Institutional (mis)trust in colorectal cancer screening: a qualitative study with Greek, Iranian, Anglo-Australian and Indigenous groups

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Abstract

Introduction Colorectal cancer (CRC) has the second highest cancer mortality rate in Australia. The Australian National Bowel Cancer Screening Program (NBCSP) aims to increase early detection of CRC by offering free Faecal Occult Blood Testing (FOBT), although uptake is low for culturally and linguistically diverse (CALD) groups.

Aim of paper To present data on trust and mistrust in the NBCSP by population groups with low uptake and thus to highlight areas in need of policy change.

Methods A qualitative study was undertaken in South Australia, involving interviews with 94 people from four CALD groups: Greek, Iranian, Anglo-Australian, and Indigenous peoples.

Results Our study highlights the complexities of institutional trust, which involves considerations of trust at interpersonal, local and national levels. In addition, trust and mistrust was found in more abstract systems such as the medical knowledge of doctors to diagnose or treat cancer or the scientific procedures in laboratories to test the FOBTs. The object of institutional (mis)trust differed between cultural groups – Anglo-Australian and Iranian groups indicated a high level of trust in the government, whereas Indigenous participants were much less trusting.

Conclusion The level and nature of trust in the screening process varied between the CALD groups. Addressing program misconceptions, clarifying the FOBT capabilities and involving medical services in collecting and transporting the samples may increase trust in the NBCSP. However, broader and more enduring mistrust in services and institutions may need to be dealt with in order to increase trust and participation.
Background and context

In 2010, there were 3982 deaths from colorectal cancer (CRC) in Australia, almost 11% of all deaths from cancer. In 2012, there were 15,840 diagnoses of CRC, second to prostate cancer. CRC presents an important opportunity for early diagnosis and the removal of curable lesions to reduce morbidity and mortality. In order to screen for CRC, the Australian National Bowel Cancer Screening Program (NBCSP) was launched, which is a government funded, population-based CRC screening program, based on an immunochemical faecal occult blood test (FOBT). At the time of the study (2008–2010), the NBCSP offered free FOBT to people turning 55 and 65 years of age in any given year, although this has subsequently been widened to include 60 and 70 year olds.

Medicare (a branch of the Australian Government) mails a pre-invitation letter alerting eligible participants to the arrival of a FOBT test kit, before sending the FOBT test kit and instructions on how to take a sample. Invitees are requested to take two separate samples of faeces and mail them to a central pathology service for analysis. Participants who return a positive result are advised by mail to visit their nominated General Practitioner (GP) for further follow-up.

Population-based screening programs such as the NBCSP target healthy individuals, likely to be asymptomatic at the time of the test. From a public health perspective, practitioners attempt to increase the proportion of the population undertaking CRC screening in order to maximise test efficiency and to identify as many cancers as possible. However, screening tests need to involve full information in easy to understand language which are free from coercion. Within this scenario, there are lots of ‘unknowns’ for the person thinking about undertaking the screening test: the person’s ‘actual’ risk of bowel cancer, scientific knowledge of how the screening test works, the likelihood the test will detect an increased risk of cancer, what would happen if the test is positive and if a cancer is detected, what the treatment would be and whether it will be curable. Due to this ‘imperfect knowledge’, a person’s decision to undertake the screening test needs to be based on trust.

This paper provides data from a qualitative study in South Australia on CRC screening within population groups known to have low participation rates, namely culturally and linguistically diverse (CALD) groups and Indigenous Australians. Previous qualitative papers by the authors from this study identified the main barriers and enablers to CRC screening and potential health service responses for CALD groups and Indigenous Australians. This paper focuses specifically on one of the key factors shaping participation in CRC screening within our study population – trust (or mistrust).

Conceptualisations of trust used in this paper

Trust as a concept has been of concern to social and behavioural scientists for many years, although its definition and conceptualisation remains debated. A fairly uncontentious issue is the idea that trust can be conceptualised as both interpersonal and institutional (also called abstract or systems-based) trust. Within this paper, we focus predominantly on the work of Luhmann and Giddens, although we recognise the important work of others.

A generally accepted definition of trust is ‘the mutual confidence that no party to an exchange will exploit the other’s vulnerability’, with a trustworthy person or institution having both good intentions and reasonable competence. It is argued that trust is a reflexive process whereby an individual uses available information or prior experience to make a decision whether to trust or mistrust. Institutional trust may include the trust a person has in groups of people (e.g. doctors), institutions (e.g. hospitals, government), or systems of knowledge (e.g. science). Indeed, Giddens argues for the centrality of institution trust, “Although
everyone is aware that the real repository of trust is in the abstract system, rather than the individuals who in specific contexts ‘represent’ it, access points carry a reminder that it is the flesh-and-blood people (who are potentially fallible) who are its operators” (p. 85). Of particular theoretical interest for this paper relates to the fact that the home-test FOBT does not include ‘flesh-and-blood people’, raising the centrality of investigating institutional trust in CRC screening.

Luhmann argues that trust is the glue that holds everything together in social life because it reduces the complexity of how individuals think about the world, enabling them to actively make decisions, such as whether or not to participate in the NBCSP.4,13 Within this paper we also use the term ‘mistrust’ as opposed to ‘distrust’. Mistrust is not simply the obverse of trust, rather mistrust occurs when an individual forfeits a course of action (i.e. chooses not to trust) while distrust is when trust would not even be considered an option.23

Trust is required when an individual lacks full knowledge about a given situation (e.g. partial knowledge of CRC screening),15 although some knowledge or prior experience is required in order to trust, since ‘Trust is not faith; we need not trust blindly’21 (p. 7). Trust however, is only required when the individual placing trust has something to lose in doing so (there is risk involved), rendering the individual vulnerable.24 If we trust, we recognise that things could go wrong, but based on our knowledge and prior experiences, we assume they will not, ‘If we trust, we believe the risk is small, and we are prepared to accept it’21 (p. 8). In relation to CRC screening, there may be differential levels of knowledge about CRC risk, detection, treatment and prognosis among potential participants, and these differences will impact their decision to (mis)trust the program. In addition there may be a ‘risk of knowing’ (existential certainty leading to the need for action) or indeed a ‘risk of not knowing’ (existential uncertainty leading to questioning) about having cancer. All of these pave a path for considerations of whether or not to undertake CRC screening, and the part that trust or mistrust may play in this decision.

Trust in CRC screening

There is a large literature on barriers and enablers of CRC screening. Individual barriers include lack of awareness of CRC risk and knowledge about screening and risk factors,25–27 lack of trust,5,28 fear of the test,29 embarrassment, negative and/or fatalist views about screening,5 and lack of perceived risk.30 Some barriers have been identified as more prevalent in CALD groups including lower levels of knowledge, less confidence in the capacity to complete the test (i.e. poor self-efficacy), literacy and language barriers and a lack of recommendation from the doctor.6,29,31

Trust is more likely to be at the heart of whether or not people participate in population-based screening programs because of the ‘imperfect information’ they possess, requiring trust via a ‘leap of faith’.8,32 Recent research has found that at times of increased risk and uncertainty, patients may forego trust and choice and simply submit their bodies to medical care.33 However, participation in the screening program differs in that participants will be asymptomatic, they will not have particular pain or symptoms which create a ‘need’ (irrespective of trust) to seek medical care.28 Therefore, in situations where risk may not be at the forefront of the decision to screen (or not), we argue that trust may become a central criterion for people on which to base their decision on whether or not to participate in the NBCSP.

Research examining the association between trust (and mistrust) and preventive screening has largely focused on trust in the medical professionals who provide care.28,34,35 This is of limited interest for examining the NBCSP, since the initial invitation is from the Australian government, not a healthcare professional. Nevertheless, it is argued that if people have high trust in their medical professional, they are more likely to undertake screening or other
preventive services, suggesting a level of ‘transferable trust’. However trust may not transfer across all preventive services. A cross-sectional study of trust in preventive services among low-income African-American women found higher trust in health-centre based procedures (e.g. Pap smear, clinical breast exam) but not in screening undertaken outside health centres (e.g. breast self-examination and FOBT). Therefore, trust is related to both inter-personal (e.g. doctor) and institutional (e.g. health centre) factors. Extrapolating the findings from this US study to the NBCSP may suggest low trust since NBCSP requires people to undertake the FOBT at home and there is no initial medical recommendation. The completion of the FOBT kit also requires a degree of unprompted initiation and autonomy following its arrival in the post. It must be completed with only written instructions and no person-to-person interaction or discussion with healthcare professionals. Therefore, researching the association between trust and the NBCSP may also involve investigating trust in the government implementing the program, capacity to accurately undertake the test process (self-efficacy), the adequacy of the test itself (response efficacy) and the laboratories testing the FOBT sample.

**Methods**

This was a qualitative study, based on interviews with people from different cultural groups in South Australia, conducted between July 2009 and Dec 2010. In-depth, focused interviews were conducted with four population sub-groups aged between 35 and 75 years: Greek, Iranian, Anglo-Australian and Indigenous Australian.

We identified these population groups, known to have low CRC screening rates, on the basis of adequate population size in South Australia, average population age, and average length of stay in Australia. We also sought ‘culturally different’ population groups in order to explore the potential for cultural explanations for barriers to CRC screening. Once we identified the target population groups, we then utilised the findings of our epidemiological analysis of NBCSP participation rates in South Australia in order to select a number of geographical areas with high and low rates of NBCSP participation. The geographical areas were also sampled to reflect different levels of socio-economic status (SES). People were interviewed in their own language, from both genders, a range of ages, and high and low SES areas. In total we interviewed 94 people: 24 Iranian, 20 Greek, 27 Anglo-Australian, and 23 Indigenous Australians. Selected details of these participants are provided in Table 1.

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NBCSP, National Bowel Cancer Screening Program.

1One Indigenous participant’s age unknown.
by an Indigenous person, through networks of Women’s Groups, Men’s Groups and Aboriginal Controlled Health Services. Whilst robust data do not exist on the age of onset of CRC for Indigenous peoples, meetings with the Aboriginal Health Council of South Australia and literature on the epidemiology of CRC in Indigenous populations suggest a lower age of onset. Therefore, we recruited Indigenous people from age 35 years, as opposed to 50 years with the other groups. Given the voluntary nature of our sampling, and the different methods used for different population groups, we may have obtained a relatively skewed sample, and therefore care needs to be taken when interpreting the relevance of our findings with those population groups.

Research in English-speaking countries involving non-English speaking communities is increasing and this is the case in Australia as researchers engage participants from multicultural and emerging communities. For the Greek and Iranian groups, we conducted interviews in participants’ native languages so that we did not only include English-speaking participants in our study. This was particularly important since language barriers were thought to be a considerable barrier to participation in CRC screening. The Iranian interviews were undertaken in Farsi by one of the authors (SJ) whose first language is Farsi. The Greek interviews were undertaken by SJ alongside a Greek translator who translated both the questions (into Greek) and the answers (into English). The same person transcribed the English portions of the text (questions and answers) for the 20 Greek interviews. The interviews with Anglo-Australian participants were also undertaken by SJ, and the interviews with Indigenous Australians were undertaken by an Indigenous researcher who had cultural knowledge of the people being interviewed.

There is a large literature on the quality of translation in research, although a ‘good’ translation is one that does its job while inscribing in the receiving language the most relevant equivalent meaning from an original. Further, translation is not a literal word-to-word process, rather, ‘It suffices to transmit the idea, the figure, the force’. To assess accuracy of the Greek translations, we employed an accredited translator to translate the Greek versions of the question and answers for four randomly selected interviews. We then compared the versions translated during the interviews and those by the independent translator and found very close accuracy, certainly adhering to the definition of the ‘good’ translation. The Iranian interviews were transcribed and translated into English by the bi-lingual researcher (SJ), and thus external validation of the transcriptions was not undertaken.

We undertook in-depth interviews and developed a set of areas of questioning from our previous systematic review of qualitative research on CRC screening but we also allowed a flexible use of the interview guide in order to allow new data to emerge (to be integrated into subsequent interviews) and to remain sensitive to cultural differences between groups. Interviews lasted for between 40 min to 1.5 h, although most interviews lasted approximately 1 h and were run at a venue convenient to the participants. Interviewers explored knowledge and experience of CRC and the screening tests, and barriers to and facilitators of bowel cancer screening uptake with a focus on the NBCSP and whether or not the participants had been invited and/or participated in the program. The screening pathway was explained and the test kit was shown to those participants who had not been invited into the screening program. All respondents were asked identical questions in the same sequence but the interviewer used participants responses to ask supplementary questions that clarified issues. Although the issue of trust was not specifically raised with participants, it clearly emerged as a key category from numerous unsolicited comments in all interviews.

Ethics committee approval was granted by the Social and Behavioural Research Ethics Committee at Flinders University, and the Aboriginal Health Research Ethics Committee.
Data analysis

All interviews were audio-recorded and transcribed by a professional transcriber (Anglo-Australian and Indigenous groups), interviewer (Iranian group) or the interpreter (Greek group). Following transcription and checking for accuracy, interview data were loaded into the qualitative software package, NVivo 8 (QSR International Pty Ltd., Version 8, 2008).

We undertook three consequential layers of analysis: open coding, focused coding and theoretical coding.41,42 Our open coding provided a description of the issues or themes arising from the data. This was undertaken throughout the data collection process, and our initial open coding informed the content of subsequent interviews. Each interview was transcribed directly (after relevant translation if required) after the interview so that the data analysis and collection could be compared. The process of open coding followed the following recognised stages: breaking down, examining, comparing, conceptualising and categorising data.42 When open coding, words or sections of text were coded using the actual words used by participants (nvivo codes), or by grouping similar words conceptually.

Focused coding was undertaken by grouping the open codes into larger categories, described as ‘more directed, selective and conceptual’ than the open coding, whereby it explains larger bodies of text by using significant or frequent codes.43 This process involved an iterative process of slotting each of the initial open codes into larger categories, based on their ‘semantic fit’ or the ways in which they seemed to be relating to a similar idea or issue. These initial focused codes were quite large and needed to be reduced over a number of analytical reading of the codes in order to permit sensible interpretation.

The theoretical coding facilitated an examination of the data from a theoretically informed perspective. This stage conceptualises possible ways that focused codes relate to each other in ways to explain a theory.43 the key purpose to, ‘...weave the fractured story back together again’.44 This stage was conducted by examining the focused codes with regards to theoretical and empirical literature on trust, highlighted data that both conformed to current theories of trust and also ‘new data’. Importantly data that fell outside the current social theory on trust were retained, thereby retaining and even venerating the interpretive epistemological basis of qualitative research. Frequent discussions within the research team occurred to validate emerging codes.

Results

We present data showing how institutional (mis)trust impacts on the decisions to participate in the NBCSP. In relation to ‘institutions’, we present data on the ways in which (mis)trust in medical science, the government, the medical system, local health systems and the postal system were all components in decisions about whether to participate in the NBCSP. Within this section, quotes are identified to represent the population group: PA = Persian-Australian, GA = Greek-Australian, IA = Indigenous-Australian, AA = Anglo-Australian.

We have published data on the barriers to participation in the NBCSP elsewhere5,6 but it is important to provide a general overview of these here because these underpinned the discussions on trust in the interviews. There was variable awareness of CRC and the NBCSP in general, which meant that risk and vulnerability were talked about differently between groups. The Greek and Indigenous participants tended to be more fatalistic, assuming cancer was not treatable, thereby questioning the point of performing the FOBT. This highlights the potential for ‘health education’ or ‘health literacy’ to increase the likelihood of participating in CRC screening. Anglo-Australians and Iranians were more generally aware of the CRC screening message. However, NBCSP participation rates are still relatively low in these groups, suggesting the need further understand the potential to increase trust and hence participation in CRC screening alongside responding to other barriers to the NBCSP.5,6,39
(Mis)trust in colorectal cancer screening in Australia, P R Ward et al.

Box 1 Examples of (mis)trust in the NBCSP

1. I thought how can a little smear like that and they can tell, get a result? It sort of felt a bit unbelievable to me (AA8)
2. that's the biggest thing for me I think, is it eective and is it worth doing it? (AA19)
3. if you are like me and you know that the test isn't 100%, I think why should I go through all this (GA3)
4. I'm not going to bother again, you know? And besides it's not accurate anyway. Look at the stu – what if they tell me the next lot is flawed? They screwed 100,000 tests, what's – oh can't be bothered (IA2)
5. I don't think the laboratory would provide the general public with satisfactory outcomes; they would not want to have to report on how many damaged or illegal specimens they receive. I don't think that's going to happen but I'm sure they do receive damaged specimens, I'm sure they do receive specimens that aren't going to provide good information (AA19)
6. I feel paranoid about that, me handling that myself and then putting it in the post and it'll go all haywire and then it's going to get contaminated and – honestly I do, that's my thoughts about it. (IA5)
7. I think if I could take it anonymously or inconspicuously to my health service where everybody else did it and it all went o in a big hit or whatever it probably wouldn't feel so bad as going down to the post office with your thing and posting it when you know that – everyone you're posting that to the thing, knows what's in there (IA5)
8. I think in some Aboriginal communities, especially small communities, you might think 'that health worker, I don't trust him' because I know that person, that person will go straight out there and tell everyone (IA7)
9. Doctors are funny people, I tell you. They are knowledgeable people but they're funny in the way that they talk to you and how they are seemingly willing to provide information or are unwilling to provide you with information because it's what they think is important and not necessarily about what you think is important (IA1)

Trust in the screening process was often determined by the interviewee's assessment of whether the laboratory testing of their FOBT would accurately identify colon abnormalities, sometimes known as the response efficacy, and whether the postal service would deliver the samples to a central laboratory safely and confidentially. The ability of faecal samples to detect potential colon abnormalities was questioned by a number of respondents from all cultural groups (see Box 1, Quote 1). Concerns included the potential for false negatives, sample contamination and the laboratory testing process. The risk of the FOBT producing an inaccurate result led some respondents to question the effort of participating (see Box 1, Quotes 2 and 3). The questioning of the efficacy of the entire screening program was stimulated by the suspension of the program for 6 months in 2010 due to test kits being unstable and ineffective in hot temperatures, which was particularly worrying in remote areas of Australia where refrigeration was not always possible. An Indigenous respondent had initially participated in the NBCSP but after the program suspension he became complacent and mistrusting of the system (see Box 1, Quote 4). However specific concerns relating to the suspension of the program were only reported by five Indigenous respondents and they existed in isolation to the majority who indicated their intention to participate in the NBCSP.

The NBCSP requires respondents to post faecal samples to a central pathology laboratory. Whilst most people did not question the 'science' behind the laboratory testing, one Anglo-Australian respondent questioned the transparency of the diagnostic process leading to considerations of mistrust in the NBCSP (see Box 1, Quote 5). However, approximately one quarter of Anglo-Australian and one-third of Indigenous respondents talked about the involvement of the postal service as a risk, although this was not a concern for the Greek or Iranian groups. The Anglo-Australians mainly identified concerns related to possible sample contamination, which were also shared by Indigenous participants (see Box 1, Quote 6). In addition, a number of Indigenous respondents also linked the use of the postal service in remote areas with a lack of privacy, which they felt would lead to
(Mis)trust in colorectal cancer screening in Australia, P R Ward et al.

embarrassment or ‘shame job’, which has previously been found as a key barrier to involvement in the NBCSP. For Indigenous participants, having ‘shame job’ as a result of distrust in the postal system was seen as a large risk to their sense of self and often outweighed the risk of not undertaking the NBCSP. Indeed, the following quote clearly articulates some of the concerns for Indigenous respondents about the NBCSP in the context of their social, cultural and environmental milieu which created added risks largely due to a lack of anonymity and confidentiality linked to the ‘shame’ of both cancer and handling faeces (see Box 1, Quote 7).

For all Indigenous respondents, this translated into a concern about their privacy, which is difficult in remote Indigenous communities, and for some, to a mistrust in some health workers (see Box 1, Quote 8). However, previous experiences of broken confidentiality did not translate into generalised or transferred mistrust – mistrust in one health worker (often, but not always, an Aboriginal Health Worker) did not necessarily transfer into mistrust in all health workers. For example, one Indigenous respondent referred to his community when he said, ‘They don’t trust all health workers. They’ll trust certain health workers’ (IA4), showing the reflexive and discerning nature of trust considerations.

Whilst trust in health workers (mainly Aboriginal Health Workers) was variable and based on previous interpersonal experience, there was broader and more generalised questioning, often leading to mistrust, of doctors who were mainly non-Indigenous. Although at present, doctors are not necessarily involved in the FOBT stage of the NBCSP, research indicates that doctor recommendation is an important influence on the decision to participate in screening.37-49 Our data show that work is required to re-build trust in Indigenous communities if doctor recommendation or referral is to be effective at increasing participation rates. For example, one Indigenous respondent questioned whether the doctors were providing information in the ‘best interest’ of Indigenous patients (see Box 1, Quote 9).

(Mis)trust in broader institutions of government

**Box 2 Examples of (mis)trust in broader institutions of government**

1. If they sent me the invitation, and they are asking me to do this, they of course are trying to do the best for you (GA5)
2. I’m proud to be Australian, I’m proud of the whole system we shouldn’t complain (AA15)
3. I believe that whatever the government tells us with their policies is 100 percent and I trust them immensely. Working for a lot of people like that, obviously sometimes things go wrong but basically I put my faith in the system completely, more into the public system than into what my private doctor tells me because the private doctor is money – profit orientated while the public health system – we do what we can with what we’ve got and we don’t over service you; that is what I feel (AA24)
4. because this sort of program is designed centrally, I do trust it much more than private sector. It is evidence based and structured. Everything is done systematically and we could trust it (PA18)
5. I see that one of things and responsibility of government is the ensure the welfare of all the citizens of the country, ok and that’s not only moral but a legal responsibility, now part of that is making sure people are in a healthy way so they promote healthy living . . . so from that sense I would trust it from that point of view (AA16)
6. there’s nothing 100 percent, but I would rather do it and if there’s any – if I have to do it again I’ll do it again, I’d have to do it again, so no it wouldn’t put me o thinking this might not be accurate, no. Maybe it’s false trust, I don’t know, but I do trust, on the whole, the system; I do (AA20)
7. Well Australians I think have a fairly well documented distrust of authority, perhaps more so than other cultures, so consequently for some I suppose to have something coming out from the government – anything that comes from the government is bad and therefore it may be better if it had come from a GP (AA7)
8. You know, everything goes down to that with our people, they don’t want to because we’ve had bad experience in the past and they still – in a lot of the older generation and it’s now gone on to the younger (IA5)
9. there’s mistrust because the hospital’s health services – and no matter black or white health services – they’re considered the biggest gossip locations. In any community, in black and white communities they’re considered the gossip centres of the communities, especially in the country areas (IA4)
10. I don’t know enough about it at this stage but I think the whole medical system doesn’t know enough about cancer yet (IA9)
A high level of institutional trust was evident by some respondents from all cultural groups, but in particular from the Anglo-Australian group. Justifications for institutional trust included perceived positive intentions, specifically, and caring for citizen health (i.e. doing their best for citizens), as one Greek respondent stated (see Box 2, Quote 1). The existence of a preventive screening program invoked a sense of patriotism, gratitude and appreciation of the medical system as outlined by one Anglo-Australian respondent (see Box 2, Quote 2). This person went on to outline how their ‘pride’ increased their ‘want’ to participate in Government-run services such as the NBCSP. In many ways, this echoes findings from the UK NBCSP which found that people talked about being ‘good citizens’ when participating.50

Two Anglo-Australian respondents explained that their high levels of trust in the government were based on its perceived impartiality and resistance to being influenced by pressures observed within private organisations (see Box 2, Quote 3). When doctors were perceived to be motivated by financial arrangements, mistrust was evident for behaviours that might satisfy these motivations (e.g. over-servicing, over-diagnosis). Indeed, there was a broad distinction made between trust in publicly and privately funded screening by some respondents, although mainly Anglo-Australians. Although the NBCSP is a free government preventive screening initiative, there are a number of other home-based CRC screening test kits that can be purchased from community pharmacies. Although trust in the kits provided about the NBCSP was reported, notwithstanding the 6 month program suspension, questions were raised about the quality of privately sourced kits. It is possible that such mistrust in private institutions may transfer to CRC screening kits produced by pharmaceutical companies not endorsed or connected to the government screening program.

Legitimacy as a source of trust extended to the government and a belief that well researched and correct processes would be adhered to, as outlined by an Iranian respondent (see Box 2, Quote 4). Legitimacy also was founded on the knowledge that the government is bound to a legislative responsibility by care for its citizens (see Box 2, Quote 5). In this way, trust in the NBCSP is bound up with broader trust in legislative mechanisms of government. Sztopmka argues for a link between legitimacy and institutional trust, stating that the perceived quality and functionality of the system fosters trust,18 with Luhmann4 going further to argue that the institutional practices become ‘established as professionally attested truth’ (p. 57). For some participants, predominantly Anglo-Australian and Iranian, trust in government was so ‘unquestioning’ that it may be regarded as ‘blind trust’ or ‘generalised trust’.33 This is illustrated in Quote 6 (Box 2). Importantly this ‘default’ or blind trust allowed the NBCSP and government errors that had occurred during Phase 2 to be overlooked. AA20 suggested that even if the data were not accurate (they recognize nothing is 100% accurate), they would ‘have to’ do the test again due to their fulsome trust in the government.

Across all cultural groups, there were also a number of comments and examples of institutional mistrust, which were expressed in different ways and towards different targets. The Anglo-Australian respondents had a number of mistrust issues with Government but also more broadly with authority, whereas both the Greek and Iranian respondents talked much less about institutional mistrust. For example, getting a letter ‘out of the blue’ from the Government led an Anglo-Australian respondent to question their ‘ulterior motive’, although did not go on to articulate what they thought this motive might be. Another Anglo-Australian suggested a generalised mistrust of authority in Australian culture (see Box 2, Quote 7). This and other examples almost speak to a sense of conspiracy theory, which has been argued to be a generalized manifestation of distrust in Western culture.52 However while they are important to mention, these responses stood apart from the majority of Greek and Iranian respondents.
who expressed a general trust in government, with Iranian respondents going even further to indicate a perceived sense of ‘institutional obligation’, or a feeling that they almost had no choice to participate because the government had advised them to.

Within the Indigenous Australians, there was almost universal mistrust in Government, which was linked by one interviewee to historical experience of maltreatment (see Box 2, Quote 8). For a number of respondents, institutional trust was so low that it shaped the decision to mistrust and thus not to participate in the NBCSP. Mistrust in institutional confidentiality was reported by over one-third of Indigenous respondents, the Quote 9 (Box 2) being representative. This mistrust was compounded by the mistrust in some health workers outlined earlier. Two respondents expressed their mistrust in the medical profession and the scientific system in relation to having enough knowledge about cancer, thereby reducing the trust in the NBCSP (see Box 2, Quote 10).

Discussion and conclusion

This paper demonstrates the central role of trust in considering whether or not to participate in CRC screening. The decision to trust is complex and influenced by various factors such as knowledge of the NBCSP and cancer prognosis, perceived risk of cancer, (mis)trust in the screening process and broader institutions of government. We argue that the findings from our paper are critically important to identify and hopefully overcome barriers to the NBCSP, particularly for CALD groups.

This study highlighted that the nature and extent of trust in the screening process varied between cultural groups, with mistrust being most prevalent for Indigenous Australians. Other studies have reported mistrust by some minority and cultural groups including African American, attributing this mistrust to historical and discriminatory practices in healthcare.53,54 Our data mirror this and relate to findings from another study in Australia,25 with all Indigenous participants talking about historical mistreatment of Indigenous people and feelings of perceived discrimination, all of which affected their trust in the Government run NBCSP.

Despite the NBCSP being a government-screening program, broader institutional trust was discussed less frequently and used interchangeably with trust in the screening process, highlighting a theoretical difficulty in distanc- ing the two concepts. The object of institutional (mis)trust differed between cultural groups, for example the Anglo-Australian and Iranian groups indicated a high level of trust in the government. Recent quantitative research in Australia highlighted lower trust in Government by people with lower socio-economic status,55 although our research provides evidence on the nature and reasons for trust and distrust in government, and its effect on decisions to participate in the NBCSP.

Our study highlights the complexities of institutional trust, which involves considerations of trust at interpersonal (e.g. local healthcare worker or GP), local (e.g. postal system, health service) and national (e.g. government) levels in addition to more abstract systems such as the medical knowledge of doctors to diagnose or treat cancer or the scientific procedures in laboratories to assess the faeces in FOBTs. Govier21 encapsulates the complexities of studying either institutional or interpersonal trust when she talked about ‘trust in objects’. ‘When we assume that an object will serve its function, we are, in effect, assuming that the various people who manufactured and marketed it did their jobs honestly and properly. If these objects do not perform, someone somewhere made a mistake’ (p. 16). In this way, for people to trust the NBCSP, the FOBT kit (as the object) needs to be inscribed with trustworthy individuals and institutions, including the government who funded it, the scientists who developed and manufactured the FOBT, the individual in terms of knowing how to ‘do’ the test correctly, the postal service who deliver it to laboratories who then test it, and to the doctors who make decisions about cancer risk and ultimately cancer incidence on the basis of it. Our paper
provides data whereby participants question their trust in each of these elements, all of which require policy responses to rectify, either through changed systems or culturally appropriate education. Our analysis of institutional trust in the NBCSP (and the related social systems) may draw parallels with other public health or social programs which do not rely on inter-personal relationships with health care professionals. Increasing participation in such ‘faceless’ programs is obviously not as straightforward as developing inter-personal relationships and rapport with the personnel delivering the program. We argue that the complex web of (mis)trust in social systems will, in the absence of inter-personal relationships, impact participation either positively or negatively.

In our study, the map of trust was difficult to navigate because of the variety of historical, social and cultural forces at play, and thus it was difficult to use this to consistently ‘predict’ participation. For example, a number of Greek participants had fatalistic views about cancer, which one may presume would mean they did not or would not participate in CRC screening. However, a number also had high levels of trust in government and expressed a perceived obligation to participate. The resultant perceived obligation to participate in a screening process that might identify a perceived ‘fatal’ illness raises some important ethical issues around perceived coercion worthy of further investigation. From our data, we do not know which one of these factors became the most important factor in making the final decision about participation because that was not a part of our research design, although future research may also explore this in more depth. Nevertheless, our paper shows that real-world emic accounts and practices of trust are ‘messier’ and more inconsistent than we might like, highlighting the importance of an inductive and inclusive methodology.

Findings suggest that the level of perceived risk has a substantial influence in the decision to trust (or mistrust). Addressing program misconceptions, clarifying the FOBT capabilities and involving medical services in collecting and transporting the samples may potentially increase trust in the NBCSP. However, broader and more enduring mistrust in services and institutions may need to be addressed in order to increase trust and participation, particularly for Indigenous populations.

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Supporting Information
Additional Supporting Information may be found in the online version of this article:
Appendix S1. Interview Schedule.

References
40 Guest G, Bunce A et al. How many interviews are enough?: an experiment with data saturation and variability. Field Methods, 2006; 18: 59–82.


