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How Patient Involvement Can Contribute to the Development of Information Materials About Malignant Melanoma for Healthy Older Men

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Abstract

The incidence for malignant melanoma (MM) in older men is 3 to 4 times higher than the rest of the population. Patient information about MM could be a way to reach men. The aim of the study was to design and develop a pamphlet in collaboration with older men. The study was conducted in two steps. In the first step, 73 men were interviewed; in the second step, the pamphlets were sent out to 306 men. All men were recruited in connection with an aorta screening. Men wanted concisely written information with illustrations and 85% of the men reported that they have read the pamphlet. The study demonstrates a cost-effective method to reach out with information to older men about MM.

Keywords

communication, content analysis, malignant melanoma, patient participation, prevention, patient safety

Introduction

In the 2000s, the global incidence of malignant melanoma (MM) increased by 5% per year among the fair-skinned population. Of these patients, 15% to 35% will develop metastases. In Europe, Sweden is one of the countries with the highest incidence[1]: In 2012, the age-adjusted incidence was 36.9 for men and 32.6 for women per 100,000. Despite this increased incidence, the survival rate for MM has significantly improved in recent decades due to earlier diagnosis. The relative 5-year survival rate for the year 2011 was 87% for men and 92% for women.[2]

There are differences in relation to gender and age.[3,4] The incidence for older men is 3 to 4 times higher than the rest of the population,[5] and older men often have thicker MM on diagnosis.[6] Moreover, men more often develop metastases than women.[7] MM is a cancerous disease that is often visible and can be detected by the individuals themselves. Early detection, diagnosis, and treatment reduce the risk of metastasizing and therefore contribute to a more favorable prognosis.[8] Metastasis primarily depends on the stage of the tumor. Patients with MM in Stage I have approximately 7% risk of developing metastases, Stage II 33%, and Stage III 51%.[9] Delays in diagnosis and treatment of MM are common, especially among men who rarely discover it themselves.[10] Men usually use a wait-and-see strategy compared with women in terms of seeking medical attention,[11] and there are also differences depending on marital status. Men living with a partner are often encouraged by the latter to seek medical attention,[12] and have significantly better chances of survival than single men.[13] In a Swedish study, the survival of more than 27,000 melanoma patients was examined, the results showing that melanoma patients with low levels of education have more advanced disease on diagnosis and therefore poorer chances of survival.[14]

Prevention

Primary prevention of MM involves reducing the risk factors. The only known, external risk factor of significance for MM is ultraviolet (UV) radiation. The damaging effects of UV have been known since the 1990s, giving good reason to influence people's sunbathing habits.[15]

Population screening to find MM is conducted in some countries with a view to detecting the disease early and consequently reducing the risk of metastasis. However, in some countries, it is not seen to be cost-effective,[16,17] as large resources are required to detect cases. In the United States,

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large public awareness campaigns about MM have been conducted, along with population screening measures. The evaluation emphasized that initiatives should be directed at risk groups such as older men,[18] and people with low socioeconomic status.[19]

Quality Improvement Project

A quality improvement project in health care is often carried out by health care staff on the basis of their activities and their perspective, without listening to the views of patients and their relatives.[20] However, in recent years, the attitude has changed and the opinions of patients and next of kin are important information as a basis for the quality improvement project.[20] Moumjid et al[21] have studied the significance of patients' contributions to the production of patient information pamphlets for cancer patients. The patient group in the study suggested several adjustments to the pamphlet so that it would meet the patients' requirements in regard to information, explanation, and readability.[22]

In a systematic review[23] about the effects of measures to increase awareness about cancer and its early detection, it was concluded that there was some support for the idea that individually tailored advice can increase awareness about cancer, but the evidence is limited in regard to the effect of interventions aimed at the population. The aim of the study was to describe what healthy older men knew about melanoma, and based on their perceptions, design information material as a pamphlet.

Methods

A pilot study was conducted during 2011 with five men aged 65 to 75 with a view to develop questions for the planned, full-scale study. The study started in the autumn of 2011 and finished in 2012 (see Figure 1). The study was conducted in two steps. In Step 1, participants were recruited from a group of men who were having aortic screening, in two local health centers in South East Sweden, the year they turned 65, 70, and 75 years. The men received an invitation to participate in the study and an informed consent together with the invitation to attend aortic screening. Confidentiality was protected by coding.

In face-to-face interviews, the men answered questions about what they knew about MM and what kind of information they preferred. After the interviews, all the men ($n = 73$) were asked if they could be contacted by telephone to give their opinions on the first draft of the pamphlet. A draft of a pamphlet was made and sent to 36 men, who had accepted to be contacted. After receiving feedback from these men, a pamphlet was produced.

In Step 2, the pamphlet was sent out to men ($n = 306$) in the year they turned 65, 70, and 75 years from two local health centers in South East in connection with an invitation to attend an aorta screening.

Both quantitative and qualitative methods were used for data collection using structured interviews. The analysis was carried out as a summative content analysis.[24]

Data Collection

Step 1

Face-to-face interviews. Of the 100 men invited to the aorta screening, 91 (91%) attended. Of these, 80% ($n = 73$) were interviewed (see Figure 1). Interviews were conducted by the first author ($n = 40$) and the third author ($n = 33$). The men were interviewed in connection with (their) aorta screening visits at their local health clinics either before or after (their) examinations of the aorta. Sociodemographic data for age, marital status, occupation, and/or previous occupation were registered. The authors followed an interview guide comprising open and closed questions (see Appendix A). The orders of the questions were tailored to suit the conversation and the responses were written by hand before being transferred to a computerized data bank (Excel). The interviews lasted 5 to 15 minutes. After the interviews, all the men ($n = 73$) were asked if they could be contacted by telephone to give their opinions on the first draft of the pamphlet that was going to be sent out.

Telephone interviews. The first draft of the pamphlet was sent out to those men who agreed to participate in the telephone interviews ($n = 36$). Nine men did not answer and after some reminders, they were excluded. A total of 27 men were interviewed by the first author ($n = 20$) and by the third author ($n = 7$). An interview guide of open and closed questions was used (see Appendix B). The order of the questions was adapted to suit the conversation. Each interview lasted between 3 and 10 minutes and the responses were entered directly into the computerized data bank (Excel) during the conversation.

Step 2

Evaluating pamphlet–telephone interviews. On the basis of Step 1, the draft pamphlet was propped up in the form of a pamphlet (see Figures 2-3). A copy of the produced pamphlet was sent out to men ($n = 306$) in southern Sweden along with an invitation to attend an aorta screening. Telephone interviews were subsequently conducted with these men 2 to 4 months after the pamphlets were sent out. Of the 306 men who had received the pamphlet, a sample was selected and every fifth man ($n = 53$) was interviewed by the first author.

The authors followed an interview guide comprising open and closed questions based on the results from Step 1(see Appendix C). The order of the questions was adapted to suit the conversation and the responses were directly typed into the computerized data bank (Excel) during the interview. Each interview lasted 10 to 15 minutes authors followed an interview guide comprising open and closed questions based on the results from Step 1 (see Appendix C).

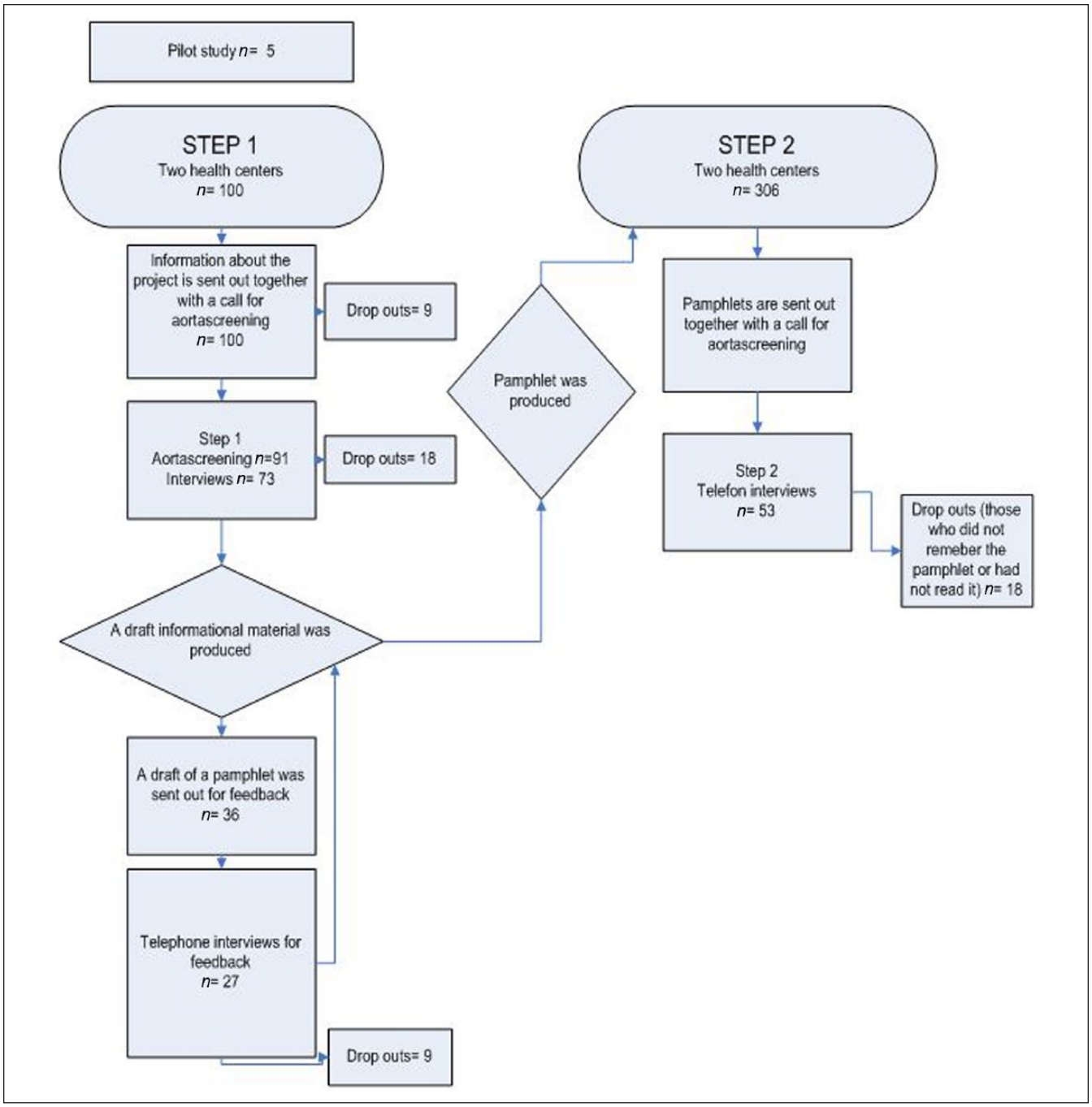

Figure 1. Overview of the various steps carried out in the study.

Data Analysis

All of the face-to-face interviews and telephone interviews (n = 145) were documented into the computerized data bank (Excel) and read through. For each interviewed man (case), a row was created and text was organized into vertical columns, question by question. The first and third authors made their own separate assessments into each category and subcategory and sorted the material. When responses to questions differed, more subcategories were created for each question. Preliminary categories and subcategories were created, with each subcategory quantified vertically (see example in Table 1). The authors then discussed how the preliminary categories and subcategories were further sorted and grouped together and labeled.

Ethical Considerations

Ethical approval for this project was granted from the Ethical Review Board in Linköping (2011/354-31).

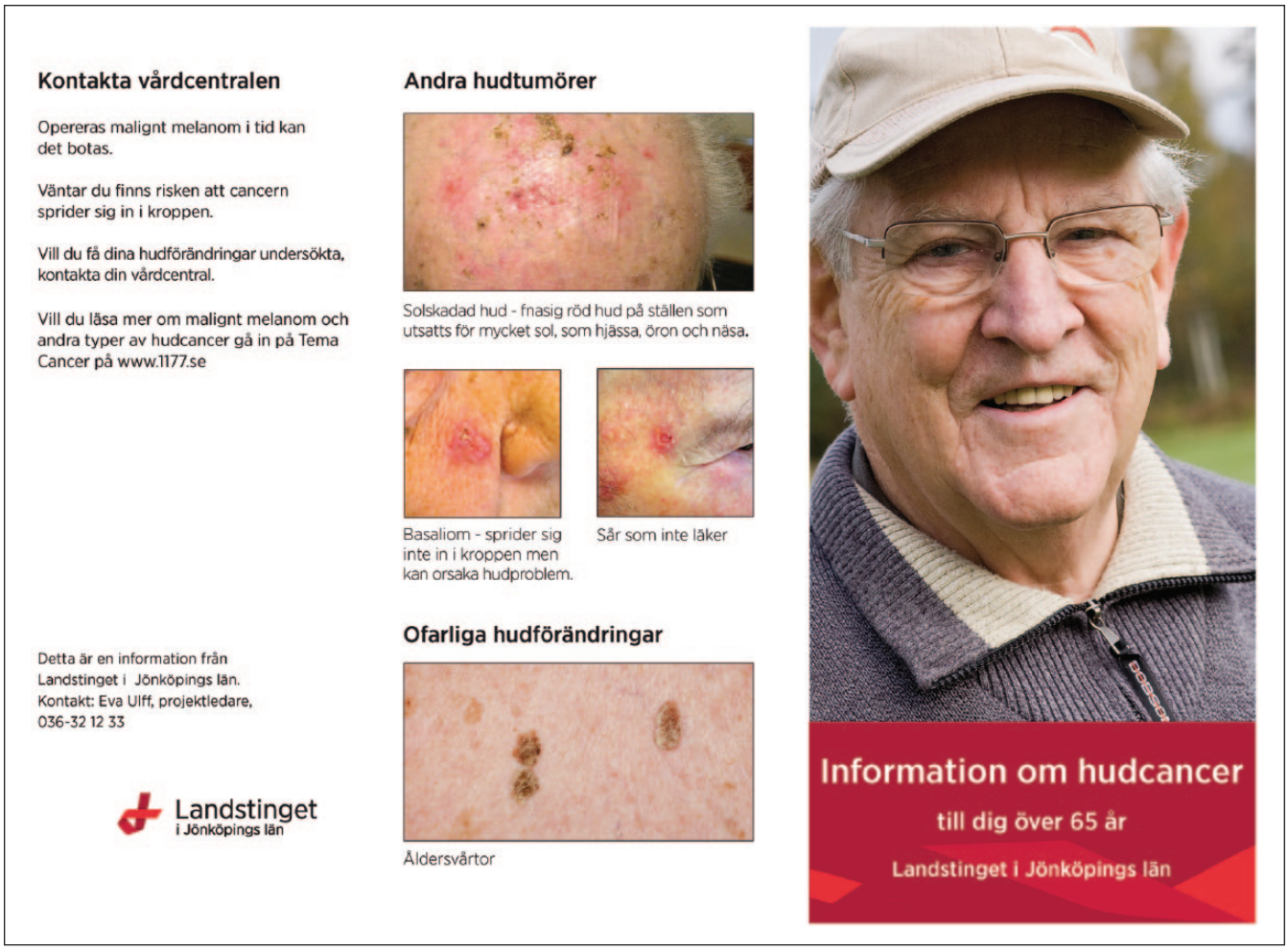

Figure 2. Front side three-part pamphlet in Swedish.

Results

The results have been compiled according to how the data were collected in the two steps. Step 1 is described with the category "The development of the first draft of the pamphlet" with the subcategories: Knowledge and self-examination, Awareness and experiences, Sun exposure habits, Written text, Illustrations and photographs, and Dispatcher. Step 2 is described with the category "The evaluation of the pamphlet" with the subcategories "Support in self-examination" and "Usefulness of the pamphlet." The categories and subcategories described in Step 1 and 2 are supported with citations.

Step 1

The development of the first draft of the pamphlet. The men's ages in years were 65 (n = 35, 48%), 70 (n = 14, 15%), and 75 (n = 24, 33%) years. The men's occupations were categorized as follows: workers (n = 34, 47%), professional employees (n = 20, 27%), self-employed or manager (n = 14, 19%), and missing (n = 5, 7%). Forty (55%) of the men stated that they lived with a partner.

Knowledge and self-examination. Forty-three (60%) of the men described that they actively observed their skin, for example, in the shower; 15 (20%) stated that they checked their backs with the aid of a mirror and 7% stated that they were extra careful to check during the summer when the risk of tick bites is the greatest. Twenty-three (32%) of the men were checked by close friends or relatives, with 1 man stating "the wife checks me." Forty-two (58%) of the men knew that they should seek medical attention if there were changes in their skin or "if something looks strange," "itches," or "bleeds." Due to uncertainty in their own observations and as a support, 5 (7%) of the men suggested that they "should check while they were at the health clinic anyway."

Awareness and experience. Twenty-five (34%) of the men were aware that it was good to monitor changes in color ("spots that change color") or growth of a skin abnormality ("pay attention to liver spots") and note recent changes in

Figure 3. Back side three-part pamphlet in Swedish.

Table 1. Example of the Initial Analysis of Responses and Compiling the Data Into Categories and Subcategories.

Question 10. How should the information be designed? In what way?					
		Preliminary category			
		Design of information			
		Preliminary subcategories			
Case	The men's answer	Written information	Simple information	Photographs/ illustrations	Sent from county council
1	What it looks like, what should you do, will read if it comes from the health authority			What it looks like	Will read if it comes from the health authority
2	Understandable text regarding what happens, what's involved	Text	Understandable text	Picture of what's involved	
3	Pamphlet, easy to grasp	Pamphlet	Easy to grasp		
Total subcategories		2	2	2	1

their skin. One man said, "It isn't always the large ones that are the most dangerous." Ten (13%) of the men had experience of MM among friends or relatives. One man said, "My son-in-law has melanoma." When asked if they were worried about being affected by MM, 6 (8%) said yes. One man said, "Yes, both my parents died of cancer," while another mentioned that he sustained severe sunburn as a child.

Sun exposure habits. Eleven (15%) of the men stated that they always sunbathed stripped to the waist. Some were

aware that the sun was dangerous. One man said, "shouldn't sunbathe but I do it anyway," while 29% said that they actively avoid the sun even though they love it. "You don't want to be old before your time," said 1 man, and several commented that they "sit in the shade."

Written text and photographs. Forty-one (56%) of the men preferred written information, "pamphlets are good, easy to grasp," and 16 (22%) wanted a simple design, "so that you get it, the simpler the better, send it home through your letterbox," and the text to be easy to understand, "simple text . . . symptoms." They also wanted the message to be clear: "if you don't go, you'll die." Name and telephone number of the health clinic should be clearly given in the pamphlet. Of 27 men, 23 (85%) thought that the pamphlet was clear and contained just the right amount of information. Illustrations and photographs were important according to 24 (33%) of the men, who thought that there should be a "series of color illustrations" showing "the differences between dangerous and harmless." Some men thought that the illustrations/photographs were unclear, with poorly contrasting colors.

Dispatcher. Five (7%) of the men emphasized the importance of the health authority being responsible for sending out the information, "that it comes from the health authorities," and that it was addressed to the man personally, "comes to you personally." One man related that he "reads what comes from the health authorities." One man looked for health care information on the Internet and six (8%) suggested that information should come via the media, for example, TV infomercials: "TV targeting interest groups."

Step 2

The evaluation of the developed pamphlet. After analyzing the data in Step 1 (see Figures 2-3), the final version of the pamphlet was produced and printed as a three-part pamphlet. The pamphlets' headlines and content were as follows: "Information about skin cancer," "Are you male and over 65, then you should pay attention to your skin," "Malignant melanoma," "Other skin tumors and benign skin lesions," and "Contact the health center and other information."

Of the 53 men selected for telephone interview in Step 2, 45 (85%) replied that they had read or looked at the pamphlet, 35 (66%) had kept it, 6 (13%) had thrown it out, and 4 (9%) could not remember. The results after analyzing the interviews are described on the basis of 45 men who had read the pamphlet. Their ages in years were 65 (n = 13, 29%), 70 (n = 15, 33%), and 75 (n = 17, 38%) and their occupations were categorized as follows: workers (n = 15, 33%), professional employees (n = 14, 31%), self-employed or managers (n = 4, 9%) and "don't know" (n = 11, 24%). Thirty-four (75%) of the men stated that they lived with a partner.

The results of the second step showed that 85% of men had read the pamphlet. The results of the evaluation in Step 2 are described with the subcategories Support in self-examination, Usefulness of pamphlet, and Design and distribution.

Support in self-examination. Eleven (24%) of the 45 men interviewed examined their skin and compared it with the changes shown in the pamphlet pictures: "checked in the mirror and compared." Several commented that they felt embarrassed about seeking medical attention at the health clinic for a small change in their skin, but the pamphlet helped them be more accepting about it: "If you've got something you're worried about, it pushes you to do something, otherwise you think they must think you're a hypochondriac calling about some tiny little spot—now we have this information to refer to."

Usefulness of pamphlets. Twenty-four (53%) of the men stated that their partners had read the pamphlet, "The wife thought it was good too," and 2 had shown it to their children, "My wife and daughter read it and then I hung it up at work." The men were all positive about the pamphlets: "Good and for me, understandable. One man thought that the pamphlet created anxiety, 4 (9%) did not know, and 40 (88%) did not worry. Several pointed out that it was good to have some food for thought and one man said it was "better to be frightened than to be asleep." Forty (82%) men stated that the pamphlet was a good way for the health authorities to provide information: "If you get a pamphlet and see something very similar—then you go and make an appointment—especially a single man like me." Several men expressed appreciation for written information: "having a leaflet at home is good. I'm going to keep it—other information gets lost." Eighteen (65%) men made it clear that they should seek medical attention at their local health clinics if needed after reading the pamphlet.

Design and distribution. Eighteen (20%) of the men spontaneously commented the layout of the pamphlet and said, "it's the pictures you look at," and "the pictures are instructive, especially as there six different ones so you understand that it can take different forms. Only one picture would have been too limited." Six of the men could not remember that they had received a pamphlet about MM: "get so much from the health authority—it's become too much" or they threw the pamphlet away. When prompted to suggest alternatives to pamphlets, 4 (9%) of the men suggested campaigns "like the ones for vaccinations" and "TV commercials, or that someone calls you at home."

Discussion

The results of Step 1 show that the men's awareness of MM was limited but that there was interest in receiving brief and easy-to-read information. The men who had given feedback on the draft pamphlet were generally positive and gave useful, constructive criticism that could be used to improve the

material. A large number ($n = 306$) of pamphlets was printed and distributed along with an invitation for an aorta screening. To find out how well the pamphlet had been received, telephone interviews were conducted in Step 2, 1 to 4 months after dispatching the pamphlets. The results show that more than half of the men checked their skin as part of their personal care and were aware that they should seek medical attention if any changes had been detected. Illustrations and photographs were important for many of the men, which can be interpreted as awareness, but also that it was not clear to them what kind of spots that needed attention. A large proportion of the interviewed men remembered and had read the pamphlet in Step 2. Many reported having kept it and a few had thrown the pamphlet away; one man thought that it was not up to date, and some had no comments at all. In a systematic review,[23] the effects of measures to increase awareness and early detection of cancer conclude that there is some support for the fact that personalized advice can raise awareness of cancer. But the evidence is limited regarding the effect of interventions targeted at the population. Studies with longer follow-up are lacking.[25] The men in the current study get a pamphlet every 5 years—65, 70 and 75 years of age. This is probably too infrequent but cost-effective as it occurs simultaneously with mailings for aortic screening.[23]

The men in the present study indicated that written information was the best and that material sent from the county council directly to their homes was the best way of receiving this type of information. The pamphlet was read by many of the men's friends and relatives, which indicates that it reached many more than the original recipients. Few of the men used the Internet as a source of information, which is congruent with research showing that older people are less likely to use the Internet to find health care information.[26,27] Patient participation in the quality improvement project is essential to achieve a high degree of information comprehensibility and usage, as confirmed by Moumjid et al.[21]

The selection of individuals in Step 1 consisted of men who had come to the aorta screening as convenience sampling. In the current study, it was important to obtain a selection of individuals that included people with lower levels of education, as this group has a greater incidence of later stage melanoma on detection.[14] For this reason, a journalist was contacted to ensure that the language was modified to reflect everyday speech and a final question scheme was devised, and we chose local health clinics supporting populations with lower levels of education. The method of conducting a large number of short interviews required very little effort on the part of the men. Many were interviewed while they waited for their aorta screening and the interviews did not take any extra time for them—a fact that probably contributed to the large number of participants.

The method of using structured interviews with open-ended questions allowed the men to talk about things in their own words. One alternative method would have been to devise a questionnaire to obtain answers but the interviews and open-ended questions reinforced and enriched the information we received. For example, several men spontaneously brought up the importance of having the county council send out information.

We decided it would be good to wait a couple of months on average to investigate whether or not the men remembered the pamphlet after some time had passed.

The credibility of the study is reinforced by the large amount of data collected: 80% of all the men who came to the aorta screening in Step 1 were interviewed. The reliability of the interviews is based on the fact that the interviewers wrote down the most important elements of what the men said, and that the texts were read and sorted by both the first and third authors. Quantitative content analysis as a method aims to facilitate generalizability of larger amounts of data, and in this study we used summative content analysis. Sorting and analysis should be objective and systematic but one is often forced into subjective interpretations. The authors are aware of their pre-understanding, and credibility might have been further enhanced by the participation of an independent assessor.

Documenting data in an Excel file and categorizing responses during the analysis was a simple and transparent method, but no material was audio-recorded, which is a disadvantage. Some of the interviews would have been better and more exact if the interviews had been recorded in their entirety. In certain cases, the interviewer repeated what the men said and asked if that was correct—if this had been done consistently, credibility would have been further improved.

The large number of interviews facilitates quantification. An alternative method in Step 2 would have been to make a questionnaire, but we decided that short interviews were the best option, as conducting a written survey of 300 people would have incurred some costs and processing the material would probably have been more time-consuming.

Conclusion

The study has highlighted that in a quality improvement project, short interviews are a simple, effective way for patients to participate. The method of interviewing, then designing information (material/pamphlets), receiving feedback, and then revising the information is uncomplicated to use and adapts information to the target group. Sending pamphlets out to older men along with invitations to aortic screenings is a good method of reaching out with information about MM. There were administrative advantages to sending out two documents in the same mailing.

Appendix A

1. Background information: age, profession/occupation, marital status
2. What do you know about malignant melanoma?

3. Do you know what to look for if you have changes to your skin?
4. Do you know what type of skin changes to be watchful of?
5. What would make you seek medical attention for a skin change?
6. Do you every check your skin/back? How?
7. Do you protect yourself in the sun? How?
8. Are you worried about getting skin cancer?
9. What worries you about skin changes?
10. How should the information be designed? In what way?
11. What is the most important thing to be informed about?

Appendix B

1. Does it tell you what you should do if you have a skin change that worries you?
2. What do you think about the amount of information? (too much, too little, just right)
3. Do you think something's missing—If so, what?
4. Does it tell you who the sender is?

Appendix C

1. Background information: age, profession/occupation, marital status
2. Did you receive a pamphlet about melanoma?
3. What did you do when you received the information material?
4. Has anyone else seen/read the information material?
5. How have you been affected by the material?
6. What do you think about getting the information sent home to you?
7. Does it worry you?
8. Feedback on the material
9. If the health authorities are going to give out information about malignant melanoma, how would you like that information?

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