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Improving public understanding of 'overdiagnosis': a population survey assessing familiarity with possible terms for labelling the concept and perceptions of appropriate terminology

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ABSTRACT

Objectives: Communicating the concept of 'overdiagnosis' to lay individuals is challenging, partly because the term itself is confusing. This study tested whether alternative descriptive labels may be more appropriate.

Design: Questionnaire preceded by a description of overdiagnosis.

Setting: Home-based, computer-assisted face-to-face survey.

Participants: 2,111 adults aged 18 to 70 years in England recruited using random location sampling by a survey company. Data from 1,888 participants were analysed after exclusions due to missing data.

Interventions: Participants were given one of two pieces of text describing overdiagnosis, allocated at random, adapted from NHS breast and prostate cancer screening leaflets.

Primary and secondary outcome measures: Main outcomes were which of several available terms (e.g. 'overdetection') participants stated they had previously encountered and which they endorsed as applicable labels for the concept as described. Demographics and previous exposure to screening information were also measured.

Results: 58.0% of participants had not encountered any of the available terms; 44.0% did not endorse any as applicable labels. No term was notably familiar; the proportion of participants stating they had previously encountered each term ranged from 15.9 to 28.3%. Each term was only endorsed as applicable by a minority of participants (range: 27.6% to 40.4%). Findings were similar for both pieces of information.

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8 *Conclusions:* Familiarity with suggested terms for overdiagnosis and levels of endorsement
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10 were low and no clear alternative labels for the concept were identified, suggesting that
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12 changing terminology alone would do little to improve understanding. Explicit descriptions may
13
14 be more effective.

15
16 Keywords: Decision Making; Surveys and Questionnaires; Early Detection of Cancer; Mass
17
18 Screening; Medical Overuse
19

20 **Strengths and limitations of this study**

- 21 • This study assessed familiarity and perceived appropriateness of a broad range of
22 possible terms for the concept of 'overdiagnosis' among a large, representative
23 sample of the general public in England.
- 24 • The concept was described based on information that was widely used by the
25 National Health Service in England, maintaining generalisability.
- 26 • The list of possible terms was not exhaustive; more suitable alternative labels may
27 have been omitted.
- 28 • Results may be time-dependent: ongoing communication initiatives may change
29 perceptions of appropriate terms for the concept of 'overdiagnosis'.
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40 **INTRODUCTION**

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42 There is growing concern about the potential for medical tests to detect asymptomatic disease
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44 that would never have become clinically apparent or resulted in death (1). 'Overdiagnosis' can
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46 harm, primarily via the subsequent risks and costs associated with unnecessary treatment but
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48 also via opportunity costs to a healthcare service due to overuse of scarce resources (2).
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8 Various initiatives have aimed to propagate understanding of the concept among patients and
9 the public so that they can make better informed decisions about their health (e.g. 3–5).
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11 However, previous studies have found that the concept is challenging to communicate to lay
12
13 people (e.g. in the context of breast cancer screening; 6,7).
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16 Little is known about how to improve communication of overdiagnosis (8). One barrier is that the
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18 term ‘overdiagnosis’ itself may be confusing (e.g. since it resembles ‘misdiagnosis’; 9). Hence,
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20 this study asked a large sample of the public in England to appraise descriptions of the concept
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22 and tested which of several possible terms people thought made sense as labels (i.e.
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24 endorsement). Alternatives included ‘overdetection’ or ‘unnecessary diagnosis’ (10) as well as
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26 terms related to unnecessary therapy (e.g. ‘overtreatment’) and terms that were less technically
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28 accurate but still had the potential to be seen as applicable (e.g. ‘false positives’; 9, 11). A
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30 limitation to the utility of ‘overdiagnosis’ as a label may be the currently low level of public
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32 awareness of the term (9, 12). Consequently, this study also measured which terms people had
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34 encountered before (i.e. familiarity) to test whether any alternatives were notably more familiar.

35 Information was derived from materials that have been widely used by the NHS Breast
36
37 Screening Programme (13) and the Prostate Cancer Risk Management Programme (14). The
38
39 study was carried out as part of Wave 3 of the Attitudes, Behaviour and Cancer UK Survey
40
41 (ABACUS). Other studies arising from this survey have also been published (e.g. 15).
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43 **METHODS**

44 **Design**

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46 Institutional approval was granted by the University College London Research Ethics
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48 Committee (5771/002). The focus of the present study was on appropriate terminology for
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8 widely used descriptions of overdiagnosis. However, the ABACUS survey was a broader piece
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10 of work that also compared the perceived clarity of different forms of overdiagnosis information.
11 Hence, elements of the design and measures have also been reported elsewhere (15). Face-to-
12 face computer-assisted interviews were conducted by TNS (a market research company) as
13 part of a weekly omnibus survey and took place in participants' homes between April and May
14 2016. Participants were informed:

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20 *"We would now like to ask you some questions about leaflets on health-related topics. The NHS*
21 *offers people a variety of screening tests to check for illnesses before symptoms have*
22 *appeared. People offered an NHS screening test are often given a leaflet that explains the risks*
23 *and benefits of having the test. The leaflet is either posted or given out by a doctor or nurse."*
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28 Participants then received information on overdiagnosis adapted from written material used by
29 the NHS in England as part of either i) the Breast Screening Programme or ii) the Prostate
30 Cancer Risk Management Programme as they existed in February 2016 (neither of which used
31 a specific label), allocated at random in a 1:1 ratio:

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36 *"The test can find an illness that would never have caused a person harm. Some people will be*
37 *diagnosed and treated for an illness that would never otherwise have been found and would not*
38 *have become life-threatening."* From the breast screening information leaflet (13)
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42 *"The test may make you worry by finding an illness that may never cause any symptoms or*
43 *shorten your life."* From the prostate screening information leaflet (14)
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References to cancer were removed so that findings could be generalised to beyond these two
specific screening contexts.

Participants

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8 Participants were members of the public in England aged 18 to 70 years. National
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10 representativeness was sought via a two-stage process. In the first instance, random location
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12 sampling was carried out using the Postcode Address File and Census statistics. Within each
13
14 selected location, participant quotas were set based on demographic characteristics (e.g. age,
15
16 gender, employment status).

17 18 **Measures**

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20 Demographics: Relevant measures consisted of age, gender, ethnicity, social grade (16),
21
22 marital status, highest level of education obtained, personal history of cancer, and whether
23
24 anyone they know had been diagnosed with cancer.

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26 Familiarity with screening information: Participants were asked whether they had ever
27
28 previously received information about screening (for cancer or other illnesses) via i) reading a
29
30 leaflet from the NHS, ii) reading an NHS website, and iii) talking with a doctor or nurse
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32 (response options: "yes", "no", "not sure").

33
34 If participants were eligible for cancer screening and had not been diagnosed with the target
35
36 disease, they were asked about their previous participation via items designed using the
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38 Precaution Adoption Process Model (PAPM; 17), a stage theory of protective health behaviour.
39
40 This measures whether participants have heard of a particular type of screening, whether they
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42 have heard of a type of screening but have never been invited, whether they have been invited
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44 but never participated, whether they have participated but not consistently, and whether they
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46 have participated consistently. Eligibility criteria and exact question wording for assessing
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48 experience have been reported elsewhere (15).

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8 Perceived clarity of information: After reading the information allocated at random, participants
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10 were asked, "How clear do you find this description of a risk of the test?" with available
11 responses of "extremely clear", "very clear", "moderately clear", "slightly clear", and "not at all
12 clear". This was followed by a question on whether they had read or heard similar information
13 about a screening test before (possible responses were: "yes", "no", and "not sure").
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18 Main outcomes: The first main outcome measure (endorsement) consisted of "Does this term
19 make sense to you as a way of describing this risk of a screening test?", followed by seven
20 terms: "overdiagnosis", "overdetection", "unnecessary diagnosis", "overtreatment", "unnecessary
21 treatment", "false positive diagnosis", and "false positive test results"¹ (responses: "yes", "no").
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23 Suggested terms were based on previous literature (e.g. 10) and group discussion among the
24 research team.
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29 The second outcome measure (familiarity) was: "Have you ever seen or heard any of the
30 previous seven terms before today?" and if participants responded "yes", they were asked
31 which out of the previous terms (responses: "yes", "no", "not sure").
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35 Analysis

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38 Participants were excluded if they declined to answer any of the measures included in this
39 study. Methods of coding ethnicity, marital status, highest level of education obtained, social
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46 ¹ Participants were also asked, "Can you think of any other terms to describe this risk that would
47 make sense to you?". However, only approximately 60 responses suggesting potentially
48 applicable terms were recorded across all participants (e.g. "oversensitivity", "unknown
49 diagnosis"), of which most were mentioned just once and so no further analysis was attempted.
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8 grade, and previous cancer screening participation (i.e. whether they had ever taking part in
9 each form of screening for which they were eligible) have been reported elsewhere (15).

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12 Sample characteristics were summarised with descriptive statistics. We report the percentages
13 of participants (with binomial 95% confidence intervals) who had previously encountered and
14 endorsed each possible number of terms (from 0 to 7 in both cases), and the percentages of
15 participants who had previously encountered and endorsed each specific term.
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19 20 21 **RESULTS**

22 23 **Participant characteristics**

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26 After excluding 223 participants with missing data, 1,888 cases were analysed. Sample
27 characteristics are presented in Table 1. Mean age was 43.6 years (standard deviation: 15.7).
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30 31 **Familiarity with terms**

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33 Table 2 illustrates that the majority of participants (58.0%) were not familiar with any of the listed
34 terms. However, the second most common number of terms recognised as familiar was all
35 seven (12.3%). The percentages of participants previously encountering between one and six
36 terms ranged from 1.1% to 9.4%. Table 2 also shows that the percentages of participants who
37 had encountered each specific term ranged from 15.9% (*“overdetection”*) to 28.3% (*“false
38 positive test results”*).
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Table 1 – Characteristics of the sample

Total N=1,888		
Characteristic	n	(%)
Overdiagnosis information		
Breast screening text	987	(52.3)
Prostate screening text	901	(47.7)
Gender		
Male	879	(46.6)
Female	1,009	(53.4)
Ethnicity		
White British	1,432	(75.8)
Other ethnic groups	456	(24.2)
Marital status		
Married or living as a couple	1,133	(60.0)
Single, widowed, divorced, or separated	755	(40.0)
Highest level of education¹		
No formal qualifications	281	(14.9)
Approximately Level 1, 2, or 3	890	(47.1)
Approximately Level 4	507	(26.9)
Other	199	(10.5)
Don't know/Not sure	11	(0.6)
Social class grade²		
Grade A or B	386	(20.4)
Grade C1 or C2	931	(49.3)
Grade D or E	571	(30.2)
Personal diagnosis of cancer		
Yes	98	(5.2)
No	1,790	(94.8)
Knows someone with cancer		
Yes	1,113	(59.0)
No	771	(40.8)
Don't know/Not sure	4	(0.2)
Any previous cervical screening experience		
Yes	652	(34.5)
No	226	(12.0)
Not eligible	1,010	(53.5)
Any previous breast screening experience		
Yes	317	(16.8)
No	83	(4.4)
Not eligible	1,488	(78.8)
Any previous bowel screening experience		
Yes	293	(15.5)
No	181	(9.6)
Not eligible	1,414	(74.9)
Any previous prostate screening experience		
Yes	77	(4.1)
No	344	(18.2)
Not eligible	1,467	(77.7)
Previously read a screening leaflet		
Yes	1,058	(56.0)
No	809	(42.8)
Don't know/Not sure	21	(1.1)
Previously read an NHS screening website		
Yes	324	(17.2)
No	1,549	(82.0)
Don't know/Not sure	15	(0.8)
Discussed screening with doctor/nurse		
Yes	624	(33.1)
No	1,251	(66.3)
Don't know/Not sure	13	(0.7)

Previously read or heard similar information

Yes	662	(35.1)
No	1,185	(62.8)
Don't know/Not sure	41	(2.2)

Perceived clarity of information

Extremely clear	170	(9.0)
Very clear	636	(33.7)
Moderately clear	685	(36.3)
Slightly clear	206	(10.9)
Not at all clear	191	(10.1)

¹Level 1-3 qualifications include e.g. GCSEs and A Levels; Level 4 qualifications include degrees and higher degrees

²Social grades are based on occupation (e.g. Grade A includes managerial roles; Grade E includes casual workers)

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Table 2 – Number of participants (and percentages and 95% CIs) previously encountering i) each number of possible terms and ii) each specific term. Participants receiving overdiagnosis information based on the Breast Screening programme or the Prostate Cancer Risk Management Programme were analysed separately.

		Number of terms previously encountered: n, %, 95% CIs							
Screening information	Total	0	1	2	3	4	5	6	7
Breast	n (%)	583 (59.1)	73 (7.4)	76 (7.7)	53 (5.4)	41 (4.2)	28 (2.8)	9 (0.9)	124 (12.6)
N=987	95% CI	56.0 to 62.1	5.9 to 9.2	6.2 to 9.5	4.1 to 6.9	3.0 to 5.5	1.9 to 4.0	0.5 to 1.7	10.6 to 14.7
Prostate	n (%)	512 (56.8)	64 (7.1)	101 (11.2)	47 (5.2)	37 (4.1)	19 (2.1)	12 (1.3)	109 (12.1)
n=901	95% CI	53.6 to 60.0	5.6 to 8.9	9.3 to 13.4	3.9 to 6.8	3.0 to 5.6	1.3 to 3.2	0.7 to 2.2	10.1 to 14.3
Total	n (%)	1,095 (58.0)	137 (7.3)	177 (9.4)	100 (5.3)	78 (4.1)	47 (2.5)	21 (1.1)	233 (12.3)
N=1,888	95% CI	55.8 to 60.2	6.2 to 8.5	8.1 to 10.8	4.4 to 6.4	3.3 to 4.1	1.9 to 3.3	0.7 to 1.7	10.9 to 13.9
		<i>"Which of the following term or terms had you heard of before?": n, %, 95% CIs</i>							
Screening information	Total	Not sure	Overdiagnosis	Overdetection	Unnecessary diagnosis	Overtreatment	Unnecessary treatment	False positive diagnosis	False positive test result
Breast	n (%)	7 (0.7)	215 (21.8)	163 (16.5)	214 (21.7)	225 (22.8)	280 (28.4)	243 (24.6)	270 (27.4)
N=987	95% CI	0.3 to 1.4	19.3 to 24.4	14.3 to 18.9	19.2 to 24.3	20.3 to 25.5	25.6 to 31.2	22.0 to 27.4	24.6 to 30.2
Prostate	n (%)	14 (1.6)	196 (21.8)	137 (15.2)	216 (24.0)	186 (20.6)	253 (28.1)	232 (25.7)	265 (29.4)
n=901	95% CI	0.9 to 2.5	19.2 to 24.5	13.0 to 17.7	21.3 to 26.8	18.1 to 23.4	25.2 to 31.1	23.0 to 28.7	26.5 to 32.4
Total	n (%)	21 (1.1)	411 (21.8)	300 (15.9)	430 (22.8)	411 (21.8)	533 (28.2)	475 (25.2)	535 (28.3)
N=1,888	95% CI	0.7 to 1.7	20.0 to 23.7	14.3 to 17.6	20.9 to 24.7	20.0 to 23.7	26.2 to 30.3	23.2 to 27.2	26.3 to 30.4

Table 3 – Number of participants (and percentages and 95% CIs) endorsing i) each number of possible terms and ii) each specific term as making sense to them

		Number of terms endorsed as making sense as a way of describing the text: n, %, 95% CIs							
Screening information	Total	0	1	2	3	4	5	6	7
Breast	n (%)	429 (43.5)	76 (7.7)	86 (8.7)	74 (7.5)	67 (6.8)	58 (5.9)	42 (4.3)	155 (15.7)
n=987	95% CI	40.4 to 46.6	6.2 to 9.5	7.1 to 10.6	6.0 to 9.3	5.3 to 8.5	4.5 to 7.5	3.1 to 5.7	13.5 to 18.1
Prostate	n (%)	408 (45.3)	59 (6.5)	73 (8.1)	68 (7.5)	66 (7.3)	48 (5.3)	37 (4.1)	142 (15.8)
n=901	95% CI	42.1 to 48.5	5.1 to 8.3	6.5 to 10.0	6.0 to 9.4	5.8 to 9.2	4.0 to 6.9	3.0 to 5.6	13.5 to 18.2
Total	n (%)	837 (44.3)	135 (7.2)	159 (8.4)	142 (7.5)	133 (7.0)	106 (5.6)	79 (4.2)	297 (15.7)
N=1,888	95% CI	42.1 to 46.6	6.1 to 8.4	7.2 to 9.7	6.4 to 8.8	6.0 to 8.3	4.6 to 6.7	3.4 to 5.2	14.1 to 17.4
		<i>"Which terms make sense as a way of describing this risk of a screening test?": n, %, 95% CIs</i>							
Screening information	Total	Overdiagnosis	Overdetection	Unnecessary diagnosis	Overtreatment	Unnecessary treatment	False positive diagnosis	False positive test results	
Breast	n (%)	334 (33.8)	275 (27.9)	349 (35.4)	336 (34.0)	409 (41.4)	324 (32.8)	338 (34.2)	
n=987	95% CI	30.9 to 36.8	25.1 to 30.7	32.4 to 38.4	31.1 to 37.0	38.4 to 44.5	30.0 to 35.8	31.3 to 37.2	
Prostate	n (%)	291 (32.3)	247 (27.4)	307 (34.1)	280 (31.1)	354 (39.3)	320 (35.5)	330 (36.6)	
n=901	95% CI	29.3 to 35.4	24.6 to 30.4	31.0 to 37.2	28.1 to 34.2	36.1 to 42.5	32.4 to 38.7	33.5 to 39.8	
Total	n (%)	625 (33.1)	522 (27.6)	656 (34.7)	616 (32.6)	763 (40.4)	644 (34.1)	668 (35.4)	
N=1,888	95% CI	31.0 to 35.3	25.7 to 29.7	32.6 to 36.9	30.5 to 34.8	38.2 to 42.6	32.0 to 36.3	33.2 to 37.6	

Terms endorsed as making sense

Table 3 shows that participants most commonly did not endorse any terms as making sense (44.3%). As with results for familiarity, the second most common number of terms endorsed was all seven (15.7%). The most commonly endorsed term was “*unnecessary treatment*” (40.4% of participants in the sample endorsed this term overall; 41.4% and 39.3% after being given the breast and prostate information, respectively). Endorsement of other terms ranged from 27.9% (“*overdetection*”) to 35.4% (“*unnecessary diagnosis*”) for information from breast screening and 27.4% (“*overdetection*”) to 36.6% (“*false positive test results*”) for information from prostate screening.

DISCUSSION

This study aimed to address a gap in the literature regarding how best to communicate the concept of overdiagnosis (8). We investigated whether people are familiar with terms used to describe overdiagnosis or related concepts, and whether these made sense as labels for widely used descriptions. We found that a majority of participants (58.0%) had never encountered any of the assessed terms before and a large proportion (44.3%) did not rate any term as making sense as a suitable label for either of two widely used descriptions of the concept. In addition, no specific term(s) emerged as being notably more familiar or applicable.

A previous similar study found that only 30.0% of the UK general public (aged 50-70) had previously encountered the specific term, ‘overdiagnosis’ (9), which is broadly comparable to the 21.8% who reported having encountered it in this study. Our findings are also consistent with those of a previous study that was part of redesign of the information materials for the NHS Breast Screening Programme (18). Women were interviewed with the aim of finding ways to

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8 communicate the concept of overdiagnosis: participants struggled to understand it, regardless
9 of whether it was labelled as 'overdiagnosis' or 'overtreatment'.

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12 Terminology can have a role in transferring information to lay individuals as part of a description
13 of technical concepts (10,19). However, the main implication of our results is that currently there
14 may only be limited value in using any of the labels that we tested. Terms used were neither
15 familiar nor rated as particularly relevant in this large, diverse sample, meaning that they may
16 be confusing, unintuitive, and hard for people to memorise and recall. Even the most technically
17 appropriate terms (e.g. 'overdiagnosis' and 'overdetection') were not endorsed as making sense
18 more frequently than suggested alternative terminology (e.g. 'unnecessary diagnosis) or more
19 inaccurate and potentially problematic terminology (e.g. 'false positive diagnosis'). To some
20 extent, the limited familiarity and low levels of endorsement at present supports UK policy
21 decisions not to use a specific term in the revised breast screening information leaflet (18).
22 Furthermore, shortly before the start of recruitment, an updated NHS information leaflet
23 regarding PSA screening was published, with additional detail on overdiagnosis and
24 overtreatment (20); this also omitted any specific descriptive label.

25
26
27 One unexpected finding was that the second most common number of terms that were familiar
28 or endorsed was all seven (12.3% and 15.7%, respectively). This may be a reflection of
29 differences between terms being subtle: members of the public may not recall exactly which
30 terms they had encountered but felt that broader concepts like diagnosis and treatment were
31 familiar.

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34 Continuing communication efforts mean that these results may change over time: it is plausible
35 that ongoing campaigns (3-5) will result in the public becoming increasingly familiar with the
36 concept and terminology, having a better understanding of the differences between similar
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8 terms (e.g. seeing 'false positives' as distinct from 'overdiagnosis'), and being more likely to
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10 endorse particular terms as applicable. However, present attempts to communicate
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12 overdiagnosis (e.g. as part of screening invitations or mainstream media stories) may be more
13
14 effective if explicit descriptions are used, such as adapted forms of information from the Breast
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16 Screening Programme. This has undergone an extensive design process (18) and is more likely
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18 to be rated as clearer than the equivalent from the Prostate Cancer Risk Management
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20 Programme. However, fewer than half of participants (46.6%) rated it as very or extremely clear,
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22 suggesting that future research could be used to improve it further (e.g. by providing additional
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24 detail; 15).

25
26 This study has limitations. The list of terms tested was not exhaustive; there may be suitable
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28 terminology that we did not assess. However, we found very similar levels of endorsement for
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30 terms that used several variations on the themes of diagnosis, treatment, and false positives,
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32 providing some evidence that any superior terms would have to be quite different. In addition,
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34 as noted in our previous study, descriptions of overdiagnosis were brief and presented outside
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36 the context of the original written information about screening from which they were adapted;
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38 comprehension may be different (either better or worse) in the presence of additional detail (15);
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40 this warrants further research.

41 **Conclusions**

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43 It has been suggested that alternative terminology to 'overdiagnosis' would help increase
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45 awareness and understanding of the concept among individuals who may face healthcare
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47 decisions that would put them at risk. These results suggest that, at present, using specific
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49 terms would have limited benefits. It may currently be more effective to refer to the concept via
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51 more explicit descriptions. Previous research indicates that information from the NHS Breast
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8 Screening Programme may be a relatively effective template for this purpose. However, future
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10 research could explore scope for improvement.

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12 **Contributors:** AG, CR, and JW conceived and designed the study. AG analysed the data. AG,
13
14 CR, and JW participated in the interpretation of results. AG, CR, and JW drafted the manuscript,
15
16 participated in critical revision, and approved the final version.

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31 **Patient consent:** Obtained.

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BMJ Open

Improving public understanding of 'overdiagnosis' in England: a population survey assessing familiarity with possible terms for labelling the concept and perceptions of appropriate terminology

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ABSTRACT

Objectives: Communicating the concept of 'overdiagnosis' to lay individuals is challenging, partly because the term itself is confusing. This study tested whether alternative descriptive labels may be more appropriate.

Design: Questionnaire preceded by a description of overdiagnosis.

Setting: Home-based, computer-assisted face-to-face survey.

Participants: 2,111 adults aged 18 to 70 years in England recruited using random location sampling by a survey company. Data from 1,888 participants were analysed after exclusions due to missing data.

Interventions: Participants were given one of two pieces of text describing overdiagnosis, allocated at random, adapted from NHS breast and prostate cancer screening leaflets.

Primary and secondary outcome measures: Main outcomes were which of several available terms (e.g. 'overdetection') participants had previously encountered and which they endorsed as applicable labels for the concept described. Demographics and previous exposure to screening information were also measured. Main outcomes were summarised with descriptive statistics. Predictors of previously encountering at least one term, or endorsing at least one as making sense, were assessed using binary logistic regression.

Results: 58.0% of participants had not encountered any suggested term; 44.0% did not endorse any as applicable labels. No term was notably familiar; the proportion of participants who had previously encountered each term ranged from 15.9 to 28.3%. Each term was only endorsed as applicable by a minority (range: 27.6% to 40.4%). Notable predictors of familiarity included

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8 education, age, and ethnicity; participants were less likely to have encountered terms if they
9 were older, not White British or had less education, Findings were similar for both pieces of
10 information.
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14 *Conclusions:* Familiarity with suggested terms for overdiagnosis and levels of endorsement
15 were low and no clear alternative labels for the concept were identified, suggesting that
16 changing terminology alone would do little to improve understanding, particularly for some
17 population groups. Explicit descriptions may be more effective.
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22 **Keywords:** Decision Making; Surveys and Questionnaires; Early Detection of Cancer; Mass
23 Screening; Medical Overuse
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27 **Strengths and limitations of this study**

- 28 • This study assessed familiarity and perceived appropriateness of a broad range of
29 possible terms for the concept of 'overdiagnosis' among a large, representative
30 sample of the general public in England.
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- 33 • The concept was described based on information that was widely used by the
34 National Health Service in England, maintaining generalisability.
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- 37 • The list of possible terms was not exhaustive; more suitable alternative labels may
38 have been omitted.
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- 41 • Results may be time-dependent: ongoing communication initiatives may change
42 perceptions of appropriate terms for the concept of 'overdiagnosis'.
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46 47 **INTRODUCTION** 48 49 50 51 52 53 54 55 56 57 58 59 60

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8 There is growing concern among healthcare providers and policymakers about the potential for
9 medical tests to detect asymptomatic disease that would never have become clinically apparent
10 or resulted in death (1). 'Overdiagnosis' can harm, primarily via the subsequent risks and costs
11 associated with unnecessary treatment but also via opportunity costs to a healthcare service
12 due to overuse of scarce resources (2). Various initiatives have aimed to propagate
13 understanding of the concept among patients and the public so that they can make better
14 informed decisions about their health (e.g. 3–5). However, previous studies have found that the
15 concept is challenging to communicate to lay people (e.g. in the context of breast cancer
16 screening; 6,7).

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25 Little is known about how to improve communication of overdiagnosis (8). One barrier is that the
26 term 'overdiagnosis' itself may be confusing and counterintuitive. For example, a previous study
27 in the UK asked members of the public to give their interpretation of what the word meant; a
28 large proportion of participants gave definitions that did not match the concept but resembled
29 other similar words (e.g. 'providing an incorrect diagnosis' since 'overdiagnosis' resembles
30 'misdiagnosis'; 9). Equivalent findings have been reported by a previous survey in Australia (10).
31 In addition, a focus group study undertaken as part of the development of a decision aid for
32 breast screening found that 'overdiagnosis' was not understood intuitively and that
33 'overdetection' may be clearer (11).

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42 These findings suggest that the term 'overdiagnosis' does not clearly reflect its intended
43 meaning for the general public and that other terms (such as 'overdetection') may be more
44 appropriate. Hence, this study asked a large sample of the public in England to appraise
45 descriptions of the concept and tested which of several possible terms people thought made
46 sense as labels (i.e. endorsement). Alternatives included 'overdetection' or 'unnecessary
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8 diagnosis' (11) as well as terms related to unnecessary therapy (e.g. 'overtreatment') and terms
9 that were less technically accurate but still had the potential to be seen as applicable (e.g. 'false
10 positives'; 9, 10). A limitation to the utility of 'overdiagnosis' as a label may be the currently low
11 level of public awareness of the term (9, 12). Consequently, this study also measured which
12 terms people had encountered before (i.e. familiarity) to test whether any alternatives were
13 notably more familiar. We also explored whether participant characteristics were associated with
14 having previously encountered these terms, or with endorsing them as making sense, as this
15 may aid targeted communication efforts.
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23 Information was derived from materials that have been widely used by the NHS Breast
24 Screening Programme (13) and the Prostate Cancer Risk Management Programme (14). The
25 study was carried out as part of Wave 3 of the Attitudes, Behaviour and Cancer UK Survey
26 (ABACUS). Other studies arising from this survey have also been published (e.g. 15).
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31 **METHODS**

32 **Design**

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35 Institutional approval was granted by the University College London Research Ethics
36 Committee (5771/002). The focus of the present study was on appropriate terminology for
37 widely used descriptions of overdiagnosis. However, the ABACUS survey was a broader piece
38 of work that also compared the perceived clarity of different forms of overdiagnosis information.
39 Hence, elements of the design and measures have also been reported elsewhere (15). Face-to-
40 face computer-assisted interviews were conducted by TNS (a market research company) as
41 part of a weekly omnibus survey and took place in participants' homes between April and May
42 2016. Participants were informed:
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8 *“We would now like to ask you some questions about leaflets on health-related topics. The NHS*
9 *offers people a variety of screening tests to check for illnesses before symptoms have*
10 *appeared. People offered an NHS screening test are often given a leaflet that explains the risks*
11 *and benefits of having the test. The leaflet is either posted or given out by a doctor or nurse.”*
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16 Participants then received information on overdiagnosis adapted from written material used by
17 the NHS in England as part of either i) the Breast Screening Programme or ii) the Prostate
18 Cancer Risk Management Programme as they existed in February 2016 (neither of which used
19 a specific label), allocated at random in a 1:1 ratio:
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24 *“The test can find an illness that would never have caused a person harm. Some people will be*
25 *diagnosed and treated for an illness that would never otherwise have been found and would not*
26 *have become life-threatening.”* From the breast screening information leaflet (13)
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30 *“The test may make you worry by finding an illness that may never cause any symptoms or*
31 *shorten your life.”* From the prostate screening information leaflet (14)
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35 The Breast Screening Programme in England offers triennial mammography to all women
36 between the ages of 50 to 70 years and registered with a General Practitioner. The Prostate
37 Screening Risk Management Programme allows men aged 50 years or older to have a Prostate
38 Specific Antigen test by requesting it from their GP after discussing the risks and benefits.
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41 References to cancer were removed so that findings could be generalised to beyond these two
42 specific screening contexts.
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46 **Participants**

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48 Participants were members of the public in England aged 18 to 70 years. National
49 representativeness was sought via a two-stage process. In the first instance, random location
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8 sampling was carried out using the Postcode Address File and Census statistics. Within each
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10 selected location, participant quotas were set based on demographic characteristics (i.e. age,
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12 gender, employment status, and presence of children in the home).

13 14 **Measures**

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17 Demographics: Relevant measures consisted of age, gender, ethnicity, social grade (16),
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19 marital status, highest level of education obtained, personal history of cancer (*"Have you ever*
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21 *been diagnosed with cancer?"*; "yes" or "no"), and whether anyone they know had been
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23 diagnosed with cancer (*"Has anyone close to you ever been diagnosed with cancer?"*; "yes",
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25 "no", or "don't know").

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27 Familiarity with screening information: Participants were asked whether they had ever
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29 previously received information about screening (for cancer or other illnesses) via i) reading a
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31 leaflet from the NHS, ii) reading an NHS website, and iii) talking with a doctor or nurse
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33 (response options: "yes", "no", "not sure").

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35 If participants were eligible for cancer screening and had not been diagnosed with the target
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37 disease, they were asked about their previous participation (e.g. only women aged 47-70 years
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39 without a breast cancer diagnosis were asked about breast screening participation) via items
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41 designed using the Precaution Adoption Process Model (PAPM; 17), a stage theory of
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43 protective health behaviour. This measures whether participants have heard of a particular type
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45 of screening, whether they have heard of a type of screening but have never been invited,
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47 whether they have been invited but never participated, whether they have participated but not
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49 consistently, and whether they have participated consistently. Eligibility criteria and exact
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51 question wording for assessing experience have been reported elsewhere (15).
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8 Perceived clarity of information: After reading the information allocated at random, participants
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10 were asked, "How clear do you find this description of a risk of the test?" with available
11 responses of "extremely clear", "very clear", "moderately clear", "slightly clear", and "not at all
12 clear". This was followed by a question on whether they had read or heard similar information
13 about a screening test before (possible responses were: "yes", "no", and "not sure").
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18 Main outcomes: The first main outcome measure (endorsement) consisted of "Does this term
19 make sense to you as a way of describing this risk of a screening test?", followed by seven
20 terms: "overdiagnosis", "overdetection", "unnecessary diagnosis", "overtreatment", "unnecessary
21 treatment", "false positive diagnosis", and "false positive test results"¹ (responses: "yes", "no").
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24 Suggested terms were based on previous literature (e.g. 11) and discussion among the
25 research team.
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29 The second outcome measure (familiarity) was: "Have you ever seen or heard any of the
30 previous seven terms before today?" and if participants responded "yes", they were asked
31 which out of the previous terms (responses: "yes", "no", "not sure").
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35 Ancillary measures: The measures used in this study were part of the broader ABACUS survey.
36 Most of the items in this study were presented at the start of the survey and so the effects of
37 priming from unrelated items were expected to be minimal. In order, the full survey included:
38 questions on decision-making style and previous exposure to cancer screening information,
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46 ¹ Participants were also asked, "Can you think of any other terms to describe this risk that would
47 make sense to you?". However, only approximately 60 responses suggesting potentially
48 applicable terms were recorded across all participants (e.g. "oversensitivity", "unknown
49 diagnosis"), of which most were mentioned just once and so no further analysis was attempted.
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8 information on overdiagnosis adapted from screening leaflets, questions on perceived clarity of
9 this information, previous exposure to similar information, the main study outcomes, and help-
10 seeking behaviour in relation to cancer screening, followed by more questions on self-rated
11 health, questions on cancer diagnoses, perceived cancer risk, screening behaviour in relation to
12 each of the applicable programmes (cervical, breast, bowel, prostate), and educational level.
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17 **Public Involvement**

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20 Public involvement consisted of input into the design of the study and development of measures
21 via pilot testing of the survey. This comprised two stages: first, a series of telephone cognitive
22 interviews (18) was used to determine whether items could be understood by lay people (n=11)
23 and that the survey was not overly burdensome. Participants were asked for feedback on any
24 items they found difficult to understand or answer and the survey was revised accordingly.
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29 Second, a web-based version of the survey was pilot-tested with 431 participants.
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32 There are currently no plans to disseminate the results to study participants.
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34 **Analysis**

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37 Participants were excluded if they declined to answer any of the measures included in this
38 study. Ethnicity and marital status were dichotomised into "White British" and "other ethnic
39 groups", and "single, widowed, divorced or separated" and "married or living as a couple",
40 respectively. Social class grade was categorised as "grades A or B", "grades C1 or C2", and
41 "grades D or E". Education was coded based on Levels 1-4 from the Office of National Statistics
42 (19) or "Other" for non-ordinal levels of education such as professional qualifications.
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49 Sample characteristics were summarised with descriptive statistics. We report the percentages
50 of participants (with binomial 95% confidence intervals) who had i) previously encountered and
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8 ii) endorsed each possible number of terms (from 0 to 7 in both cases), and the percentages of
9 participants who had previously encountered and endorsed each specific term.

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11 Responses to i) and ii) were also recoded into “previously seen or heard one or more terms”
12 (familiarity) and “endorsed one or more terms as making sense to them” (endorsement) for
13 further evaluation e.g. “was familiar with at least one term” vs. “was not familiar” (including
14 responses of “not sure”). Two exploratory logistic regression models tested the null hypothesis
15 that predictor variables were unrelated to either of these outcomes. In both models, predictor
16 variables consisted of demographic characteristics, familiarity with screening information, the
17 overdiagnosis information condition (breast vs. prostate), and perceived clarity. In addition, each
18 model included the outcome from the other as a predictor (e.g. the endorsement model included
19 familiarity as a potential predictor variable). Variance Inflation Factors were small (all <2.969
20 and <2.972, respectively), indicating that (multi)collinearity was limited and a Box-Tidwell
21 procedure found little evidence to suggest that the age variable violated the assumption of
22 linearity (p-values: .110 and .508). Adjusted odds-ratios (ORs), accompanying 95% CIs, and p-
23 values for having previously seen or heard one or more terms before and endorsing one or
24 more term as making sense are reported alongside descriptive statistics.
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38 **RESULTS**

39 **Participant characteristics**

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41 After excluding 223 participants with missing data, 1,888 cases were analysed. Sample
42 characteristics are presented in Table 1. Mean age was 43.6 years (standard deviation: 15.7).
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48 **Familiarity with terms**

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8 Table 2 illustrates that the majority of participants (58.0%) were not familiar with any of the listed
9 terms. However, the second most common number of terms recognised as familiar was all
10 seven (12.3%). The percentages of participants previously encountering between one and six
11 terms ranged from 1.1% to 9.4%. Table 2 also shows that the percentages of participants who
12 had encountered each specific term ranged from 15.9% (*“overdetection”*) to 28.3% (*“false*
13 *positive test results”*).
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19 Table 3 reports predictors of familiarity with at least one term. Among demographic
20 characteristics, there was strong evidence against the null hypothesis for ethnicity, education,
21 and age: White British participants were more likely to be familiar with at least one term
22 compared with other ethnic groups. Participants with a higher (or ‘other’) level of education were
23 also more likely to be familiar with one or more terms compared with participants who had no
24 formal qualifications (or did not know). Older participants were less likely to be familiar with one
25 or more terms. Participants were also more likely to be familiar with one or more terms if they
26 knew someone with cancer, had previously read an NHS website about screening, discussed
27 screening with a doctor or nurse, had previously read or seen similar information, or endorsed
28 one or more terms as making sense as labels.
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38 Finally, there was moderate evidence against the null hypothesis for an association with social
39 class grade with participants in grades A or B being more likely to be familiar with at least one
40 term compared with participants in grades D or E.
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45 **Terms endorsed as making sense**

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47 Table 4 shows that participants most commonly did not endorse any terms as making sense
48 (44.3%). As with results for familiarity, the second most common number of terms endorsed was
49 all seven (15.7%). The most commonly endorsed term was *“unnecessary treatment”* (40.4% of
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8 participants in the sample endorsed this term overall; 41.4% and 39.3% after being given the
9 breast and prostate information, respectively). Endorsement of other terms ranged from 27.9%
10 (“*overdetection*”) to 35.4% (“*unnecessary diagnosis*”) for information from breast screening and
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12 27.4% (“*overdetection*”) to 36.6% (“*false positive test results*”) for information from prostate
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14 screening.
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18 Other than familiarity (Table 3), the logistic regression analysis of predictors of endorsement
19 only showed strong evidence against the null hypothesis for gender and knowing someone with
20 cancer: males and participants who knew someone diagnosed with cancer were more likely to
21 endorse at least one term as making sense (Table 5).
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Table 1 – Characteristics of the sample

		Total N=1,888	
Characteristic	n	(%)	
Overdiagnosis information			
Breast screening text	987	(52.3)	
Prostate screening text	901	(47.7)	
Gender			
Male	879	(46.6)	
Female	1,009	(53.4)	
Ethnicity			
White British	1,432	(75.8)	
Other ethnic groups	456	(24.2)	
Marital status			
Married or living as a couple	1,133	(60.0)	
Single, widowed, divorced, or separated	755	(40.0)	
Highest level of education¹			
No formal qualifications	281	(14.9)	
Approximately Level 1, 2, or 3	890	(47.1)	
Approximately Level 4	507	(26.9)	
Other	199	(10.5)	
Don't know/Not sure	11	(0.6)	
Social class grade²			
Grade A or B	386	(20.4)	
Grade C1 or C2	931	(49.3)	
Grade D or E	571	(30.2)	
Personal diagnosis of cancer			
Yes	98	(5.2)	
No	1,790	(94.8)	
Knows someone with cancer			
Yes	1,113	(59.0)	
No	771	(40.8)	
Don't know/Not sure	4	(0.2)	
Any previous cervical screening experience			
Yes	652	(34.5)	
No	226	(12.0)	
Not eligible	1,010	(53.5)	
Any previous breast screening experience			
Yes	317	(16.8)	
No	83	(4.4)	
Not eligible	1,488	(78.8)	
Any previous bowel screening experience			
Yes	293	(15.5)	
No	181	(9.6)	
Not eligible	1,414	(74.9)	
Any previous prostate screening experience			
Yes	77	(4.1)	
No	344	(18.2)	
Not eligible	1,467	(77.7)	
Previously read a screening leaflet			
Yes	1,058	(56.0)	
No	809	(42.8)	
Don't know/Not sure	21	(1.1)	
Previously read an NHS screening website			
Yes	324	(17.2)	
No	1,549	(82.0)	
Don't know/Not sure	15	(0.8)	
Discussed screening with doctor/nurse			
Yes	624	(33.1)	
No	1,251	(66.3)	
Don't know/Not sure	13	(0.7)	
Previously read or heard similar information			
Yes	662	(35.1)	

1	No	1,185	(62.8)
2	Don't know/Not sure	41	(2.2)
3	Perceived clarity of information		
4	Extremely clear	170	(9.0)
5	Very clear	636	(33.7)
6	Moderately clear	685	(36.3)
7	Slightly clear	206	(10.9)
8	Not at all clear	191	(10.1)

8 ¹Level 1-3 qualifications include e.g. GCSEs and A Levels; Level 4

9 qualifications include degrees and higher degrees

10 ²Social grades are based on occupation (e.g. Grade A includes

11 managerial roles; Grade E includes casual workers)

For peer review only

Table 2 – Number of participants (and percentages and 95% CIs) previously encountering i) each number of possible terms and ii) each specific term. Participants receiving overdiagnosis information based on the Breast Screening programme or the Prostate Cancer Risk Management Programme were analysed separately.

		Number of terms previously encountered: n, %, 95% CIs							
Screening information	Total	0	1	2	3	4	5	6	7
Breast	n (%)	583 (59.1)	73 (7.4)	76 (7.7)	53 (5.4)	41 (4.2)	28 (2.8)	9 (0.9)	124 (12.6)
N=987	95% CI	56.0 to 62.1	5.9 to 9.2	6.2 to 9.5	4.1 to 6.9	3.0 to 5.5	1.9 to 4.0	0.5 to 1.7	10.6 to 14.7
Prostate	n (%)	512 (56.8)	64 (7.1)	101 (11.2)	47 (5.2)	37 (4.1)	19 (2.1)	12 (1.3)	109 (12.1)
n=901	95% CI	53.6 to 60.0	5.6 to 8.9	9.3 to 13.4	3.9 to 6.8	3.0 to 5.6	1.3 to 3.2	0.7 to 2.2	10.1 to 14.3
Total	n (%)	1,095 (58.0)	137 (7.3)	177 (9.4)	100 (5.3)	78 (4.1)	47 (2.5)	21 (1.1)	233 (12.3)
N=1,888	95% CI	55.8 to 60.2	6.2 to 8.5	8.1 to 10.8	4.4 to 6.4	3.3 to 4.1	1.9 to 3.3	0.7 to 1.7	10.9 to 13.9
		<i>"Which of the following term or terms had you heard of before?": n, %, 95% CIs</i>							
Screening information	Total	Not sure	Overdiagnosis	Overdetection	Unnecessary diagnosis	Overtreatment	Unnecessary treatment	False positive diagnosis	False positive test result
Breast	n (%)	7 (0.7)	215 (21.8)	163 (16.5)	214 (21.7)	225 (22.8)	280 (28.4)	243 (24.6)	270 (27.4)
N=987	95% CI	0.3 to 1.4	19.3 to 24.4	14.3 to 18.9	19.2 to 24.3	20.3 to 25.5	25.6 to 31.2	22.0 to 27.4	24.6 to 30.2
Prostate	n (%)	14 (1.6)	196 (21.8)	137 (15.2)	216 (24.0)	186 (20.6)	253 (28.1)	232 (25.7)	265 (29.4)
n=901	95% CI	0.9 to 2.5	19.2 to 24.5	13.0 to 17.7	21.3 to 26.8	18.1 to 23.4	25.2 to 31.1	23.0 to 28.7	26.5 to 32.4
Total	n (%)	21 (1.1)	411 (21.8)	300 (15.9)	430 (22.8)	411 (21.8)	533 (28.2)	475 (25.2)	535 (28.3)
N=1,888	95% CI	0.7 to 1.7	20.0 to 23.7	14.3 to 17.6	20.9 to 24.7	20.0 to 23.7	26.2 to 30.3	23.2 to 27.2	26.3 to 30.4

Table 3 – Familiarity with one or more vs. no terms: descriptive statistics, adjusted ORs, 95% CIs, and p-values for variables in the multivariable binary logistic regression model

Characteristic	Total (N=1,888)	Familiarity with no terms vs. at least one term: n (%)		Adjusted OR, 95% CI	p-value
		No term (n=1,095; 58.0%)	At least one term (n=793; 42.0%)		
Overdiagnosis information					
Breast screening text vs. Prostate screening text	987	583 (59.1)	404 (40.9)	0.87, 0.70 to 1.09	.224
Gender					
Male vs. Female	879	534 (60.8)	345 (39.2)	1.00, 0.79 to 1.26	.998
Ethnicity					
White British vs. Other ethnic groups	1,432	775 (54.1)	657 (45.9)	2.14, 1.61 to 2.84	<.0005
Marital status					
Married or living as a couple vs. Single, widowed, divorced, or separated	1,133	661 (58.3)	472 (41.7)	0.87, 0.69 to 1.09	.216
Highest level of education					
Other levels	199	116 (58.3)	83 (41.7)	2.32, 1.46 to 3.68	Overall: <.0005
Approximately Level 4	507	219 (43.2)	288 (56.8)	4.17, 2.75 to 6.33	<.0005
Approximately Level 1, 2, or 3	890	532 (59.8)	358 (40.2)	2.19, 1.52 to 3.15	<.0005
vs. No formal qualifications or don't know	292	228 (78.1)	64 (21.9)		
Social class grade					
Grade A or B vs. Grade C1 or C2 vs. Grade D or E	386	170 (44.0)	216 (56.0)	1.54, 1.09 to 2.17	Overall: .050
	931	542 (58.2)	389 (41.8)	1.19, 0.91 to 1.55	.014
	571	383 (67.1)	188 (32.9)		.201
Personal diagnosis of cancer					
Yes vs. No	98	49 (50.0)	49 (50.0)	1.10, 0.68 to 1.80	.690
	1,790	1,046 (58.4)	744 (41.6)		
Knows someone with cancer					
Yes vs. No or don't know	1,113	562 (50.5)	551 (49.5)	1.50, 1.19 to 1.89	.001
	775	533 (68.8)	242 (31.2)		
Previously read a screening leaflet					
Yes vs. No or not sure	1,058	535 (50.6)	523 (49.4)	1.27, 0.97 to 1.66	.089
	830	560 (67.5)	270 (32.5)		
Previously read an NHS screening website					
Yes vs. No or not sure	324	125 (38.6)	199 (61.4)	1.45, 1.07 to 1.97	.016
	1,564	970 (62.0)	594 (38.0)		
Discussed screening with doctor/nurse					
Yes vs. No	624	276 (44.2)	348 (55.8)	1.34, 1.03 to 1.74	.030
	1,264	819 (64.8)	445 (35.2)		
Previously read or heard similar information					
Yes vs. No or not sure	662	266 (40.2)	396 (59.8)	2.30, 1.81 to 2.94	<.0005
	1,226	829 (67.6)	397 (32.4)		
Endorsed any term(s) as making sense					
Yes vs. No	1,051	426 (40.5)	625 (59.5)	4.92, 3.94 to 6.17	<.0005
	837	669 (79.9)	168 (20.1)		
Perceived clarity of information					
Extremely clear vs. Very clear vs. Moderately clear vs. Slightly clear vs. Not at all clear	170	87 (51.2)	83 (48.8)	0.85, 0.52 to 1.40	Overall: .534
	636	339 (53.3)	297 (46.7)	0.97, 0.65 to 1.43	.525
	685	424 (61.9)	261 (38.1)	0.78, 0.53 to 1.16	.860
	206	130 (63.1)	76 (36.9)	0.92, 0.57 to 1.49	.225
	191	115 (60.2)	76 (39.8)		.745
Mean (SD)					
Age (in years)	1,888	43.8 (15.7)	43.3 (15.8)	0.99, 0.98 to 1.00	.003

N.B. Adjusted ORs and 95% CIs are relative to a stated reference category except age, which is per unit increase; p-values <.05 are in bold; all predictor variables are included in the model

Table 4 – Number of participants (and percentages and 95% CIs) endorsing i) each number of possible terms and ii) each specific term as making sense to them as a label

		Number of terms endorsed as making sense as a way of describing the text: n, %, 95% CIs							
Screening information	Total	0	1	2	3	4	5	6	7
Breast	n (%)	429 (43.5)	76 (7.7)	86 (8.7)	74 (7.5)	67 (6.8)	58 (5.9)	42 (4.3)	155 (15.7)
n=987	95% CI	40.4 to 46.6	6.2 to 9.5	7.1 to 10.6	6.0 to 9.3	5.3 to 8.5	4.5 to 7.5	3.1 to 5.7	13.5 to 18.1
Prostate	n (%)	408 (45.3)	59 (6.5)	73 (8.1)	68 (7.5)	66 (7.3)	48 (5.3)	37 (4.1)	142 (15.8)
n=901	95% CI	42.1 to 48.5	5.1 to 8.3	6.5 to 10.0	6.0 to 9.4	5.8 to 9.2	4.0 to 6.9	3.0 to 5.6	13.5 to 18.2
Total	n (%)	837 (44.3)	135 (7.2)	159 (8.4)	142 (7.5)	133 (7.0)	106 (5.6)	79 (4.2)	297 (15.7)
N=1,888	95% CI	42.1 to 46.6	6.1 to 8.4	7.2 to 9.7	6.4 to 8.8	6.0 to 8.3	4.6 to 6.7	3.4 to 5.2	14.1 to 17.4
		<i>"Which terms make sense as a way of describing this risk of a screening test?": n, %, 95% CIs</i>							
Screening information	Total	Overdiagnosis	Overdetection	Unnecessary diagnosis	Overtreatment	Unnecessary treatment	False positive diagnosis	False positive test results	
Breast	n (%)	334 (33.8)	275 (27.9)	349 (35.4)	336 (34.0)	409 (41.4)	324 (32.8)	338 (34.2)	
n=987	95% CI	30.9 to 36.8	25.1 to 30.7	32.4 to 38.4	31.1 to 37.0	38.4 to 44.5	30.0 to 35.8	31.3 to 37.2	
Prostate	n (%)	291 (32.3)	247 (27.4)	307 (34.1)	280 (31.1)	354 (39.3)	320 (35.5)	330 (36.6)	
n=901	95% CI	29.3 to 35.4	24.6 to 30.4	31.0 to 37.2	28.1 to 34.2	36.1 to 42.5	32.4 to 38.7	33.5 to 39.8	
Total	n (%)	625 (33.1)	522 (27.6)	656 (34.7)	616 (32.6)	763 (40.4)	644 (34.1)	668 (35.4)	
N=1,888	95% CI	31.0 to 35.3	25.7 to 29.7	32.6 to 36.9	30.5 to 34.8	38.2 to 42.6	32.0 to 36.3	33.2 to 37.6	

Table 5 – Endorsed one or more vs. no terms as making sense: descriptive statistics, adjusted ORs, 95% CIs, and p-values for variables in the multivariable binary logistic regression model

Characteristic	Total (N=1,888)	Endorsed no vs. at least one term as making sense: n (%)		Adjusted OR, 95% CI	p-value
		No term (n=837; 44.3%)	At least one term (n=1,051; 55.7%)		
Overdiagnosis information					
Breast screening text vs. Prostate screening text	987 901	429 (43.5) 408 (45.3)	558 (56.5) 493 (54.7)	1.16, 0.95 to 1.42	.148
Gender					
Male vs. Female	879 1,009	380 (43.2) 457 (45.3)	499 (56.8) 552 (54.7)	1.40, 1.13 to 1.74	.002
Ethnicity					
White British vs. Other ethnic groups	1,432 456	592 (41.3) 245 (53.7)	840 (58.7) 211 (46.3)	1.25, 0.97 to 1.61	.080
Marital status					
Married or living as a couple vs. Single, widowed, divorced, or separated	1,133 755	500 (44.1) 337 (44.6)	633 (55.9) 418 (55.4)	1.05, 0.85 to 1.30	.671
Highest level of education					Overall: .556
Other levels	199	88 (44.2)	111 (55.8)	1.21, 0.80 to 1.82	.374
Approximately Level 4	507	190 (37.5)	317 (62.5)	1.27, 0.88 to 1.84	.204
Approximately Level 1, 2, or 3	890	396 (44.5)	494 (55.5)	1.24, 0.91 to 1.70	.169
vs. No formal qualifications or don't know	292	163 (55.8)	129 (44.2)		
Social class grade					Overall: .574
Grade A or B	386	137 (35.5)	249 (64.5)	1.09, 0.78 to 1.51	.617
Grade C1 or C2	931	420 (45.1)	511 (54.9)	0.94, 0.74 to 1.19	.604
vs. Grade D or E	571	280 (49.0)	291 (51.0)		
Personal diagnosis of cancer					
Yes vs. No	98 1,790	37 (37.8) 800 (44.7)	61 (62.2) 990 (55.3)	1.08, 0.68 to 1.74	.741
Knows someone with cancer					
Yes vs. No or don't know	1,113 775	427 (38.4) 410 (52.9)	686 (61.6) 365 (47.1)	1.35, 1.09 to 1.68	.005
Previously read a screening leaflet					
Yes vs. No or not sure	1,058 830	416 (39.3) 421 (50.7)	642 (60.7) 409 (49.3)	1.18, 0.91 to 1.52	.206
Previously read an NHS screening website					
Yes vs. No or not sure	324 1,564	109 (33.6) 728 (46.5)	215 (66.4) 836 (53.5)	1.01, 0.75 to 1.37	.955
Discussed screening with doctor/nurse					
Yes vs. No	624 1,264	217 (34.8) 620 (49.1)	407 (65.2) 644 (50.9)	1.25, 0.97 to 1.61	.091
Previously read or heard similar information					
Yes vs. No or not sure	662 1,226	224 (33.8) 613 (50.0)	438 (66.2) 613 (50.0)	1.18, 0.93 to 1.50	.185
Previously encountered any term(s)					
Yes vs. No	1,051 837	168 (21.2) 669 (61.1)	625 (78.8) 426 (38.9)	4.88, 3.89 to 6.11	<.0005
Perceived clarity of information					Overall: .148
Extremely clear	170	67 (39.4)	103 (60.6)	1.36, 0.85 to 2.17	.204
Very clear	636	255 (40.1)	381 (59.9)	1.38, 0.96 to 1.98	.083
Moderately clear	685	308 (45.0)	377 (55.0)	1.39, 0.97 to 1.98	.073
Slightly clear	206	109 (52.9)	97 (47.1)	0.99, 0.64 to 1.53	.953
vs. Not at all clear	191	98 (51.3)	93 (48.7)		
		Mean (SD)			
Age (in years)	1,888	43.4 (15.6)	43.7 (15.8)	1.00, 0.99 to 1.00	.262

N.B. Adjusted ORs and 95% CIs are relative to a stated reference category except age, which is per unit increase; p-values <.05 are in bold; all predictor variables are included in the model

DISCUSSION

This study aimed to address a gap in the literature regarding how best to communicate the concept of overdiagnosis (8). We investigated whether people are familiar with terms used to describe overdiagnosis or related concepts, and whether these made sense as labels for widely used descriptions. We found that a majority of participants (58.0%) had never encountered any of the assessed terms before and a large proportion (44.3%) did not rate any term as making sense as a suitable label for either of two widely used descriptions of the concept. In addition, no specific term(s) emerged as being notably more familiar or applicable.

A previous similar study found that only 30.0% of the UK general public (aged 50-70) had previously encountered the specific term, 'overdiagnosis' (9), which is broadly comparable to the 21.8% who reported having encountered it in this study. Our findings are also consistent with those of a previous study that was part of redesign of the information materials for the NHS Breast Screening Programme (20). Women were interviewed with the aim of finding ways to communicate the concept of overdiagnosis: participants generally struggled to understand it, regardless of whether it was labelled as 'overdiagnosis' or 'overtreatment'.

Terminology can have a role in transferring information to lay individuals as part of a description of technical concepts (11,21). However, the main implication of our results is that currently there may only be limited value in using any of the labels that we tested. Terms used were neither familiar nor rated as particularly relevant in this large, diverse sample, meaning that they may be confusing, unintuitive, and hard for people to memorise and recall. Even the most technically appropriate terms (e.g. 'overdiagnosis' and 'overdetection') were not endorsed as making sense more frequently than suggested alternative terminology (e.g. 'unnecessary diagnosis) or more inaccurate and potentially problematic terminology (e.g. 'false positive diagnosis'). To some

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8 extent, the limited familiarity and low levels of endorsement at present supports UK policy
9 decisions not to use a specific term in the revised breast screening information leaflet (20).
10 Furthermore, shortly before the start of recruitment, an updated NHS information leaflet
11 regarding PSA screening was published, with additional detail on overdiagnosis and
12 overtreatment (22); this also omitted any specific descriptive label.
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18 One unexpected finding was that the second most common number of terms that were familiar
19 or endorsed was all seven (12.3% and 15.7%, respectively). This may be due to differences
20 between terms being subtle: members of the public may not recall exactly which terms they had
21 encountered but felt that broader concepts like diagnosis and treatment were familiar.
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26 We found that participants with a lower level of education, who were not White British, were
27 older, or (possibly) were from a lower social class grade were less likely to have previously
28 encountered any term(s), suggesting that these groups may be particularly poorly served by the
29 use of any specific terminology. Unsurprisingly, those who had previous exposure to cancer (i.e.
30 by knowing someone with a diagnosis) and those who had encountered potentially relevant
31 information (e.g. those who had previously discussed screening with a doctor or nurse) were
32 more likely to have encountered any term(s). In some respects, this latter finding was surprising
33 because although medical staff might be expected to discuss overdiagnosis with patients, there
34 is evidence that the topic is explained only rarely (23). Those who knew someone with cancer
35 were also more likely to endorse at least one term as making sense. It is unclear why males
36 were more likely to endorse term(s) as making sense. This may warrant further research
37 (possible explanations may include a degree of over-confidence in men or under-confidence in
38 women), although this should be considered in the context of small absolute differences
39 observed here (56.8% vs. 54.7% endorsing at least one term).
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8 Continuing communication efforts mean that these results may change over time: it is plausible
9 that ongoing campaigns (3-5) will result in the public becoming increasingly familiar with the
10 concept and terminology, having a better understanding of the differences between similar
11 terms (e.g. seeing 'false positives' as distinct from 'overdiagnosis'), and being more likely to
12 endorse particular terms as applicable. However, present attempts to communicate
13 overdiagnosis (e.g. as part of screening invitations or mainstream media stories) may be more
14 effective if explicit descriptions are used, such as adapted forms of information from the Breast
15 Screening Programme. This has undergone an extensive design process (20) and is more likely
16 to be rated as clearer than the equivalent from the Prostate Cancer Risk Management
17 Programme. However, fewer than half of participants (46.6%) rated it as very or extremely clear,
18 suggesting that future research could be used to improve it further (e.g. by providing additional
19 detail; 15).

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21 This study has limitations. The data collection method used by the survey company meant that
22 demographic characteristics used to ensure population-representativeness were not exhaustive
23 (e.g. they omitted ethnicity and education) and response rates were not available. The list of
24 terms tested was also not exhaustive; there may be suitable terminology that we did not assess.
25 However, we found very similar levels of endorsement for terms that used several variations on
26 the themes of diagnosis, treatment, and false positives, providing some evidence that any
27 superior terms would have to be quite different. In addition, as noted in our previous study,
28 descriptions of overdiagnosis were brief and presented outside the context of the original written
29 information about screening from which they were adapted; comprehension may be different
30 (either better or worse) in the presence of additional detail (15); this warrants further research.

31 32 33 34 35 36 37 38 39 40 41 42 43 44 45 46 47 48 49 **Conclusions**

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8 Alternative terminology to 'overdiagnosis' may help increase awareness and understanding of
9 the concept among individuals who may face healthcare decisions that would put them at risk.
10 These results suggest that, at present, using specific terms would have limited benefits and may
11 be less well suited to particular groups (e.g. less educated or non-White British individuals). It
12 may currently be more effective to refer to the concept via more explicit descriptions. Previous
13 research indicates that information from the NHS Breast Screening Programme may be a
14 relatively effective template for this purpose. However, future research could explore scope for
15 improvement.
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23 **Contributors:** AG, CR, and JW conceived and designed the study. AG analysed the data. AG,
24 CR, and JW participated in the interpretation of results. AG, CR, and JW drafted the manuscript,
25 participated in critical revision, and approved the final version.
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27
28

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39 **Competing interests:** None declared.
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41 **Patient consent:** Obtained.
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44 **Data sharing:** No additional data are available.
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Improving public understanding of 'overdiagnosis' in England: a population survey assessing familiarity with possible terms for labelling the concept and perceptions of appropriate terminology

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ABSTRACT

Objectives: Communicating the concept of 'overdiagnosis' to lay individuals is challenging, partly because the term itself is confusing. This study tested whether alternative descriptive labels may be more appropriate.

Design: Questionnaire preceded by a description of overdiagnosis.

Setting: Home-based, computer-assisted face-to-face survey.

Participants: 2,111 adults aged 18 to 70 years in England recruited using random location sampling by a survey company. Data from 1,888 participants were analysed after exclusions due to missing data.

Interventions: Participants were given one of two pieces of text describing overdiagnosis, allocated at random, adapted from NHS breast and prostate cancer screening leaflets.

Primary and secondary outcome measures: Main outcomes were which of several available terms (e.g. 'overdetection') participants had previously encountered and which they endorsed as applicable labels for the concept described. Demographics and previous exposure to screening information were also measured. Main outcomes were summarised with descriptive statistics. Predictors of previously encountering at least one term, or endorsing at least one as making sense, were assessed using binary logistic regression.

Results: 58.0% of participants had not encountered any suggested term; 44.0% did not endorse any as applicable labels. No term was notably familiar; the proportion of participants who had previously encountered each term ranged from 15.9 to 28.3%. Each term was only endorsed as applicable by a minority (range: 27.6% to 40.4%). Notable predictors of familiarity included

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8 education, age, and ethnicity; participants were less likely to have encountered terms if they
9 were older, not White British or had less education, Findings were similar for both pieces of
10 information.
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14 *Conclusions:* Familiarity with suggested terms for overdiagnosis and levels of endorsement
15 were low and no clear alternative labels for the concept were identified, suggesting that
16 changing terminology alone would do little to improve understanding, particularly for some
17 population groups. Explicit descriptions may be more effective.
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22 **Keywords:** Decision Making; Surveys and Questionnaires; Early Detection of Cancer; Mass
23 Screening; Medical Overuse
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27 **Strengths and limitations of this study**

- 28 • This study assessed (predictors of) familiarity and perceived appropriateness of a
29 broad range of possible terms for the concept of 'overdiagnosis' among a large,
30 representative sample of the general public in England.
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- 33 • The concept was described based on information that was widely used by the
34 National Health Service in England, maintaining generalisability.
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- 37 • The demographic criteria used to achieve population-representativeness were not
38 comprehensive and response rates were not available.
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- 41 • The list of possible terms was also not exhaustive; more suitable alternative labels
42 may have been omitted.
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- 45 • Results may be time-dependent: ongoing communication initiatives may change
46 perceptions of appropriate terms for the concept of 'overdiagnosis'.
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INTRODUCTION

There is growing concern among healthcare providers and policymakers about the potential for medical tests to detect asymptomatic disease that would never have become clinically apparent or resulted in death (1). 'Overdiagnosis' can harm, primarily via the subsequent risks and costs associated with unnecessary treatment but also via opportunity costs to a healthcare service due to overuse of scarce resources (2). Various initiatives have aimed to propagate understanding of the concept among patients and the public so that they can make better informed decisions about their health (e.g. 3–5). However, previous studies have found that the concept is challenging to communicate to lay people (e.g. in the context of breast cancer screening; 6,7).

Little is known about how to improve communication of overdiagnosis (8). One barrier is that the term 'overdiagnosis' itself may be confusing and counterintuitive. For example, a previous study in the UK asked members of the public to give their interpretation of what the word meant; a large proportion of participants gave definitions that did not match the concept but resembled other similar words (e.g. 'providing an incorrect diagnosis' since 'overdiagnosis' resembles 'misdiagnosis'; 9). Equivalent findings have been reported by a previous survey in Australia (10). In addition, a focus group study undertaken as part of the development of a decision aid for breast screening found that 'overdiagnosis' was not understood intuitively and that 'overdetection' may be clearer (11).

These findings suggest that the term 'overdiagnosis' does not clearly reflect its intended meaning for the general public and that other terms (such as 'overdetection') may be more appropriate. Hence, this study asked a large sample of the public in England to appraise descriptions of the concept and tested which of several possible terms people thought made

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8 sense as labels (i.e. endorsement). Alternatives included 'overdetection' or 'unnecessary
9 diagnosis' (11) as well as terms related to unnecessary therapy (e.g. 'overtreatment') and terms
10 that were less technically accurate but still had the potential to be seen as applicable (e.g. 'false
11 positives'; 9, 10). A limitation to the utility of 'overdiagnosis' as a label may be the currently low
12 level of public awareness of the term (9, 12). Consequently, this study also measured which
13 terms people had encountered before (i.e. familiarity) to test whether any alternatives were
14 notably more familiar. We also explored whether participant characteristics were associated with
15 having previously encountered these terms, or with endorsing them as making sense, as this
16 may aid targeted communication efforts.
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25 Information was derived from materials that have been widely used by the NHS Breast
26 Screening Programme (13) and the Prostate Cancer Risk Management Programme (14). The
27 study was carried out as part of Wave 3 of the Attitudes, Behaviour and Cancer UK Survey
28 (ABACUS). Other studies arising from this survey have also been published (e.g. 15).
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33 **METHODS**

34 **Design**

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36 Institutional approval was granted by the University College London Research Ethics
37 Committee (5771/002). The focus of the present study was on appropriate terminology for
38 widely used descriptions of overdiagnosis. However, the ABACUS survey was a broader piece
39 of work that also compared the perceived clarity of different forms of overdiagnosis information.
40 Hence, elements of the design and measures have also been reported elsewhere (15). Face-to-
41 face computer-assisted interviews were conducted by TNS (a market research company) as
42 part of a weekly omnibus survey and took place in participants' homes between April and May
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8 *"We would now like to ask you some questions about leaflets on health-related topics. The NHS*
9 *offers people a variety of screening tests to check for illnesses before symptoms have*
10 *appeared. People offered an NHS screening test are often given a leaflet that explains the risks*
11 *and benefits of having the test. The leaflet is either posted or given out by a doctor or nurse."*
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16 Participants then received information on overdiagnosis adapted from written material used by
17 the NHS in England as part of either i) the Breast Screening Programme or ii) the Prostate
18 Cancer Risk Management Programme as they existed in February 2016 (neither of which used
19 a specific label), allocated at random in a 1:1 ratio:
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24 *"The test can find an illness that would never have caused a person harm. Some people will be*
25 *diagnosed and treated for an illness that would never otherwise have been found and would not*
26 *have become life-threatening."* From the breast screening information leaflet (13)
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30 *"The test may make you worry by finding an illness that may never cause any symptoms or*
31 *shorten your life."* From the prostate screening information leaflet (14)
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35 The Breast Screening Programme in England offers triennial mammography to all women
36 between the ages of 50 to 70 years and registered with a General Practitioner. The Prostate
37 Screening Risk Management Programme allows men aged 50 years or older to have a Prostate
38 Specific Antigen test by requesting it from their GP after discussing the risks and benefits.
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40 References to cancer were removed so that findings could be generalised to beyond these two
41 specific screening contexts.
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46 **Participants**

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48 Participants were members of the public in England aged 18 to 70 years. National
49 representativeness was sought via a two-stage process. In the first instance, random location
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8 sampling was carried out using the Postcode Address File and Census statistics. Within each
9
10 selected location, participant quotas were set based on demographic characteristics (i.e. age,
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12 gender, employment status, and presence of children in the home).

13 14 **Measures**

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17 Demographics: Relevant measures consisted of age, gender, ethnicity, social grade (16),
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19 marital status, highest level of education obtained, personal history of cancer (*"Have you ever*
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21 *been diagnosed with cancer?"*; "yes" or "no"), and whether anyone they know had been
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23 diagnosed with cancer (*"Has anyone close to you ever been diagnosed with cancer?"*; "yes",
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25 "no", or "don't know").

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27 Familiarity with screening information: Participants were asked whether they had ever
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29 previously received information about screening (for cancer or other illnesses) via i) reading a
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31 leaflet from the NHS, ii) reading an NHS website, and iii) talking with a doctor or nurse
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33 (response options: "yes", "no", "not sure").

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35 If participants were eligible for cancer screening and had not been diagnosed with the target
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37 disease, they were asked about their previous participation (e.g. only women aged 47-70 years
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39 without a breast cancer diagnosis were asked about breast screening participation) via items
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41 designed using the Precaution Adoption Process Model (PAPM; 17), a stage theory of
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43 protective health behaviour. This measures whether participants have heard of a particular type
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45 of screening, whether they have heard of a type of screening but have never been invited,
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47 whether they have been invited but never participated, whether they have participated but not
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49 consistently, and whether they have participated consistently. Eligibility criteria and exact
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51 question wording for assessing experience have been reported elsewhere (15).
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8 Perceived clarity of information: After reading the information allocated at random, participants
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10 were asked, "How clear do you find this description of a risk of the test?" with available
11 responses of "extremely clear", "very clear", "moderately clear", "slightly clear", and "not at all
12 clear". This was followed by a question on whether they had read or heard similar information
13 about a screening test before (possible responses were: "yes", "no", and "not sure").
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18 Main outcomes: The first main outcome measure (endorsement) consisted of "Does this term
19 make sense to you as a way of describing this risk of a screening test?", followed by seven
20 terms: "overdiagnosis", "overdetection", "unnecessary diagnosis", "overtreatment", "unnecessary
21 treatment", "false positive diagnosis", and "false positive test results"¹ (responses: "yes", "no").
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24 Suggested terms were based on previous literature (e.g. 11) and discussion among the
25 research team.
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29 The second outcome measure (familiarity) was: "Have you ever seen or heard any of the
30 previous seven terms before today?" and if participants responded "yes", they were asked
31 which out of the previous terms (responses: "yes", "no", "not sure").
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35 Ancillary measures: The measures used in this study were part of the broader ABACUS survey.
36 Most of the items in this study were presented at the start of the survey and so the effects of
37 priming from unrelated items were expected to be minimal. In order, the full survey included:
38 questions on decision-making style and previous exposure to cancer screening information,
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46 ¹ Participants were also asked, "Can you think of any other terms to describe this risk that would
47 make sense to you?". However, only approximately 60 responses suggesting potentially
48 applicable terms were recorded across all participants (e.g. "oversensitivity", "unknown
49 diagnosis"), of which most were mentioned just once and so no further analysis was attempted.
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8 information on overdiagnosis adapted from screening leaflets, questions on perceived clarity of
9 this information, previous exposure to similar information, the main study outcomes, and help-
10 seeking behaviour in relation to cancer screening, followed by more questions on self-rated
11 health, questions on cancer diagnoses, perceived cancer risk, screening behaviour in relation to
12 each of the applicable programmes (cervical, breast, bowel, prostate), and educational level.
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17 **Public Involvement**

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20 Public involvement consisted of input into the design of the study and development of measures
21 via pilot testing of the survey. This comprised two stages: first, a series of telephone cognitive
22 interviews (18) was used to determine whether items could be understood by lay people (n=11)
23 and that the survey was not overly burdensome. Participants were asked for feedback on any
24 items they found difficult to understand or answer and the survey was revised accordingly.
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26 Second, a web-based version of the survey was pilot-tested with 431 participants. There are
27 currently no plans to disseminate the results to study participants.
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33 **Analysis**

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36 Participants were excluded if they declined to answer any of the measures included in this
37 study. Ethnicity and marital status were dichotomised into "White British" and "other ethnic
38 groups", and "single, widowed, divorced or separated" and "married or living as a couple",
39 respectively. Social class grade was categorised as "grades A or B", "grades C1 or C2", and
40 "grades D or E". Education was coded based on Levels 1-4 from the Office of National Statistics
41 (19) or "Other" for non-ordinal levels of education such as professional qualifications.
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48 Sample characteristics were summarised with descriptive statistics. We report the percentages
49 of participants (with binomial 95% confidence intervals) who had i) previously encountered and
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8 ii) endorsed each possible number of terms (from 0 to 7 in both cases), and the percentages of
9 participants who had previously encountered and endorsed each specific term.

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11 Responses to i) and ii) were also recoded into “previously seen or heard one or more terms”
12 (familiarity) and “endorsed one or more terms as making sense to them” (endorsement) for
13 further evaluation e.g. “was familiar with at least one term” vs. “was not familiar” (including
14 responses of “not sure”). Two exploratory logistic regression models tested the null hypothesis
15 that predictor variables were unrelated to either of these outcomes. In both models, predictor
16 variables consisted of demographic characteristics, familiarity with screening information, the
17 overdiagnosis information condition (breast vs. prostate), and perceived clarity. In addition, each
18 model included the outcome from the other as a predictor (e.g. the endorsement model included
19 familiarity as a potential predictor variable). Variance Inflation Factors were small (all <2.969
20 and <2.972, respectively), indicating that (multi)collinearity was limited and a Box-Tidwell
21 procedure found little evidence to suggest that the age variable violated the assumption of
22 linearity (p-values: .110 and .508). Adjusted odds-ratios (ORs), accompanying 95% CIs, and p-
23 values for having previously seen or heard one or more terms before and endorsing one or
24 more term as making sense are reported alongside descriptive statistics.
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38 **RESULTS**

39 **Participant characteristics**

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41 After excluding 223 participants with missing data, 1,888 cases were analysed. Sample
42 characteristics are presented in Table 1. Mean age was 43.6 years (standard deviation: 15.7).
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48 **Familiarity with terms**

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8 Table 2 illustrates that the majority of participants (58.0%) were not familiar with any of the listed
9 terms. However, the second most common number of terms recognised as familiar was all
10 seven (12.3%). The percentages of participants previously encountering between one and six
11 terms ranged from 1.1% to 9.4%. Table 2 also shows that the percentages of participants who
12 had encountered each specific term ranged from 15.9% (*“overdetection”*) to 28.3% (*“false*
13 *positive test results”*).
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19 Table 3 reports predictors of familiarity with at least one term. Among demographic
20 characteristics, there was strong evidence against the null hypothesis for ethnicity, education,
21 and age: White British participants were more likely to be familiar with at least one term
22 compared with other ethnic groups. Participants with a higher (or ‘other’) level of education were
23 also more likely to be familiar with one or more terms compared with participants who had no
24 formal qualifications (or did not know). Older participants were less likely to be familiar with one
25 or more terms. Participants were also more likely to be familiar with one or more terms if they
26 knew someone with cancer, had previously read an NHS website about screening, discussed
27 screening with a doctor or nurse, had previously read or seen similar information, or endorsed
28 one or more terms as making sense as labels.
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38 Finally, there was moderate evidence against the null hypothesis for an association with social
39 class grade with participants in grades A or B being more likely to be familiar with at least one
40 term compared with participants in grades D or E.
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44 **Terms endorsed as making sense**

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46 Table 4 shows that participants most commonly did not endorse any terms as making sense
47 (44.3%). As with results for familiarity, the second most common number of terms endorsed was
48 all seven (15.7%). The most commonly endorsed term was *“unnecessary treatment”* (40.4% of
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8 participants in the sample endorsed this term overall; 41.4% and 39.3% after being given the
9 breast and prostate information, respectively). Endorsement of other terms ranged from 27.9%
10 (“*overdetection*”) to 35.4% (“*unnecessary diagnosis*”) for information from breast screening and
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12 (“*overdetection*”) to 36.6% (“*false positive test results*”) for information from prostate
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14 screening.
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18 Other than familiarity (Table 3), the logistic regression analysis of predictors of endorsement
19 only showed strong evidence against the null hypothesis for gender and knowing someone with
20 cancer: males and participants who knew someone diagnosed with cancer were more likely to
21 endorse at least one term as making sense (Table 5).
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Table 1 – Characteristics of the sample

Total N=1,888		
Characteristic	n	(%)
Overdiagnosis information		
Breast screening text	987	(52.3)
Prostate screening text	901	(47.7)
Gender		
Male	879	(46.6)
Female	1,009	(53.4)
Ethnicity		
White British	1,432	(75.8)
Other ethnic groups	456	(24.2)
Marital status		
Married or living as a couple	1,133	(60.0)
Single, widowed, divorced, or separated	755	(40.0)
Highest level of education¹		
No formal qualifications	281	(14.9)
Approximately Level 1, 2, or 3	890	(47.1)
Approximately Level 4	507	(26.9)
Other	199	(10.5)
Don't know/Not sure	11	(0.6)
Social class grade²		
Grade A or B	386	(20.4)
Grade C1 or C2	931	(49.3)
Grade D or E	571	(30.2)
Personal diagnosis of cancer		
Yes	98	(5.2)
No	1,790	(94.8)
Knows someone with cancer		
Yes	1,113	(59.0)
No	771	(40.8)
Don't know/Not sure	4	(0.2)
Any previous cervical screening experience		
Yes	652	(34.5)
No	226	(12.0)
Not eligible	1,010	(53.5)
Any previous breast screening experience		
Yes	317	(16.8)
No	83	(4.4)
Not eligible	1,488	(78.8)
Any previous bowel screening experience		
Yes	293	(15.5)
No	181	(9.6)
Not eligible	1,414	(74.9)
Any previous prostate screening experience		
Yes	77	(4.1)
No	344	(18.2)
Not eligible	1,467	(77.7)
Previously read a screening leaflet		
Yes	1,058	(56.0)
No	809	(42.8)
Don't know/Not sure	21	(1.1)
Previously read an NHS screening website		
Yes	324	(17.2)
No	1,549	(82.0)
Don't know/Not sure	15	(0.8)
Discussed screening with doctor/nurse		
Yes	624	(33.1)
No	1,251	(66.3)
Don't know/Not sure	13	(0.7)
Previously read or heard similar information		
Yes	662	(35.1)
No	1,185	(62.8)
Don't know/Not sure	41	(2.2)

Perceived clarity of information

1	Extremely clear	170	(9.0)
2	Very clear	636	(33.7)
3	Moderately clear	685	(36.3)
4	Slightly clear	206	(10.9)
5	Not at all clear	191	(10.1)

¹Level 1-3 qualifications include e.g. GCSEs and A Levels; Level 4 qualifications include degrees and higher degrees

²Social grades are based on occupation (e.g. Grade A includes managerial roles; Grade E includes casual workers)

For peer review only

Table 2 – Number of participants (and percentages and 95% CIs) previously encountering i) each number of possible terms and ii) each specific term. Participants receiving overdiagnosis information based on the Breast Screening programme or the Prostate Cancer Risk Management Programme were analysed separately.

		Number of terms previously encountered: n, %, 95% CIs							
Screening information	Total	0	1	2	3	4	5	6	7
Breast	n (%)	583 (59.1)	73 (7.4)	76 (7.7)	53 (5.4)	41 (4.2)	28 (2.8)	9 (0.9)	124 (12.6)
N=987	95% CI	56.0 to 62.1	5.9 to 9.2	6.2 to 9.5	4.1 to 6.9	3.0 to 5.5	1.9 to 4.0	0.5 to 1.7	10.6 to 14.7
Prostate	n (%)	512 (56.8)	64 (7.1)	101 (11.2)	47 (5.2)	37 (4.1)	19 (2.1)	12 (1.3)	109 (12.1)
n=901	95% CI	53.6 to 60.0	5.6 to 8.9	9.3 to 13.4	3.9 to 6.8	3.0 to 5.6	1.3 to 3.2	0.7 to 2.2	10.1 to 14.3
Total	n (%)	1,095 (58.0)	137 (7.3)	177 (9.4)	100 (5.3)	78 (4.1)	47 (2.5)	21 (1.1)	233 (12.3)
N=1,888	95% CI	55.8 to 60.2	6.2 to 8.5	8.1 to 10.8	4.4 to 6.4	3.3 to 4.1	1.9 to 3.3	0.7 to 1.7	10.9 to 13.9
		<i>"Which of the following term or terms had you heard of before?": n, %, 95% CIs</i>							
Screening information	Total	Not sure	Overdiagnosis	Overdetection	Unnecessary diagnosis	Overtreatment	Unnecessary treatment	False positive diagnosis	False positive test result
Breast	n (%)	7 (0.7)	215 (21.8)	163 (16.5)	214 (21.7)	225 (22.8)	280 (28.4)	243 (24.6)	270 (27.4)
N=987	95% CI	0.3 to 1.4	19.3 to 24.4	14.3 to 18.9	19.2 to 24.3	20.3 to 25.5	25.6 to 31.2	22.0 to 27.4	24.6 to 30.2
Prostate	n (%)	14 (1.6)	196 (21.8)	137 (15.2)	216 (24.0)	186 (20.6)	253 (28.1)	232 (25.7)	265 (29.4)
n=901	95% CI	0.9 to 2.5	19.2 to 24.5	13.0 to 17.7	21.3 to 26.8	18.1 to 23.4	25.2 to 31.1	23.0 to 28.7	26.5 to 32.4
Total	n (%)	21 (1.1)	411 (21.8)	300 (15.9)	430 (22.8)	411 (21.8)	533 (28.2)	475 (25.2)	535 (28.3)
N=1,888	95% CI	0.7 to 1.7	20.0 to 23.7	14.3 to 17.6	20.9 to 24.7	20.0 to 23.7	26.2 to 30.3	23.2 to 27.2	26.3 to 30.4

Table 3 – Familiarity with one or more vs. no terms: descriptive statistics, adjusted ORs, 95% CIs, and p-values for variables in the multivariable binary logistic regression model

Characteristic	Total (N=1,888)	Familiarity with no terms vs. at least one term: n (%)		Adjusted OR, 95% CI	p-value
		No term (n=1,095; 58.0%)	At least one term (n=793; 42.0%)		
Overdiagnosis information					
Breast screening text vs. Prostate screening text	987 901	583 (59.1) 512 (56.8)	404 (40.9) 389 (43.2)	0.87, 0.70 to 1.09	.224
Gender					
Male vs. Female	879 1,009	534 (60.8) 561 (55.6)	345 (39.2) 448 (44.4)	1.00, 0.79 to 1.26	.998
Ethnicity					
White British vs. Other ethnic groups	1,432 456	775 (54.1) 320 (70.2)	657 (45.9) 136 (29.8)	2.14, 1.61 to 2.84	<.0005
Marital status					
Married or living as a couple vs. Single, widowed, divorced, or separated	1,133 755	661 (58.3) 434 (57.5)	472 (41.7) 321 (42.5)	0.87, 0.69 to 1.09	.216
Highest level of education					
Other levels vs. No formal qualifications or don't know	199 292	116 (58.3) 228 (78.1)	83 (41.7) 64 (21.9)	2.32, 1.46 to 3.68	Overall: <.0005 <.0005
Approximately Level 4	507	219 (43.2)	288 (56.8)	4.17, 2.75 to 6.33	<.0005
Approximately Level 1, 2, or 3	890	532 (59.8)	358 (40.2)	2.19, 1.52 to 3.15	<.0005
Social class grade					
Grade A or B vs. Grade D or E	386 571	170 (44.0) 383 (67.1)	216 (56.0) 188 (32.9)	1.54, 1.09 to 2.17	Overall: .050 .014
Grade C1 or C2	931	542 (58.2)	389 (41.8)	1.19, 0.91 to 1.55	.201
Personal diagnosis of cancer					
Yes vs. No	98 1,790	49 (50.0) 1,046 (58.4)	49 (50.0) 744 (41.6)	1.10, 0.68 to 1.80	.690
Knows someone with cancer					
Yes vs. No or don't know	1,113 775	562 (50.5) 533 (68.8)	551 (49.5) 242 (31.2)	1.50, 1.19 to 1.89	.001
Previously read a screening leaflet					
Yes vs. No or not sure	1,058 830	535 (50.6) 560 (67.5)	523 (49.4) 270 (32.5)	1.27, 0.97 to 1.66	.089
Previously read an NHS screening website					
Yes vs. No or not sure	324 1,564	125 (38.6) 970 (62.0)	199 (61.4) 594 (38.0)	1.45, 1.07 to 1.97	.016
Discussed screening with doctor/nurse					
Yes vs. No	624 1,264	276 (44.2) 819 (64.8)	348 (55.8) 445 (35.2)	1.34, 1.03 to 1.74	.030
Previously read or heard similar information					
Yes vs. No or not sure	662 1,226	266 (40.2) 829 (67.6)	396 (59.8) 397 (32.4)	2.30, 1.81 to 2.94	<.0005
Endorsed any term(s) as making sense					
Yes vs. No	1,051 837	426 (40.5) 669 (79.9)	625 (59.5) 168 (20.1)	4.92, 3.94 to 6.17	<.0005
Perceived clarity of information					
Extremely clear vs. Not at all clear	170 191	87 (51.2) 115 (60.2)	83 (48.8) 76 (39.8)	0.85, 0.52 to 1.40	Overall: .534 .525
Very clear	636	339 (53.3)	297 (46.7)	0.97, 0.65 to 1.43	.860
Moderately clear	685	424 (61.9)	261 (38.1)	0.78, 0.53 to 1.16	.225
Slightly clear	206	130 (63.1)	76 (36.9)	0.92, 0.57 to 1.49	.745
Mean (SD)					
Age (in years)	1,888	43.8 (15.7)	43.3 (15.8)	0.99, 0.98 to 1.00	.003

N.B. Adjusted ORs and 95% CIs are relative to a stated reference category except age, which is per unit increase; p-values <.05 are in bold; all predictor variables are included in the model

Table 4 – Number of participants (and percentages and 95% CIs) endorsing i) each number of possible terms and ii) each specific term as making sense to them as a label

		Number of terms endorsed as making sense as a way of describing the text: n, %, 95% CIs								
Screening information	Total	0	1	2	3	4	5	6	7	
Breast	n (%)	429 (43.5)	76 (7.7)	86 (8.7)	74 (7.5)	67 (6.8)	58 (5.9)	42 (4.3)	155 (15.7)	
n=987	95% CI	40.4 to 46.6	6.2 to 9.5	7.1 to 10.6	6.0 to 9.3	5.3 to 8.5	4.5 to 7.5	3.1 to 5.7	13.5 to 18.1	
Prostate	n (%)	408 (45.3)	59 (6.5)	73 (8.1)	68 (7.5)	66 (7.3)	48 (5.3)	37 (4.1)	142 (15.8)	
n=901	95% CI	42.1 to 48.5	5.1 to 8.3	6.5 to 10.0	6.0 to 9.4	5.8 to 9.2	4.0 to 6.9	3.0 to 5.6	13.5 to 18.2	
Total	n (%)	837 (44.3)	135 (7.2)	159 (8.4)	142 (7.5)	133 (7.0)	106 (5.6)	79 (4.2)	297 (15.7)	
N=1,888	95% CI	42.1 to 46.6	6.1 to 8.4	7.2 to 9.7	6.4 to 8.8	6.0 to 8.3	4.6 to 6.7	3.4 to 5.2	14.1 to 17.4	
		<i>"Which terms make sense as a way of describing this risk of a screening test?": n, %, 95% CIs</i>								
Screening information	Total	Overdiagnosis	Overdetection	Unnecessary diagnosis	Overtreatment	Unnecessary treatment	False positive diagnosis	False positive test results		
Breast	n (%)	334 (33.8)	275 (27.9)	349 (35.4)	336 (34.0)	409 (41.4)	324 (32.8)	338 (34.2)		
n=987	95% CI	30.9 to 36.8	25.1 to 30.7	32.4 to 38.4	31.1 to 37.0	38.4 to 44.5	30.0 to 35.8	31.3 to 37.2		
Prostate	n (%)	291 (32.3)	247 (27.4)	307 (34.1)	280 (31.1)	354 (39.3)	320 (35.5)	330 (36.6)		
n=901	95% CI	29.3 to 35.4	24.6 to 30.4	31.0 to 37.2	28.1 to 34.2	36.1 to 42.5	32.4 to 38.7	33.5 to 39.8		
Total	n (%)	625 (33.1)	522 (27.6)	656 (34.7)	616 (32.6)	763 (40.4)	644 (34.1)	668 (35.4)		
N=1,888	95% CI	31.0 to 35.3	25.7 to 29.7	32.6 to 36.9	30.5 to 34.8	38.2 to 42.6	32.0 to 36.3	33.2 to 37.6		

Table 5 – Endorsed one or more vs. no terms as making sense: descriptive statistics, adjusted ORs, 95% CIs, and p-values for variables in the multivariable binary logistic regression model

Characteristic	Total (N=1,888)	Endorsed no vs. at least one term as making sense: n (%)		Adjusted OR, 95% CI	p-value
		No term (n=837; 44.3%)	At least one term (n=1,051; 55.7%)		
Overdiagnosis information				At least one term endorsed (vs. No terms endorsed)	
Breast screening text vs. Prostate screening text	987 901	429 (43.5) 408 (45.3)	558 (56.5) 493 (54.7)	1.16, 0.95 to 1.42	.148
Gender					
Male vs. Female	879 1,009	380 (43.2) 457 (45.3)	499 (56.8) 552 (54.7)	1.40, 1.13 to 1.74	.002
Ethnicity					
White British vs. Other ethnic groups	1,432 456	592 (41.3) 245 (53.7)	840 (58.7) 211 (46.3)	1.25, 0.97 to 1.61	.080
Marital status					
Married or living as a couple vs. Single, widowed, divorced, or separated	1,133 755	500 (44.1) 337 (44.6)	633 (55.9) 418 (55.4)	1.05, 0.85 to 1.30	.671
Highest level of education					Overall: .556
Other levels	199	88 (44.2)	111 (55.8)	1.21, 0.80 to 1.82	.374
Approximately Level 4	507	190 (37.5)	317 (62.5)	1.27, 0.88 to 1.84	.204
Approximately Level 1, 2, or 3	890	396 (44.5)	494 (55.5)	1.24, 0.91 to 1.70	.169
vs. No formal qualifications or don't know	292	163 (55.8)	129 (44.2)		
Social class grade					Overall: .574
Grade A or B	386	137 (35.5)	249 (64.5)	1.09, 0.78 to 1.51	.617
Grade C1 or C2	931	420 (45.1)	511 (54.9)	0.94, 0.74 to 1.19	.604
vs. Grade D or E	571	280 (49.0)	291 (51.0)		
Personal diagnosis of cancer					
Yes vs. No	98 1,790	37 (37.8) 800 (44.7)	61 (62.2) 990 (55.3)	1.08, 0.68 to 1.74	.741
Knows someone with cancer					
Yes vs. No or don't know	1,113 775	427 (38.4) 410 (52.9)	686 (61.6) 365 (47.1)	1.35, 1.09 to 1.68	.005
Previously read a screening leaflet					
Yes vs. No or not sure	1,058 830	416 (39.3) 421 (50.7)	642 (60.7) 409 (49.3)	1.18, 0.91 to 1.52	.206
Previously read an NHS screening website					
Yes vs. No or not sure	324 1,564	109 (33.6) 728 (46.5)	215 (66.4) 836 (53.5)	1.01, 0.75 to 1.37	.955
Discussed screening with doctor/nurse					
Yes vs. No	624 1,264	217 (34.8) 620 (49.1)	407 (65.2) 644 (50.9)	1.25, 0.97 to 1.61	.091
Previously read or heard similar information					
Yes vs. No or not sure	662 1,226	224 (33.8) 613 (50.0)	438 (66.2) 613 (50.0)	1.18, 0.93 to 1.50	.185
Previously encountered any term(s)					
Yes No	1,051 837	168 (21.2) 669 (61.1)	625 (78.8) 426 (38.9)	4.88, 3.89 to 6.11	<.0005
Perceived clarity of information					Overall: .148
Extremely clear	170	67 (39.4)	103 (60.6)	1.36, 0.85 to 2.17	.204
Very clear	636	255 (40.1)	381 (59.9)	1.38, 0.96 to 1.98	.083
Moderately clear	685	308 (45.0)	377 (55.0)	1.39, 0.97 to 1.98	.073
Slightly clear	206	109 (52.9)	97 (47.1)	0.99, 0.64 to 1.53	.953
vs. Not at all clear	191	98 (51.3)	93 (48.7)		
		Mean (SD)			
Age (in years)	1,888	43.4 (15.6)	43.7 (15.8)	1.00, 0.99 to 1.00	.262

N.B. Adjusted ORs and 95% CIs are relative to a stated reference category except age, which is per unit increase; p-values <.05 are in bold; all predictor variables are included in the model

DISCUSSION

This study aimed to address a gap in the literature regarding how best to communicate the issue of overdiagnosis (8). We investigated whether people are familiar with terms used to define overdiagnosis or related concepts, and whether these made sense as labels for either of two widely used descriptions. We found that a majority of participants (58.0%) had never encountered any of the assessed terms before and a large proportion (44.3%) did not rate any as making sense as a suitable label. In addition, no specific term(s) emerged as being notably more familiar or applicable.

An earlier similar study found that only 30.0% of the UK general public (aged 50-70) had previously encountered the specific term, 'overdiagnosis' (9), which is broadly comparable to the 21.8% who reported having encountered it in this study. Our findings are also consistent with those of a previous study carried out as part of the redesign of the information materials for the NHS Breast Screening Programme (20). Women were interviewed with the aim of finding ways to communicate the concept of overdiagnosis: participants generally struggled to understand it, regardless of whether it was labelled as 'overdiagnosis' or 'overtreatment'.

Terminology can have a role in transferring information to lay individuals as part of a description of technical concepts (11,21). However, the main implication of our results is that there may currently only be limited value in using any of the labels that we tested. Terms used were neither familiar nor rated as particularly relevant in this large, diverse sample, meaning that they may be confusing, unintuitive, and hard for people to memorise and recall. Even the most technically appropriate terms (e.g. 'overdiagnosis' and 'overdetection') were not endorsed as making sense more frequently than suggested alternative terminology (e.g. 'unnecessary diagnosis) or more inaccurate and potentially problematic terminology (e.g. 'false positive

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8 diagnosis'). To some extent, the currently limited familiarity and low levels of endorsement
9 supports UK policy decisions not to use a specific term in the revised breast screening
10 information leaflet (20). Furthermore, shortly before the start of recruitment, an updated NHS
11 information leaflet regarding PSA screening was published, with additional detail on
12 information leaflet regarding PSA screening was published, with additional detail on
13 overdiagnosis and overtreatment (22); this also omitted any specific descriptive label.
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18 A potential explanation for the low proportions of participants endorsing each term comes from
19 a recent survey in the United States. This used a similar design to the present study in which
20 women aged 35-55 years were recruited to respond to brief descriptions of overdiagnosis and
21 overtreatment. Only a small minority of participants (approximately 15-20%) endorsed
22 messages as either believable and something with which they agreed (23). To some extent, this
23 is consistent with qualitative research showing that the concept is often surprising and confusing
24 to lay people (6, 7). Limited acceptance of the description of overdiagnosis itself may have
25 resulted in participants disengaging with the concept and hence not rating any of the available
26 terms as appropriate. It may be relevant that both sets of descriptions were presented outside of
27 contexts in which they would normally be encountered (e.g. the original screening information
28 leaflets from which they were adapted). Both comprehension and acceptance may be different
29 (either better or worse) in the presence of additional detail (15), either from a full leaflet or as
30 part of a discussion with a clinician. This warrants further research.
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42 One unexpected finding was that the second most common number of terms that were familiar
43 or endorsed was all seven (12.3% and 15.7%, respectively). This may be due to the differences
44 between terms being subtle: members of the public may not recall exactly which terms they had
45 encountered but felt that broader concepts like diagnosis and treatment were familiar.
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8 We found that participants with a lower level of education, who were not White British, were
9 older, or (possibly) were from a lower social class grade were less likely to have previously
10 encountered any term(s), suggesting that these groups may be particularly poorly served by the
11 use of any specific terminology. Unsurprisingly, those who had previous exposure to cancer (i.e.
12 by knowing someone with a diagnosis) and those who had encountered potentially relevant
13 information (e.g. those who had previously discussed screening with a doctor or nurse) were
14 more likely to have encountered any term(s). In some respects, this latter finding was surprising
15 because although medical staff might be expected to discuss overdiagnosis with patients, there
16 is evidence that the topic is explained only rarely (24). Those who knew someone with cancer
17 were also more likely to endorse at least one term as making sense. It is unclear why males
18 were more likely to endorse term(s) as making sense. This may warrant further research
19 (possible explanations may include a degree of over-confidence in men or under-confidence in
20 women), although this should be considered in the context of small absolute differences
21 observed here (56.8% vs. 54.7% endorsing at least one term).
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34 Continuing communication efforts mean that these results may change over time: it is plausible
35 that ongoing campaigns (e.g. 3-5) will result in the public becoming increasingly familiar with the
36 concept and terminology, having a better understanding of the differences between similar
37 terms (e.g. seeing 'false positives' as distinct from 'overdiagnosis'), and being more likely to
38 endorse particular terms as applicable. However, present attempts to communicate
39 overdiagnosis (e.g. as part of screening invitations or mainstream media stories) may be more
40 effective if explicit descriptions are used, such as adapted forms of information from the Breast
41 Screening Programme. This has undergone an extensive design process (20) and is more likely
42 to be rated as clearer than the equivalent from the Prostate Cancer Risk Management
43 Programme. However, fewer than half of participants (46.6%) rated it as very or extremely clear,
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8 suggesting that future research could be used to improve it further (e.g. by providing additional
9 detail; 15).

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12 This study has limitations. The data collection method used by the survey company meant that
13 demographic characteristics used to ensure population-representativeness were not exhaustive
14 (e.g. they omitted ethnicity and education) and response rates were not available. The list of
15 terms tested was also not exhaustive; there may be suitable terminology that we did not assess.
16 However, we found very similar levels of endorsement for terms that used several variations on
17 the themes of diagnosis, treatment, and false positives, providing some evidence that any
18 superior terms would have to be quite different.
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25 26 **Conclusions**

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28 Alternative terminology to 'overdiagnosis' may help increase awareness and understanding of
29 the concept among individuals who may face healthcare decisions that would put them at risk.
30 These results suggest that, at present, using specific terms would have limited benefits and may
31 be less well suited to particular groups (e.g. less educated or non-White British individuals). It
32 may currently be more effective to refer to the concept via more explicit descriptions. Previous
33 research indicates that information from the NHS Breast Screening Programme may be a
34 relatively effective template for this purpose. However, future research could explore scope for
35 improvement.
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45 CR, and JW participated in the interpretation of results. AG, CR, and JW drafted the manuscript,
46 participated in critical revision, and approved the final version.
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18 **Competing interests:** None declared.
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20 **Patient consent:** Obtained.
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23 **Data sharing:** No additional data are available.
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