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The association between health literacy and cancer screening participation: A cross-sectional study across three organised screening programmes in Denmark

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ABSTRACT

Objective: Health literacy may be related to non-participation in cancer screening, but there is limited understanding of its association with participation across all cancer screening programmes. This study aims to explore the associations between health literacy and advancing in participation in cancer screening programmes.
Methods: We conducted a cross-sectional study involving women aged 53–65 years residing in Denmark on 31 March 2018. Data utilised was from population registries and self-reported health literacy (HLS-EU-Q16) collected autumn 2017. Uni- and multivariate ordinal logistic regression models were employed to assess associations between health literacy levels and the likelihood of increased attendance in cancer screening programmes. Results were presented as odds ratios (ORs) with 95 % confidence intervals (CIs).
Results: Of the women included, 2668 (69.8 %) responded to the health literacy questionnaire. Among these, 53.3 % demonstrated adequate health literacy, 34.4 % had problematic, and 12.3 % inadequate. In total, 71.2 % attended three screening programmes, 20.1 % attended two, 6.2 % attended one, and 2.5 % attended none. There were no differences in the ORs for advancing in screening attendance when comparing problematic (OR = 1.18, 95 % CI: 0.97–1.42) or inadequate (OR = 0.96, 95 % CI: 0.74–1.26) health literacy levels with an adequate level.
Conclusions: Our study suggests that health literacy does not significantly influence cancer screening participation among the studied population in Denmark. Therefore, interventions aimed at increasing screening participation in this group should not only target health literacy but also focus on other aspects of non-participation.

1. Introduction

Health literacy refers to an individual's ability to access, understand, appraise and apply health information in order to make informed decisions about their health (Sørensen et al., 2012). A national study estimates that around four out of 10 Danes struggle to navigate the complexities of health management (Svendsen et al., 2020), which falls within the range of estimated health literacy scores across European countries (Sørensen et al., 2015). A pronounced social gradient in health literacy has been documented internationally, with disadvantaged social and socioeconomic conditions related to lower health literacy levels (Svendsen et al., 2020; Stormacq et al., 2019; Nutbeam and Lloyd, 2021), which in turn are associated with poorer health outcomes (Berkman et al., 2011). Emerging evidence suggests that health literacy plays a vital role in health behaviours, including participation in preventive care (Stormacq et al., 2019; Scott et al., 2002; Cho et al., 2008).

Cancer screening programmes are effective preventive offers enabling timely interventions and improving outcomes for individuals at risk (Armaroli et al., 2015). However, despite widespread implementation of population-based screening programmes for cervical, colorectal,

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and breast cancer in many western countries, a notable proportion of eligible individuals do not participate (Cancer Screening in the European Union, 2017). In a Danish context, 55 % of women eligible for all three screening programmes participated in all of them, while 38 % attended only some, and 7 % did not participate in any (Njor et al., 2023).

Existing literature presents conflicting findings regarding the association between health literacy and non-participation in different screening programmes (Ritchie et al., 2022; Oldach and Katz, 2014; Baccolini et al., 2022). The earliest review identified a trend suggesting inadequate health literacy was associated with lower screening participation, though no statistically significant association was found (Oldach and Katz, 2014). The latest review and meta-analysis reported an association between health literacy levels and breast and cervical cancer screening but found no statistically significant relationship for colorectal cancer screening (Baccolini et al., 2022). Furthermore, limited research has focused on the combination of screening participation patterns across multiple cancer screening programmes (Njor et al., 2023; Rebolj et al., 2020; Kregting et al., 2022), highlighting a gap in our understanding of the ones not taking part in the offered cancer screening programmes. Addressing this gap is essential for developing targeted interventions to enhance participation rates and reduce social disparities in cancer screening.

Therefore, this study aims to examine the associations between health literacy and advancing in participation in cancer screening programmes in Denmark. By elucidating the role of health literacy in screening behaviour across programmes, we aim to inform strategies for optimising screening efforts.

2. Materials and methods

2.1. Setting

Denmark operates a healthcare system characterised by centralised policy-making, but with administrative responsibilities distributed among five distinct regions. The country is inhabited by around 5.9 million residents, of which 1.3 million is residing in the Central Denmark Region (The division of research services, 2024). The Danish healthcare system is primarily funded through taxes, and cancer screening programmes are provided free of charge, including clinical follow-up and subsequent treatments.

Denmark provides organised screening programmes for breast, colorectal and cervical cancers. Cervical cancer screening was nationally organised in the late 1990s (Lynge et al., 2006). Currently, women aged 23–64 years are offered cervical cancer screening at intervals of three to five years, depending on age and screening test (cervical samples tested for abnormal cytology or high-risk Human Papillomavirus types). While primarily conducted by general practitioners, the implementation of vaginal self-sampling is currently underway. Colorectal cancer screening was gradually implemented through 2014–2017, targeting individuals aged 50–74 years (Njor et al., 2018). Residents receive a Faecal Immunochemical Test (FIT) kit by mail every two years, complete with user-instructions and a prepaid return envelope. Breast cancer screening reached national coverage in 2010 (Christiansen et al., 2014). The programme is directed towards women aged 50–69 years, offering biennial mammography appointments at a regional breast cancer screening unit. All three screening programmes employ reminder systems in case of non-participation.

Invitations and reminders are integrated within a comprehensive call-recall system, which tracks invitations, reminders, and individuals who have unsubscribed.

2.2. Study design and population

The study employed a cross-sectional design, utilising secondary analyses of questionnaire responses to assess health literacy and comprehensive register data on screening participation and socio-demographic variables.

The target population consisted of residents who had received a health literacy questionnaire and were eligible in all three cancer screening programmes (Fig. 1). In a prior trial (Gabel et al., 2020), a total of 15,030 individuals residing in the Central Denmark Region, aged 50–74 years, received a health literacy questionnaire (Gabel et al., 2019). Among them, 4348 women aged 53–65 years were included in this study as they met the eligibility criteria for all three programmes and had sufficient response time for each programme's invitation (Njor et al., 2023). Women with a prior diagnosis of cervical, colorectal, or breast cancer, as well as women who had undergone hysterectomy were excluded.

2.3. Data collection

Included individuals received an electronic questionnaire in August/September 2017 to assess their health literacy. Non-responders received a digital reminder after two weeks, followed by telephone contact after four weeks to offer completion of the questionnaire via phone. Data collection was completed in April 2018. Health literacy levels were assessed using self-reported data from the European Health Literacy Short Scale, consisting of 16 items (HLS-EU-Q16). The questionnaire is a unidimensional and shorter version of the 47-item European Health Literacy Survey (HLS-EU-Q47), developed by the HLS-EU Consortium (Sørensen et al., 2013), to assess the health literacy levels of general populations in terms of accessing, understanding, appraising and applying information. The HLS-EU-Q16 has been used and validated internationally (Pelikan et al., 2022). Respondents' health literacy levels were categorised according to the scale's manual as follows: 'adequate' (13–16 points), 'problematic' (9–12 points), or 'inadequate' (0–8 points). Any missing items were scored as 0, and if more than two items were missing, the total score was considered missing (Gabel et al., 2019).

Screening history data were collected on 31 March 2018.

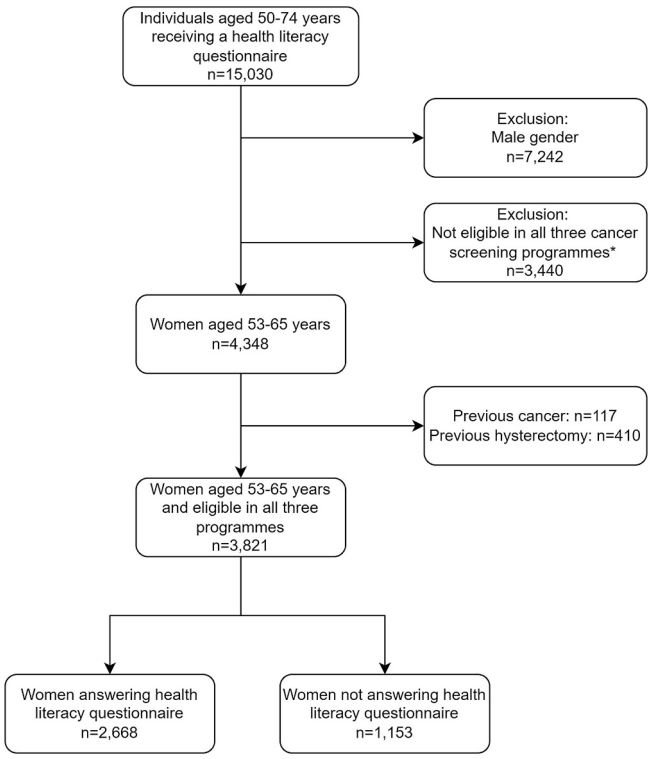

Fig. 1. Study flowchart of individuals aged 50-74 years in Central Denmark Region receiving a health lieracy questionnaire in 2017.

Participation in each cancer screening was defined as having undergone at least one cervical sample, FIT, or mammography between 1 April 2012 and 31 March 2018. Participation was categorised according to number of screening programmes attended (none, one, two or three). Data on participation in cervical cancer screening was retrieved from the Danish Pathology Registry, on colorectal cancer screening from the Danish Colorectal Cancer Screening Database, and on breast cancer screening from the Danish Breast Cancer Screening Database, as detailed in previous publication (Njor et al., 2023).

Sociodemographic characteristics at an individual level were gathered from Statistics Denmark from 2016 to 2018. The following categories were used to classify sociodemographic characteristics: Cohabitating individuals included those who were married, living in a registered partnership, or cohabitating. Household income was categorised according to the Organization for Economic Co-operation and Development (OECD)-modified equivalence scale, divided into tertiles, and rounded to the nearest 1000 Euros. Education levels were classified according to the UNESCO classification system.

Data on previous cancer diagnoses were sourced from the Danish Pathology Registry, while information on hysterectomies was obtained from the Danish National Patient Registry.

Individual-level linkage of register data on screening participation, sociodemographic characteristics, and health literacy scores was facilitated through the use of the Civil Personal Registration (CPR) number, which is assigned to every resident upon birth or immigration to Denmark.

2.4. Statistical analysis

Characteristics of sociodemographic factors for respondents and non-respondents, and for respondents participating in none, one, two or three programmes, respectively, were presented using descriptive statistics (numbers and proportions). Differences in sociodemographic variables were evaluated using Pearson chi-squared test.

Crude and adjusted ordinal logistic regression analyses were performed to evaluate the association between health literacy levels and the likelihood of increased participation in cancer screening programmes. The results are reported as odds ratios (ORs) with 95 % confidence intervals (CIs). The proportional odds assumption was evaluated using the Brant test. The adjusted models accounted for age, marital status, income and education level. Ethnicity was not included because of the limited number of immigrants in the study population.

All statistical tests were two-sided, and a significance level of *P*-values <0.05 were considered statistically significant. Statistical analyses were carried out using STATA version 17.

2.5. Ethics approval

The study was registered in the record of processing activities for research projects within the Central Denmark Region (R. No.: 1–16–02-217-21). In accordance with Danish Legislation, notification of register-based research projects to the research ethics committee system is not required.

3. Results

Among the 15,030 individuals invited to complete the health literacy questionnaire, 7242 men were excluded, and 3440 women were excluded for not meeting the age criteria required for participation in all three screening programmes within the allotted time (Fig. 1). Additionally, 527 women were excluded based on previous diagnosis of breast, colorectal, or cervical cancer or having undergone a hysterectomy. Of the remaining 3821 women, 69.8 % ($n = 2668$) completed the health literacy questionnaire.

Statistically significant differences were detected between questionnaire responders and non-responders in ethnicity, marital status, income, education levels, and the number of screening programmes attended ($p < 0.001$ for all variables) (Table 1). Age distribution did not differ significantly between the two groups ($p = 0.49$).

Among the women who completed the health literacy questionnaire, health literacy levels were distributed as follows: 53.3 % ($n = 1423$) had adequate health literacy, 34.3 % ($n = 914$) had problematic health literacy, and 12.4 % ($n = 331$) had inadequate health literacy. A total of 71.2 % ($n = 1900$) participated in all three offered screening programmes, 20.1 % ($n = 536$) in two, 6.2 % ($n = 165$) in one, and 2.5 % ($n = 67$) did not participate in any screening programme. Characteristics of these populations are detailed in Table 2. No statistically significant differences among individuals participating in none, one, two, or three programmes in relation to age ($p = 0.89$) and level of health literacy ($p = 0.57$) were detected. Significant disparities were observed in relation to ethnicity, marital status, income, and education level ($p < 0.01$ for all variables).

When adjusting for age, marital status, income and educational attainment, no statistically significant difference in the OR for advancing in screening attendance was observed for problematic (OR = 1.18, 95 % CI: 0.97–1.42) or inadequate health literacy (OR = 0.96, 95

Table 1
Sociodemographic characteristics of women aged 53–65 in Central Denmark Region (2012–2018), eligible for all three cancer screening programmes and receiving a questionnaire on health literacy.

	Total population invited		Respondents		Non-respondents		P-value[a]
	N = 3821		*n* = 2668		*n* = 1153		
	n	%	n	%	n	%	
Age group (years)							0.49
Median in years	59.3		59.3		59.3		
53–55	805	21.1	552	20.7	253	21.9	
56–60	1557	40.8	1082	40.6	475	41.2	
61–65	1459	38.2	1034	38.8	425	36.9	
Ethnicity							<0.001
Danish	3586	93.9	2554	95.8	1032	89.5	
Western immigrants	85	2.2	57	2.1	28	2.4	
Non-Western immigrants	150	3.9	57	2.1	93	8.1	
Marital status							<0.001
Cohabitating[b]	2698	70.6	2011	75.4	687	59.6	
Living alone	1123	29.4	657	24.6	466	40.4	
Income[c]							<0.001
High tertile (>49.000 Euros)	1235	32.6	960	36.0	275	23.9	
Middle tertile (34.000–49.000 Euros)	1280	33.5	964	36.1	316	27.4	
Low tertile (<34.000 Euros)	1306	34.2	744	27.9	562	48.7	
Education[d]							<0.001
High (>15 years)	1147	30.0	847	31.8	300	26.0	
Middle (11–15 years)	1706	44.7	1234	46.3	472	40.9	
Low (≤10 years)	897	23.5	554	20.8	343	29.8	
Missing	71	1.9	33	1.2	38	3.3	
Screening participation							<0.001
0/3	276	7.2	67	2.5	209	18.1	
1/3	378	9.9	165	6.2	213	18.5	
2/3	889	23.3	536	20.1	353	30.6	
3/3	2278	59.6	1900	71.2	378	32.8	

[a] Tested by Pearson chi-squared test.
[b] Cohabitating includes being married, living in a registered partnership and cohabitating.
[c] Household income according to the Organization for Economic Co-operation and Development (OECD)-modified equivalence scale. Based on tertiles and rounded off to the nearest 1000 Euros.
[d] According to the classification of United Nations Educational, Scientific and Cultural Organization.

Table 2
Sociodemographic characteristics of women responding to the health literacy questionnaire, by screening participation status, Central Denmark Region, 2012–2018 (N = 2668).

	0/3 screening programmes		1/3 screening programmes		2/3 screening programmes		3/3 screening programmes		P-value[a]
	n = 67 (2.5 %)		**n = 165 (6.2 %)**		**n = 536 (20.1 %)**		**n = 1900 (71.2 %)**		
	n	%	n	%	n	%	n	%	
Age group (years)									0.89
Median in years	59.3		59.3		59.3		59.3		
53–55	14	20.9	33	20.0	107	20.0	398	21.0	
56–60	32	47.8	66	40.0	221	41.2	763	40.2	
61–65	21	31.3	66	40.0	208	38.8	739	38.9	
Ethnicity									<0.001
Danish	60	89.6	155	93.9	512	95.5	1827	96.2	
Western immigrants	7[b]	10.5[b]	5	3.0	10	1.9	37	2.0	
Non-Western immigrants	–	–	5	3.0	14	2.6	36	1.9	
Marital status									<0.001
Cohabitating[c]	44	65.7	95	57.6	379	70.7	1493	78.6	
Living alone	23	34.3	70	42.4	157	29.3	407	21.4	
Income[d]									<0.001
High tertile (>49.000 Euros)	10	14.9	42	25.5	180	33.6	728	38.3	
Middle tertile (34.000–49.000 Euros)	31	46.3	54	32.7	170	31.7	709	37.3	
Low tertile (<34.000 Euros)	26	38.8	69	41.8	186	34.7	463	24.4	
Education[e]									0.002
High (>15 years)	17	25.4	53	32.1	194	36.2	583	30.7	
Middle (11–15 years)	25	37.3	69	41.8	234	43.7	906	47.7	
Low (≤10 years)	25[f]	37.3[f]	43[f]	26.1[f]	98	18.3	391	20.6	
Missing	–	–	–	–	10	1.9	20	1.1	
Health Literacy									0.57
Adequate (n = 1423)	35	52.2	94	57.0	294	54.9	1000	52.6	
Problematic (n = 914)	22	32.8	47	28.5	174	32.5	671	35.3	
Inadequate (n = 331)	10	14.9	24	14.6	68	12.7	229	12.1	

[a] Tested by Pearson chi-squared test.
[b] Western immigrants and non-Western immigrants have been combined to comply with Danish data protection legislation concerning small sample sizes.
[c] Cohabitating includes being married, living in a registered partnership and cohabitating.
[d] Household income according to the Organization for Economic Co-operation and Development (OECD)-modified equivalence scale. Based on tertiles and rounded off to the nearest 1000 Euros.
[e] According to the classification of United Nations Educational, Scientific and Cultural Organization.
[f] Missing data have been combined with the category of low educational attainment to comply with Danish data protection legislation concerning small sample sizes (<5 women).

% CI: 0.74–1.26) compared with adequate health literacy (Table 3).

Sensitivity analyses were conducted by excluding the education variable in the ordinal logistic regression model. These analyses did not result in significant changes to the observed ORs (data not presented).

4. Discussion

4.1. Main findings

Among the 2668 women who had completed the health literacy questionnaire and were eligible in all three cancer screening programmes in Denmark, no statistically significant difference in health literacy levels was identified for advancing in screening participation. Furthermore, health literacy levels did not appear to impact the likelihood of participating in multiple screening programmes, and adjusting for sociodemographic factors did not modify this relationship.

Table 3
Crude and adjusted associations between health literacy and advancing in screening participation among women in Central Denmark Region (2012–2018), with odds ratios (ORs) and 95 % confidence intervals (95 % CI).

	Crude ORs (95 % CI)	Adjusted ORs[b] (95 % CI)
Health literacy[a]		
Adequate	1 (ref)	1 (ref)
Problematic	1.17 (0.97–1.41)	1.18 (0.97–1.42)
Inadequate	0.94 (0.73–1.21)	0.96 (0.74–1.26)

[a] Points on HLS-EU-Q16 scale: Adequate: 13–16 points, Problematic: 9–12 points, Inadequate: 0–8 points.
[b] Adjusted for age, marital status, income and education.

4.2. Comparison with other studies

Among the respondents, 53.3 % demonstrated adequate health literacy, slightly lower than the 62.5 % reported within a comparable age group in the Danish study by Svendsen et al. (Svendsen et al., 2020), indicating that a larger group of individuals with problematic or inadequate health literacy were reached.

Our study did not identify a statistically significant association between health literacy and participation across all three screening programmes among women aged 53–65 years in Denmark. Prior research has reported inconsistent findings regarding the impact of health literacy on screening participation within each individual screening programme (Oldach and Katz, 2014; Baccolini et al., 2022; Zanobini et al., 2023; Pancar and Mercan, 2021; Yalçın Gürsoy and Bulut, 2023; Yalçın Gürsoy and Uçan, 2024). However, variations in screening programmes and tests, populations investigated, as well as differences in the measurement tools used to assess health literacy, may reduce the comparability between studies. The most recent review and meta-analysis by Baccolini et al. (Baccolini et al., 2022) report a significant association between health literacy levels and participation in breast and cervical cancer screening but not in colorectal cancer screening. Notably, all studies included in the review for cervical cancer screening were conducted in the US, as were all but one (Yılmazel, 2018) for breast cancer screening, potentially limiting generalisability to European settings. Most studies included in the reviews used health literacy measurement tools that assessed functional health literacy through reading comprehension and numeracy (Oldach and Katz, 2014; Baccolini et al., 2022).

Our study employed a more multidimensional tool, which limits direct comparability of the results. However, a recent study of an Italian population also identified a significant association with breast cancer screening (Zanobini et al., 2023), using the HLS-EU-Q6, a version of the tool used in our study that measures similar components. In contrast, previous studies conducted in Danish settings did not find such associations (Horshauge et al., 2020; Egsgaard et al., 2023). So far, however, no previous studies have investigated overall screening participation across cancer screening programmes.

Denmark boasts a population that is generally well-educated and exhibits high levels of trust in Danish health authorities (Organisation for Economic Co-operation and Development, 2022; World Values Survey (WVS), 2024). With a robust and inclusive healthcare system offering free services to all citizens and supported by numerous health promotion polices, the impact of health literacy on screening participation might not be as pronounced in this context. However, in countries characterised by larger disparities in health services (Sørensen et al., 2015), health literacy may play a more substantial role in cancer screening participation.

It is conceivable that the Danish screening and invitation system already adequately addresses the needs associated with varying levels of health literacy, as indicated by the consistently and relatively high participation rates compared with many other countries. A contrary argument could be that multiple factors contributing to non-participation exist simultaneously for women with both low and high health literacy. For instance, women with high health literacy may deliberately choose not to participate due to weighing benefits and harms, while those with low health literacy may struggle to navigate the complex health system, leading to non-participation. This could potentially minimize the disparity between groups and obscure the apparent influence of health literacy on screening participation (Egsgaard et al., 2023).

Although health literacy may not pose a significant barrier to participating in cancer screening, its influence on adherence to follow-up procedures remains important to address, as previous studies have shown an association between health literacy and treatment adherence (Miller, 2016; Holden et al., 2021). Compliance to follow-up procedures following a positive screening result is crucial for realising the benefits of screening programmes. Therefore, the potential relationship between health literacy and follow-up adherence warrants further investigation in future studies.

Disparities in health outcomes are exacerbated by unequal participation in cancer screening, with marginalised individuals often facing greater barriers to accessing and utilising preventive services, thus widening existing health gaps (Vaccarella et al., 2023; Minas et al., 2021). Hence, improving participation rates among these vulnerable subgroups must remain a priority.

5. Strengths and limitations

The study employed extensive and high-quality individual-level register data on both screening participation and sociodemographic variables, complemented by questionnaire data on health literacy. The questionnaire attained a fairly high response rate of 69.8 %. Additional efforts were undertaken to engage individuals who initially did not complete the questionnaire, including outreach via telephone and offering the option to complete the questionnaire orally.

However, it is a limitation that the population that completed the health literacy questionnaire is not representative of the total study population invited for all three cancer screening programmes. A total of 71.2 % of the respondents participated in all three screening programmes (Njor et al., 2023) compared to 32.8 % participation rate in all three programmes among the non-responders. Furthermore, non-responders displayed more vulnerable sociodemographic characteristics, skewing the generalisability of the results. It is recognised that a socioeconomic gradient exists in health literacy levels, with certain subgroups demonstrating higher proportions of individuals with limited health literacy than the general population (Svendsen et al., 2020; Sørensen et al., 2015). Consequently, in this study, there may be a risk of overestimating health literacy among the screening-eligible population.

Furthermore, it is plausible that individuals with low health literacy who complete the health literacy questionnaire may differ in their levels of trust in health authorities, willingness to engage in health services, and attention to preventive care. This could potentially result in higher screening rates among this subgroup compared to other subgroups with low health literacy. Therefore, the association between health literacy and screening participation might be more pronounced among vulnerable populations who do not respond, reflecting potential selection bias among the respondents.

The HLS-EU-Q16 questionnaire has been extensively tested and employed across various countries (Svendsen et al., 2020; Sørensen et al., 2013; Levin-Zamir et al., 2016). However, questions have been raised regarding the suitability of the HLS-EU-Q16, as it does not include all aspects intended to be measured by HLS-EU-Q47 (Pelikan et al., 2022; Finbråten et al., 2018).

A limitation to our study is the insufficient data to include ethnicity in our adjusted model, despite immigration status serving as a risk-factor for non-participation (Bhargava et al., 2018; Bozhar et al., 2022).

6. Conclusion and implications

Based on the findings of this study, health literacy does not appear to play a significant role in influencing participation in cancer screening programmes among the study population of women aged 53–65 years in Denmark. Therefore, interventions to increase participation should prioritise addressing other factors associated with non-participation. However, the findings should be interpreted cautiously, and further research is warranted to better understand the dynamics of health literacy in broader screening contexts.

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CRediT authorship contribution statement

Anne Dorte Lerche Helgestad: Writing – original draft, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Alexandra Winkler Karlsen:** Writing – review & editing, Methodology, Formal analysis, Data curation. **Sisse Njor:** Writing – review & editing, Supervision, Methodology. **Berit Andersen:** Writing – review & editing, Supervision, Methodology, Conceptualization. **Mette Bach Larsen:** Writing – review & editing, Validation, Supervision, Methodology, Formal analysis, Conceptualization.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Data availability

In compliance with Danish data privacy regulations, the register-based datasets generated and analyzed in this project are not publicly available and are restricted to pre-approved researchers at Statistics Denmark. Access to these data may be granted upon submission of a reasonable scientific proposal to Statistics Denmark, limited to the scope of the current project and solely for scientific purposes. Participants in this study did not agree for their questionnaire data to be shared publicly, so supporting questionnaire data is not available.

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