about what's best for your health?</p> <p>How often do you think that the important medical decisions will be taken by your doctor and not by yourself?</p>	'Never (score 1), sometimes (score 2), often (score 3), always (score 4)'
<p><b>Subjective norm</b></p> <p><b>My partner</b> thinks that I should let the doctor decide what is best for my health. My partner would prefer that to me having to make a choice.</p> <p><b>My family</b> thinks that I should let the doctor decide what is best for my health. My family would prefer that to me having to make a choice.</p> <p><b>The people I consider important</b> think that I should let the doctor decide what is best for my health. The people I consider important would prefer that to me having to make a choice.</p> <p><b>My partner</b> thinks that the most important medical decisions should be taken by my doctor and not by me.</p> <p><b>My family</b> thinks that the most important medical decisions should be taken by my doctor and not by me.</p> <p><b>The people I consider important</b> think that the most important medical decisions should be taken by my doctor and not by me.</p>	'Completely disagree (score 1) to completely agree (score 5) + not applicable, I don't have...'
<p><b>Descriptive norm</b></p> <p>How often do you think that <b>your partner</b> allows the doctor to decide what is best for his or her health?</p> <p>How often do you think that <b>your family</b> allows the doctor to decide what is best for their health?</p> <p>How often do you think that <b>the people you consider important</b> allow the doctor to decide what is best for their health?</p> <p>How often do you think that the most important medical decisions will be taken by the doctor and not by <b>your partner</b>?</p> <p>How often do you think that the most important medical decisions will be taken by the doctor and not by <b>your family</b>?</p> <p>How often do you think that the most important medical decisions will be taken by the doctor and not by <b>the people you consider important</b>?</p>	'Never (score 1), sometimes (score 2), often (score 3), always (score 4) + not applicable, I don't have...'

background characteristics of the panel members are known such as their age, gender and level of education. At the time of this study (May 2015), the Consumer Panel consisted of about 12 000 people aged 18 years and older. Each individual panel member receives a questionnaire about three times a year and can quit the panel at any time. At the start of their membership, panel members can choose whether they want to receive questionnaires by post or through the internet. There is no possibility of people signing up for the panel on their own initiative. The Consumer Panel is renewed on a regular basis. Data are processed anonymously and the protection of the data collected is registered with the Dutch Data Protection Authority (nr. 1262949). A privacy regulation is available for the Consumer Panel. According to Dutch legislation, neither obtaining informed consent nor approval by a medical ethics committee is obligatory for conducting research through the panel.<sup>18</sup>

### Questionnaire

A questionnaire was sent to a sample of 2116 panel members in late May 2015. We sampled all migrants (both western and non-western) included in our panel ( $N=1058$ ) and sampled the same number of non-migrants ( $N=1058$ ). The group of non-migrants was matched to the group of migrants based on gender, age and educational level. According to their previously stated preference, 967 members received a questionnaire by post and 1149 through the internet. One postal reminder (after 2 weeks), and two electronic reminders (after 1 and after 2 weeks) were sent to panel members who had not yet responded. The closing date was 4 weeks after the initial sending. The questionnaire was returned by 974 (46%) panel members.

### Measurements

#### Involvement in medical decision-making

We used two questions to measure involvement in medical decision-making (Table 1). These questions were based on two propositions developed by Flynn et al. (2006).<sup>19</sup> We evaluated whether the two questions measured a single concept by calculating the internal consistency given by Cronbach's alpha. Only respondents who filled out both questions were included (included:  $N=956$ , excluded:  $N=18$ ). The internal consistency was reasonable (alpha 0.78, 95% CI: 0.75–0.81). A mean score over the two questions was calculated ranging from 1 to 4, in which higher scores indicated that respondents reported being less involved in medical decision-making.

#### Subjective and descriptive norms

The subjective and descriptive norms were both measured by two sets of three questions (Table 1). The questions were developed by the research team and based on research about social norms.<sup>20,21</sup> We recoded the answer option 'not applicable, I don't have...' to 'missing' for all questions, since it provided no information about social norms. Factor analysis showed two factors: one consisting of the six questions on subjective norms (Cronbach's alpha 0.95, 95% CI: 0.94–0.95), and a second consisting of the six questions on descriptive norms (Cronbach's alpha 0.91, 95% CI: 0.90–0.92). A mean score was calculated for the subjective norm [range 1 (completely disagree) to 5 (completely agree)] and the descriptive norm [range 1 (never) to 4 (always)]. We based both mean scores on the questions that were filled out by a respondent. Only respondents with missing values on all six questions measuring a norm were excluded (excluded subjective norm:  $N=46$ ; excluded descriptive norm:  $N=61$ ). Higher scores indicated more 'conservative' social norms, i.e. leaving the decision to the physician.

**Table 2** Descriptive statistics of the respondents

	N	% or mean (SD)
<b>Gender</b>	974	
Male	461	47.3
Female	513	52.7
<b>Age</b>	974	63 (15.7)
<b>Level of education</b>	955	
Low (none, primary school or pre-vocational education)	154	16.1
Middle (secondary or vocational education)	485	50.8
High (professional higher education or university)	316	33.1
<b>Ethnicity</b>	974	
Non-migrant	532	54.6
Western migrant	353	36.2
Non-western migrant	89	9.1
<b>Self-reported general health</b>	925	
Excellent/very good	257	27.8
Good	454	49.1
Fair/bad	214	23.1
<b>Questionnaire</b>	974	
Post	499	51.2
Internet	475	48.8
<b>Involvement in medical decision-making</b> (range 1–4)	956	2.60 (0.78)
<b>Subjective norm</b> (range 1–5)	928	2.69 (1.06)
<b>Descriptive norm</b> (range 1–4)	913	2.51 (0.82)

Correlation between the two composite variables was 0.63. This can be explained by the fact that both variables measure social norms, although in a different way. Additionally, a likelihood ratio (LR)-test was conducted to examine whether a more complex model (including both social norms) fits significantly better than a simple model (including one social norm) for explaining involvement in medical decision-making. The LR-test confirmed that a more complex model fits better. Therefore, both the subjective and the descriptive norm were included in our analyses.

### Socio-demographics

The following socio-demographics were included: age (continuous), gender (0 = man, 1 = woman), highest level of education completed (1 = low, 2 = middle and 3 = high), ethnicity (1 = non-migrant, 2 = western migrant and 3 = non-western migrant) and self-reported general health (1 = excellent/very good, 2 = good and 3 = fair/bad).

### Statistical analyses

First, we performed descriptive statistics to describe the characteristics of the study population. Secondly, we tested whether our data were consistent with empirical studies showing that involvement in medical decision-making is associated with socio-demographics. We conducted a multiple linear regression analysis (model-I) in which we included involvement in medical decision-making as a dependent variable, and the socio-demographics (gender, age, educational level, ethnicity and self-reported general health) as independent variables. Thirdly, we examined whether social norms are an explanation for the association between socio-demographics and involvement in medical decision-making. We conducted two multiple linear regression analyses in which we included the subjective norm and the descriptive norm, respectively, as dependent variables, and the socio-demographics as independent variables. Finally, we tested the association between social norms and involvement in medical decision-making and added the subjective and descriptive norm as additional independent variables to model-I (model-II). We controlled all models for whether a respondent filled out the

questionnaire through the internet (1), or by post (0). In the regression analyses, categorical variables (educational level, ethnicity and self-reported general health) were recoded into dummy variables. The level of statistical significance was fixed at 0.05. All statistical analyses were carried out using STATA, version 13.1.

### Results

Approximately half (53%) of the respondents were women, and the mean age of the respondents was 63 years (range 19–90 years; Table 2). About half (51%) had a middle level of education. Table 1 shows that 55% of the respondents were non-migrant, 36% western migrant and 9% non-western migrant. General health was self-reported as excellent/very good in 28% of the cases. When compared with the general Dutch population aged 18 years and older, mainly elderly (65 years and older) and western migrants were overrepresented in the group of respondents.<sup>17</sup> The reason for this is that these groups were also over-represented in the study sample due to the fact that the questionnaire was also used for other studies focusing on migrant groups.

The mean score for involvement in medical decision-making was 2.60 (SD 0.78) on a scale from 1 (more involvement) to 4 (less involvement) (Table 2). Almost half (49%) of the respondents had a score of 3 or higher. This means that on average respondents were slightly more inclined not to be involved in the decision-making process. The mean scores for the subjective and descriptive norm were 2.69 (SD 1.06, range 1–5, higher scores indicated more conservative norms) and 2.51 (SD 0.82, range 1–4, higher scores indicated more conservative norms), respectively (Table 2). This means that, on average, the social norms of the respondents were slightly more focused on leaving the decision to the physician.

Our data were consistent with empirical studies showing that involvement in medical decision-making is associated with socio-demographic characteristics. Younger people and women stated to be more involved in medical decision-making (model-I Table 3). Also, people with a high level of education stated to be more involved in medical decision-making compared with people with a low level of education. No significant association was observed for ethnicity and self-reported general health. The explained variance of the model was low: 7%.

We found an association between socio-demographics and social norms (not shown in Table 3). Women and people with a high level of education have less conservative norms compared with men and people with low level of education. No significant association was observed for age, ethnicity and self-reported general health.

In model-II, we added the subjective and descriptive norms as explanatory variables in order to examine the association between social norms and involvement in medical decision-making. Table 3 shows that both social norms were significantly related to involvement in such decision-making. The more conservative subjective and descriptive norms were, the fewer respondents reported being involved in medical decision-making, confirming our hypotheses. The effects of both norms were comparable (see standardized coefficients in Table 3). In model-II, age and gender were no longer significantly associated with involvement in medical decision-making. Just as in model-I, people with a high level of education were more involved in medical decision-making, although the effect is smaller. The explained variance of model-II was 48%.

### Discussion

This study explored the relationship between social norms and involvement in medical decision-making. In line with our hypotheses, we found that social norms are associated with involvement in such decision-making. With regards to the subjective norm, we found that the more a person thinks that according to significant others

**Table 3** Regression models to examine the association between socio-demographics, social norms and involvement in medical decision-making

Involvement in medical decision-making (1 = more involved; 4 = less involved)	Model-I (N = 897)			Model-II (N = 857)		
	Coefficient (95% CI)	Beta*	P-values	Coefficient (95% CI)	Beta*	P-values
<b>Gender</b> (0 = man; 1 = woman)	-0.188 (-0.289 to -0.088)	-0.121	<b>0.000</b>	-0.024 (-0.103 to 0.055)	-0.015	0.554
<b>Age</b> (continuous)	0.005 (0.002 to 0.009)	0.102	<b>0.004</b>	0.002 (-0.000 to 0.005)	0.049	0.072
<b>Level of education</b>						
Low (none, primary school or prevocational education)	Reference	Reference	Reference	Reference	Reference	Reference
Middle (secondary or vocational education)	-0.112 (-0.254 to 0.030)	-0.072	0.123	-0.095 (-0.205 to 0.016)	-0.061	0.094
High (professional higher education or university)	-0.394 (-0.548 to -0.239)	-0.240	<b>0.000</b>	-0.194 (-0.315 to -0.073)	-0.118	<b>0.002</b>
<b>Ethnicity</b>						
Non-migrant	Reference	Reference	Reference	Reference	Reference	Reference
Western migrant	0.008 (-0.098 to 0.114)	0.005	0.879	-0.004 (-0.085 to 0.078)	-0.002	0.929
Non-western migrant	0.025 (-0.161 to 0.211)	0.009	0.790	-0.041 (-0.187 to 0.106)	-0.014	0.585
<b>Self-reported general health</b>						
Excellent/very good	Reference	Reference	Reference	Reference	Reference	Reference
Good	-0.050 (-0.169 to 0.069)	-0.032	0.412	-0.048 (-0.140 to 0.043)	-0.031	0.299
Fair/bad	-0.055 (-0.200 to 0.089)	-0.030	0.452	-0.107 (-0.218 to 0.004)	-0.058	0.058
<b>Subjective norm</b> (1–5, higher scores indicate more conservative norms)	'Not included in model-I'			0.280 (0.232 to 0.328)	0.378	<b>0.000</b>
<b>Descriptive norm</b> (1–4, higher scores indicate more conservative norms)	'Not included in model-I'			0.345 (0.285 to 0.404)	0.361	<b>0.000</b>
Questionnaire (1 = internet; 0 = post)	-0.140 (-0.244 to -0.035)	-0.090	<b>0.009</b>	-0.003 (-0.084 to 0.079)	-0.002	0.951
<b>Constant</b>	2.662 (2.388 to 2.936)	-	<b>0.000</b>	1.008 (0.759 to 1.258)	-	<b>0.000</b>
<b>Adjusted R<sup>2</sup></b>		0.070			0.479	

\*: Standardized coefficients.

Bold type indicates  $P < 0.05$ .

he or she has to leave the decision to the physician, the less that person reports being involved in medical decision-making. The same results were found for the descriptive norm: the more people think that significant others leave the decision to the physician, the less they report being involved in the decision-making process. An explanation for this is that people behave according to the norms of their social environment, as this will result in social approval. For instance, it can be common in someone's social environment to leave medical decisions to physicians, since there is great deal of respect for them. If this is the situation, then people are expected to leave the decision to physicians in order to obtain social approval. Social norms might thus be a barrier against people participating in medical decision-making.

Consistent with previous empirical studies,<sup>6,10–12</sup> we found that involvement in medical decision-making is associated with individual patient characteristics. However, when social norms are included as an explanatory mechanism, most individual patient characteristics are no longer associated with involvement in such decision-making. This means that social norms are related to individual patient characteristics, as was confirmed in our analyses. Furthermore, we observed that people with a high level of education stated to be more involved in medical decision-making than people with a low level even when social norms are included as an explanatory mechanism. However, here, the effect of educational level on involvement is then much smaller. Based on this, we argue that social norms are less decisive for people with a high level of education and they are less dependent on others in their decision to be involved in medical decision-making compared with people with a low level. Our study gives a first insight into the idea that the decision to be involved in medical decision-making is not as individual as it first seems; someone's social context also plays a role. Our results suggest that differences in patient involvement have also to be examined at the level of the patient's social context, and not just at the individual patient level.

Our model including social norms explains much, but not all, variation in whether patients are actively involved in medical decision-making. This means that there are other mechanisms besides social norms that too influence patient involvement. One possible mechanism is the availability of social support in someone's social network. It would be interesting for further research to examine whether social support is related to involvement in medical decision-making, as well as whether the mechanisms of social support and social norms enhance each other, or are in conflict with each other, e.g. a situation where conservative norms and receiving support both exist. Another possible mechanism might be someone's health literacy. This is 'the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions'.<sup>22</sup> In the context of medical decision-making, it can be reasoned that those who are better able to obtain information, and to understand and judge it, are better prepared and more able to take an active role in such decision-making. It would be interesting to include health literacy in future research on patient involvement in medical decision-making.

The strengths of this study are the fact that the questionnaire was both sent by post and through the internet and the large sample size, even though there was a relatively low response rate. Our respondents were not representative of the general Dutch population aged 18 years and older.<sup>17</sup> When compared with this population, people aged 65 and over and western migrants were especially overrepresented. We expect that this does not affect our regression results, since all subgroups are of sufficient size to perform association analyses. Nevertheless, we performed sensitivity analyses in which we analysed model-II for non-migrants and migrants, respectively. The sensitivity analyses showed the same results. For both non-migrants and migrants, social norms are strongly related to their involvement in medical decision-making. Furthermore, it can be argued that health care panel members are more interested in health care, and, for instance, are more involved in the

decision-making process. This might have affected our results. In addition, a limitation might be that we examined self-reported involvement in medical decision-making, instead of actual observed behaviour. It remains unclear from this study whether people participate in the decision-making process in real life. Another limitation is the correlation between the measurements we used for the dependent and independent variables. The questions of the different concepts resembled each other, and therefore it is debatable whether the questions were sufficiently distinctive for the respondents. Moreover, there might be the possibility of same-source bias, since we measured involvement in medical decision-making and social norms in the same questionnaire. Thus, the way we measured our questions might have had an impact on our results. Further research is recommended to examine what happens when social norms are measured in a different way. One possible option is measuring the actual norms of network members, instead of measuring the network norms as perceived by the actor.<sup>23</sup> For future research, it would be interesting to ask network members themselves about their norms. Nevertheless, to our knowledge, no standardized measurements are available to measure social norms in the context of our study. We, therefore, believe that we provide a good starting point for developing such measures. Lastly, our data were obtained using a cross-sectional study design, and therefore, do not give insight into the question of causality. From the literature, it is known that people choose network members who are similar to them (selection). On the other hand, network members influence the way people think about various aspects (contagion).<sup>24</sup> In our context, this might imply that people choose network members who think the same about patient involvement, and that the way they think about this is influenced by their network members. Further research would have to make use of longitudinal data to gain insight into the question of causality.

## Conclusion

This study indicates that social norms do play a role as a mechanism in explaining involvement in medical decision-making. We found that the more conservative social norms are, the less likely it is that people are involved in such decision-making. Our study offers a first insight into the idea that the decision to be involved in medical decision-making is not as individual as it first seems; someone's social context also plays a role. Strategies aimed at emphasising patient involvement have to address this social context.

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*Conflicts of interest:* None declared.

## Key points

- This study explored the relationship between social norms and involvement in medical decision-making.
- The more conservative social norms are, the less likely it is that people are involved in medical decision-making.

- The decision to be involved in medical decision-making is not as individual as it first seems; someone's social context also plays a role.
- Strategies aimed at emphasising patient involvement have to address this social context.

## References

- 1 Institute of Medicine. *Crossing the Quality Chasm: A New Health System for the 21st Century*. Washington, DC: National Academies Press, 2001.
- 2 Ouwens M, van der Brug S, Faber M, et al. Shared decision making & Zelfmanagement. *Literatuuronderzoek naar begrippen*. Nijmegen: UMC St Radboud, IQ healthcare, 2012.
- 3 Charles C, Gafni A, Whelan T. Decision-making in the physician-patient encounter: revisiting the shared treatment decision-making model. *Soc Sci Med* 1999;49:651–61.
- 4 Emanuel EJ, Emanuel LL. Four models of the physician-patient relationship. *JAMA* 1992;267:2221–6.
- 5 Elwyn G, Laitner S, Coulter A, et al. Implementing shared decision making in the NHS. *BMJ* 2010;341:c5146.
- 6 Chewning B, Bylund CL, Shah B, et al. Patient preferences for shared decisions: a systematic review. *Patient Educ Couns* 2012;86:9–18.
- 7 van den Brink-Muinen A, van Dulmen SM, de Haes HC, et al. Has patients' involvement in the decision-making process changed over time? *Health Expect* 2006;9:333–42.
- 8 Arora NK, McHorney CA. Patient preferences for medical decision making: who really wants to participate? *Med Care* 2000;38:335–41.
- 9 Degner LF, Sloan JA. Decision making during serious illness: what role do patients really want to play? *J Clin Epidemiol* 1992;45:941–50.
- 10 Brom L, Hopmans W, Pasman HR, et al. Congruence between patients' preferred and perceived participation in medical decision-making: a review of the literature. *BMC Med Inform Decis Mak* 2014;14:25.
- 11 Ende J, Kazis L, Ash A, et al. Measuring patients' desire for autonomy: decision making and information-seeking preferences among medical patients. *J Gen Intern Med* 1989;4:23–30.
- 12 Say R, Murtagh M, Thomson R. Patients' preference for involvement in medical decision making: a narrative review. *Patient Educ Couns* 2006;60:102–14.
- 13 Burke NJ, Joseph G, Pasick RJ, et al. Theorizing social context: rethinking behavioral theory. *Health Educ Behav* 2009;36:55s–70s.
- 14 Coleman J. *Foundations of Social Theory*. Cambridge, MA: Belknap, 1990.
- 15 Cialdini RB, Kallgren CA, Reno RR. A focus theory of normative conduct: A theoretical refinement and reevaluation of the role of norms in human behavior. *Adv Exp Soc Psychol* 1991;24:1–243.
- 16 Ravis A, Sheeran P. Descriptive norms as an additional predictor in the theory of planned behaviour: a meta-analysis. *Curr Psychol* 2003;22:218–33.
- 17 Brabers A, Reitsma-van Rooijen M, De Jong J. *Consumentenpanel Gezondheidszorg: Basisrapport Met Informatie Over Het Panel (2015)*. Utrecht: NIVEL, 2015.
- 18 CCMO. Your research: does it fall under the WMO? [internet]. The Hague. Available at: <http://www.ccmo.nl/en/your-research-does-it-fall-under-the-wmo> (26 August, 2015, date last accessed).
- 19 Flynn KE, Smith MA, Vanness D. A typology of preferences for participation in healthcare decision making. *Soc Sci Med* 2006;63:1158–69.
- 20 Sieverding M, Mattered U, Ciccarello L. What role do social norms play in the context of men's cancer screening intention and behavior? Application of an extended theory of planned behavior. *Health Psychol* 2010;29:72–81.
- 21 Mackie G, Moneti F, Denny E, et al. *What are social norms? How are they measured*. University of California at San Diego-UNICEF Working Paper, San Diego, 2012.
- 22 Institute of Medicine. *Health Literacy: A Prescription to End Confusion*. Washington, DC: The National Academies Press, 2004.
- 23 Van Dijk L, Siegers J. *Norms of Networks Members and Labour Supply by Dutch Mothers with Young Children. Child Care and Female Labour Supply in the Netherlands*. Amsterdam: Thesis Publishers, 1998; 57–80.
- 24 Leenders RTAJ. Structure and influence: statistical models for the dynamics of actor attributes, network structure and their interdependence. PhD thesis. University of Groningen, 1995.

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## Health literacy in Europe: the development and validation of health literacy prediction models

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In this publication the terms ‘performance-based’ and ‘self-assessed’ health literacy were used, where in the HEALIT4EU project respectively the terms ‘objective’ and ‘perceived’ health literacy were used to refer to the two types of health literacy.<sup>1</sup>

**Background:** Health literacy is an important determinant of health, but national health literacy levels are known for only some European countries. This study aims to examine to what extent national health literacy levels can be estimated based on publicly available census data. **Method:** Multivariate models were used to predict two types of health literacy on population level. Predictors were selected based on literature, the European Health Literacy Survey (HLS-EU) and the Adult Literacy and Life Skills Survey (ALL). The HLS-EU provides insight into self-assessed health literacy and the ALL into the performance of individuals on health literacy tasks (performance-based health literacy). Dutch HLS-EU and ALL data were used to construct prediction models based on 2/3 of this data, which were validated in the remaining 1/3 of the data and (in case of self-assessed health literacy) in data from seven other European countries. **Results:** Education is a significant predictor of perceived and performance-based health literacy. Age and working status are significant predictors of performance-based health literacy, whereas gender and income are significant predictors of self-assessed health literacy. Both typologies of health literacy can satisfactorily be predicted within samples of the Dutch population. The accuracy of estimated self-assessed health literacy varied between the seven other European countries. **Conclusion:** Prediction models based on publicly available census data can be used for estimating self-assessed and performance-based health literacy on population level. Observed health literacy levels or better prediction models are required when one is interested in ranking European countries.

### Introduction

Health literacy entails the skills to access, understand, appraise and apply information to make health-related decisions.<sup>2</sup> Health literacy is recognized as an important determinant of health<sup>3–7</sup> and there is a social gradient for health literacy as there is for health.<sup>8,9</sup> In the past decade the number of studies indicating that lower health literacy is related to adverse health outcomes and higher healthcare costs has grown exponentially.<sup>10,11</sup> Studies show that lower health literacy is associated with a lower mental and physical health status, adverse disease specific outcomes, mortality, more use of healthcare and less use of preventive care.<sup>10</sup> Also poorer self-management and less satisfaction with care are associated with a lower level of health literacy.<sup>10,12</sup>

Although the topic of health literacy has gained attention in European research, policy and practice, only for some European member states knowledge is available concerning the level of health literacy of their population.<sup>8</sup> Measures of health literacy require in-person assessment, which is time-consuming and costly. In many European countries health literacy and national health

literacy assessment are not a focus of policy,<sup>1</sup> but there are few where it already is (e.g. Austria, Ireland). It is important to have insight into health literacy of populations across Europe, in order to identify countries or regions in which health literacy of the population is relatively low or in order to evaluate the effect of interventions. Unlike many health determinants which are difficult to modify, competencies could be taught and learned. Given the fact that competencies are distributed unevenly within a population, often along socio-demographic characteristics, a competencies-based approach focusing on health literacy can enrich current understanding of health inequalities. This requires insight into populations' level of health literacy.

Most European countries have insight into the socioeconomic and demographic distribution of their population. Since previous research shows that health literacy is closely related to socioeconomic and demographic characteristics,<sup>8,13</sup> it has been put forward that health literacy on population level could be estimated by applying prediction models based on these characteristics, when actual health literacy measures are absent. Yet few studies have explored this possibility.<sup>14,15</sup> This includes the study of Martin and