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A survey of public definitions of the term 'overdiagnosis' in the UK

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FULL TITLE PAGE:**Title:** A survey of public definitions of the term 'overdiagnosis' in the UK**Manuscript type:** Research report**Authors:**Alex Ghanouni^a BSc MSc PhDSusanne F Meisel^a BAppSc MSc PhDCristina Renzi^a MD MScJane Wardle^a BA MPhil PhDJo Waller^a BA MSc PhD**Affiliations:**^aHealth Behaviour Research Centre, Department of Epidemiology and Public Health,
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ABSTRACT

Objectives: To determine how 'overdiagnosis' is currently conceptualised among older adults in the UK in light of previous research, which has found that the term is difficult for the public to understand and awareness is low. This study aims to add to contemporary debates on healthcare in which overdiagnosis is a prominent issue.

Design: An observational, web-based survey was administered by a survey company.

Setting: Participants completed the survey at a time and location of their choosing.

Participants: 390 consenting UK adults aged 50-79 years. Quota sampling was used to achieve approximately equal numbers in three categories of education.

Primary outcome measures: Participants were asked whether they had seen or heard the term 'overdiagnosis'. If they had, they were then invited to explain in a free text field what they understood it to mean. If they had not previously encountered it, they were invited to say what they thought it meant. Responses were coded and interpreted using content analysis and descriptive statistics.

Results: Data from 390 participants were analysed. Almost a third (30.0%) of participants reported having previously encountered the term. However, their responses often indicated that they had no knowledge of its meaning. The most prevalent theme consisted of responses related to the diagnosis itself. Subthemes indicated common misconceptions, including an '*overly negative or complicated diagnosis*', '*false positive diagnosis*' or '*misdiagnosis*'. Other recurring themes consisted of responses related to testing (i.e. '*too many tests*'), treatment (e.g. '*overtreatment*'), and patient psychology (e.g. '*overthinking*'). Responses categorised as consistent with '*overdiagnosis*' (defined as detection of a disease that would not cause symptoms or death) were notably rare (n=10; 2.6%).

Conclusions: Consistent with previous research, public awareness of 'overdiagnosis' in the UK is low and its meaning is often misunderstood or misinterpreted.

Article summary

Strengths and limitations of this study:

- This is the first study to investigate how the UK general public understands and interprets the term ‘overdiagnosis’.
- Free-text fields allowed participants to respond in their own words without being limited to categories pre-selected by the researchers.
- The results of this study corroborate those of a previous survey in Australia and are consistent with previous research indicating that overdiagnosis is a difficult concept for people to understand.
- An appreciable proportion of participants’ responses were ambiguous in their meaning and some could not be coded into a specific category.

INTRODUCTION

Academics, healthcare professionals, and policymakers are becoming increasingly concerned about circumstances in which the health benefits of a given intervention are not considered to clearly justify the associated risks. The British Medical Journal has been a prominent voice in this area through their “Too Much Medicine” campaign,¹ which has recently gained support from the Academy of Medical Royal Colleges.² A central topic within the campaign is ‘overdiagnosis’, defined here as the diagnosis of disease which would never have become clinically apparent in a person’s lifetime (i.e. causing neither symptoms nor death).^{3,4} Debate continues regarding the magnitude, significance, and implications of overdiagnosis. Much attention is focused on breast cancer screening, where estimates of the ratio of screening-prevented breast cancer deaths to overdiagnosed breast cancer cases range from 9:4⁵ to 5:17³ for 1,000 women screened over 20 years. There is also an increasingly common view that screening invitees should appreciate the possibility of overdiagnosis before deciding whether to participate,⁶ although there is professional controversy regarding how best to inform people about the concept.⁷

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3 Public awareness of overdiagnosis appears to be low. Moynihan et al. recently reported a
4 survey of 500 Australian adults drawn from the general population, who were asked to state
5 whether they had seen or heard the term, before indicating what they thought it meant. The
6 majority (50-63%) reported having encountered the term before but only 41% of the sample
7 were categorised as responding with even an approximately correct definition of the term.
8 Participants categorised as being approximately correct often described it in terms of
9 misdiagnosis, too many diagnoses, or overstating the significance of a diagnosis, with 35%
10 of responses falling into one of these categories.⁸ Although these have some similarities with
11 the intended meaning of overdiagnosis, there is an apparent lack of awareness regarding its
12 specific meaning. This suggests that despite attention in health-related literature,
13 overdiagnosis has not become a familiar term among the general public.
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26 The present study extends the previous work by exploring people's definitions of
27 'overdiagnosis' as part of a web-based survey of older adults in the UK. We used the same
28 measures of awareness as Moynihan et al.⁸ to allow comparability between studies.
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33 **METHOD**

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36 This study took place as part of a web-based survey of attitudes and beliefs about cancer in
37 February 2015. The sample consisted of consenting members of the UK general population
38 aged 50-70 years, recruited through a survey company. Quotas were used to ensure an
39 equal proportion of men and women, and equal proportions of participants with different
40 levels of education (three categories: leaving school before 16 years; completing CSEs, O-
41 levels, or equivalent; completing A-levels, higher, university education, or equivalent).
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49 As in the Australian study, participants were first asked: *"have you seen or heard the term*
50 *'overdiagnosis' before today"*. Those responding "yes" were then asked *"what do you*
51 *understand the term 'overdiagnosis' to mean"*, those who responded "no" were asked *"what*
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3 *do you think the term 'overdiagnosis' means*¹. Participants responded to the latter two
4 questions by completing a free-text field. They were also asked for basic demographic
5 information (gender, age, level of education, and ethnicity).
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10 The questions on overdiagnosis formed part of a larger survey on views relating to cancer
11 screening. Screening-specific questions always came after questions on overdiagnosis and
12 so responses could not have been influenced by the questions on screening (results not
13 reported here).
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18 Demographic data and self-reported recognition of the term 'overdiagnosis' were analysed
19 using simple descriptive statistics. Content analysis was used to examine responses to free-
20 text questions.⁹ Responses were categorised independently by two researchers (AG &
21 SFM), who read participants' answers repeatedly before assigning a provisional code (e.g.
22 '*misdiagnosis*') to each one, based on their interpretation. After both researchers had
23 completed their separate coding, the two lists were compared and disagreements resolved
24 through discussion. The final list of codes was then reviewed to determine whether several
25 codes could be meaningfully renamed, grouped together or split into further codes. The
26 overarching themes and specific subthemes identified were then summarised using
27 descriptive statistics and illustrated using exemplar quotes. Responses of participants who
28 reported having seen or heard the term before and those of participants who reported no
29 previous exposure to the term were reported separately.
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43 **RESULTS**

44 **Participant characteristics**

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53 ¹ An error in the skip-logic of the survey meant that participants who responded "yes" were also asked
54 the second question. Hence, data on questions asked in error were not analysed since participants
55 often responded with the same answer or noted that they had already answered a very similar
56 question. One participant who responded "no" was able to complete both questions and so was
57 excluded from the analysis since their answer to the second (correctly asked) question may have
58 been affected by the first (incorrectly asked) question.
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3 The sample comprised 390 adults (201 women; 51.5%) with a median age of 60 years
4 (interquartile range [IQR]: 55 to 65). Most stated their ethnicity as White (n=382; 97.9%).
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6 Approximately equal numbers had left school before 16 years (133; 34.1%), completed
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8 CSEs, O-levels, or equivalent (125; 32.1%), and had completed A-levels, higher, or
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10 university degree, or equivalent (132; 33.8%).
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13 14 **Definitions of 'overdiagnosis'**

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17 117 participants (30.0%) reported having seen or heard the term previously. Median length
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19 of free text responses relating to participants' understanding was 7 words (range: 1 to 42;
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21 IQR: 4 to 12.5); for responses from participants who had not seen or heard it before, it was 4
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23 words (range: 1 to 28; IQR: 2 to 8).
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26 For both groups, responses could be categorised into one of six broad themes. These are
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28 summarised in Table 1 and Table 2, respectively, along with exemplar quotes. Participants
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30 commonly reported either no knowledge of what the term meant (even when they reported
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32 having encountered it before) or responded in a way that could not be categorised
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34 (frequently because the response was too vague or entirely unclear). Three other themes
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36 were aligned with different stages of a patient trajectory: from testing (*'too many tests'*) to
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38 diagnosis, and treatment. The theme relating to diagnosis was the most prevalent; 38.5%
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40 and 26.1% of responses from participants who had and had not been previously exposed to
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42 the term were categorised into this theme. Relevant subthemes included an *'overly negative*
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44 *or complicated diagnosis'*, a *'false positive diagnosis'*, and a *'misdiagnosis'*. Treatment-
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46 related responses referred to *'overtreatment'*, *'inappropriate treatment'* and *'unbeneficial*
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48 *treatment'*. A further broad theme referred to conceptions of how patients' psychology
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50 related to overdiagnosis, with the most common sub-theme being *'overthinking'*. The final
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52 grouping consisted of other responses that could not be categorised into one of the
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54 preceding five themes.
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3 Responses were rarely consistent with '*overdiagnosis*' itself, whether or not participants had
4 previously been exposed to the term (n=9, 7.7%; n=1; 0.4%). All such responses are
5 reported in Table 3.
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Table 1 - Understanding of 'overdiagnosis' among participants who had previously encountered the term (n=117): emerging (sub-)themes

Category	Exemplar quote (spelling errors corrected)	n (%)
Response not categorised or no knowledge		
Incoherent, irrelevant, or too vague to interpret	"More than a person says"	21 (17.9)
No knowledge	"Not sure"	10 (8.5)
Diagnosis-related responses		
Overly negative or complicated diagnosis	"Where certain illnesses are overstated in their severity"	12 (10.3)
False positive diagnosis	"Diagnosis of a condition that is not really there"	11 (9.4)
Overdiagnosis	"I think it means the diagnosis of a disease that will not cause symptoms or death"	9 (7.7)
Too many diagnoses	"Finding out all the complaints that may be wrong with you"	8 (6.8)
Overly detailed diagnosis	"A condition has been over-described"	4 (3.4)
Misdiagnosis	"Diagnosing minor problems rather than the real problem at source"	1 (0.9)
Diagnosis based on stereotypes	"Diagnosis based on stereotypes e.g. The patient is overweight therefore he will have a CVA"	1 (0.9)
Test-related responses		
Too many tests	"Patient undergoing more tests than necessary to diagnose a disease"	6 (5.1)
Treatment-related responses		
Inappropriate treatment	"Taking medicine not needed"	1 (0.9)
Overtreatment	"Had taken too many pills, or dr. prescribe too many different pills the person must take, when don't need"	1 (0.9)
Responses related to patients' psychology		
Overthinking	"When you think things through to such an extent that you confuse things or make them more complicated or important than they deserve to be"	20 (17.1)
Overly health-sensitive	"Over-analysing of minor conditions until you are convinced that there is a condition to be treated"	4 (3.4)
Anticipating a worse diagnosis	"Presuming something nasty is wrong before running tests"	3 (2.6)
Other responses		
Medicalising issues unrelated to health	"When non-health-related issues are medicalised"	2 (1.7)
Defensive medicine	"Must have an answer, doctors not wanted to be sued"	1 (0.9)
Iatrogenic illness	"Iatrogenic illness"	1 (0.9)
Too many attempts at prevention	"Too much preventing what may happen or not"	1 (0.9)

Table 2 – Interpretation of 'overdiagnosis' among participants who had not previously encountered the term (n=273): emerging (sub-)themes

Category	Exemplar quote (spelling errors corrected)	n (%)
Response not categorised or no knowledge		
No knowledge	"Don't know"	103 (37.7)
Incoherent, irrelevant, or too vague to categorise	"Going over the top"	44 (16.1)
Diagnosis-related responses		
Overly negative or complicated diagnosis	"Diagnosing a disease to a worse state than actual"	30 (11.0)
False positive diagnosis	"It sounds like being told you have things you don't have."	13 (4.8)
Misdiagnosis	"The wrong diagnosis of an illness"	12 (4.4)
Overly detailed diagnosis	"Too much information on a probable problem"	9 (3.3)
Too many diagnoses	"Too many different diagnosis from various medical professionals"	6 (2.2)
Overdiagnosis	"Making People Sick in the Pursuit of Health"	1 (0.4)
Test-related responses		
Too many tests	"Too many health checks"	6 (2.2)
Treatment-related responses		
Overtreatment	"Treating an illness in a stronger way than necessary"	6 (2.2)
Inappropriate treatment	"Wrong treatment or pills"	2 (0.7)
Unbeneficial treatment	"Giving medical assistance when there is no hope."	1 (0.4)
Responses related to patients' psychology		
Overthinking	"Complicating a problem by thinking too much about it"	15 (5.5)
Overly health-sensitive	"Worrying too much about health issues, continually seeking explanations"	10 (3.7)
Anticipating a worse diagnosis	"Looking at worst case scenario before having all the facts"	8 (2.9)
Other responses		
Multiple (medical) opinions	"Too many people involved in a medical decision."	5 (1.8)
Defensive medicine	"Treatment, just to be on the safe side"	2 (0.7)

Table 3 - All responses coded as consistent with 'overdiagnosis'

Response (spelling errors corrected)**Participants reporting having previously seen or heard the term**

"An example would be with some forms of health screening you get a positive result which leads to further investigation and treatment for a condition which would probably never have killed you. There is a type of breast cancer (DCIS) which falls [response was truncated by survey character limit]"

"Treating conditions like tiny lesions in the breast that may have resolved themselves without treatment"

"I think it means the diagnosis of a disease that will not cause symptoms or death"

"Yes, it is the diagnosis of a disease that will not cause the death of a patient"

"Reacting too much to minor and potentially insignificant things found during an investigation, with the result that they are treated unnecessarily."

"When you are screened for something it is a false positive or a positive on something that would not harm you in your likely lifespan"

"A diagnosis of a disease that will never happen or cause a problem"

"Some people can be diagnosed and have unsuitable or unnecessary treatment"

"Overdiagnosis is the diagnosis of disease that will never cause symptoms or death during a patient's lifetime."

Participants reporting no previous exposure to the term

"Making People Sick in the Pursuit of Health"

DISCUSSION

This survey of definitions of 'overdiagnosis' among older adults in the UK found that despite approximately 1 in 3 people stating that they had seen or heard the term before, only a minority provided a response that was even broadly consistent with the meaning considered correct: diagnosis of a disease that would not cause symptoms or death.³ This finding can be interpreted in light of the inconsistent usage of the term among academics and clinicians. As Carter et al. note, the intended meaning can vary, depending on the specific context being addressed within the general domain of "Too Much Medicine".⁴ Hence, it is not surprising that a singular, clear meaning has not reached public awareness. However, concerns regarding overdiagnosis are likely to be an increasingly influential aspect of both

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3 policy- and patient-level decisions. Consequently, policymakers, healthcare providers and
4 communicators may consider this to be an important concept that the public should
5 understand. One risk of a lack of awareness is scepticism regarding the true purpose of an
6 attempt to reduce the delivery healthcare interventions (e.g. the belief that it is an attempt to
7 reduce costs). This may account for the generally negative views among women regarding
8 the US Preventive Services Task Force recommendation that women aged 40-49 should not
9 undergo routine mammography screening.^{10,11} The present findings indicate that there is
10 substantial potential to increase public awareness.
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15 After excluding responses that could not be categorised and those where participants stated
16 they had no knowledge, the most commonly occurring themes were related to diagnosis,
17 including an '*overly negative or complicated diagnosis*', or a '*false positive diagnosis*'. These
18 findings are similar to those of the Australian survey,⁸ in which 22% thought it meant
19 exaggerating an existing condition and 10% thought it meant diagnosing a non-existent
20 condition. The patient-related subthemes such as '*overthinking*' were more surprising,
21 showing that patients do not necessarily only consider the healthcare provider's or the
22 healthcare system's responsibility in influencing overdiagnosis, but also recognise the
23 possible influence of patient attitudes towards health and illness. Some previous studies
24 (e.g. Hersch et al.¹²) have provided participants with information that aims to clarify the
25 distinction between overdiagnosis and false positives; the present findings suggest that there
26 may be additional assumptions to be addressed.
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45 Our findings are also consistent with discussion group studies where the term
46 'overdiagnosis' was explained to lay members of the public in the context of breast cancer
47 screening. Most participants found the term counterintuitive, in part because it involved
48 understanding that some medical conditions, including cancer, will never cause harm.^{13,14}
49 The term was also seen as difficult for participants to understand. Participants were given
50 detailed information on overdiagnosis using a method that allowed them to ask and receive
51 answers to questions that arose. However, when asked a multiple choice question on the
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3 most applicable definition, 16% gave an incorrect answer and a further 24% gave only a
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5 partially correct answer.¹³
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8 This study has limitations. Coding of participants' definitions necessarily relied on the
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10 authors' interpretations of brief free-text responses, and so the reader may disagree with
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12 some of our coding. Furthermore, as previously noted, there is continuing academic debate
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14 regarding the most appropriate definition of overdiagnosis (e.g. Carter et al.⁴, Marcus et
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16 al.¹⁵). In addition, some responses coded as consistent with overdiagnosis also contained
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18 misconceptions (e.g. relating to false positives). In these cases, the most appropriate code to
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20 use was ambiguous. Similarly, the brevity of participants' responses precluded an in-depth
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22 understanding of their intended meanings, resulting in categories which warrant further
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24 exploration (in particular '*overthinking*'), as well as an appreciable proportion that could not
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26 be coded. Future qualitative research could be undertaken to address this. Future research
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28 could also evaluate whether alternative terminology (e.g. '*overdetection*'¹²) would be more
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30 intuitive to participants, resulting in a greater proportion of correct interpretations.
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33 In conclusion, this study found that 'overdiagnosis' was rarely defined correctly by the public,
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35 indicating substantial scope to increase awareness. Future research should be designed
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37 with an assumption of extremely low pre-existing knowledge of the concept in the general
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39 population.
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Participant consent: Obtained.

Ethics approval: This study consisted of a non-sensitive, anonymous survey and was considered exempt from ethical approval by the host institution.

Data sharing agreement: Anonymised survey data will be made available to interested researchers.

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ABSTRACT

Objectives: To determine how 'overdiagnosis' is currently conceptualised among adults in the United Kingdom (UK) in light of previous research, which has found that the term is difficult for the public to understand and awareness is low. This study aims to add to current debates on healthcare in which overdiagnosis is a prominent issue.

Design: An observational, web-based survey was administered by a survey company.

Setting: Participants completed the survey at a time and location of their choosing.

Participants: 390 consenting UK adults aged 50-70 years. Quota sampling was used to achieve approximately equal numbers in three categories of education.

Primary outcome measures: Participants were asked whether they had seen or heard the term 'overdiagnosis'. If they had, they were then invited to explain in a free text field what they understood it to mean. If they had not previously encountered it, they were invited to say what they thought it meant. Responses were coded and interpreted using content analysis and descriptive statistics.

Results: Data from 390 participants were analysed. Almost a third (30.0%) of participants reported having previously encountered the term. However, their responses often indicated that they had no knowledge of its meaning. The most prevalent theme consisted of responses related to the diagnosis itself. Subthemes indicated common misconceptions, including an '*overly negative or complicated diagnosis*', '*false positive diagnosis*' or '*misdiagnosis*'. Other recurring themes consisted of responses related to testing (i.e. '*too many tests*'), treatment (e.g. '*overtreatment*'), and patient psychology (e.g. '*overthinking*'). Responses categorised as consistent with '*overdiagnosis*' (defined as detection of a disease that would not cause symptoms or death) were notably rare (n=10; 2.6%).

Conclusions: Consistent with previous research, public awareness of 'overdiagnosis' in the UK is low and its meaning is often misunderstood or misinterpreted.

Article summary

Strengths and limitations of this study:

- This is the first study to investigate how the UK general public understands and interprets the term ‘overdiagnosis’.
- Free-text fields allowed participants to respond in their own words without being limited to categories pre-selected by the researchers.
- The results of this study corroborate those of a previous survey in Australia and are consistent with previous research indicating that overdiagnosis is a difficult concept for people to understand.
- An appreciable proportion of participants’ responses were ambiguous in their meaning and some could not be coded into a specific category.

INTRODUCTION

Academics, healthcare professionals, and policymakers are becoming increasingly concerned about circumstances in which the health benefits of a given intervention are not considered to clearly justify the associated risks. The British Medical Journal has been a prominent voice in this area through their “Too Much Medicine” campaign,¹ which has recently gained support from the Academy of Medical Royal Colleges.² A central topic within the campaign is ‘overdiagnosis’, defined here as the diagnosis of disease which would never have become clinically apparent in a person’s lifetime (i.e. causing neither symptoms nor death).^{3,4} Debate continues regarding the magnitude, significance, and implications of overdiagnosis. Much attention is focused on breast cancer screening, where estimates of the ratio of screening-prevented breast cancer deaths to overdiagnosed breast cancer cases range from 9:4⁵ to 5:17³ for 1,000 women screened over 20 years. There is also an increasingly common view that screening invitees should appreciate the possibility of overdiagnosis before deciding whether to participate,⁶ although there is professional controversy regarding how best to inform people about the concept.⁷

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3 Public awareness of overdiagnosis appears to be low in many countries. A study from 2000
4 in the United States found that only a small minority (7%) of women were aware of the
5 concept of non-progressive breast cancer.⁸ More recently, a focus group study in Korea
6 found that women had difficulty understanding the meaning of overdiagnosis in the context
7 of thyroid cancer screening.⁹ Very similar findings have been reported in a small interview
8 study about breast cancer screening based in Denmark.¹⁰ In addition, Moynihan et al.
9 recently reported a survey of 500 Australian adults drawn from the general population, who
10 were asked to state whether they had seen or heard the term, before indicating what they
11 thought it meant. The majority (50-63%) reported having encountered the term before but
12 only 41% of the sample were categorised as responding with even an approximately correct
13 definition of the term. Participants categorised as being approximately correct often
14 described it in terms of misdiagnosis, too many diagnoses, or overstating the significance of
15 a diagnosis, with 35% of responses falling into one of these categories.¹¹ Although these
16 have some similarities with the intended meaning of overdiagnosis, there is an apparent lack
17 of awareness regarding its specific meaning. This suggests that despite attention in health-
18 related literature, overdiagnosis has not become a familiar term among the general public.

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The present study extends the previous work by exploring people's definitions of
'overdiagnosis' as part of a web-based survey of adults in the United Kingdom (UK). We
used the same measures of awareness as Moynihan et al.¹¹ to allow comparability between
studies.

METHOD

This study took place as part of a web-based survey of attitudes and beliefs about cancer in
February 2015. The sample consisted of consenting members of the UK general population
aged 50-70 years, recruited through a survey company (Survey Sampling International; SSI).
SSI maintains a panel of potential survey participants; these individuals are periodically
invited to complete online surveys in exchange for small amounts of compensation (e.g. air

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3 miles) via a generic recruitment email. The email contained a link that directed participants to
4 the online survey. Quotas were used to ensure an equal proportion of men and women, and
5 equal proportions of participants with different levels of education (three categories: leaving
6 school before 16 years; completing CSEs, O-levels, or equivalent; completing A-levels,
7 higher, university education, or equivalent).

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12 As in the Australian study, participants were first asked: *"have you seen or heard the term*
13 *'overdiagnosis' before today"*. Those responding "yes" were then asked *"what do you*
14 *understand the term 'overdiagnosis' to mean"*, those who responded "no" were asked *"what*
15 *do you think the term 'overdiagnosis' means"*¹. Participants responded to the latter two
16 questions by completing a free-text field. They were also asked for basic demographic
17 information (gender, age, level of education, and ethnicity).

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22 The questions on overdiagnosis formed part of a larger survey on views relating to cancer
23 screening, hence participants were selected to be approaching or at an age at which they
24 would be eligible for breast or colorectal cancer screening in the UK. Screening-specific
25 questions always came after questions on overdiagnosis and so responses could not have
26 been influenced by the questions on screening (results not reported here).

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Demographic data and self-reported recognition of the term 'overdiagnosis' were analysed
using simple descriptive statistics. Content analysis was used to examine responses to free-
text questions.¹² Responses were categorised independently by two researchers (AG &
SFM), who read participants' answers repeatedly before assigning a provisional code (e.g.
'*misdiagnosis*') to each one, based on their interpretation. After both researchers had
completed their separate coding, the two lists were compared and disagreements resolved
through discussion. The final list of codes was then reviewed to determine whether several

¹ An error in the skip-logic of the survey meant that participants who responded "yes" were also asked the second question. Hence, data on questions asked in error were not analysed since participants often responded with the same answer or noted that they had already answered a very similar question. One participant who responded "no" was able to complete both questions and so was excluded from the analysis since their answer to the second (correctly asked) question may have been affected by the first (incorrectly asked) question.

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3 codes could be meaningfully renamed, grouped together or split into further codes. The
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5 overarching themes and specific subthemes identified were then summarised using
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7 descriptive statistics and illustrated using exemplar quotes. Responses of participants who
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9 reported having seen or heard the term before and those of participants who reported no
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11 previous exposure to the term were reported separately.
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13 14 **RESULTS**

15 16 17 **Participant characteristics**

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19 The sample comprised 390 adults (201 women; 51.5%) with a median age of 60 years
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21 (interquartile range [IQR]: 55 to 65). Most stated their ethnicity as White (n=382; 97.9%). Per
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23 our quota sampling, approximately equal numbers had left school before 16 years (133;
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25 34.1%), completed CSEs, O-levels, or equivalent (125; 32.1%), and had completed A-levels,
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27 higher, or university degree, or equivalent (132; 33.8%).
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30 31 **Definitions of 'overdiagnosis'**

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33 117 participants (30.0%) reported having seen or heard the term previously. Median length
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35 of free text responses relating to participants' understanding was 7 words (range: 1 to 42;
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37 IQR: 4 to 12.5); for responses from participants who had not seen or heard it before, it was 4
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39 words (range: 1 to 28; IQR: 2 to 8).
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43 Responses are presented separately for those who had and those who had not previously
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45 encountered the term. For both groups, responses could be categorised into one of six
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47 broad themes. These are summarised in Table 1 (for participants who had previously
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49 encountered the term) and Table 2 (for those who had not), respectively, along with
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51 exemplar quotes. Participants commonly reported either no knowledge of what the term
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53 meant (even when they reported having encountered it before) or responded in a way that
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55 could not be categorised (frequently because the response was too vague or entirely
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57 unclear). Three other themes were aligned with different stages of a patient trajectory: from
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3 testing (*'too many tests'*) to diagnosis, and treatment. The theme relating to diagnosis was
4 the most prevalent; 38.5% and 26.1% of responses from participants who had and had not
5 been previously exposed to the term were categorised into this theme. Relevant subthemes
6 included an *'overly negative or complicated diagnosis'*, a *'false positive diagnosis'*, and a
7 *'misdiagnosis'*. Treatment-related responses referred to *'overtreatment'*, *'inappropriate*
8 *treatment'* and *'unbeneficial treatment'*. A further broad theme referred to conceptions of how
9 patients' psychology related to overdiagnosis, with the most common sub-theme being
10 *'overthinking'*. The final grouping consisted of other responses that could not be categorised
11 into one of the preceding five themes.

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13 Responses were rarely consistent with *'overdiagnosis'* itself, whether or not participants had
14 previously been exposed to the term (n=9, 7.7%; n=1; 0.4%). All such responses are
15 reported in Table 3.
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Table 1 - Understanding of 'overdiagnosis' among participants who had previously encountered the term (n=117): emerging (sub-)themes

Category	Exemplar quote (spelling errors corrected)	n (%)
Response not categorised or no knowledge		
Incoherent, irrelevant, or too vague to interpret	<i>"More than a person says"</i>	21 (17.9)
No knowledge	<i>"Not sure"</i>	10 (8.5)
Diagnosis-related responses		
Overly negative or complicated diagnosis	<i>"Where certain illnesses are overstated in their severity"</i>	12 (10.3)
False positive diagnosis	<i>"Diagnosis of a condition that is not really there"</i>	11 (9.4)
Overdiagnosis	<i>"I think it means the diagnosis of a disease that will not cause symptoms or death"</i>	9 (7.7)
Too many diagnoses	<i>"Finding out all the complaints that may be wrong with you"</i>	8 (6.8)
Overly detailed diagnosis	<i>"A condition has been over-described"</i>	4 (3.4)
Misdiagnosis	<i>"Diagnosing minor problems rather than the real problem at source"</i>	1 (0.9)
Diagnosis based on stereotypes	<i>"Diagnosis based on stereotypes e.g. The patient is overweight therefore he will have a CVA"</i>	1 (0.9)
Test-related responses		
Too many tests	<i>"Patient undergoing more tests than necessary to diagnose a disease"</i>	6 (5.1)
Treatment-related responses		
Inappropriate treatment	<i>"Taking medicine not needed"</i>	1 (0.9)
Overtreatment	<i>"Had taken too many pills, or dr. prescribe too many different pills the person must take, when don't need"</i>	1 (0.9)
Responses related to patients' psychology		
Overthinking	<i>"When you think things through to such an extent that you confuse things or make them more complicated or important than they deserve to be"</i>	20 (17.1)
Overly health-sensitive	<i>"Over-analysing of minor conditions until you are convinced that there is a condition to be treated"</i>	4 (3.4)
Anticipating a worse diagnosis	<i>"Presuming something nasty is wrong before running tests"</i>	3 (2.6)
Other responses		
Medicalising issues unrelated to health	<i>"When non-health-related issues are medicalised"</i>	2 (1.7)
Defensive medicine	<i>"Must have an answer, doctors not wanted to be sued"</i>	1 (0.9)
Iatrogenic illness	<i>"Iatrogenic illness"</i>	1 (0.9)
Too many attempts at prevention	<i>"Too much preventing what may happen or not"</i>	1 (0.9)

Table 2 – Interpretation of 'overdiagnosis' among participants who had not previously encountered the term (n=273): emerging (sub-)themes

Category	Exemplar quote (spelling errors corrected)	n (%)
Response not categorised or no knowledge		
No knowledge	"Don't know"	103 (37.7)
Incoherent, irrelevant, or too vague to categorise	"Going over the top"	44 (16.1)
Diagnosis-related responses		
Overly negative or complicated diagnosis	"Diagnosing a disease to a worse state than actual"	30 (11.0)
False positive diagnosis	"It sounds like being told you have things you don't have."	13 (4.8)
Misdiagnosis	"The wrong diagnosis of an illness"	12 (4.4)
Overly detailed diagnosis	"Too much information on a probable problem"	9 (3.3)
Too many diagnoses	"Too many different diagnosis from various medical professionals"	6 (2.2)
Overdiagnosis	"Making People Sick in the Pursuit of Health"	1 (0.4)
Test-related responses		
Too many tests	"Too many health checks"	6 (2.2)
Treatment-related responses		
Overtreatment	"Treating an illness in a stronger way than necessary"	6 (2.2)
Inappropriate treatment	"Wrong treatment or pills"	2 (0.7)
Unbeneficial treatment	"Giving medical assistance when there is no hope."	1 (0.4)
Responses related to patients' psychology		
Overthinking	"Complicating a problem by thinking too much about it"	15 (5.5)
Overly health-sensitive	"Worrying too much about health issues, continually seeking explanations"	10 (3.7)
Anticipating a worse diagnosis	"Looking at worst case scenario before having all the facts"	8 (2.9)
Other responses		
Multiple (medical) opinions	"Too many people involved in a medical decision."	5 (1.8)
Defensive medicine	"Treatment, just to be on the safe side"	2 (0.7)

Table 3 - All responses coded as consistent with 'overdiagnosis'

Response (spelling errors corrected)**Participants reporting having previously seen or heard the term**

"An example would be with some forms of health screening you get a positive result which leads to further investigation and treatment for a condition which would probably never have killed you. There is a type of breast cancer (DCIS) which falls [response was truncated by survey character limit]"

"Treating conditions like tiny lesions in the breast that may have resolved themselves without treatment"

"I think it means the diagnosis of a disease that will not cause symptoms or death"

"Yes, it is the diagnosis of a disease that will not cause the death of a patient"

"Reacting too much to minor and potentially insignificant things found during an investigation, with the result that they are treated unnecessarily."

"When you are screened for something it is a false positive or a positive on something that would not harm you in your likely lifespan"

"A diagnosis of a disease that will never happen or cause a problem"

"Some people can be diagnosed and have unsuitable or unnecessary treatment"

"Overdiagnosis is the diagnosis of disease that will never cause symptoms or death during a patient's lifetime."

Participants reporting no previous exposure to the term

"Making People Sick in the Pursuit of Health"

DISCUSSION

This survey of definitions of 'overdiagnosis' among adults in the UK found that despite approximately 1 in 3 people stating that they had seen or heard the term before, only a minority (2.6% of all participants) provided a response that was even broadly consistent with the meaning considered correct: diagnosis of a disease that would not cause symptoms or death.³ This finding can be interpreted in light of the inconsistent usage of the term among academics and clinicians. As Carter et al. note, the intended meaning can vary, depending on the specific context being addressed within the general domain of "Too Much Medicine".⁴ For example, the term may be used to describe detection of 'incidentalomas' in lung cancer screening (e.g. Harris et al.¹³), or diagnosis due to diagnostic criteria being expanded (e.g.

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3 pre-diabetes¹⁴ and attention-deficit/hyperactivity disorder¹⁵). Hence, it is not surprising that a
4 single clear meaning has not reached public awareness. However, concerns regarding
5 overdiagnosis are likely to be an increasingly influential aspect of both policy- and patient-
6 level decisions. Consequently, policymakers, healthcare providers and communicators may
7 consider this to be an important concept that the public should understand. One risk of a lack
8 of awareness is scepticism regarding the true purpose of an attempt to reduce the delivery
9 healthcare interventions (e.g. the belief that it is an attempt to reduce costs). This may
10 account for the generally negative views among women regarding the US Preventive
11 Services Task Force recommendation that women aged 40-49 should not undergo routine
12 mammography screening^{16,17} and it might be hypothesised that there are similar negative
13 perceptions among men regarding the USPSTF recommendation against prostate-specific
14 antigen screening in 2012.¹⁸ The present findings indicate that there is substantial potential
15 to increase public awareness.
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30 After excluding responses that could not be categorised and those where participants stated
31 they had no knowledge, the most commonly occurring themes were related to diagnosis,
32 including an '*overly negative or complicated diagnosis*', or a '*false positive diagnosis*'. These
33 findings are similar to those of the Australian survey,¹¹ in which 22% thought it meant
34 exaggerating an existing condition and 10% thought it meant diagnosing a non-existent
35 condition. The patient-related subthemes such as '*overthinking*' were more surprising,
36 showing that patients do not necessarily only consider the healthcare provider's or the
37 healthcare system's responsibility in influencing overdiagnosis, but also recognise the
38 possible influence of patient attitudes towards health and illness. Some previous studies
39 (e.g. Hersch et al.¹⁹) have provided participants with information that aims to clarify the
40 distinction between overdiagnosis and false positives; the present findings suggest that there
41 may be additional assumptions to be addressed.
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55 Our findings are also consistent with discussion group studies in the UK and Australia where
56 the term 'overdiagnosis' was explained to lay members of the public in the context of breast
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3 cancer screening. These studies reported that most participants found the term
4 counterintuitive, in part because it involved understanding that some medical conditions,
5 including cancer, will never cause harm.^{20,21} The term was also seen as difficult for
6 participants to understand. Participants were given detailed information on overdiagnosis
7 using a method that allowed them to ask and receive answers to questions that arose.
8 However, when asked a multiple choice question on the most applicable definition, 16%
9 gave an incorrect answer and a further 24% gave only a partially correct answer.²⁰
10 Comparable trends have also been seen in both quantitative⁸ and qualitative studies^{9,10} from
11 other countries, which have reported both low levels of awareness and difficulty
12 understanding the term.
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24 This study has limitations. Coding of participants' definitions necessarily relied on the
25 authors' interpretations of brief free-text responses, and so the reader may disagree with
26 some of our coding. Furthermore, as previously noted, there is continuing academic debate
27 regarding the most appropriate definition of overdiagnosis (e.g. Carter et al.⁴, Marcus et
28 al.²²). In addition, some responses coded as consistent with overdiagnosis also contained
29 misconceptions (e.g. relating to false positives). In these cases, the most appropriate code to
30 use was ambiguous. Similarly, the brevity of participants' responses precluded an in-depth
31 understanding of their intended meanings, resulting in categories that warrant further
32 exploration. In particular, participants' ideas regarding '*overthinking*' may have been related
33 to the source and context in which they encountered the term but these factors were not
34 recorded in the present study. There was also an appreciable proportion of responses that
35 could not be coded. Future qualitative research could be undertaken to address this. Future
36 research could also evaluate whether alternative terminology (e.g. '*overdetection*'¹⁹) would
37 be more intuitive to participants, resulting in a greater proportion of correct interpretations.
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52 Finally, survey response rates were not available from the survey company, creating
53 uncertainty regarding the representativeness of the sample.
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3 In conclusion, this study found that 'overdiagnosis' was rarely defined correctly by the public,
4 indicating substantial scope to increase awareness. Future research should be designed
5 with an assumption of extremely low pre-existing knowledge of the concept in the general
6 population.
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21 the writing of the manuscript; or in the decision to submit for publication.
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29 **Contributors:** SFM, CR, Jane W and Jo W conceived the study and participated in the
30 design. Jo W participated in the acquisition of the data. AG and SFM participated in analysis
31 of the data. All authors participated in interpretation of data, drafting and critical revision of
32 the manuscript, and approved the final version.
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38 **Participant consent:** Obtained.
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41 **Ethics approval:** This study consisted of a non-sensitive, anonymous survey and was
42 considered exempt from ethical approval by the host institution.
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46 **Data sharing agreement:** Anonymised survey data will be made available to interested
47 researchers.
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