

Talking about the not talked about: use of, and reactions to, a DVD promoting bowel cancer screening to Aboriginal people

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Bowel cancer has a long preclinical stage and can be identified through bowel screening using a Faecal Occult Blood Test (FOBT) before any symptoms emerge. Several randomised controlled trials have demonstrated that bowel cancer mortality could be reduced by 15–33% through regular, population-based bowel screening.¹ Australia is one of a few countries, along with the UK, France, and Germany, that has a formal, government-funded, population-based bowel cancer screening program.² The National Bowel Cancer Screening Program (NBCSP), using the FOBT, commenced in Australia in 2006, and by 2020 all Australians aged between 50 and 74 will receive a FOBT kit every two years.¹

Bowel cancer is rarely noted as a significant health issue among Indigenous Australians. However, it is the third most common cancer after lung and breast, accounting for about 9% of all cancers for Indigenous Australians.³ Although the incidence and death rates from bowel cancer are lower than the non-Indigenous population,^{3,4} the actual extent is not clear due to problems associated with under-ascertainment of Indigenous status in cancer registries.⁵ It is estimated that, on average, 79 Indigenous Australians are diagnosed with bowel cancer each year.⁶

Monitoring of the NBCSP has revealed disparities in bowel cancer screening uptake, with Indigenous Australians participating at a lower rate than the non-Indigenous population.^{2,7,8} Barriers to participation

In this paper, the term Aboriginal has been used to refer to the Indigenous people of WA. The term Indigenous is used when referring to features that are identified across different Indigenous peoples.

Abstract

Objective: To examine a) the implementation and use of a DVD developed to educate Aboriginal people about bowel cancer and bowel cancer screening; and b) broader aspects of Aboriginal participation in the National Bowel Cancer Screening Program.

Methods: Qualitative methods and descriptive approaches were used. Data were collected using face-to-face and telephone interviews and focus group discussions. There were 67 participants, including those involved in the development and distribution of the DVD, health professionals and Aboriginal community members.

Results: Although the DVD received a positive reaction from participants, fewer than half the DVDs had been distributed. Furthermore, the small number of DVDs that had been distributed were under-utilised.

Conclusion: The weaknesses do not appear to lie with the resource itself but can be attributed partly to poor distribution and promotion. This may have been compounded by the structure of the National Bowel Cancer Screening Program, which limited the engagement of Aboriginal community members and health providers whose focus is largely directed towards more pressing health care issues.

Implications: Interest in the resource may increase once the Aboriginal component of the screening program is more closely linked with primary care.

Key words: bowel cancer, screening, health promotion, resource, Aboriginal

exist at the individual, health service and screening program levels.^{9,10} Individual level barriers include poor knowledge and awareness of bowel cancer and screening options; language/literacy barriers; fatalistic beliefs regarding cancer; absence of symptoms; embarrassment about the sensitive nature of the topic; and lack of confidence in carrying out the test. Health service level barriers include lack of support from health workers; lack of health promotion materials in Indigenous languages and poor understanding of the cultural needs of Indigenous Australians. Features of the NBCSP's model also act as barriers. These include recruitment via Medicare; distribution of screening kits via post; recording of Indigenous status via

self-identification at time of screening; and necessity for participants to have access to privacy and appropriate storage facilities.^{9,10} The widespread distrust in government services (including programs such as the NBCSP) reportedly felt by many Indigenous Australians, is identified as a further barrier.¹¹ Health promotion and education have been identified as important mechanisms to help address factors affecting the health of people and communities.¹² Historically, promoting the NBCSP has been both challenging and fragmented, due to the limited eligible cohort and, prior to 2012, lack of sustained commitment by the Australian Government to a permanent, fully implemented biennial screening program. Nationally coordinated health promotion activity has been limited,

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with the majority of resources developed at jurisdictional levels to meet local needs as the NBCSP has evolved. To address these issues and to raise awareness about bowel cancer and screening in a culturally relevant way among Aboriginal people in Western Australia (WA), the Western Australian Cancer and Palliative Care Network (WACPCN) adapted a Queensland-developed Indigenous specific flipchart in 2008. The WACPCN later commissioned work to evaluate the flipchart⁹ in line with recommended best practice.¹³ Evaluations of health promotion tools have been identified as being particularly important for tools which have been developed for Indigenous populations, in order to optimise the potential of these tools to contribute to Indigenous health promotion and reduce the health disparities that currently exist.¹³

One of the key findings from the flipchart evaluation was that additional resources to help promote the NBCSP and improve self-confidence in completing the FOBT were required in order to increase screening uptake in the Aboriginal community.⁹ It was noted that a DVD would be particularly useful as it would circumvent the difficulties associated with written resources and could reduce staff time in disseminating messages about the NBCSP. Cancer Council WA (CCWA), as contracted partners of WACPCN, developed a DVD, *Making Time for Bowel Cancer Screening*.¹⁴ CCWA included their Aboriginal Projects Advisory Group in the process to ensure that the content and the design of the DVD were culturally appropriate. It was developed in collaboration with an independent video production company and was completed in 2013. The seven-minute DVD outlined recommended behaviour around bowel cancer prevention including screening and the NBCSP. The completed DVD was uploaded to CCWA's website, accessible at www.cancerwa.asn.au/resources/publications/aboriginal/, and to YouTube. Copies were also distributed to Health Service Providers (HSPs) who requested a copy.

WACPCN commissioned a further study to examine the implementation and use of the DVD, as well as broader aspects of Aboriginal participation in the NBCSP. The evaluation's aim was to build on previous lessons learnt regarding the development of efficacious resources for Aboriginal communities, discuss shortcomings and identify future opportunities. This paper outlines the results of that study and sets out the challenges

encountered during the course of the evaluation. It also reports the study findings on distribution and use of the DVD, its suitability and acceptability for Aboriginal consumers and attitudes towards bowel cancer and the NBCSP, as held by Aboriginal people.

Methods

Ethics approval was obtained from the Human Research and Ethics Committee (HREC) of the University of Western Australia (UWA) and the West Australian Aboriginal Health Ethics Committee (WAAHEC).

Data collection

Qualitative methods and primarily descriptive approaches were used in the evaluation. Data collection was carried out using the following four approaches, summarised in Figure 1:

- Face-to-face and telephone interviews were undertaken with those involved in the development and distribution of the DVD to understand the rationale behind these processes. A semi-structured guide was used to stimulate and facilitate discussion.
- Telephone interviews were carried out with HSPs working with Aboriginal communities, to whom the DVD had been sent, to assess the extent to which the DVD was being used and its usefulness as an educational tool. These interviews used a questionnaire which comprised a mixture of both open and closed questions.
- A video-conferenced Focus Group Discussion (FGD) was held with a number of health professionals, who worked in Aboriginal and rural health, to obtain their feedback on the DVD. They had all viewed the DVD in advance and the group discussion was held on an informal basis.
- FGDs were held with Aboriginal community members and HSPs to gain feedback and opinion regarding the appropriateness and effectiveness of the DVD and perceptions of bowel cancer and the NBCSP. A theme list was used to stimulate and facilitate discussion in the group following the viewing of the DVD.

Participants were provided with a Participant Information Sheet (by hand or email) before each interview and/or FGD. Written consent was provided by FGD participants and face-to-face interviewees. Verbal consent was obtained for telephone interviews and the FGD which included videoconferencing.

With the permission of participants, all interviews and group discussions (including

the videoconference meeting) were audio recorded to ensure accurate representation of participant responses.

Data analysis

All audio recordings were transcribed. NVivo was used to analyse the data by organising the responses and comments into themes according to how they addressed the research objectives. Two researchers reviewed and discussed the findings to agree the key themes.

Results

Making Time for Bowel Cancer Screening DVD

The DVD consisted of two scenes, one an informal family barbecue setting and another more formal monologue presented by a well-known Aboriginal doctor. The family setting provided an overview of bowel cancer and outlined the importance of screening. This was followed by a voice over that gave more detailed information. General health promotion messages, about the significance of a healthy lifestyle as a means of reducing bowel cancer risk, were reinforced throughout the DVD. The video was designed to appeal to the key target audience by involving Aboriginal men and women aged over 50, by using simple language and by conveying much of the information graphically and through voice over.

Participants

Individuals who had contributed to the DVD's production and distribution were key to the evaluation. However, due to the two-year time lapse between these stages and the evaluation, and staff turnover, contact was not always possible. Five individuals (from a list of 12) who had been involved in producing and distributing the DVD were eventually located and agreed to be interviewed.

Another group of participants were the HSPs to whom the DVD had been sent. The DVD recipient list provided by CCWA was used to contact these 41 individuals who worked in a wide range of locations (predominantly in regional areas throughout WA) and health service settings. As with the group involved in the production and distribution of the DVD, challenges emerged in contacting these participants primarily due to the time lapse since the DVD had been distributed. A total of 123 telephone calls were made in attempts to contact the 41 DVD recipients. However, even when contact was made, few recipients could recall receiving the DVD and most were

unsure of its contents. Only 15 of the original 41 recipients could be contacted directly by telephone and, of these, only two people had seen the DVD and were sufficiently familiar with it to participate in an interview.

A further group of study participants were health professionals (15 in total, with backgrounds in nursing, medicine, physiotherapy, podiatry and social science). None was directly involved with the DVD production or distribution but many had experience in developing educational materials for Aboriginal populations. An existing weekly slot held at a Perth university, during which a range of professional development issues are discussed, was used to capture the views of this group.

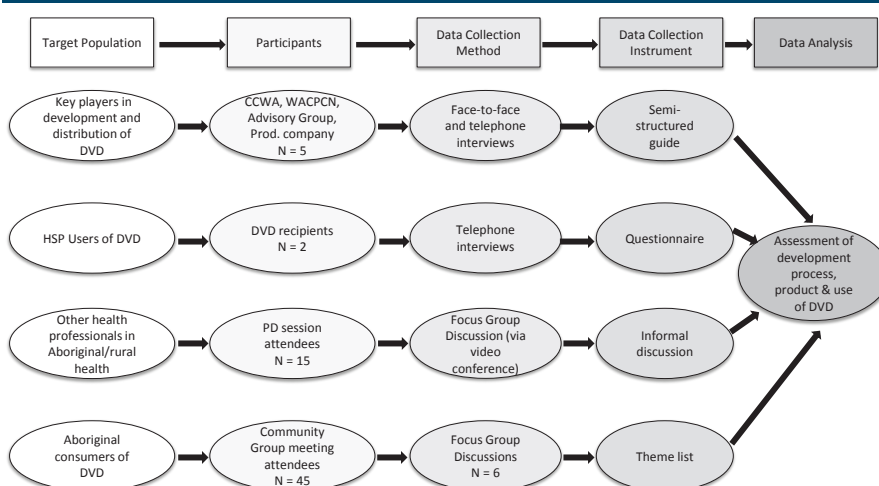
The final group of participants were Aboriginal community members who were recruited by inviting attendees at regular community group meetings, such as men's/women's groups and art groups, held at Perth metropolitan and regional locations in the South and Mid-West. Six FGDs were held. There were 5-10 participants in each FGD; in total, about 45 participants (comprising a mix of genders and age groups) attended the sessions. The convenience approach resulted in a sample which was largely female, from metropolitan and regional locations, and those that tended to access health services and community groups regularly.

Evaluation findings

DVD distribution process

The primary objective of the DVD distribution strategy had been to target HSPs considered likely to use the product as an educational resource. The strategy took into account lessons learnt from the distribution of the flipchart resource, offering more targeted and supported engagement. A letter was sent from CCWA to almost 3,000 health professionals throughout WA, who were working with Aboriginal patients in some capacity. The letter invited recipients to complete and return an order form to obtain a copy of the DVD. This resulted in 80 DVDs being mailed to 41 individuals who responded to the letter. In addition, a small number of individuals received copies of the DVD by other means, for example by picking up copies at conferences or a complimentary copy. In total, about half the original consignment of 200 DVDs were distributed. By mid-November 2015, the online version of the DVD had been viewed 867 times since

Figure 1: Flow diagram of evaluation process.



its launch, indicating that many more views had occurred this way than through the hard copy DVD distribution. Although it can be established that the average view duration of the DVD was just over four minutes, and therefore viewers watched a significant proportion of the entire production, to what extent these online viewers represented the target group is unknown. A further issue with electronic means of distribution is that there is no control over associated YouTube content. In this case, other material, with a conflicting message questioning the benefits of population-based cancer screening, was co-located. Such conflicting material has the potential to attract some viewers' attention and potentially persuade them against bowel or other types of cancer screening.

Financial and staffing constraints were reported as having limited further promotion or follow-up of the DVD. These weaknesses in the promotion and distribution of the resource were reflected in the small number of DVDs distributed, lack of education sessions in use of the DVD requested by HSPs, and the small number of DVD recipients who could recall its contents. As one participant commented, "... we can develop extremely effective resources through consultative processes. However, when it comes to dissemination and effective utilisation of the resource, it's another kettle of fish."

Participants' views on DVD content

The study found that most participants felt that the DVD was highly appropriate as an educational tool. In general, it was considered to be clear and simple and, above all, informative. Participants felt that it covered a sensitive topic in an appropriate manner, and watching the DVD helped diminish any

potential feelings of shame by "de-stigmatising a taboo topic". Many participants thought such a resource would help to raise awareness of a little-discussed and much feared topic. After having watched the DVD, people felt that they were better informed about bowel cancer and the importance of participating in the NBCSP. In addition, the audio-visual style was compared favourably with text, being particularly useful for those with limited literacy skills and/or those for whom English was not their first language. This synergised with the oral and visual tradition of Aboriginal culture.

A number of suggestions were made regarding ways in which the DVD could be improved. As some audiences may find the DVD too long, it was suggested that it could be separated into two videos, one containing health promotion material and the other explaining how to use the kit. It was also suggested that humour should be used to assist in delivering information on a difficult topic. Some felt that in order for the DVD to make an impact with men it needed to be 'stronger', i.e. contain messages that were more forceful and memorable. It was also suggested that there could be two DVDs: one for males and one for females, each respecting appropriate cultural protocols.

Participants' views on bowel cancer and the NBCSP

Feedback from both health professionals and Aboriginal participants was that bowel cancer is not widely discussed within Aboriginal communities. The main reason was that bowel cancer is not highlighted to be a health priority as there are other more immediate health concerns among Aboriginal Australians that have been widely

canvassed. In addition, bowel cancer was reported as being a taboo topic which many within the Aboriginal community are not comfortable discussing and would not raise spontaneously. "Participating in screening is down the list of things that are important," one HSP participant noted. Participants also identified many reasons (program-related and individual) why people may be reluctant to participate in the NBCSP. Box 1 sets out a selection of quotes from participants which explain some of the barriers to participation.

In terms of program-related barriers, many participants said that, though eligible, they had never received a kit in the mail. This suggests that the absence of Medicare registration containing an up-to-date address may be a factor which precludes Aboriginal people receiving a FOBT kit. Of those who had received a kit, most commented that the instructions were complicated and did not help them to use the kit successfully. Of individual barriers cited for non-use of the kit, psychological factors played a key role. Fear that the result may be positive was a factor. Shame and embarrassment were commonly reported due to the testing being related to body parts perceived as being private and due to the unpleasant nature of the test.

Discussion

There is an extensive range of tools available to guide and support effective health promotion practice in Indigenous communities.¹⁵ However, only a small number of evaluations of Indigenous health promotion tools, of generally moderate quality, have been undertaken.¹³ While evaluation challenges are faced by all health promotion practitioners,¹⁶ additional challenges may be experienced in the course of evaluating Indigenous health promotion tools due to issues typically present in rural/remote and Indigenous health settings. These

issues include frequent workforce turnover; staff overloaded with multiple responsibilities (thus having limited capacity to pursue evaluations); limited funding; and short time-frame of projects in general.¹⁷ Such difficulties, some of which were experienced in the course of this evaluation, help explain the paucity of evaluation studies carried out in the Indigenous health promotion sector.

When explicitly asked and deliberately shown the DVD, both Aboriginal consumers and health professionals who participated in the study had positive reactions. This is similar to the findings from the earlier evaluation of the flipchart developed to educate Aboriginal consumers about bowel cancer.^{9,18} However, this positive feedback from study participants must be balanced against the limited distribution of the DVD. Furthermore, the small number of DVDs that had been distributed were under-utilised, as occurred with the flipchart.^{9,18} This was highlighted by the fact that only two of the 41 recipients had sufficient recollection of the material to be able to provide feedback for use in the study. While the interval between distribution of the DVD and follow-up may have contributed to this poor recollection, it is most likely due to low utilisation of the DVDs.

As had been noted in previous studies, having a new, culturally appropriate health promotion resource is not in itself an answer.¹⁹ Indeed, more effective distribution of the DVD would not have guaranteed its utilisation.⁹ Possessing a health education tool, even if it is of good quality, does not ensure that the resource will be used by HSPs.¹⁸ HSPs regularly receive health education materials but the lack of human resources, competing priorities, and health workers busy dealing with patients presenting with existing diseases, result in staff lacking the time to use these resources effectively.²⁰ The capacity and resources of practitioners working in Indigenous

primary health care services to utilise health promotion resources, in the context of other demands, is particularly limited.¹² Despite the DVD's distribution strategy considering lessons learnt from the flipchart's evaluation, a clear model has yet to be devised that is effective. Greater consideration, consultation and planning of distribution and subsequent follow-up are required as part of any future resource dissemination design.

The low utilisation of the DVD has been compounded by the lack of engagement in the NBCSP by HSPs who work with Indigenous communities. This deficiency may, in part, be attributed to the current structure of the program, which sends FOBT kits directly to participants and bypasses HSPs. This structure fails to consider the organisational and community context within which the program is implemented, factors which must be considered for a health promotion program to succeed.¹³ Recent initiatives by the Australian Government to pilot an alternative bowel cancer screening pathway, targeting Indigenous Australians through greater involvement of Indigenous primary health care services in distribution and follow-up of FOBT kits, indicate a willingness to adhere to recommendations that greater consideration be given to the patient population when implementing population-based screening programs.^{21,22} Where there is greater involvement of primary care in bowel cancer screening, as in Ontario, Canada, there are participation rates of 53% of the eligible population, compared to the current participation of 38% in the NBCSP.²³ Other studies have shown that endorsement by the primary care practitioner increases participation in screening.^{24,25} In addition to addressing NBCSP deficits for Indigenous Australians, a further benefit of greater primary health care services involvement will be to make more effective use of the available health promotion tools.

Another reason the DVD had been under-utilised was attributed to the beliefs and perceptions of Aboriginal communities towards bowel cancer and the NBCSP. The study found that bowel cancer and the NBCSP are subjects that are still not widely discussed within Aboriginal communities partly due to a perception that bowel cancer is not a priority health issue for Aboriginal people. This view is supported by other studies.^{10,26} Shame and embarrassment associated with discussing a sensitive topic, let alone having tests carried out, were identified as reasons why individuals

Box 1: Reasons for Non-Participation in NBCSP.

Program-related barriers

"It looks really hard to do."

"The instructions aren't that clear."

"Like a lot of people can't read. So show it to them and they'll know what to do by the time they get one."

"We had them [the test kits] sent out but we didn't know how to use them."

Individual barriers

"A lot of people frightened to know they've got it."

"The main issue with Indigenous people is fear....all of a sudden you think you're a gonner. So it's best not knowing at all."

"Some people probably too frightened or shamed to find out what's going on inside their bodies."

"It's a private part of your body and it's embarrassing."

"There's that yucky factor."

may be reluctant to participate in the NBCSP. A recent systematic review of international literature also found that Indigenous peoples tend to have less knowledge, less favourable attitudes, and a higher propensity to refuse screening than non-Indigenous populations.²⁷ This lack of enthusiasm further diminishes the status of bowel cancer as a health priority for HSPs working with Aboriginal people who usually have to deal with more pressing health care issues.

Implications for practice

Promoting a national health program of under-appreciated importance, such as the NBCSP, can be particularly challenging and has contributed to reluctance on the part of HSPs to accept it as their responsibility to promote the program within Aboriginal communities.¹⁸ While the DVD was intended to make raising the NBCSP easier and less time consuming for HSPs, there has been low utilisation of the DVD. This demonstrates that HSPs, and nurses, in particular, require awareness of the underlying problem and their role in health promotion and education needs to be clearly articulated.^{20,28,29} In addition, specific training to ensure their understanding of the program and engage them in promoting it is required before resources are sent out to them.¹⁸ The proposed transition to biennial screening from 2020, when the full cohort of those aged 50–74 years will be included in the program, makes it essential that consideration is given to the development of effective engagement and promotion strategies which suit the needs of a wider audience.

Limitations

There are several limitations to the study to be considered when interpreting the findings. These include difficulties locating key individuals due to the time elapsed after the DVD had been produced and distributed. This ultimately reduced the number of available participants, already limited due to the small quantity of the resource distributed. Therefore, the information gathered may not be as comprehensive as if the evaluation had been carried out sooner. The approach to recruitment of FGD participants through health service contacts and Aboriginal community organisations means the participants are likely to have greater health-seeking behaviours in a way not typical of all Aboriginal people. A higher proportion of those accessing these services tend to be female and live predominately in the Perth

metropolitan/regional areas. Furthermore, due to the sensitive nature of the topic, the views of those who are more outspoken were heard at the FGDs.

Conclusion

Although the largely positive reaction to the DVD suggests that a quality health education resource was developed, the low utilisation is a concern. It is not likely that a different resource would have generated greater interest and uptake as there was a similar outcome observed with the flipchart resource. Therefore, the weaknesses do not appear to lie with the resource itself but can be attributed in part to poor distribution and promotion, and the low priority of the NBCSP to health providers and Aboriginal community members. HSPs are not sufficiently engaged with the NBCSP, due in part to the distribution of FOBT kits directly to participants without the involvement of HSPs, and due to their focus on more pressing health care issues. Increased utilisation of the DVD resource should occur when the Indigenous component of the NBCSP is more closely linked with primary care.

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