BMJ Open  Survey of public definitions of the term ‘overdiagnosis’ in the UK

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ABSTRACT

Objectives: To determine how ‘overdiagnosis’ is currently conceptualised among 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 aimed 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 and equal numbers of men and women.

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 (ie, ‘too many tests’), treatment (eg, ‘overtreatment’) and patient psychology (eg, ‘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.

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, which has recently gained support from the Academy of Medical Royal Colleges. 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 (ie, causing neither symptoms nor death). 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 9:4 to 5:17 for 1000 women screened over 20 years. There is also an increasingly common view that screening invites should appreciate the possibility of overdiagnosis before deciding whether to participate, although there is professional controversy regarding how best to inform people about the concept.

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

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 UK. We used the same measures of awareness as Moynihan et al11 to allow comparability between studies.

METHODS

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

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

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

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 and SFM), who read participants’ answers repeatedly before assigning a provisional code (eg, 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 codes could be meaningfully renamed, grouped together or split into further codes. The overarching themes and specific subthemes identified were then summarised using descriptive statistics and illustrated using exemplar quotes. Responses of participants who reported having seen or heard the term before and those of participants who reported no previous exposure to the term were reported separately.

RESULTS

Participant characteristics

The sample comprised 390 adults (201 women; 51.5%) with a median age of 60 years (interquartile range (IQR) 55–65). Most stated their ethnicity as Caucasian (n=382; 97.9%). Per our quota sampling, approximately equal numbers had left school before 16 years (133; 34.1%), completed CSEs, O-levels or equivalent (125; 32.1%), and had completed A-levels, higher, or university degree, or equivalent (132; 33.8%).

Definitions of ‘overdiagnosis’

One hundred and seventeen participants (30.0%) reported having seen or heard the term previously. Median length of free-text responses relating to participants’ understanding was seven words (range 1–42; IQR 4–12.5); for responses from participants who had not seen or heard it before, it was four words (range 1–28; IQR 2–8).

Responses are presented separately for those who had and those who had not previously encountered the term. For both groups, responses could be categorised into one of six broad themes. These are summarised in

1An 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.
The most common subtheme being patients. A further broad theme referred to conceptions of how ‘Treatment-related responses referred to’ included an ‘Inappropriate treatment’ and ‘unbeneficial treatment’.

A further broad theme referred to conceptions of how patients’ psychology related to overdiagnosis, with the most common subtheme being ‘overthinking’. The final grouping consisted of other responses that could not be categorised into one of the preceding five themes.

Responses were rarely consistent with ‘overdiagnosis’ itself, whether or not participants had previously been exposed to the term (n=9, 7.7%; n=1, 0.4%). All such responses are reported in box 1.

**DISCUSSION**

This survey of definitions of ‘overdiagnosis’ among adults in the UK found that despite approximately one in three 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 al4 note, the intended meaning can vary, depending on the specific context being addressed within the general domain of ‘Too Much Medicine’. For

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

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example, the term may be used to describe detection of ‘incidentalomas’ in lung cancer screening,\(^{13}\) or diagnosis due to diagnostic criteria being expanded (eg, pre-diabetes\(^{14}\) and attention-deficit/hyperactivity disorder\(^{15}\)). Hence, it is not surprising that a single clear meaning has not reached public awareness. However, concerns regarding overdiagnosis are likely to be an increasingly influential aspect of both policy-level and patient-level decisions. Consequently, policymakers, healthcare providers and communicators may consider this to be an important concept that the public should understand. One risk of a lack of awareness is scepticism regarding the true purpose of an attempt to reduce the delivery healthcare interventions (eg, the belief that it is an attempt to reduce costs). This may account for the generally negative views among women regarding the true purpose of an attempt to reduce the context of breast cancer screening. These studies assumed to be addressed.

Our findings are also consistent with discussion group studies in the UK and Australia where the term ‘overdiagnosis’ was explained to lay members of the public in the context of breast cancer screening. These studies reported that most participants found the term counterintuitive, in part because it involved understanding that some medical conditions, including cancer, will never cause harm.\(^{20,21}\) The term was also seen as difficult for participants to understand. Participants were given detailed information on overdiagnosis using a method that allowed them to ask and receive answers to questions that arose. However, when asked a multiple choice question on the most applicable definition, 16% gave an incorrect answer and a further 24% gave only a partially correct answer.\(^{20}\) Comparable trends have also been

| 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 | “Don’t know.” | 103 (37.7) |
| Incoherent, irrelevant or too vague to categorise | “Going over the top.” | 44 (16.1) |
| 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” | 6 (2.2) |
| Treatment-related responses | “Treating an illness in a stronger way than necessary.” | 6 (2.2) |
| Over-treatment | “Wrong treatment or pills.” | 2 (0.7) |
| Unnecessary treatment | “Giving medical assistance when there is no hope.” | 1 (0.4) |
| Responses related to patients’ psychology | “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 | “Too many people involved in a medical decision.” | 5 (1.8) |
| Multiple (medical) opinions | “Treatment, just to be on the safe side.” | 2 (0.7) |
| Defensive medicine | | |
Box 1 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.”

seen in both quantitative and qualitative studies from other countries, which have reported both low levels of awareness and difficulty understanding the term. This study has limitations. Coding of participants’ definitions necessarily relied on the authors’ interpretations of brief free-text responses, and so the reader may disagree with some of our coding. Furthermore, as previously noted, there is continuing academic debate regarding the most appropriate definition of overdiagnosis. In addition, some responses coded as consistent with overdiagnosis also contained misconceptions (eg, relating to false positives). In these cases, the most appropriate code to use was ambiguous. Similarly, the brevity of participants’ responses precluded an in-depth understanding of their intended meanings, resulting in categories that warrant further exploration. In particular, participants’ ideas regarding ‘overthinking’ may have been related to the source and context in which they encountered the term but these factors were not recorded in the present study. There was also an appreciable proportion of responses that could not be coded. Future qualitative research could be undertaken to address this. Future research could also evaluate whether alternative terminology (eg, overdetection) would be more intuitive to participants, resulting in a greater proportion of correct interpretations. Finally, survey response rates were not available from the survey company, creating uncertainty regarding the representativeness of the sample.

In conclusion, this study found that ‘overdiagnosis’ was rarely defined correctly by the public, indicating substantial scope to increase awareness. Future research should be designed with an assumption of extremely low pre-existing knowledge of the concept in the general population.

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REFERENCES
1. Glasziou P, Moynihan R, Richards T. Too much medicine; too little care. BMJ 2013;347:f4247.
2. Malhotra A, Maughan D, Ansell J, et al. Choosing Wisely in the UK: the Academy of Medical Royal Colleges’ initiative to reduce the harms of too much medicine. BMJ 2015;350:h2308.
3. Independent UK Panel on Breast Cancer Screening. The benefits and harms of breast cancer screening: an independent review. Lancet 2012;380:1778–86.
4. Carter SM, Rogers W, Heath I, et al. The challenge of overdiagnosis begins with its definition. BMJ 2015;350:h689.
5. Paci E, Broeders M, Hofvind S, et al. European breast cancer service screening outcomes: a first balance sheet of the benefits and harms. Cancer Epidemiol Biomarkers Prev 2014;23:1159–63.
6. Richards M. An independent review is under way. BMJ 2011;343: d6843.
7. Sasienski P, Smith R, Duffy S. Informed decision-making and breast cancer screening. J Med Screen 2015;22:165–7.
8. Schwartz L, Woloshin S, Sox HC, et al. US women’s attitudes to false positive mammography results and detection of ductal carcinoma in situ: cross sectional survey. BMJ 2000;320:307–12.
9. Park SH, Lee B, Choi E, et al. A qualitative study of women’s views on overdiagnosis and screening for thyroid cancer in Korea. BMC Cancer 2015;15:858.
10. Henriksen MJV, Glissora AD, Brodersen J. Preconceptions influence women’s perceptions of information on breast cancer screening: a qualitative study. BMC Res Notes 2015;8:404.
11. Moynihan R, Nickel B, Hersch J, et al. What do you think overdiagnosis means? A qualitative analysis of responses from a national community survey of Australians. BMJ Open 2015;5:e007436.
12. Fereday J, Muir-Cochrane E. Demonstrating rigor using thematic analysis: a hybrid approach of inductive and deductive coding and theme development. Int J Qual Methods 2006;5:80–92.
13. Harris RP, Sharidjan SL, Lewis CL, et al. The harms of screening: a proposed taxonomy and application to lung cancer screening. JAMA Intern Med 2014;174:281–5.
14. Yudkin JS, Montori VM. The epidemic of pre-diabetes: the medicine and the politics. BMJ 2014;349:g4485.
15. Thomas R, Mitchell GK, Babstra L. Attention-deficit/hyperactivity disorder: are we helping or harming? BMJ 2013;347:f6172.
16. Kiviniemi MT, Hay JL. Awareness of the 2009 US Preventive Services Task Force recommended changes in mammography screening guidelines, accuracy of awareness, sources of knowledge about recommendations, and attitudes about updated screening guidelines in women ages 40–49 and 50+. BMC Public Health 2012;12:899.

17. Allen JD, Bluethmann SM, Sheets M, et al. Women’s responses to changes in U.S. Preventive Task Force’s mammography screening guidelines: results of focus groups with ethnically diverse women. BMC Public Health 2013;13:1169.

18. Moyer VA, on behalf of the U.S. Preventive Services Task Force. Screening for prostate cancer: U.S. Preventive Services Task Force Recommendation Statement. Ann Intern Med 2012;157:120–34.

19. Hersch J, Jansen J, Barratt A, et al. Overdetection in breast cancer screening: development and preliminary evaluation of a decision aid. BMJ Open 2014;4:e006016.

20. Hersch J, Jansen J, Barratt A, et al. Women’s views on overdiagnosis in breast cancer screening: a qualitative study. BMJ 2013;346:f158.

21. Waller J, Douglas E, Whitaker KL, et al. Women’s responses to information about overdiagnosis in the UK breast cancer screening programme: a qualitative study. BMJ Open 2013;3:e002703.

22. Marcus PM, Prorok PC, Miller AB, et al. Conceptualizing overdiagnosis in cancer screening. J Natl Cancer Inst 2015;107: djv014.