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The view from two sides: a qualitative study of community and medical perspectives on screening for colorectal cancer using FOBT

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Abstract

Background. Population-wide screening for people at average risk of colorectal cancer (CRC) by faecal occult blood test (FOBT) is under consideration in Australia.

Methods. Qualitative methods were used to examine the views of community members who did ($n = 18$) or did not ($n = 12$) participate in a pilot program of FOBT screening. In addition, views were obtained from general practitioners (GPs) and specialist gastroenterologists directly involved in the implementation of the program. Two focus group sessions were conducted with screening participants and interviews were conducted with non-participants, GPs and gastroenterologists.

Results. The findings suggest that CRC screening by FOBT distributed to households by mail was well accepted by the community and by the medical practitioners involved in its implementation. The trial had little negative effect on general practice. Both medical practitioners and consumers raised concerns about the efficacy of FOBT screening. Medical practitioners were also concerned about the potential burden mass screening could place on the public (government-funded) health care sector.

Conclusions. It would seem that CRC screening using FOBT will not enjoy unqualified support from the community or from medical practitioners involved in the continuum of screening. Information about the objectives of screening programs, in general, and the efficacy of FOBT screening in particular, needs to be provided to the community to ensure informed individual choice.

Introduction

Colorectal cancer (CRC) screening for average risk Australians has been recommended, based on the results of international population based randomised trials^[1]. Many countries have provisions for colorectal screening or recommendations for screening their average-risk populations; however, the model currently being trialled in Australia represents a planned approach to population screening that most closely approximates the one underway in the UK^[2]. Pilot CRC screening programs offering a faecal occult blood test (FOBT) biennially, followed by colonoscopy if positive results are obtained, are currently underway in Australia^[1 and 2]. Kits are being sent directly to eligible participants by mail from a central registry. General Practitioner (GP) participation is integral to the program as participants are asked to nominate a preferred GP to whom results can be sent. Pilot participants are also referred to their GP to discuss symptoms, family history or a positive FOBT result or for any additional information they require about the test^[3]. Gastroenterologists are also integral to this process as they provide all follow-up of positive results with colonoscopy. Both GPs and gastroenterologists have been involved in the planning phase of the Australian pilots.

CRC is the most commonly diagnosed cancer in Australia and the second most common cause of cancer death. Its incidence has increased by approximately 0.4% in men and 0.1% in women annually between 1990 and 2000, and increases significantly with age^[4]. Despite this, there is a low acceptance of screening for CRC amongst the general population and there also appears to be a low acceptance of the need to screen average risk people amongst GPs^[5].

As with any screening program, the successful reduction in mortality from CRC is dependent upon high rates of participation by both the general population and medical practitioners. Most studies investigating early detection of CRC outside randomised trials have been unable to achieve participation rates above 70%^[6 and 7]. The reasons for non-participation in FOBT screening are well documented^[6 and 8]. The need for dietary restrictions, handling of the stool, embarrassment, uncertainty about correct stool collection and preference for other tests have all been found to reduce participation^[9, 10, 11, 12 and 13]. Perception of individual risk^[14, 15, 16, 17 and 18], lack of understanding of the reasons for screening without symptoms^[15, 17, 19, 20, 21 and 22], fear of further tests or surgery and fear of the results have also been found to increase non-participation^[16]. Clinician barriers have also been identified^[8]. In the Australian context, these include: inconsistent guidelines and limited knowledge of guidelines^[23]; scepticism about the benefits of screening^[23 and 24] and the existence of a gender bias in relation to screening which favours men over women^[23].

To date, there is little in-depth data available on the experience of FOBT screening in Australia. The aim of this pilot programme was to test the acceptability and feasibility of FOBT screening and to provide an in-depth understanding of the screening process from the perspectives of consumers and medical practitioners, both GPs and specialist gastroenterologists.

Methods

This FOBT screening project was conducted in a rural Queensland community with a population of approximately 4200 residents aged 50 years or older. The area is situated approximately 100 km from a large regional centre with the necessary facilities to provide colonoscopy follow-up. Four general practices provide medical services to the residents and all practices agreed to participate in the study. Each practice provided a contact list of all patients aged 50–74 years. These patients were mailed a FOBT kit free of charge, with a letter from the GP explaining why CRC screening is important and inviting their participation.

Two different kits were used and assigned by GP practice. The Hemoccult-II® kit is a guaiac FOBT and requires restrictions in diet and medications commencing 3 days before providing the first sample of stool and continuing until the third consecutive stool sample has been collected. Stool samples must be collected before contact with water occurs. The sample is applied to cardboard slides. The completed kit cannot be sent by mail and requires the patient to deliver their test samples to the local hospital for transport to a pathology laboratory. The second kit, !nform®, is an immunochemical FOBT and does not require diet restrictions. Toilet water is collected by brush from around two consecutive bowel movements and then applied to a cardboard slide. Once completed, the kit is posted to the laboratory for analysis.

All participants undertaking an FOBT were mailed their test results, and a copy was also sent to their GP. Anyone with a positive FOBT result was encouraged to consult a GP for follow-up recommendations. A free Information Line was also established to answer queries about the trial. All colonoscopies were provided by accredited gastroenterologists and were free of charge to study participants.

Focus groups

Focus groups were used to obtain data from those who had completed an FOBT. This approach was expected to provide a stimulating environment that would maximise the data collected by allowing participants to respond to each other and to share their experiences and stories with the group as well as with the interviewer. Respondents were selected to ensure maximum variation in terms of the type of FOBT kit used, gender and age groups ^[25]. Potential participants were approached using a letter from their GP requesting them to contact the researchers if they were willing to participate.

One hundred and thirty-nine people known to have completed an FOBT were identified from a database of all age-eligible patients and invited to participate in focus group discussions. Eighteen respondents (nine men and nine women) agreed to participate in one of two focus groups. The mean age of the focus group participants was 58 years (range 52–70). All but one focus group participant was living with a partner. Three men had received both kits (two of whom used the !nform® kit, one used both kits), nine participants had used the Hemoccult-II kit, and the remaining six participants had used the !nform® kit. Eleven people (four men and seven women) participated in the first group, of these two men and one woman had previously used a FOBT, one man and one woman had previously had a colonoscopy and one woman had had a barium enema. Of the seven (four men and three women) people participating in the second group, one man and one woman had previously participated in FOBT screening and one woman had had a colonoscopy. Although there were no differences in terms of themes arising from the two groups, the men who participated were highly committed to CRC screening and perceived this as an issue of gender equity as, in Australia, there are presently no population-based screening programs aimed specifically at men.

A semi-structured interview guide was developed for the focus groups. This covered: prior experience with CRC screening and other screening; reaction to the invitation to participate in the FOBT screening; beliefs about screening; personal susceptibility to CRC and other cancers; and further ideas to improve future screening programs. A trained facilitator and an observer led the focus group discussions, which lasted about 90 min. At the end of each, group participants were invited to ask any questions or express any concerns they may have had about FOBT screening.

Interview participants

One hundred and forty-four residents who were eligible for screening but had not completed an FOBT were also selected from the patient database and were sent a letter inviting them to participate in an interview. Given the potential sensitivity of some of the issues associated with non-participation, it was decided to use telephone interviewing. This approach has been used successfully with older people who had declined flexible sigmoidoscopy^[19]. It allowed people to discuss potentially sensitive issues and decision-making while maintaining some level of anonymity. In-depth telephone interviews were conducted with 12 non-participants (five men and seven women), none of whom had any previous experience with screening for CRC. These lasted between 20 and 30 min. An interview guide covered topics similar to those asked in the focus groups, including: previous experiences with screening; beliefs about personal susceptibility to CRC and reasons for non-participation. This provided a core of common data across groups and interviews, but also allowed sufficient flexibility for individuals to discuss issues and experiences of importance to them^[25].

Doctors

After completion of the trial, at least one GP within each practice was contacted and interviewed to obtain a doctor's perspective on the trial and any issues regarding sustainability of population-based CRC screening using FOBT. In addition, three gastroenterologists, that is, all the gastroenterologists with practices in the regional centre, were interviewed about the impact of the trial on their practices and to obtain their views on the final stage of screening from the perspective of their specialty.

All focus groups and in-depth interviews were tape recorded, with participant consent, and later transcribed verbatim. The Queensland University of Technology Human Research Ethics Committee approved the research.

Data analysis

Following data collection and transcription, the research team developed coding categories. Themes were developed and the analysis proceeded using an iterative inductive process involving repeated readings of the transcripts^[26]. Focus group transcripts were firstly analysed by group and then analysed across groups to ensure consistency in meaning. Individual coding of all transcripts was cross-checked by multiple readers^[27]. A primary reader (MJ) completed the first phase of the analysis and produced summary themes for the focus groups and interviews. These were reviewed by a second reader (AC) against the original transcripts. Questions about coding and interpretation were resolved through discussion.

Results

Community perceptions

A range of factors including prior experience, the nature of the test itself, as well as individual perceptions of risk mediated participation in CRC screening using FOBT. Table 1 and Table 2 provide a summary of the key themes emerging from the interviews and focus groups.

Table 1

Consumer views on the acceptability and feasibility of a planned approach to screening for colorectal cancer using FOBT: themes emerging from interviews^a

Key themes participants	Key themes nonparticipants
<p><i>Distribution of the FOBT kit by mail</i></p> <p>"I never used the Rotary one, because I couldn't be bothered. This one came in the mail and was so private" (female)</p>	<p><i>Distribution of the FOBT kit by mail</i></p> <p>"I was alarmed when I got the letter, I was frightened and just threw it away" (female)</p> <p>"if I knew that I had some cancer . . . all I'd do is worry all the time" (male)</p>
<p><i>GP involvement</i></p> <p>"It has much more value if it comes from your doctor" (female)</p>	<p><i>Kit characteristics</i></p> <p>Following the instructions</p> <p>"I thought, I don't know how to do this, it's a lot of mucking around was my initial reaction" (male)</p>
<p><i>Perceptions of risk and risk factors</i></p> <p>Community awareness of cancer</p> <p>"Farming areas like our area with the sprays and chemicals . . . it's accepted that the area is high in cancer . . . and these areas are pure cancer zones" (male)</p>	<p>Completing the test</p> <p>"we simply were too busy to settle down and read through the instructions and complete the FOBT" (female)</p> <p>"I just kept putting it off and putting it off and then when I eventually thought yep, I'll do it, I looked at the back of it and it was out of date" (female)</p>
<p>Age: link between age and ill health</p> <p>" . . . we should do it (use FOBT) because we are getting older so we should look after ourselves" (female)</p>	<p>Diet restrictions</p> <p>"the only thing was the food you knew? I thought we have to sort of not eat this and that for a couple of days that was the only thing" (male)</p>
<p>Gender: equity</p> <p>" . . . not always everything for the women" (male)</p>	<p><i>Perceptions of risk and risk factors</i></p> <p>Hereditary and lifestyle factors</p> <p>"it's not hereditary in my family so I doubt very much whether I would have it" (female)</p>
<p><i>Concerns about FOBT</i></p> <p>"How often should it (FOBT) be done? Yearly, every two years?" (female)</p> <p>"I take it that the sign of bowel cancer is bleeding . . . But that can sometimes be too hard can't it" (male)</p> <p>"If you're getting this (the FOBT) all the time and it showed clear you don't need a colonoscopy?" (male)</p>	<p>Symptoms</p> <p>"I don't suffer from any blood or anything like that . . . I haven't got any symptoms at the moment (so, I don't think I would have it)" (female)</p> <p>Competing risks</p> <p>"If I'm gonna die of anything I'm gonna die of lung cancer and that's my own stupid fault" (female)</p> <p>Age</p> <p>"I am 67 so my life could be over in another two years or one year" (male)</p>

^a Note: quotes have been selected to reflect common responses.

Table 2. The medical perspective

Key themes	Illustrations (note: quotes have been selected to reflect common responses)
Workloads	<p>“my practice is very busy so I haven’t noticed the difference, but a lot of my patients actually come about other things but they also come about screening” (GP)</p> <p>“Well, it was fairly painless for me” (GP)</p> <p>“No, it hasn’t had any serious impact on the practice, ... I think it enhances my practice” (Gastro in private practice)</p>
GP involvement in screening	<p>“I think the most significant problem I encountered was inappropriate referrals for colonoscopy ... You can’t just have someone go and do an FOBT and then turn up for a colonoscopy. You’re going to have to have filters in the system” (Gastro in private practice)</p>
Follow-up of FOBT positive patients	<p>“The only real problem is the follow-up, that will impact on our practice if we personally have to follow them up ...” (GP)</p>
Perceived benefits	<p>“well we’ve picked up two of my patients with cancer—so there was a real benefit” (GP)</p> <p>“we’re actually broadening the therapeutic net by doing this because there are a few that have come out of the woodwork that we haven’t seen for a long while” (GP)</p>
<i>Specialist follow-up</i>	
Overburdening the public system	<p>“you may increase the number of colonoscopies by 20 to 30% if you start screening, there may be a bit of a jump to start with, but it’ll be absorbed. The public system won’t cope though ... it is just not designed to cope with high turnover routine work (Private Gastro)</p> <p>“More than 60% of the population don’t have health insurance and all those would come into this system (the public system) which would have major implications (in terms of the systems capacity to cope) ... the private sector is never going to have any problems it’s the public sector that will have problems” (GP)</p>
Informed choice	<p>“I think it’s very important that people are given a choice. I can’t imagine that I’d be able to convince a gastroenterologist or an endoscopy nurse or anyone with a tertiary degree or anyone who reads a book that FOB testing would provide them with a high level of protection against bowel cancer” (Gastro in private practice)</p>

Prior experience with FOBT

Service clubs such as Rotary and Lions have distributed FOBT kits throughout Australia [28]. Almost 40% of focus group participants had used an FOBT before as part of a local Rotary Club initiative, and approximately 20% had previously had a colonoscopy. Previous experience was an important determinant of willingness to participate in this trial with those who had participated in the Rotary initiatives expressing both a willingness to continue to participate and a belief that this was a ‘good thing.’

Methods of service delivery

Distribution of the FOBT by mail

Rather than using more common approaches to distributing kits (i.e., through pharmacies or community-testing programs), kits were sent from the local GPs using the mail service. With few exceptions, participants commented favourably on this approach. The majority thought ‘it was a good idea’ and ‘an interesting’ approach. Several participants suggested that if they received an FOBT kit in the mail every year, it could become habitual behaviour. This was compared to the mailed reminder cards used by the Australia-wide mammography screening program. One woman said: ‘You get the reminder [for the mammography] and just get your appointment straight away, without even thinking.’

GP involvement

Some participants were especially motivated to complete the FOBT, since the kit was sent by the GP. However, one woman, who decided not to participate, found that simply receiving the kit and letter by mail raised feelings of fear in her sufficient to prevent her participation.

For some, privacy was an important issue. The nature of the kit itself and embarrassment about it had precluded some people from obtaining it ‘over the counter,’ the distribution approach used by the service clubs.

Kit characteristics

Following the instructions

Depending on the kit, the instructions were between two and four pages long. Despite their length, participants generally found the instructions simple and easy to understand and follow. No one from either of the focus groups had needed to contact the doctor for additional help or explanation on the correct completion of the FOBT, but about 30% had discussed the instructions with their partner. The project information line did, however, receive several calls from participants concerning the pragmatics of taking the test. Three non-participants mentioned difficulties with the instructions as a possible reason for not completing the FOBT.

Completing the test

A commonly identified barrier to use of FOBT is that the test is perceived to be unpleasant or even disgusting. This was not evident amongst participants. In contrast, the focus group situation encouraged the exchange of stories and comments about innovative approaches to collecting the stool samples. The use of ice cream containers, cardboard and the like were described in detail. Although the majority of participants completed the test straight away, delay was common. It was also common for non-participants to state that the FOBT was a good idea and that they would have done it if they could—but they forgot or did not find time. Non-participants commonly stated that ‘I regret now, that I did not do it,’ or ‘I was just a bit lazy I suppose,’ ‘I just lost my kit, so I did not do it.’

Diet restrictions

Although one test imposed no dietary restrictions before completion, the other did. Participants using the kit requiring dietary restrictions did not believe that having to make informed food selections for up to 7 days affected completion. Because it was impossible to avoid overlaps between practice databases, some participants received more than one kit in the mail. When given the choice, participants generally chose to use the test without diet restrictions. However, one man used both kits, ‘to see if the two tests would give the same result.’ The diet and medication restrictions were, however, commonly given as reasons for non-compliance. The need to restrict their diet was a sufficient barrier to preclude participation.

Community knowledge and attitudes

The most common reason for participation was ‘peace of mind.’ Awareness of cancer was high in this community. Participants, non-participants and doctors all mentioned a widely held community perception of high cancer incidence in the area. It was not surprising then that the majority of respondents knew of someone, within their family or amongst their friends, who had experienced some form of cancer. This type of experience worked in two ways, it either motivated participation ‘I think it is a good idea (FOBT) because my wife died with cancer of the bowel and the doctor didn't pick it up’ or created such fear that it precluded participation. As one nonparticipant said ‘... my father had lung cancer and my mother-in-law had cancer as well ... I just don't want to know.’ Gender equity was also a reason commonly given for male participation, as FOBT was seen as a screening test for both genders.

Perceptions of risk

Amongst non-participants, two factors stood out: the perception of individual risk and the fear of a positive diagnosis. Compared to participants, some of the non-participants believed their risk of CRC was low or average.

Heredity and life style factors were important components of perceptions of individual risk.

Having no family history of CRC and being fit and healthy both contributed to the perception of being at low risk. As one couple said '... we are both fairly fit for our age and fairly healthy and have no problems.'

When judging their level of risk, it was common for non-participants to refer to the fact that they did not have specific symptoms and therefore were not at risk.

Competing risks

The belief of being at greater risk of developing other forms of cancer offset concerns about CRC for some and contributed to non-participation. For several long-term smokers, concern about CRC was peripheral. Age was also used in two ways: firstly, it was commonly provided as a reason for participating because older people needed to look after their health. It was also given as a reason for non-participation, that is, the person was too old and too close to death to search for illness.

Questioning the value of screening

Towards the end of each session, participants were encouraged to ask questions about FOBT screening and CRC. Both participants and non-participants questioned the value of FOBT screening. Some had experienced rapidly growing cancers in friends or family and based their scepticism of screening on this experience '... (every) six months you go see your doctor and he said you got no cancer, next six month you see your doctor he says you are going to die' Participants asked about the value of doing an FOBT and expressed concerns about the timing of tests; some participants asked about the appropriate interval between tests. Several participants raised concerns about the value of a negative FOBT result and the level of certainty the FOBT provides and asked whether the sigmoidoscopy or colonoscopy might be the more appropriate test, as they provide a higher level of certainty.

Doctors' perceptions

GP involvement in screening

GPs placed considerable importance on screening programs being medically driven and organised to ensure appropriate referral to screening and correct diagnostic follow-up. This was a view that was also shared by the specialists. The gastroenterologists saw the role of the GP as that of "gatekeeper" charged with ensuring the eligibility of those accessing specialist services. The approach used in this pilot program was clearly preferred by the GPs over the centrally organised system used in Australia for mammography screening, as it facilitated patient management. GPs found that the FOBT trial increased community awareness of CRC, educated patients about CRC and instigated discussions about personal risk and family history of CRC. One positive outcome of the pilot was that GP involvement facilitated patient follow-up by re-establishing contact with patients who had not been seen for considerable lengths of time and by the identification of patients with cancer.

Workloads

The local GPs actively supported the trial. The greatest impact on their time occurred at the commencement of the trial with the necessity to compile a comprehensive database of eligible patients for the mail-out of FOBT kits. After the kits were distributed, queries regarding completion of the test and personal eligibility were commonly addressed by practice

receptionists and only occasionally by the doctors. The doctors found that queries concerning the FOBT kit, (e.g., whether the patient should complete the kit and clarifications about diet restrictions) commonly occurred within a consultation for a different health topic.

Overall, the GPs reported that the workload generated by the screening trial was low and easily manageable. One GP estimated that a total of 15–20 additional staff hours were generated over the 8-month period of the trial. An area of concern, however, was the follow-up of FOBT-positive patients who did not make contact with the GP to discuss further options.

Specialist follow-up

The three gastroenterologists involved in the trial found the impact of the trial on their practices was reasonable and manageable. The main concerns expressed related to the impact a population-based screening program would have on the public health system. Australia has a two-tiered system: a public system that is funded by the government and is provided at no cost to the patient and a private system that is primarily for those with private health insurance and the capacity to pay for services provided. The gastroenterologists believed that if population-wide screening was introduced in Australia, the private system would be able to increase the number of colonoscopies it could provide. They did, however, express doubts about the capacity of the public health care system to cope.

The specialists also stressed the importance of colonoscopies being provided only by highly qualified and trained personnel and highlighted the potential morbidity and mortality associated with colonoscopy if it was performed by insufficiently trained personnel. 'I think quality management and supervision is really critical and demands surveillance of what goes on in procedural units.'

Informed choice

Both the GPs and gastroenterologists stressed the importance of informing potential participants about the issues associated with CRC screening to ensure that potential participants could make an informed choice about screening. There was also some concern expressed about the decision to proceed with FOBT screening. As one gastroenterologist said, "My opinion is we should have done colonoscopies now (rather than FOBT)."

Discussion

It is possible that a population-based FOBT screening program for CRC will be introduced into Australia within the next few years. This trial was initiated to determine the acceptability or otherwise of this approach to screening in one regional area of Australia. Qualitative methods, in this context, can provide a more in-depth understanding of the issues, beliefs, assumptions and misperceptions associated with the implementation of, and participation in, a new screening program than do quantitative approaches. The issues identified can then be addressed through education and service modifications.

The findings suggest that the approach to screening used here was well accepted both by the community and by medical practitioners. Participants found the distribution of the kits acceptable^[29], the FOBT reasonably easy to complete, and doctors reported few contacts that were solely devoted to screening issues. As has been found previously, the use of a letter from the person's GP was well received and enhanced compliance [30]. In common with other studies, when given a choice, participants preferred the immunochemical kit with fewer and easier collections and no dietary restrictions^[31]. Compliance was also higher amongst those receiving an immunochemical kit (Hughes et al., unpublished results). Unlike other studies^[32], however, there was little evidence amongst participants of an aversion to things 'rectal or faecal.'

Participants appreciated the convenience and privacy of receiving the FOBT by mail. In an earlier Australian study, inconvenience was one of the most commonly cited reasons for non-participation in FOBT screening^[9]. The distribution by mail was also a very effective strategy for reaching large numbers of eligible households. Although some participants received more than one test, most participants did not perceive this as a disadvantage.

Previous research of GP involvement in mass screening for CRC using FOBT has found that the motivation of GPs is integral to patient compliance^[33]. The medical practitioners involved in this trial were supportive of the idea of screening for CRC, particularly as screening was provided through their practices. They favoured a program delivered through existing medical practices because it has the advantage of offering continuity of care to patients who may have a cancer detected by the screening program and of streamlining the referral process for specialist colonoscopy services. However, the capacity of already stretched public (i.e., government-funded) services to cope with increased demand for specialist gastroenterological services remains a concern.

Maximising the participation rates of eligible people is an important aspect of any screening program and this was no exception. It was evident from the focus group discussions and interviews that people were drawing upon a broad range of experiential and knowledge-based factors to assess their level of risk and their willingness to participate^[34]. Just as people draw upon a range of factors such as lifestyle, weight and heredity to identify those at risk of diseases such as cardiovascular disease^[35], participants in this study held beliefs about CRC and the types of people who will get it. Factors such as heredity and lifestyle were commonly mentioned, as both participants and non-participants appeared well informed about risk factors for CRC compared to earlier studies^[9]. However, in this community, there was also a heightened awareness of cancer risk imposed by environmental factors, especially chemicals used within the farming industry, and a commonly held belief was that the incidence of a range of cancers was higher here than elsewhere in Australia.

One clear distinction between participants and non-participants in this study was the appreciation of screening in an asymptomatic person. Participation was motivated by the wish to stay healthy, while non-participants described their current personal well-being and low perceived susceptibility to developing CRC as reasons for not utilising the FOBT. Similar to the findings of McCaffery et al.^[19], the majority of non-participants considered themselves to be healthy and argued that screening was therefore unnecessary (i.e., screening is only for the sick or unhealthy). This reflects a limited understanding of the intention of screening to detect illness at an asymptomatic stage and the potential benefits of early detection^[17 and 36].

Several participants had prior experience with FOBT, and this increased their willingness to take the FOBT again^[18]. Past screening participation predicts the uptake of screening for melanoma^[37], mammography screening^[38] and screening for CRC by sigmoidoscopy^[39]. However, there was also a level of uncertainty attached to screening for CRC using FOBT, expressed by both community members and medical professionals particularly in relation to the efficacy of FOBT. Doctors also stressed the importance of informed choice and of individual preference, maintaining a distinction between population-based screening and clinical practice^[40]. In line with other studies^[8], the gastroenterologists showed a preference for the use of colonoscopy over FOBT as the screening method of choice.

To ensure informed consent, information about the efficacy of FOBT screening should be provided to community members^[41]. As the Australian National Health and Medical Research Council (NHMRC)^[42] recommends, ‘... it must be pointed out to these individuals that it (the

FOBT) is not a diagnostic test, but a selection process for those who should undergo colonoscopy' (p. 27). However, new aids used in screening programs to inform participants need to be tested in randomised controlled trials since they may not always have the desired effect of better informing screening participants^[43].

Several limitations need to be born in mind when considering the findings reported here, Firstly, some consideration needs to be given to the insights provided by participants and non-participants and the possible constraints they may have been under when interviewed. Both those who underwent FOBT screening and those who declined were approached by their GP and asked to participate in this study. The researchers were clearly aligned with the screening program and socially desirable responses can often be a problem in this context^[19]. Efforts were made to reassure all people willing to be interviewed that their decision to participate or not in screening was respected. All respondents were quite candid about their decision-making. The results reported here show that the reasons to reject FOBT screening are based largely on individuals' assessments of their level of risk as well as upon judgements about capacity to deal with the potential threat of being diagnosed with a potentially life-threatening disease^[17].

Secondly, only a small number of gastroenterologists were interviewed. This represented all gastroenterologists involved in the pilot project. These specialists were able to provide an insight and perspective on their experiences of the end-stage of the screening process, particularly the burden that was likely to be placed on their service by a population-based screening program. The consistency of their insights suggests that their experiences are likely to be shared by other gastroenterologists should a population-based program be implemented. What this study does provide is an understanding of the issues associated with participation in colorectal screening from those involved across the continuum of screening.

Conclusions

Based on the results presented here, it would seem that CRC screening using FOBT will not enjoy unqualified support from the community^[44] or from medical practitioners involved in the continuum of screening. Participants in this study expressed a desire to receive correct and up-to-date information to assist informed decision-making. Doctors considered that it was their role to be involved in a population-based screening program; however, they also stressed the importance of informed choice and individual preference.

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