BMJ Open

What do you think overdiagnosis means? A qualitative analysis of responses from a national community survey of Australians

Ray Moynihan,[1] Brooke Nickel,[2] Jolyn Hersch,[2] Jenny Doust,[1] Alexandra Barratt,[2] Elaine Beller,[1] Kirsten McCaffery[2]

ABSTRACT

Objective: Overdiagnosis occurs when someone is diagnosed with a disease that will not harm them. Against a backdrop of growing evidence and concern about the risk of overdiagnosis associated with certain screening activities, and recognition of the need to better inform the public about it, we aimed to ask what the Australian community understood overdiagnosis to mean.

Design, setting and participants: Content analysis of verbatim responses from a randomly sampled community telephone survey of 500 Australian adults, between January and February 2014. Data were analysed independently by two researchers.

Main outcome measures: Analysis of themes arising from community responses to open-ended questions about the meaning of overdiagnosis.

Results: The sample was broadly representative of the Australian population. Forty per cent of respondents thought overdiagnosis meant exaggerating a condition that was there, diagnosing something that was not there or too much diagnosis. Twenty-four per cent described overdiagnosis as overprescribing, overtesting or overtreatment. Only 3% considered overdiagnosis meant doctors gained financially. No respondents mentioned screening in conjunction with overdiagnosis, and over 10% of participants were unable to give an answer.

Conclusions: Around half the community surveyed had an approximate understanding of overdiagnosis, although no one identified it as a screening risk and a quarter equated it with overuse. Strategies to inform people about the risk of overdiagnosis associated with screening and diagnostic tests, in clinical and public health settings, could build on a nascent understanding of the nature of the problem.

[1]Centre for Research in Evidence-Based Practice, Bond University, Robina, Australia
[2]School of Public Health, University of Sydney, Sydney, Australia

Correspondence to
Raymond Moynihan;
raymoynihan@bond.edu.au

Strengths and limitations of this study

- This is the first study to ask the general community about the meaning of overdiagnosis, a problem attracting growing research attention.
- Our survey sample was generally representative of the Australian community.
- Findings offer a unique and rich data set of public understanding, to help inform strategies to communicate better about overdiagnosis and overuse.
- Limitations arise from the modest response and cooperation rates, though similar rates are now common with telephone surveys.
- Another limitation arises because survey participants had little time to reflect on the meaning of overdiagnosis before responding.

conditions.[1] There are a number of drivers of overdiagnosis, including the medicalisation of risk,[2] improvements in diagnostic technology that identifies ever-smaller 'abnormalities', widening disease definitions and cultural enthusiasm for early detection.[3] Appearing in the medical literature as early as the 1970s, the complex and counter-intuitive concept is attracting increasing research attention as part of a wider interest in preventing avoidable medical excess, and is manifested in initiatives including *JAMA Internal Medicine's* Less is More,[4] Choosing Wisely[5] and The *BMJ's* Too Much Medicine series on expanding disease definitions and the risk of overdiagnosis.[6] To our knowledge, however, there are no data on what the community understands overdiagnosis to mean.

Narrowly defined, overdiagnosis occurs when a healthy person is diagnosed with a disease or condition that will not go on to cause them harm, and can occur, for example, when screening programmes lead to the diagnosis of cancers that will never

INTRODUCTION

Overdiagnosis occurs when a person is diagnosed with a disease that would not have harmed them, and evidence is emerging that the problem is associated with a range of

progress.[1] More broadly, overdiagnosis is part of the wider problem of too much medicine,[6] and there is currently scientific discussion about how to precisely delineate overdiagnosis from other issues including over-medicalisation and overutilisation.[7]

While debate about the nature and extent of overdiagnosis continues,[8] there is a growing consensus that it is a source of significant harm for those who receive an unnecessary diagnosis, and a waste for the health system, with evidence most well advanced in the field of cancer screening. After assessing all available evidence, an independent panel in 2012 estimated 19% of breast cancers detected during mammography screening may be overdiagnosed: defined as detection of cancers that do not progress to be symptomatic and "would never have been found were it not for the screening test".[9] In the same year, the US Preventive Services Task Force pointed to 'convincing evidence that PSA-based screening leads to substantial overdiagnosis of prostate tumours', with estimates ranging from 17% to 50%.[10]

This evidence has contributed to recognition of the need for greater professional and public awareness of the problem. In 2013, a working group, convened under the auspices of the US National Cancer Institute, stated, "Physicians, patients, and the general public must recognize that overdiagnosis is common and occurs more frequently with cancer screening".[11] In late 2014, the science and technology committee of the UK parliament produced a report calling for routine communication of the benefits and risks of screening programmes.[12] In November 2014, a report from the Academy of Medical Royal Colleges signalled a 'cultural shift' away from unnecessary medical care,[13] underscoring the need for new clinical approaches, including 'de-prescribing' strategies designed to confront inappropriate polypharmacy.[14] In order to inform ongoing scientific and policy debates about how to effectively communicate about overdiagnosis and related overuse, in clinical and public health settings, we aimed to discover what the community currently understood overdiagnosis to mean.

METHODS

We conducted a Computer-Assisted Telephone Interview (CATI) survey of randomly selected adult Australians to explore understanding of overdiagnosis. The survey recruited 500 Australians aged 18 years and older, using a randomly selected dual frame sample, including landlines and mobile phones. As per formulae from the American Association for Public Opinion Research (AAPOR),[15] we calculated the AAPOR response rate—which includes in its denominator estimations of the proportion of cases of unknown eligibility that are actually eligible and calculations involve all households including those where no contact at all was made—and the AAPOR cooperation rate—which excludes un-contacted households, and calculates the proportion of those contacted who cooperated.

A survey questionnaire was developed iteratively and piloted with a convenience sample of 20 adult Australians and then through an experienced social research company, The Social Research Centre, with an additional 20 recruited participants. The survey was introduced with the words: "We're doing a short survey across Australia about community views on the way doctors diagnose diseases. This is an emerging issue and the results will help researchers find better ways for doctors to communicate about the risks and benefits of medical tests and treatments" (see online supplementary file 1).

Participants were assured responses would be anonymous and not recorded, and in order to maximise informed consent, a Participant Information Sheet was developed and made available to be read on request, and posted on accessible websites. The information sheet and the process for seeking informed consent were explicitly approved by BUHREC. The final CATI survey lasted for an average of 15 min and was conducted by The Social Research Centre between January and February 2014.

Following an initial question asking "Have you seen or heard the term 'overdiagnosis' before today?", participants who answered "yes" were then asked "What do you understand the term 'overdiagnosis' to mean?"; if they had answered "no" to the first question, or "don't know" to the second, they were asked, "What do you think the term 'overdiagnosis' means?" If needed, interviewers would add a clarifying statement: "We are discussing overdiagnosis of medical illnesses, diseases and conditions". Responses were transcribed verbatim. Quantitative elements of the survey are being analysed and reported separately from this qualitative analysis of participants' verbatim responses.

On completion of the survey, we used content analysis of the verbatim responses to identify and code emergent themes that captured the diverse understanding of overdiagnosis.[16] Two authors (RM, BN) independently reviewed the verbatim responses from the 500 participants, and identified salient themes. To ensure rigour of the analysis, we used constant comparison methods[17][18] to look for similarities and differences in the themes across responses. The two sets of independently identified major themes were documented and discussed with coauthors (JD, JH, KM, AB), and an initial coding framework of themes was developed and then pilot tested, by independent double coding of 50 of the verbatim responses by RM and BN. By comparing and reviewing the pilot data, and with more discussion with the experienced qualitative researcher on our research team (KM), the final coding framework was then developed. For final coding, the 500 verbatim responses were randomised, and two authors (RM, BN) independently coded 300 responses each, including 100 responses that were double coded, resulting in agreement in over 80% of cases in assigning responses to themes. A single response could be coded to more than one theme.

RESULTS

Of 4156 landline and mobile calls initiated, 3307 eligible numbers were identified and contact made with 1282 numbers, from which 500 completed interviews, plus 20 pilots, were achieved (figure 1). The response rate was 20.4% (AAPOR, RR3) and the cooperation rate (people who completed the survey, as a proportion of those who completed, plus those who refused), 43.8% (AAPOR, COOP3). The sample was generally representative, but included a higher proportion of women and older adults than the general Australian community, as is typical with telephone-based health surveys, and slightly higher levels of education (table 1).

Of 500 participants, 433 offered a response to the question about the meaning of the term overdiagnosis. The average response was 14 words. After independent content analysis of themes by RM and BN, for nine major themes there was clear agreement between the two authors on the nature of the theme. Following discussion with coauthors and piloting of the coding framework, a final list of 10 themes was agreed on. Following independent double coding of 100 responses, in 82 cases there was agreement on the theme/s a response was coded to, including 5 cases where one or another coder assigned the response to an additional theme as well. All discrepancies were resolved by discussion.

The final 10 themes and their accompanying explanations are listed in table 2. These 10 themes were then divided into three categories described as: (1) approximate understanding of overdiagnosis; (2) overuse; and (3) other. The most prevalent theme of the responses was 'exaggerating something that is there', which included responses suggesting overdiagnosis meant 'diagnosing a condition to be more serious/severe than what it actually is; overmedicalising; overcomplicating'. Twenty-two per cent of responses were coded as fitting into this theme, exemplified by the comment, "Someone's condition has been made out to be worse than what it is" (table 3). Responses in this theme revolved around ideas that diagnostic labels made problems seem more severe than what they were, causing unnecessary fear or worry (see more examples of all themes in box 1). Another example of a comment in this theme was: "When a patient presents with symptoms and the doctor diagnoses it as something more serious than it is, for example, when a boisterous child is diagnosed with ADHD when they just have a lot of energy". ADHD was the condition most commonly mentioned, appearing in a total of 14 responses (including ADD and hyperactivity). Other conditions mentioned as examples of overdiagnosis included cancer (3 times), with one mention only for asthma, autism, cholesterol and mental illness.
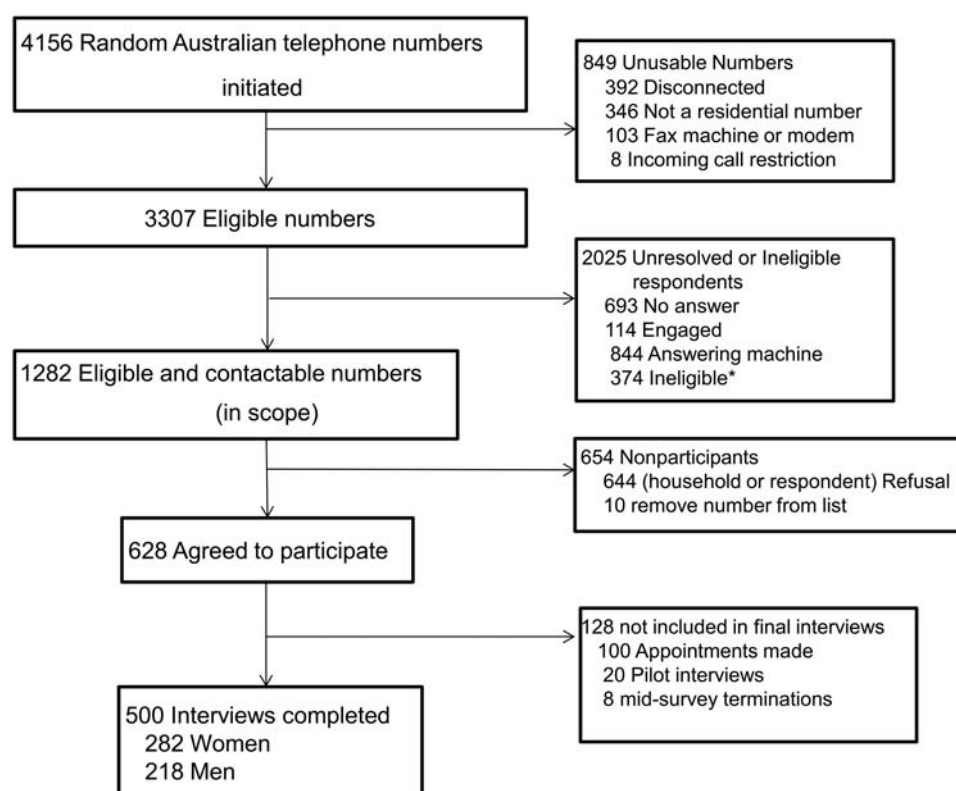

Figure 1 Participant Recruitment for Telephone Interview Survey of 500 Australians. Ineligible participants included: persons under 18 years of age; those with a medical condition rendering them physically unable to complete the interview; people with language difficulties; respondents away for duration of fieldwork; people claiming to have carried out survey or named person not known.

Table 1 Characteristics of respondents questioned about the meaning of overdiagnosis

Characteristic	Number of survey respondents n=500 (%)
Age, years	
18–49	215 (43.0) *(57.8)
50–	285 (57.0) *(42.2)
Sex	
Men	218 (43.6) *(49.4)
Women	282 (56.4) *(50.6)
Education	
<High school	74 (14.8) *(26.9)
High school graduate	169 (33.8) *(38.7)
Bachelor degree/advanced diploma	168 (33.6) *(26.5)
>Bachelor degree	89 (17.8) *(7.7)
Employment	
Employed	298 (59.6)
Unemployed	20 (4)
Not working	182 (36.4)
Cancer diagnosis	
Yes	70 (14.0)
No	430 (86.0)

*Australian population data from the Australian Bureau of Statistics 2011 Census.

Related to the 'exaggeration' theme was the theme described as 'diagnosing something not there', which included responses that defined overdiagnosis as 'diagnosing a condition that the person does not actually have/does not exist' and exemplified by the comment "Sort of pre-empting a potential disease when there isn't one". This theme occurred in 10% of responses. Also related was the theme 'too much or too many

diagnoses', explained as 'doctors making a diagnosis more frequently than what is needed/people being diagnosed with too many conditions'. This theme was exemplified by the response, "For example cholesterol, they just use a level in the blood and if you are over the level you have that and they lower the level so everyone has it", and this occurred in 9% of responses. While none of the three related themes corresponds exactly with the current definitions of overdiagnosis being debated within the scientific community, they can be seen to approximate an understanding of the problem of an unnecessary and unhelpful diagnosis.

The second most common set of themes related to overuse of interventions, occurring in 24% of responses. The theme of 'overprescribing'—which was described as 'prescribing too many medications/more than is needed'—ran through 14% of responses, exemplified by the comment, "A doctor is handing out medication willy nilly." This theme related closely to 'overtreatment'—defined as 'unnecessary medical interventions and services provided, including referrals; overservicing.' The overtreatment theme was exemplified by the comment, "Overservicing or providing greater service than is essential for the correct diagnosis" and occurred in 5% of responses. The theme 'overtesting'—defined as 'a doctor performing or a person having too many unnecessary tests to get a diagnosis'—was exemplified by the comment "Where too many tests are done, particularly with prostate cancer", and occurred in 7% of responses.

Relatively small numbers of participants made responses coded into themes including 'doctors looking too much', (4%) 'patients driving it', (4%) 'wrong diagnosis', (4%) and 'doctors' financial gain' (3%). Around 13% of

Table 2 Coding framework for analysis of responses to "What do you think overdiagnosis means?"

Theme	Explanation of theme
Overdiagnosis	
Exaggerating something that is there	Diagnosing a condition to be more serious/severe than what it actually is; overmedicalising; overcomplicating
Diagnosing something that is not there	Diagnosing a condition that the person does not actually have/does not exist
Too much diagnosis/too many diagnoses	Doctors making a diagnosis more frequently than what is needed/people being diagnosed with too many conditions
Overuse	
Overprescribing	Prescribing too many medications—more than is needed
Overtreatment	Unnecessary medical interventions and services provided, including referrals; overservicing
Overtesting	A doctor performing or a person having too many unnecessary tests to get a diagnosis
Others	
Doctors looking too much into things	Doctors looking too hard, too much or too often, for a problem to diagnose
Patients/people driving it	Patients/people who search for too much unnecessary medical information or are unusually anxious or worried about their health
Wrong diagnosis	Wrongly diagnosed with a condition (with no suggestion of exaggerating something)
Doctors financial gain as a driver	doctors whose ultimate goal is to make money or cover themselves for financial or litigation reasons

Table 3 What do you think overdiagnosis means? Response theme, example and frequency

Theme	Example of comment	Number	(% of 500)*
Overdiagnosis			
Exaggerating something that's there	"Someone's condition has been made out to be worse than what it is"	112	22
Diagnosing something that's not there	"Sort of pre-empting a potential disease when there isn't one"	48	10
Too much/too many diagnoses	"I take it to mean something like ADHD, where previously it hadn't been diagnosed and now it is and suddenly people find it everywhere"	45	9
Overuse			
Overprescribing	"A doctor is handing out medication willy nilly"	69	14
Overtreatment	"Overservicing or providing greater service than is essential for the correct diagnosis"	26	5
Overtesting	"Where too many tests are done, particularly with prostate cancer"	33	7
Others			
Doctors looking too much	"Looking too far into a problem"	21	4
Patients driving it	"People get on the internet and diagnosing themselves with things they don't have"	22	4
Wrong diagnosis	"That they haven't diagnosed you correctly or they have given you the wrong diagnosis"	20	4
Doctors' financial gain	"They want to make more cost for patients and make more money or they sometimes go further to cover themselves"	17	3
Non-responses			
Did not respond at all		67	13
Miscellaneous/do not know/unsure		61	12

*Does not add to 100% as some responses coded to more than one theme.

participants failed to respond, and for another 12%, responses were unable to be categorised into the final 10 themes, because, for example, a participant answered by saying 'probably overdiagnosis'. No responses mentioned screening.

DISCUSSION

Our survey of 500 Australian adults found almost half of participants thought the term overdiagnosis meant exaggerating a problem that exists, diagnosing something that is not there, or deploying too many diagnoses and another quarter equated the term with some form of overuse, including overprescribing, overtesting or overtreating. A significant minority offered either no response, or a response unable to be categorised. Only a tiny proportion gave responses that made mention of doctors' financial gain, and, notably, no respondent mentioned the association between overdiagnosis and screening.

This study has several limitations. First, the brevity of participant responses made coding into themes more difficult for answers where comprehensibility was in doubt, and roughly 1 in 10 responses were unable to be categorised into our final 10 themes. Second, the open-ended question to participants about the meaning of overdiagnosis was asked at the very start of the survey, enabling valuable analysis of unprompted understanding of the term, but not giving participants much time to

reflect or think through responses. A third limitation arises from the AAPOR response rate of 20.4% and cooperation rate of 43.8%. While modest, these rates are now, however, common and satisfactory for community surveys of this type. In 2012, the well regarded Pew Research Centre stated its standard telephone surveys were achieving AAPOR response rates of 9% and cooperation rates of 14%, and that the 9% response rate was similar to that achieved by other major survey organisations.[19] With the rates achieved in our survey, there is a possibility of systematically different responses between respondents and non-respondents, though this possibility is lessened by the general representativeness of sample respondents.

Study strengths include the strong level of agreement on themes in the initial independent coding of the 500 responses, pointing to a thematic coherence in the community's response, and notwithstanding demographic variations between our random sample and population data, the study's 500 Australian adults were generally representative. Most importantly, to the best of our knowledge this is the first time internationally that general community members have been asked what they understand overdiagnosis to mean, with responses providing a unique data set. Other data on public understanding or views about overdiagnosis are extremely limited. A quantitative survey by Schwartz et al[20] in 2004 found widespread enthusiasm for screening, unmodified by awareness of potential harms, while a qualitative study

Box 1 What do you think overdiagnosis means? Additional examples of responses

Exaggerating something that is there
"I'm guessing it means a mountain made out of a mole hill"
"Making diseases more severe than they are"
"When a patient presents with symptoms and the doctor diagnoses it as something more serious than it is, for example, when a boisterous child is diagnosed with ADHD when they just have a lot of energy"
"Someone's condition has been made out to be worse than what it is"
"Maybe reading too much into symptoms"
"Something that's not really serious making it sound as though it is really bad"
"They over diagnose what's going on with a person and they scare them more than they need to"
"It might mean that they've given a diagnosis that you're far worse off than you really are"
"When you're diagnosed with something but it's not as life threatening as it's being explained to be"
Diagnosing something that is not there
"When they assign diseases to people who aren't ill"
"Diagnosing a disease someone doesn't have"
"Doctor seeing things that aren't there"
"*There* is so many different ailments around and now there are so many different medications now it's possible that doctors are describing things that aren't there"
Too much diagnosis/too many diagnoses
"When there are more people given a label than you would expect to be the case"
"For example cholesterol, they just use a level in the blood and if you are over the level you have that and they lower the level so everyone has it"
"I take it to mean something like ADHD, where previously it hadn't been diagnosed and now it is and suddenly people find it everywhere"
Overprescribing
"Too much medication"
"Doctors trying to give out drugs that don't need to be taken to cure an ailment"
"You are being given too much medication when you don't need it"
Overtreatment
"If you have an illness where there are too many treatments for it"
"Overservicing of a patient's needs"
Overtesting
"Doctors sending people for too many tests"
"I think they send you off to have this test or that test and it's all a bit unnecessary"
Doctors looking too much
"When a doctor is looking for too many things"
Patients driving it
"If you go on the internet and you're looking at things you're just taking the information but it's probably the wrong information"
Wrong diagnosis
"The doctor wrongly diagnoses"
Doctors' gain
"Generally speaking it's a doctor who is milking the system to get more funds"

published in 2013, involving focus groups with 50 Australian women aged 40–79, found few had heard of overdiagnosis, though there was a desire to know more.[21] In 2014, researchers found that brief written information about overdiagnosis and mammography, of the sort currently sent to women in the UK, was incompletely understood and may not be enough to facilitate informed choice.[22]

At a time when the scientific community is still debating the definition of overdiagnosis, it makes little sense to judge the accuracy of community comprehension. Instead, we interpret the results to suggest that while many people grasp the basic idea, 'overdiagnosis means too many unnecessary diagnoses', many others failed to offer even an approximate understanding. For clinicians attempting to explain to their patients the counter-intuitive concepts such as the risk of overdiagnosis or the value of choosing not to test or to reduce or stop medication, for instance,[13 14] our results point to an encouraging though limited reservoir of community recognition of the potential dangers of excess. Clinicians may also take heart from how very few respondents identified doctors' financial gain as relevant to the meaning of overdiagnosis. Our finding that almost one in four respondents associated overdiagnosis with overuse suggests overdiagnosis might be best communicated about not in isolation, but within a wider context of its potential harms, including overuse. And finally, we believe the failure to associate overdiagnosis with screening should be interpreted as a strong signal to policymakers to introduce more routine communication about potential benefits and harms into screening programmes.

While there are ongoing and complex debates about how to define and measure overdiagnosis,[7] and resulting disagreements over its magnitude and extent,[8] there is a growing consensus around the need to better communicate with the community about the problem, particularly as a risk of screening. Our findings offer a rich data set of lay understanding to researchers and policymakers, to help inform development of effective communication strategies. Notwithstanding the complexity of the issues, the community responses provide some refreshingly simple and clear insights, reinforcing the need to intimately involve community members in developing and evaluating future communication strategies.

REFERENCES

1. Welch HG, Schwartz LM, Woloshin S. *Overdiagnosed: making people sick in the pursuit of health*. Boston: Beacon Press, 2011.
2. Armstrong D. The rise of surveillance medicine. *Sociol Health Illn* 1995;17:393–404.
3. Moynihan R, Doust J, Henry D. Preventing overdiagnosis: how to stop harming the healthy. *BMJ* 2012;344:e3502.
4. Grady D, Redberg R. Less is more: how less health care can result in better health. *Arch Intern Med* 2010;170:749–50.
5. Choosing Wisely. US physician groups identify commonly used tests or procedures they say are often not necessary. Press release, 2012. http://choosingwisely.org/wp-content/uploads/2012/03/033012_Choosing-Wisely-National-Press-Rls-FINAL.pdf (accessed 9 Dec 2014).
6. Glasziou P, Moynihan R, Richards T, *et al*. Too much medicine; too little care. *BMJ* 2013;346:f4247.
7. Carter SM, Rogers W, Heath I, *et al*. The challenge of overdiagnosis begins with its definition. *BMJ* 2015;350:h869.
8. Carter JL, Coletti RJ, Harris RP. Quantifying and monitoring overdiagnosis in cancer screening: a systematic review of methods. *BMJ* 2015;350:g7773.
9. Independent UK Panel on Breast Cancer Screening. The benefits and harms of breast cancer screening: an independent review. *Lancet* 2012;380:1778–86.
10. Moyer VA, on behalf of the US Preventive Services Task Force. Screening for prostate cancer: US preventive services task force recommendation statement. *Ann Intern Med* 2012;157:120–34.
11. Esserman L, Thompson I, Reid B. Overdiagnosis and overtreatment in cancer an opportunity for improvement. *JAMA* 2013;310:797–8.
12. House of Commons Science and Technology Committee. National Health Screening. Third Report of Session 2014–15; 29 October 2014. http://www.publications.parliament.uk/pa/cm201415/cmselect/cmsctech/244/244.pdf (accessed 9 Dec 2014).
13. Academy of Royal Medical Colleges. Protecting resources, promoting value: a doctor's guide to cutting waste in clinical care. November 2014. http://www.aomrc.org.uk/dmdocuments/Promoting%20value%20FINAL.pdf (accessed 9 Dec 2014).
14. Scott I, Anderson K, Freeman C, *et al*. First do no harm: a real need to deprescribe in older patients. *Med J Aust* 2014;201:1–3.
15. The American Association for Public Opinion Research. *Standard definitions: final dispositions of case codes and outcome rates for surveys*. 7th edn. AAPOR, 2011. http://www.aapor.org/AAPORKentico/AAPOR_Main/media/MainSiteFiles/StandardDefinitions2011_1.pdf (accessed 21 Mar 2015).
16. 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;5:1–11.
17. Hewitt-Taylor J. Use of constant comparative analysis in qualitative research. *Nurs Stand* 2001;15:39–42.
18. Pope C, Ziebland S, Mays N. Qualitative research in health care. Analysing qualitative data. *BMJ* 2000;320:114.
19. The Pew Research Centre, Assessing the Representativeness of Public Opinion Surveys May 15 2012. http://www.people-press.org/2012/05/15/assessing-the-representativeness-of-public-opinion-surveys/ (accessed 9 Dec 2014).
20. Schwartz LM, Woloshin S, Fowler FJ, *et al*. Enthusiasm for cancer screening in the United States. *JAMA* 2004;291:71–8.
21. Hersch J, Jansen J, Barratt A, *et al*. Women's views on overdiagnosis in breast cancer screening: a qualitative study. *BMJ* 2013;346:f158.
22. Waller J, Whitaker KL, Winstanley K, *et al*. A survey study of women's responses to information about overdiagnosis in breast cancer screening in Britain. *Br J Cancer* 2014;111:1831–5.

Bond University

"Medical Over-diagnosis"

16 January, 2014

Questionnaire version 8 (including pilot changes)

[PROGRAMMER NOTE:
- **Use standard SMS list**
- **Use standard RR1 list]**

*INTRODUCTION & SCREENING

*(PHONE ANSWERER)
INTRO1: Good (morning/afternoon/evening) my name is (…) and I am calling from the Social Research Centre on behalf of Bond and Sydney Universities.

We're doing a short survey across Australia about community views on the way doctors diagnose diseases. This is an emerging issue and the results will help researchers find better ways for doctors to communicate about the risks and benefits of medical tests and treatments.

1. Continue

*(LANDLINE)
INTRO2a: We would like to speak to the person in your household who is aged 18 years or over and who had the LAST birthday? Would that be you?

[REINTRODUCE IF NECESSARY: Good (morning/afternoon/evening) my name is (…) and I am calling from the Social Research Centre on behalf of Bond and Sydney Universities. We're doing a short survey across Australia about community views on the way doctors diagnose diseases. This is an emerging issue and the results will help researchers find better ways for doctors to communicate about the risks and benefits of medical tests and treatments.]

1. Yes (continue)
2. Not a good time: appointment (MAKE APPOINTMENT)
3. Household refusal (GO TO RR1)
4. Language difficulty (NO follow up) (GO TO TERM2)
5. Wants more information before participating (GO TO INFO1)
6. No one aged 18+ in household (GO TO TERM1)
7. Queried about how telephone number was obtained (GO TO TEL_LAND)

*(MOBILE)
INTRO2b. Can I ask whether you are aged 18 years or over?

1. Yes (continue)
2. Not a good time: appointment (GO TO MOB1)
3. Mobile answerer refusal (GO TO RR1)
4. Language difficulty (NO follow up) (GO TO TERM2)
5. Wants more information before participating (GO TO INFO1)
6. Under 18 years of age (GO TO TERM1)
7. Queried about how telephone number was obtained (GO TO TEL_MOB)
8. Queried why mobile was called (GO TO TINFO_MOB)

*(IF INTRO2a=5 OR INTRO2b=5 – MORE INFO REQUIRED)
INFO1. You can find more information online from the Social Research Centre website (www.srcentre.com.au, on the 'participants' tab under 'current surveys'. This includes links to the Bond University and the University of Sydney websites.)

1. Make appointment [PROGRAMMER NOTE: IF MOBILE GO TO MOB1, ELSE MAKE APPOINTMENT]
2. (Wants info but NO INTERNET) (COLLECT MAILING DETAILS THEN IF MOBILE GO TO MOB1, ELSE MAKE APPOINTMENT; SET UP GETDET!]

*(QUERIED HOW LANDLINE NUMBER WAS OBTAINED)
TEL_LAND   Your telephone number has been chosen at random from all possible telephone numbers. We find that this is the best way to obtain a representative sample of people across Australia.

1. Snap back to previous question

*(QUERIED HOW MOBILE NUMBER WAS OBTAINED)
TEL_MOB   Your mobile number was randomly generated by a computer. We're calling mobile phones as well as landlines so we can get a representative sample of people across Australia.

1. Snap back to previous question

*(QUERIED WHY MOBILE WAS CALLED)
TINFO_MOB   One of the issues currently facing telephone survey researchers in Australia is the increasing proportion of households without a landline telephone. We are calling mobile phones as well as landlines so we can get a representative sample of people across Australia.

    1.   Snap back to previous question

*(MOBILE SAMPLE)
MOB2. May I just check whether or not it is safe for you to take this call at the moment? If not, I am happy to call you back when it is more convenient for you.

    1.   Safe to take call
    2.   Not safe to take call
    3.   Respondent refusal (GO TO RR1)

*(MOBILE SAMPLE)
MOB1. Just so I know your time zone, can you tell me which state you're in?

    1.   NSW
    2.   VIC
    3.   QLD
    4.   SA
    5.   WA
    6.   TAS
    7.   NT
    8.   ACT
    9.   (Refused)

*PROGRAMMER NOTE – WRITE STATE / TERRITORY TO SAMPLE RECORD

[PREMOBAPPT IF INTRO2b=2 OR 5, OR MOB2=2 CONTINUE (mob appointment), ELSE GO TO INTRO3a]

*(MOBILE SAMPLE NEEDING APPOINTMENT)
MOB_APPT   Do you want me to call you back on this number or would you prefer I call back on another phone?

    1.   This number (TYPE STOP, MAKE APPOINTMENT)
    2.   Another number (TYPE STOP, MAKE APPOINTMENT, RECORD ALT NUMBER)
    3.   Respondent refusal (GO TO RR1)

*(ALL)
INTRO3a: Thank you. Now, I'm just going to run some details past you about the study….

    1.   Continue
    2.   Not a good time (MAKE APPOINTMENT)
    3.   Respondent refusal (GO TO RR1)
    4.   Language difficulty (NO follow up) (GO TO TERM2)
    5.   More info "go to www.srcentre.com.au, on the 'participants' tab under 'current surveys'. This includes links to the Bond University and the University of Sydney websites." (MAKE APPOINTMENT)
    6.   (Wants info but NO INTERNET: collect details to mail info sheet) (MAKE APPOINTMENT)

4

*(ALL)
INTRO3b:

The survey has been approved by the Bond University Ethics Committees and participation is completely voluntary. You can choose not to answer any question or to cease the survey at any time. Your phone number was selected randomly, your answers will remain completely anonymous and we will not be recording this phone call. It will only take around 15 minutes to complete.

Would you like more information or would you be willing to participate in this important study?

[INTERVIEWER NOTE: If more information requested, read the abridged Participant Information Sheet. If potential participant doesn't want to be read information, offer to provide website details and arrange an appointment.]

1. Continue
2. Not a good time (MAKE APPOINTMENT)
3. Respondent refusal (GO TO RR1)
4. More info "go to www.srcentre.com.au, on the 'participants' tab under 'current surveys'. This includes links to the Bond University and the University of Sydney websites." (MAKE APPOINTMENT)
5. (NO INTERNET ACCESS: arrange to send information sheet) (MAKE APPOINTMENT)

*(ALL)
MON: This call may be monitored for training and quality purposes but will NOT be recorded. Is that OK?

1. Monitor
2. Do not monitor

*(ALL)
S1a. Thank you. Now, before we begin the survey, would you mind telling me your age?
1. (Record number in years) [RANGE 18 to 105]
2. (Refused) (GO TO S1b)

*(IF S1a=2 – Refused age)
S1b. Could you please tell me which of the following age groups you are in?

1. 18-29
2. 30-49
3. 50-69
4. 70 and over
5. (Refused)

*(ALL)
S2. As we are talking about the way doctors diagnose diseases and medical treatments which affect men and women differently would you mind confirming your gender?

[IF NECESSARY: we need to ask this question of everyone to make sure we ask people the right questions throughout the survey]
[INTERVIEWER NOTE: If 'refuse' or 'other', allocate at your discretion]

1. Male
2. Female

*(ALL)
S3. What is the post code of the area in which you live?

1. (Record post code _____) [RANGE: 800 to 9999]
2. (Don't know)(Specify suburb)
3. (Refused)

[PROGRAMMER NOTE: DERIVE 'STATE' WHERE RESPONDENT CAN PROVIDE POSTCODE; IF NO ELIGIBLE POSTCODE PROVIDED ALLOCATE TO 'OTHER' STATE]

*SECTION A: GENERAL KNOWLEDGE ABOUT OVER-DIAGNOSIS

Just to start our survey…

*(ALL)
A1.   Have you seen or heard the term 'over-diagnosis' before today?

[IF NECESSARY: We are discussing over-diagnosis of medical illnesses, diseases and conditions].
1. Yes
2. No
3. (Don't know)
4. (Refused)

[PRE A2 IF A1=1 use A2i ELSE use A2ii]
*(ALL)
A2i.   What do you understand the term 'over-diagnosis' to mean?
A2ii. What do you think the term 'over-diagnosis' means?

[IF NECESSARY: We are discussing over-diagnosis of medical illnesses, diseases and conditions].

1. Response Given (Specify) *(PROGRAMMER NOTE: Set up as full verbatim)
2. (Don't know / can't say)
3. (Refused)

*(ALL)
A3.   A generally accepted view is that over-diagnosis happens when people are diagnosed with a disease that would never have harmed them. This could be due to the condition being so slow developing or them displaying only very minor symptoms.

Given this explanation, have you seen or heard the term or concept of 'over-diagnosis'?

[IF NECESSARY:For example sometimes people are diagnosed with cancer, but that cancer would be so slow growing it would not cause them any harm in their lifetime, or a person with very mild problems may be diagnosed with a mental disorder such as ADHD.
We are discussing over-diagnosis of medical illnesses, diseases and conditions].

1. Yes
2. No
3. (Don't know)
4. (Refused)

*(ALL)
A4.   Has a doctor ever told you that healthy people can be over-diagnosed as a result of being screened or tested for a disease?

1. Yes
2. No
3. (Don't know)
4. (Refused)

*(ALL)
A5.   Routine screening means testing healthy people to find signs of diseases such as cancer.

Do you think routine screening tests for healthy people are almost always a good idea?

1. Yes
2. No
3. (Don't know)
4. (Refused)

*(ALL)
A6.   Do you agree or disagree that routine screening tests for healthy people are important for their health?

PROBE: IS THAT COMPLETELY, MOSTLY OR SLIGHTLY AGREE / DISAGREE?

(RESPONSE FRAME) (DO NOT READ OUT)
1. Completely agree
2. Mostly agree
3. Slightly agree
4. (Neither agree nor disagree)
5. Slightly disagree
6. Mostly disagree
7. Completely disagree
8. (Don't know / Can't say)
9. (REFUSED)

*(ALL)
A7.   When healthy people are considering having a screening test - along with being told about the potential benefits of the screening test – do you agree or disagree that they should be informed about the potential risk of over-diagnosis?

[IF NECESSARY: For example a screening test for prostate or breast cancer, chronic kidney disease or other diseases and illnesses].

PROBE: IS THAT COMPLETELY, MOSTLY OR SLIGHTLY AGREE / DISAGREE?

(RESPONSE FRAME) (DO NOT READ OUT)
1. Completely agree
2. Mostly agree
3. Slightly agree
4. (Neither agree nor disagree)
5. Slightly disagree
6. Mostly disagree
7. Completely disagree
8. (Don't know / Can't say)
9. (REFUSED)

*(ALL)
TS1_Section A

*SECTION B: SCREENING EXPERIENCES

*(ALL)
B0.   I will now ask you a few brief questions about your experiences with medical screening tests.

[PREB1a: IF S2=2 (female) GO TO PREB2; ELSE CONTINUE]

*(S2=1 – Males only)
B1a   Have you ever had a screening test, sometimes called a PSA test before for prostate cancer?

  1. Yes
  2. No (GO TO B3)
  3. (Don't know) (GO TO B3)
  4. (Refused) (GO TO B3)

*(B1a=1 – had screening test)
B1b. Were you told about the risk of over-diagnosis (of this test)?
    [IF NECESSARY: In other words, were you told by a doctor, GP, or the person who offered or administered the test that you may be diagnosed and treated for a cancer that would never have caused you any harm in your lifetime?]

  1. Yes I was told
  2. No I wasn't told
  3. (Don't know)
  4. (Refused)

[PREB2: IF S2=1 (male) GO TO B3; ELSE CONTINUE]

*(S2=1 – Females only)
B2a   Have you ever had a mammogram to screen for breast cancer?

    [IF NECESSARY: "We are interested in finding out if women have had a screening test when they didn't have any problem in their breast, such as a lump, as opposed to having a 'diagnostic' mammogram, where there was a problem being investigated.]

  1. Yes
  2. No (GO TO B3)
  3. (Don't know) (GO TO B3)
  4. (Refused) (GO TO B3)

*(B2a=1 – had screening test)
B2b. Were you told about the risk of over-diagnosis (of this test)?
    [IF NECESSARY: In other words, were you told by a doctor, GP, or the person who offered or administered the test that you may be diagnosed and treated for a cancer that would never have caused you any harm in your lifetime?]

  1. Yes I was told
  2. No I wasn't told
  3. (Don't know)
  4. (Refused)

*(ALL)
B3.   Have you ever had a genetic screening test?
    [IF NECESSARY: A genetic screening test, or DNA testing, seeks to identify inherited diseases or diseases passed on through blood relations]

  1. Yes
  2. No
  3. (Don't know)
  4. (Refused)

*(ALL)
TS2_Section B

*SECTION C: INTEREST IN GENETIC SCREENING

*(ALL)
C1.   Imagine that there was a genetic screening test which could analyse your genes and identify all the diseases you may ever get, for which some had effective treatments and some did not. Would you be likely or unlikely to have that screening test?

PROBE: IS THAT COMPLETELY, MOSTLY OR SOMEWHAT LIKELY / UNLIKELY?

(RESPONSE FRAME)
1.   Completely likely
2.   Mostly likely
3.   Somewhat likely
4.   (Neither likely nor unlikely)
5.   Somewhat unlikely
6.   Mostly unlikely
7.   Completely unlikely
8.   (Don't know)
9.   (Refused)

*(ALL)
C2.   Imagine now that the results of the genetic screening test were often uncertain, and the predictions could be wrong. Would you be likely or unlikely then to have that screening test?

PROBE: IS THAT COMPLETELY, MOSTLY OR SOMEWHAT LIKELY / UNLIKELY?

(RESPONSE FRAME)
1.   Completely likely
2.   Mostly likely
3.   Somewhat likely
4.   (Neither likely nor unlikely)
5.   Somewhat unlikely
6.   Mostly unlikely
7.   Completely unlikely
8.   (Don't know)
9.   (Refused)

*(ALL)
TS3_Section C

*SECTION D: BREAST SCREENING (MALES VS FEMALES)

*(ALL)
D0.　In this next section I'm going to describe a particular scenario about screening for cancer, then ask you some questions about that scenario. Sometimes people can find these questions personal or sensitive. If you are unsure how to answer or do not want to answer any question please let me know and I will move on.

[PROGRAMMER NOTE: create dummy variable to randomly assign males and females to relevant Option 1 and Option 2. Each respondent to respond to one scenario.]

*(ALL) [PROGRAMMER NOTE: All respondents need to be assigned a code at RAND; minimum of 100 respondents per code]
RAND: "Random assignment of males and females to Option 1 and Option 2"
1. S2=2 + random assignment (Female, Option 1)
2. S2=2 + random assignment (Female, Option 2)
3. S2=1 + random assignment (Male, Option 3)
4. S2=1 + random assignment (Male, Option 4)

[PRED1: IF RAND=1, CONTINUE. ELSE GO TO PRED5]

*(RAND=1 – Female, Option 1)
D1.　Breast screening (mammograms) detects abnormal changes of cells in the breast as well as finding breast cancers. In some women these abnormal cells can progress to invasive cancer and in others they do not. It's estimated that if left untreated about one-third may progress to breast cancer over 10 years or more. That means that for about two-thirds of women these abnormal cells may not become cancer.

Imagine you had an abnormal breast screen and follow-up tests showed that there were abnormal cells found in your breast.

How concerned would you be about your result? Would you say…

[IF NECESSARY: 'Invasive' cancer means potentially life threatening.]

(RESPONSE FRAME) (READ OUT)
1. Extremely concerned
2. Moderately concerned
3. (Neither concerned nor unconcerned)
4. Not really concerned
5. Not concerned at all
6. (Don't know)
7. (Refused)
8. (Respondent does not understand terminology / issues) (GO TO TS4)

*(RAND=1 – Female, Option 1)
D2.　Abnormal breast cells are usually treated by surgery, radiation or drugs as in the case of breast cancer. Another approach is called watchful waiting, where doctors closely monitor the abnormal breast cells with regular mammograms and only treat if cells become more abnormal.

If research shows that watchful waiting is a safe and effective option, how do you think you would prefer to manage these abnormal cells? Would you say…

[IF NECESSARY: If people want more information on exactly what watchful waiting would entail - say, that's what research would determine.]

(RESPONSE FRAME) (READ OUT)
1. Definitely prefer treatment
2. Probably prefer treatment
3. (Prefer to do nothing)
4. Probably prefer watchful waiting (close monitoring by doctors)
5. Definitely prefer watchful waiting (close monitoring by doctors)
6. (Don't know)
7. (Refused)
8. (Respondent does not understand terminology / issues) (GO TO TS4)

*(RAND=1 – Female, Option 1)

D3.   Thinking again about the previous scenario, if these abnormal cells in your breast were instead called <u>pre-invasive breast cancer cells (rather than abnormal cells),</u> would you be more concerned or less concerned about your screening test result?

(RESPONSE FRAME)
1. More concerned
2. (No difference)
3. Less concerned
4. (Don't know)
5. (Refused)
6. (Respondent does not understand terminology / issues) (GO TO TS4)

*(RAND=1 – Female, Option 1)

D4.   And if research shows that watchful waiting is a safe and effective option, how do you think you would prefer to manage these <u>pre-invasive breast cancer cells</u>? Would you say…

(RESPONSE FRAME) (READ OUT)
1. Definitely prefer treatment
2. Probably prefer treatment
3. (Prefer to do nothing)
4. Probably prefer watchful waiting (close monitoring by doctors)
5. Definitely prefer watchful waiting (close monitoring by doctors)
6. (Don't know)
7. (Refused)
8. (Respondent does not understand terminology / issues) (GO TO TS4)

[PRED5: IF RAND=2, CONTINUE. ELSE GO TO PRED9]

*(RAND=2 – Female, Option 2)
D5.   Breast screening (mammograms) detects <u>pre-invasive breast cancer cells</u> in the breast as well as finding breast cancers. In some women these <u>pre-invasive breast cancer cells</u> can progress to invasive cancer and in others they do not. It's estimated that if left untreated about one-third may progress to breast cancer over 10 years or more. That means that for about two-thirds of women these <u>pre-invasive breast cancer cells</u> may not become cancer.

Imagine you had a breast screen and follow-up tests showed that there were <u>pre-invasive breast cancer cells</u> found in your breast.

How concerned would you be about your result? Would you say…

[IF NECESSARY: 'Invasive' cancer means potentially life threatening.]

(RESPONSE FRAME) (READ OUT)
1.   Extremely concerned
2.   Moderately concerned
3.   (Neither concerned nor unconcerned)
4.   Not really concerned
5.   Not concerned at all
6.   (Don't know)
7.   (Refused)
8.   (Respondent does not understand terminology / issues) (GO TO TS4)

*(RAND=2 – Female, Option 2)
D6.   <u>Pre-invasive breast cancer cells</u> are usually treated by surgery, radiation or drugs as in the case of breast cancer. Another approach is called watchful waiting, where doctors closely monitor the <u>pre-invasive breast cancer cells</u> with regular mammograms and only treat if cells become more invasive.

If research shows that watchful waiting is a safe and effective option, how do you think you would prefer to manage these <u>pre-invasive breast cancer cells</u>? Would you say…

[IF NECESSARY: If people want more information on exactly what watchful waiting would entail - say, that's what research would determine.]

(RESPONSE FRAME) (READ OUT)
1.   Definitely prefer treatment
2.   Probably prefer treatment
3.   (Prefer to do nothing)
4.   Probably prefer watchful waiting (close monitoring by doctors)
5.   Definitely prefer watchful waiting (close monitoring by doctors)
6.   (Don't know)
7.   (Refused)
8.   (Respondent does not understand terminology / issues) (GO TO TS4)

*(RAND=2 – Female, Option 2)
D7.   Thinking again about the previous scenario, if these pre-invasive breast cancer cells were instead called <u>abnormal cells</u> (rather than pre-invasive cells), would you be more concerned or less concerned about your screening test result?

(RESPONSE FRAME)
1.   More concerned
2.   (No difference)
3.   Less concerned
4.   (Don't know)
5.   (Refused)
6.   (Respondent does not understand terminology / issues) (GO TO TS4)

*(RAND=2 – Female, Option 2)
D8.   And if research shows that watchful waiting is a safe and effective option, how do you think you would prefer to manage these <u>abnormal cells</u>? Would you say…

(RESPONSE FRAME) (READ OUT)
1.   Definitely prefer treatment
2.   Probably prefer treatment
3.   (Prefer to do nothing)
4.   Probably prefer watchful waiting (close monitoring by doctors)
5.   Definitely prefer watchful waiting (close monitoring by doctors)
6.   (Don't know)
7.   (Refused)
8.   (Respondent does not understand terminology / issues) (GO TO TS4)

[PRED9: IF RAND=3, CONTINUE. ELSE GO TO PRED13]

13

*(RAND=3 – Male, Option 3)

D9.   Breast screening (mammograms) detects abnormal changes of the cells in the breast as well as finding breast cancers. In some women these abnormal cells can progress to invasive cancer and in others they do not. It's estimated that if left untreated about one-third may progress to breast cancer over 10 years or more. That means that for about two-thirds of women these abnormal cells may not become cancer.

Imagine your wife, daughter, mother or close female friend had an abnormal breast screen and follow-up tests showed that there were abnormal cells found in her breast.

How concerned would you be about her result? Would you say…

[IF NECESSARY: 'Invasive' cancer means potentially life threatening.]

(RESPONSE FRAME) (READ OUT)
1.   Extremely concerned
2.   Moderately concerned
3.   (Neither concerned nor unconcerned)
4.   Not really concerned
5.   Not concerned at all
6.   (Don't know)
7.   (Refused)
8.   (Respondent does not understand terminology / issues) (GO TO TS4)

*(RAND=3 – Male, Option 3)

D10. Abnormal breast cells are usually treated by surgery, radiation or drugs as in the case of breast cancer. Another approach is called watchful waiting, where doctors closely monitor the abnormal breast cells with regular mammograms and only treat if cells become more abnormal.

If research shows that watchful waiting is a safe and effective option, how do you think you would prefer she manage these abnormal cells? Would you say…

[IF NECESSARY: If people want more information on exactly what watchful waiting would entail - say, that's what research would determine.]

(RESPONSE FRAME) (READ OUT)
1.   Definitely prefer treatment
2.   Probably prefer treatment
3.   (Prefer to do nothing)
4.   Probably prefer watchful waiting (close monitoring by doctors)
5.   Definitely prefer watchful waiting (close monitoring by doctors)
6.   (Don't know)
7.   (Refused)
8.   (Respondent does not understand terminology / issues) (GO TO TS4)

*(RAND=3 – Male, Option 3)

D11. Thinking again about the previous scenario and the same person, if these abnormal breast cells were now called pre-invasive breast cancer cells (rather than abnormal cells), would you be more concerned or less concerned about her screening test result?

(RESPONSE FRAME)
1.   More concerned
2.   (No difference)
3.   Less concerned
4.   (Don't know)
5.   (Refused)
6.   (Respondent does not understand terminology / issues) (GO TO TS4)

*(RAND=3 – Male, Option 3)

D12. And if research shows that watchful waiting is a safe and effective option, how do you think you would prefer your wife, daughter, mother or close female friend manage these <u>pre-invasive breast cancer cells</u>? Would you say…

(RESPONSE FRAME) (READ OUT)
1. Definitely prefer treatment
2. Probably prefer treatment
3. (Prefer to do nothing)
4. Probably prefer watchful waiting (close monitoring by doctors)
5. Definitely prefer watchful waiting (close monitoring by doctors)
6. (Don't know)
7. (Refused)
8. (Respondent does not understand terminology / issues) (GO TO TS4)

[PRED13: IF RAND=4, CONTINUE. ELSE GO TO TS4_SECTION D]

*(RAND=4 – Male, Option 4)
D13. Breast screening (mammograms) detects <u>pre-invasive breast cancer cells</u> in the breast as well as finding breast cancers. In some women these <u>pre-invasive breast cancer cells</u> can progress to invasive cancer and in others they do not. It's estimated that if left untreated about one-third may progress to breast cancer over 10 years or more. That means that for about two-thirds of women these <u>pre-invasive breast cancer cells</u> may not become cancer

Imagine your wife, daughter, mother or close female friend had a breast screen and follow-up tests showed that there were <u>pre-invasive breast cancer cells</u> found in her breast.

How concerned would you be about her result? Would you say…

[IF NECESSARY: 'Invasive' cancer means potentially life threatening.]

(RESPONSE FRAME) (READ OUT)
1. Extremely concerned
2. Moderately concerned
3. (Neither concerned nor unconcerned)
4. Not really concerned
5. Not concerned at all
6. (Don't know)
7. (Refused)
8. (Respondent does not understand terminology / issues) (GO TO TS4)

*(RAND=4 – Male, Option 4)
D14. <u>Pre-invasive breast cancer cells</u> are usually treated by surgery, radiation or drugs as in the case of breast cancer. Another approach is called watchful waiting, where doctors closely monitor the <u>pre-invasive breast cancer cells</u> with regular mammograms and only treat if cells become more invasive.

If research shows that watchful waiting is a safe and effective option, how do you think you would prefer she manage these <u>pre-invasive breast cancer cells</u>? Would you say…

[IF NECESSARY: If people want more information on exactly what watchful waiting would entail - say, that's what research would determine.]

(RESPONSE FRAME) (READ OUT)
1. Definitely prefer treatment
2. Probably prefer treatment
3. (Prefer to do nothing)
4. Probably prefer watchful waiting (close monitoring by doctors)
5. Definitely prefer watchful waiting (close monitoring by doctors)
6. (Don't know)
7. (Refused)
8. (Respondent does not understand terminology / issues) (GO TO TS4)

*(RAND=4 – Male, Option 4)
D15. Thinking again about the previous question and the same person, if these pre-invasive breast cancer cells were now called <u>abnormal cells</u> (rather than pre-invasive cells), would you be more concerned or less concerned about her screening test result?

(RESPONSE FRAME)
1. More concerned
2. (No difference)
3. Less concerned
4. (Don't know)
5. (Refused)
6. (Respondent does not understand terminology / issues) (GO TO TS4)

*(RAND=4 – Male, Option 4)

D16. And if research shows that watchful waiting is a safe and effective option, how do you think you would prefer your wife, daughter, mother or close female friend manage these <u>abnormal cells</u>? Would you say…

(RESPONSE FRAME) (READ OUT)
1. Definitely prefer treatment
2. Probably prefer treatment
3. (Prefer to do nothing)
4. Probably prefer watchful waiting (close monitoring by doctors)
5. Definitely prefer watchful waiting (close monitoring by doctors)
6. (Don't know)
7. (Refused)
8. (Respondent does not understand terminology / issues) (GO TO TS4)

*(ALL)
TS4_Section D

*SECTION E: DISEASE DEFINITION

*(ALL)
E0.   Next, I'd like to ask you a couple of questions about the way diseases are defined.

    1. Continue

*(ALL)
E1.   From time to time, doctors who specialise in a particular disease will come together to discuss the characteristics of that disease, to decide who should be diagnosed with it and who requires treatment for it. These are called panels and currently some doctors on these panels HAVE financial ties with pharmaceutical companies who market drugs for that disease and some DO NOT.

Is it appropriate or inappropriate for doctors who HAVE financial ties with pharmaceutical companies to be members of these panels?

PROBE: IS THAT COMPLETELY, MOSTLY OR SLIGHTLY APPROPRIATE / INAPPROPRIATE?

(IF NECESSARY: Financial ties mean do paid work such as being a speaker or a consultant)

(RESPONSE FRAME) (DO NOT READ OUT)
1. Completely appropriate
2. Mostly appropriate
3. Slightly appropriate
4. (Neither appropriate nor inappropriate)
5. Slightly inappropriate
6. Mostly inappropriate
7. Completely inappropriate
8. (Don't know)
9. (Refused)

*(ALL)
E2.   Sometimes, these panels decide to change the definition of a disease in a way that means larger or smaller numbers of people may be treated for it. A recent study found on average, roughly three-quarters of doctors on these panels had financial ties with the pharmaceutical companies selling medicines for the same diseases.

Based on this knowledge, how appropriate or inappropriate is it for doctors with financial ties to pharmaceutical companies who market drugs for that disease to be on these panels?

PROBE: IS THAT COMPLETELY, MOSTLY OR SLIGHTLY APPROPRIATE / INAPPROPRIATE?

(RESPONSE FRAME)
1. Completely appropriate
2. Mostly appropriate
3. Slightly appropriate
4. (Neither appropriate nor inappropriate)
5. Slightly inappropriate
6. Mostly inappropriate
7. Completely inappropriate
8. (Don't know)
9. (Refused)

*(ALL)
E3.   Ideally, what proportion of the panel should be made up of doctors with financial ties to pharmaceutical companies who market drugs for that disease?

(READ OUT)
1.   None (0%)
2.   A minority - less than 50%
3.   A majority - 50% or more
4.   (Don't care)
5.   (Don't know)
6.   (Refused)

*(ALL)
TS5_Section E

*SECTION F: EXPERIENCE WITH CANCER

*(ALL)
F0.   We're almost finished. Now I'm going to ask you a few brief questions about your experiences with cancer and cancer screening. Sometimes people can find these questions quite personal or sensitive. If you prefer not to answer any question, please let me know and I will move on.

1.   Continue

[PREF1:
IF B1a=1 DISPLAY "have had a PSA test to screen for prostate cancer"
IF B1a=2 DISPLAY "have NOT had a PSA test to screen for prostate cancer"
IF B1a=3 DISPLAY "didn't know if you had been screened for prostate cancer"
IF B1a=4 DISPLAY "would prefer not to say if you had been screened for prostate cancer"
IF B2a=1 DISPLAY "have had a mammogram to screen for breast cancer"
IF B2a=2 DISPLAY "have NOT had a mammogram to screen for breast cancer"
IF B1a=3 DISPLAY "didn't know if you had been screened for breast cancer"
IF B1a=4 DISPLAY "would prefer not to say if you had been screened for breast cancer"]

*(ALL)
F1.   Earlier you mentioned that you < have had a PSA test to screen for prostate cancer / have NOT had a PSA test to screen for prostate cancer / didn't know if you had been screened for prostate cancer / would prefer not to say if you had been screened for prostate cancer / have had a mammogram to screen for breast cancer / have NOT had a mammogram to screen for breast cancer / didn't know if you had been screened for breast cancer / would prefer not to say if you had been screened for breast cancer>.

Have you been screened for other forms of cancer?

1.   Yes
2.   No
3.   (Don't know)
4.   (Refused)

*(ALL)
F2a.   Have you ever been diagnosed with cancer?

1.   Yes
2.   No (GO TO F3a)
3.   (Don't know) (GO TO F3a)
4.   (Refused) (GO TO F3a)

*(IF F2a=1 – has been diagnosed with cancer)
F2b.   What type of cancer?

(ACCEPT MULTIPLES) (DO NOT READ OUT UNLESS REQUIRED)
1.   Bowel
2.   Breast
3.   Cervical
4.   Lung
5.   Lymphoma
6.   Melanoma
7.   Prostate
8.   Response Given (Specify) *(PROGRAMMER NOTE: Set up as full verbatim)
9.   (Don't know)
10.   (Refused)

*(ALL)
F3a.   Have any of your immediate family, that is your parents, siblings or children, ever been diagnosed with cancer?

1.   Yes
2.   No (GO TO TS6_Section F)
3.   (Don't know) (GO TO TS6_Section F)
4.   (Refused) (GO TO TS6_Section F)

*(IF F3a=1 – has a family history of cancer)
F3b.   What's their relationship to you?

   (SELECT MULTIPLE)
   1. Mother
   2. Father
   3. Sister
   4. Brother
   5. Daughter
   6. Son
   7. (Don't know / can't say)
   8. (Refused)

*(IF F3a=1 – has a family history of cancer)
F3c.   What type or types of cancer were they diagnosed with?

   (ACCEPT MULTIPLES) (DO NOT READ OUT UNLESS REQUIRED)
   1. Bowel
   2. Breast
   3. Cervical
   4. Lung
   5. Lymphoma
   6. Melanoma
   7. Prostate
   8. Response Given (Specify) *(PROGRAMMER NOTE: Set up as full verbatim)
   9. (Don't know)
   10. (Refused)

*(ALL)
TS6_Section F

*SECTION G: DEMOGRAPHICS

*(ALL)
G0.   Now I would like to ask you a few demographic questions to make sure we speak with a good cross-section of the community. Again, I'd like to assure you that everything you tell me today is anonymous.

*(ALL)
G1.   Are you of Aboriginal and/or Torres Strait Islander origin?

1. Yes
2. No

*(ALL)
G2.   What is the main language you speak at home?

1. English
2. Other (specify_____)

*(ALL)
G5.   What is your employment status?

1. Permanent or on-going
2. Casual/temporary (with no paid sick or annual leave)
3. Fixed-term contract
4. Self-employed
5. (On paid leave: e.g. maternity leave)
6. Unemployed (e.g. looking or not looking for work)
7. Not working / not in the labour force (e.g. student, home duties, retired)

*(ALL)
G6.   Are you now or have you ever worked as a health professional? This includes Doctors, Specialists, Nurses or Pharmacists.
1. Yes
2. No

*(ALL)
G7.   What is the highest level of education that you have completed?

(INTERVIEWER NOTE: Prompt if year 12 or below: Have you completed TAFE, trade or apprenticeship qualifications?)

(RESPONSE FRAME])

1. Postgraduate Degree
2. Graduate Diploma/Graduate Certificate
3. Bachelor Degree
4. Advanced Diploma/Diploma
5. Certificate III/IV
6. Certificate I/II
7. Certificate not further defined
8. Year 12
9. Year 11
10. Year 10 or below
11. Level not determined
98. (Don't know)
99. (Refused)

*(ALL)
TS7_Section G

*SECTION H: DUAL FRAME WEIGHTING

[PRESMP1 IF SAMPLE=LANDLINE CONTINUE, ELSE GO TO PRESMP3]

*(LANDLINE SAMPLE)
SMP1. How many residential phone numbers do you have in your household, not including lines dedicated to faxes, modems or business phone numbers? Do not include mobile phones.

(IF NECESSARY: How many individual LANDLINE numbers are there at your house that you can use to make and receive telephone calls?)

1. Number of lines given (Specify_____) RECORD WHOLE NUMBER (ALLOWABLE RANGE 1 TO 99) *(DISPLAY "UNLIKELY RESPONSE" IF = >3)
2. Don't know/ Not stated (PROGRAMMER NOTE: RECORD IN DATA AS 999)
3. Refused (PROGRAMMER NOTE: RECORD IN DATA AS 888)

*(LANDLINE SAMPLE)
SMP2 Do you also have a working mobile phone?

1. Yes (GO TO SMP5)
2. No (GO TO SMP5)
3. (Don't know) (GO TO SMP5)
4. (Refused) (GO TO SMP5)

[PRESMP3 IF SAMPLE=MOBILE CONTINUE, ELSE GO TO SMP5]

*(MOBILE SAMPLE)
SMP3 Is there at least one working fixed line telephone inside your home that is used for making and receiving calls?

1. Yes
2. No (GO TO SMP5)
3. (Don't know) (GO TO SMP5)
4. (Refused) (GO TO SMP5)

*(SMP3=1 - MOBILE SAMPLE, HAS AT LEAST ONE WORKING FIXED LINE IN HOUSEHOLD)
SMP4 How many residential phone numbers do you have in your household, not including lines dedicated to faxes, modems or business phone numbers. Do not include mobile phones.

(IF NECESSARY: How many individual LANDLINE numbers are there at your house that you can use to make and receive telephone calls?)

1. Number of lines given (Specify_____) RECORD WHOLE NUMBER (ALLOWABLE RANGE 1 TO 99) *(DISPLAY "UNLIKELY RESPONSE" IF = >3)
2. Don't know/ Not stated (PROGRAMMER NOTE: RECORD IN DATA AS 999)
3. Refused (PROGRAMMER NOTE: RECORD IN DATA AS 888)

*(ALL)
SMP5 And how many people in your household are aged 18 years or over?

1. One
2. Two or more (Specify) [ALLOWABLE RANGE 2-6]
3. (Don't know)
4. (Refused)

*(ALL)
TELDUM (COMPUTE TELEPHONE STATUS)
1. Mobile only (SMP3=2,3,4)
2. Landline only (SMP2=2,3,4)
3. Dual user (SMP2=1 or SMP3=1)

*CLOSE & RECONTACT

*(ALL)
CLOSE0: This brings us to the end of the survey questions. Just before we finish...

1. Continue

*(ALL)
REC1. The University of Sydney are planning to conduct another telephone survey, with similar questions to the ones you answered today, within the next 12 months. Would you be interested in being a potential participant in this future study?

(IF NECESSARY: Saying "yes" at this stage means you may be invited, but you will not be obliged to participate)

1. Yes (GO TO REC2)
2. No (GO TO END1a)

*(REC1=1 – agrees to recontact)
REC2. And can I confirm that you consent to the Social Research Centre passing your contact details (name and telephone phone number) and survey responses to Sydney University so that they will be able to contact you for the future study?

(IF NECESSARY: All of your information will be sent securely to the University of Sydney researchers and used for research purposes only. Survey responses would need to be passed on to the University of Sydney to enable re-contact based on views and experiences)

1. Yes (GO TO REC3name)
2. No (GO TO END1a)

*(REC2=1 – Agrees to recontact & to passing of details and responses)
REC3name Can you please tell me your name?

1. (Specify_____)

REC3telnum. Is this the phone number you'd like the researchers to contact you on? (If no: can you please tell me a preferred phone number?)

1. Yes
2. No – ENTER NEW TELNUM (INCLUDE AREA CODE)

RECaltnum As this survey will be conducted sometime over the next 12 months, do you have an alternative number you could give us (such as a mobile phone), just in case we can't reach you on this phone number?

1. Yes – ENTER ALTERNATE NUM (INCLUDE AREA CODE)
2. No

*(ALL)
END1a. And finally, is over-diagnosis something you would like to know more about?
1. Yes (GO TO END1B)
2. No (GO TO END2)
3. (Don't know) (GO TO END2)
4. (Refused) (GO TO END2)

*(IF End1a=1 – Yes would like to know more)
END1b. You can find more information on the not-for-profit website 'Preventing Over-diagnosis', at www.preventingoverdiagnosis.net)

1. Continue

*(ALL)
END2. Thank you for your involvement in this survey. All of the information you provided today will be kept secure and only used for research purposes.

Just in case you missed it my name is (…) and this survey was conducted on behalf of Bond and Sydney Universities. If you have any questions there is a phone number I can give you if you like…..

1. Wants contact details (GO TO END3)
2. Does not want contact details (GO TO CLOSE1)

*(END2=1 - WANTS CONTACT DETAILS)
END3.

Questions about who is conducting the survey and how your telephone number was obtained: The Social Research Centre, Phone: 1800 023 040

Questions concerning the manner in which this research is being conducted - Bond University Human Research Ethics Committee, c/o Bond University Office of Research Services. Bond University, Gold Coast, 4229 Phone: +61 7 5595 4194 Fax: +61 7 5595 1120 Email: buhrec@bond.edu.au

If you have any queries or would like to be informed about the summary of research findings, please contact: Jenny Doust (Principal Investigator) Centre for Research in Evidence-Based Practice, Faculty of Health Sciences and Medicine, Bond University, Gold Coast, Queensland, Australia, 4229, Phone: 07 5595 5518; Email: jdoust@bond.edu.au

Cancer Council National Helpline:131120

*(ALL)
CLOSE1. Thank you very much for your time.

*(ALL)
TS8_CLOSE

*TERMINATION SCRIPTS

TERM1. Thank you anyway but we need to speak with people who are aged 18 years and over.

TERM2. Thank you for your time.

ALLTERM

Code	Definition	Description	SUR category
1		Completed interview	Interview
2	INTRO2a=3	Household refusal	Refusal
3	INTRO2a=4	Language other than English	Screen out
4	INTRO2a=6	No one aged 18+ in household	Screen out
5	INTRO2b=3	Mobile answerer refusal	Refusal
6	INTRO2b=4	Language other than English	Screen out
7	INTRO2b=6	Under 18 years	Screen out
8	MOB2=3	Respondent refusal	Refusal
9	MOB_APPT=3	Respondent refusal	Refusal
10	INTRO3a=3	Respondent refusal	Refusal
11	INTRO3a=4	Language other than English	Screen out
12	INTRO3b=3	Respondent refusal	Refusal
13	All other	Midway termination	Refusals