


BMJ Open Recruitment of participants with pancreatic cancer to a mixed media study for optimal recruitment in an Australasian survey of pancreatic enzyme replacement

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ABSTRACT

Background Pancreatic cancer is relatively rare and aggressive, with digestion and malabsorption issues often leading to significant weight loss. Recruitment of people with this malignancy into studies can be challenging, and innovative methods need to be explored to improve recruitment rates.

Aim To describe a mixed media methodology and the outcomes used to recruit patients to participate in a binational survey.

Methods The details of the mixed media method used to identify and recruit people with pancreatic cancer are described. This method was used to investigate pancreatic enzyme replacement therapy use in people with pancreatic cancer across Australia and Aotearoa New Zealand.

Results The mixed media approach was successful in reaching 334 participants from a range of ethnicities and regions. Results showed that social media platforms were notably more efficient and cost-effective than radio and newspaper but required additional expertise, including graphic design and media strategy knowledge.

Conclusions Social media is an effective and efficient method of recruiting people with pancreatic cancer to a national survey. Studies using media to recruit patients may need to include team members with a range of skills.

INTRODUCTION

Pancreatic cancer is diagnosed in almost half a million people globally each year.¹ Despite progress in the diagnosis and management of this malignancy, the 5-year survival rate sits at approximately 12%.² Malignancies of the pancreas affect the exocrine function of this organ, leading to a reduction in pancreatic enzyme secretion or the inability for the enzymes to reach the duodenum.³ This results in a high percentage of malabsorption for people with pancreatic cancer. Malabsorption can cause symptoms such as bloating, wind, weight loss, abdominal pain, diarrhoea and nausea, leading to a decreased quality

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Members of the research team had strong networks with relevant clinicians across both countries that could be used for dissemination.
- ⇒ The research team had little experience with this type of recruitment and learnt from experience during the recruitment phase which required a flexible approach.
- ⇒ There was potential to miss participants without access to devices or the internet.
- ⇒ Social media favoured the younger generations and those with the resource to fund devices and ongoing costs.
- ⇒ This patient population may also have a considerable symptom burden, leading to an inability to complete or see the relevance of completing a survey.

of life.^{4 5} Pancreatic enzyme replacement therapy (PERT) has been shown to improve symptoms and quality of life and possibly prolong survival in patients with pancreatic malignancy.^{4 6}

PERT is effective, well tolerated and recommended in international guidelines.⁷ A recent systematic literature review highlighted the paucity of evidence and use of PERT globally.⁸ In Australia and New Zealand, PERT is funded and available. However, anecdotal evidence would suggest the medication is possibly still not being used at appropriate rates. The need for information about prescribing rates, dosing regimens and side effects is required to ensure the best possible outcomes for patients with pancreatic malignancies.

Palliative care research has traditionally faced challenges due to funding priorities, recruitment difficulties and participants with rapidly changing physiology.^{9 10} Clinical trials are costly and require extensive infrastructure to ensure high-quality outcomes. In



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palliative care, resources to conduct large, complex trials are limited.¹¹ Various methodologies are therefore used such as qualitative, cohort and mixed methods. A recent editorial in Palliative Medicine described the importance of reporting palliative care study methodologies to help guide future research design.¹² Most people diagnosed with pancreatic cancer are palliative at diagnosis. Study recruitment for this population is inherently difficult as there is a narrow window of opportunity in a small pool of potential participants before their condition deteriorates.¹³

With the challenges of palliative care research and the limited ability to access participants with pancreatic cancer, innovative research methodologies are needed. Research design that enables data collection from people with pancreatic cancer and their experience of PERT will inform implementation strategies of best practice at both a community and clinical level. The aim of this study is to describe the methodology used to recruit adults with pancreatic cancer in Aotearoa New Zealand (ANZ) and Australia using a mixed media design. While social media recruitment strategies have been successful in some settings,^{14 15} there is a perception that the palliative care population is often elderly and, therefore, less likely to be engaged in this type of modality.¹⁶ The research team will outline findings related to recruitment, the strengths of this mixed media approach and the challenges faced to inform future research design.

METHODS

Questionnaire development

This study was a population survey across ANZ and Australia. The target population of the questionnaire was adults aged 18 years or older diagnosed with pancreatic cancer currently living in either country. The survey instrument was developed by a multidisciplinary team including dietitians, doctors and consumers which focused on knowledge, beliefs and practices pertaining to PERT. The full survey (online supplemental file 1) included 32 unique question items and was administered via Qualtrics (Provo, UT). The questionnaire was piloted by both the research team and consumers to check for comprehension and clarity. Survey items collected data on the following:

- ▶ Demographics of the respondent
- ▶ Knowledge of PERT
- ▶ Dosage of PERT
- ▶ Symptoms of malabsorption prior to beginning PERT
- ▶ Symptom improvement after beginning PERT
- ▶ Side effects from PERT

Māori (Indigenous peoples of ANZ) consultation occurred throughout the development of the questionnaire to ensure Māori engagement in the study was optimised. Consultation with Indigenous peoples of Australia did not occur.

Changes were made to the questionnaire in response to feedback from those testing the instrument. Initially,

participants were asked a single screening question ‘Have you heard of pancreatic enzyme replacement (PERT), for example, CREON prior to this study?’ The research team then recognised that there were another group of participants who had heard of PERT but not been started on enzymes. As the survey objective was to gather information on the prescribing and use of PERT, a second eligibility question was added which excluded this group. The second eligibility question was ‘Have you been started on pancreatic enzyme replacement therapy (PERT)?’ to allow the research team to understand prescribing practices. A negative response to either question directed participants to a ‘thank you’ message and a webpage with a link to a PERT patient information brochure designed by the research group. Eligible participants who wished to complete the survey in more than one sitting were able to resume the survey at any time by reusing their own personalised link. Partially completed surveys were automatically recorded if no activity was observed for 1 week.

All study materials and procedures, including questionnaire and advertisement images, were submitted to University of Otago Ethics Committee (Human) review. The study was ratified by the University of Technology Sydney (UTS) Ethics Committee.

Recruitment strategy

Recruitment across ANZ and Australia required a flexible and adaptable strategy due to different health systems and local research processes. The traditional methods of recruiting through clinicians and via hospital departments were deemed insufficient to reach the wider pancreatic cancer population who may not be engaged with these services. A multimedia strategy for participant recruitment was designed by a research team member (AK) with a communications background. Initially, the research team focused heavily on the use of traditional media such as radio and newspapers, the rationale being that eligible participants would likely be older and therefore more likely to interact with these forms of media. These methods proved costly and unproductive in regard to translation into survey responses.

Social media platform accounts were then organised by a research team member (PM) and linked to a webpage located on the UTS website. Social media platforms included Facebook, Instagram, Twitter and LinkedIn. Google AdWords were also used later in the campaign. The research team created and populated a Facebook page called Aotearoa Australia Pancreatic Enzyme Replacement Therapy (ASPERT) research group, with the intention of using this for recruitment as well as study updates and the building of general awareness of this treatment option. The associated Meta Business Suite was used to develop paid advertisements shown to selected audiences across Facebook and Instagram.

Relationships were formed with consumer organisations such as Palliative Care Aotearoa New Zealand (PCANZ) and the National Gut Cancer Foundation in ANZ. To ensure the research team achieved a representative study

population, the Māori advisor contacted indigenous organisations such as the Māori Women's League and Māori health providers within each region of ANZ. The Whipple's Warriors in Australia contacted the research team early in the recruitment period, and a reciprocal arrangement occurred with social media posts and information being shared. The Australian Pancreatic Cancer Foundation (PanKind) hosted a free online seminar which two members of the research team hosted, which led to survey completions. Throughout the recruitment process, these support groups encouraged survey participation from their members by posting on their Facebook groups as well as sharing video resources from the ASPERT team.

Recruitment budget

Approximately \$5600 was initially budgeted for marketing the study, over a recruitment period of 6 months. The overall marketing objective set for the advertisements was completed surveys. A secondary objective was the number of views of our assets, which potentially could correlate with an increased awareness of pancreatic cancer and PERT in the general population.

In establishing a budget for the advertisement, Meta required the selection of an optimisation focus for advertisement delivery. The 'link clicks' optimisation strategy was chosen to best use our budget and show our advertisements to the audience most likely to engage. An initial daily budget of \$7.50 per country was set for the first day of advertising. The amount was manually adjusted throughout the recruitment period based on monitoring of the response rate in ANZ and Australia. This daily budget reflected an approximate amount Facebook would spend on distributing the advertisement each day. If the algorithm detected a higher recruitment potential on a specific day, it may spend up to 25% above the daily budget. However, it would not exceed the stipulated daily budget when averaged across the week meaning over a 7 day period not more than \$52.50 would be spent.

Meta advertisement allowed the selection of audience demographics based on data collected on users. For the broad demographical selections, we set locations as ANZ and Australia, the age ranges from 40 to 65+ and to all genders. For our initial advertisements, the research team selected detailed targeting categories including interest-based options such as 'pancreatic disease', 'diabetes health' and 'digestive enzyme.' The research team also kept 'Advantage detailed targeting' on, which allowed our advertisements to be shown to people outside of our targeted demographic where it may perform well in relation to our campaign goal of lowest cost per click. During the recruitment campaign, Facebook changed the guidelines on interest-based options, and the research team was required to broaden the categories.

In addition to the main advertising campaign, the research team improved our reach and link clicks by 'boosting' posts from our Facebook page. 'Boosting' involved allocating money to a particular post, so it was

highlighted in a target audience's Facebook feed. These posts were varied and included informative videos about tips for taking PERT, preliminary findings from the survey and awareness posts about pancreatic cancer. Facebook allocated a specific budget for selected posts to use as short-term advertisements. Most often the research team set the budget at approximately \$50 and ran the post for 4 days. These posts would then show as ads across Facebook and associated platforms.

The research team also used Google AdWords to set up search-word triggered advertising that would be displayed at the top of a Google search. This involved creating keywords that would prompt our advertisement to be shown. Phrases such as 'pancreatic cancer', 'pancreatic enzyme replacement' and 'pancreatic cancer research' were used. The research team then set up a simple text advertisement with the link to the survey.

Advertisement design and evaluation

In designing the assets for the Facebook campaign, the 'single image' format was selected. Facebook then prompted the creator to add media, primary text, headline and a description as well as the website URL which was displayed and linked by a 'call to action' button. The research team ensured that wording for our primary text was simple and brief and that headlines were accurate and striking. The team used the 'optimise creative mode' which allowed the inputting of various headlines and text. The programme then optimised which version of the ad to display to individuals.

The research team initially began with an 'A/B Test' which allowed comparison of results between two slightly differing advertisements. The measured parameter was set as cost per link click, with each advertisement being shown with a 'learn more' button as our 'call to action'. This opened a website link to the UTS which hosted a generic study page. With the 'A/B Test', an image-based advertisement was created and compared with a block colour background with text type advertisement. This was set to run with a budget of \$15 per day for 5 days as a short, inexpensive way to test survey completions. The more effective advertisement was the image-based option, with a cost per click of \$0.14, and it was decided to continue using this media. As an example, in one version of the advertisement, the image of a torso with the pancreas highlighted was displayed to draw people's attention.

The 'boosted' post-type advertisements were created using Canva (Canva Pty Ltd, Perth) and were a mix of videos and infographic style posts. PM developed an ASPERT brand pallet which allowed the colouring of the assets to be cohesive across posts (figure 1). Most of these posts had a similar banner style with a 'Learn more' button alongside the survey link.

Recruitment adjustments

Recruitment adjustments were required as survey completion started well then tapered off after a few months. It also became clear over time which modalities were

What is the most Creon capsules I can take in a day?

85kg man
max. dose =
34 Creon
25,000/day

65kg woman
max. dose =
26 Creon
25,000/day

“

Within 2 or 3 days of starting to take it I felt a lot more **energetic and alert and alive** and could focus and concentrate before I couldn't - on anything.

PANCREATIC CANCER PATIENT, ON STARTING PERT
(PANCREATIC ENZYME REPLACEMENT THERAPY)

Tips for taking PERT

With Helen Brown (Dietitian)

ASPERT

Figure 1 Advertising assets in ASPERT brand pallet.

more successful and cost-effective. Monitoring of views, impressions and clicks allowed the research team to focus time and money into more effective methods. The team increased the budget and boosted more assets around particular relevant events such as Pancreatic Cancer Awareness month. The budget, therefore, needed to be flexible over the whole recruitment period.

Over time, it became obvious that Australian advertisements were not translating to survey completions and therefore required further adjustments. The daily budget across all social media platforms for the Australian advertisements was increased, and the team ensured that the wording was Australia-specific. We also selected the best delivery system to optimise placements across Facebook and Instagram including across newsfeeds, stories, in-stream video and marketplace. In creating our advertisements after the initial test, the research team decided to create two separate ad sets under the same campaign for the different countries. This allowed wording to be country-specific and for budget alterations in response to recruitment numbers. A step-by-step guide designed by the research team in using mixed media to recruit

participants for a study is included (online supplemental file 2).

Patient and public involvement

The development of the research question was informed by consumers on the wider research team and previous study findings from the same team.¹⁷ The survey instrument was reviewed by consumers, and their feedback led to changes in the design. Patient advocate support groups were fundamental to the dissemination of the survey. The results will be disseminated through similar channels.

RESULTS

Participant characteristics

A total of 334 participant responses were recorded, of which 199 were from Australia and 135 were from ANZ. This includes partial and full responses. In ANZ, 135 participants consented with 109 (80%) filling in one demographical detail or more. In comparison to the demographics of people diagnosed with pancreatic cancer in Australia and ANZ, the participants were

Table 1 Characteristics of participants with pancreatic cancer who engaged with the national survey of PERT usage

	Aotearoa New Zealand n=109	Australia n=199
Age (%)		
20–29	4 (3.67)	0
30–39	2 (1.83)	3 (1.68)
40–49	12 (11.01)	9 (5.03)
50–59	18 (16.51)	44 (24.58)
60–69	48 (44.04)	66 (36.87)
70–79	23 (21.10)	48 (26.82)
80–89	1 (0.9)	9 (5.03)
90+	1 (0.9)	0
Gender (%)		
Female	64 (58.72)	95 (53.07)
Male	45 (41.28)	84 (46.93)
Non-binary	0	0
Area (%)		
Major urban area (100 000+)	43 (39.45)	62 (34.64)
Large urban area (30 000 to 99 999)	15 (13.76)	38 (21.23)
Medium urban area (10 000 to 29 999)	15 (13.76)	21 (11.73)
Small urban area (1 000 to 9 999)	11 (10.09)	30 (16.76)
Rural (300 to 999)	16 (14.68)	18 (10.06)
Remote (<300)	2 (1.83)	6 (3.35)
Did not answer	5 (4.59)	4 (2.23)

more likely to be female and younger.¹⁸ The over-75 age group usually represents over 40% of all those diagnosed with pancreatic malignancy.¹⁸ In this study there was low participation from this group.

All the regions of ANZ were represented except the West Coast, the smallest district. Similarly, in Australia all states participated except the Northern Territory. Sixteen per cent of participants in ANZ identified as Māori; this is only slightly lower than the national average (17.4%).¹⁹ Just under 2% of the participants from Australia were identified as indigenous Australians, with the national average 3.8%.²⁰ An overview of participant characteristics is shown in table 1. In both countries, but particularly ANZ, participants were more likely to be living in rural populations than the national average which sits at approximately 13%.^{21 22}

Recruitment outcomes

Participants were asked how they had heard about the survey at the commencement of the questionnaire. The ASPERT social media pages, assets and paid advertising were the most effective recruitment modalities throughout the study across ANZ and Australia, making up 61% and 76% of respondents, respectively (figure 2).

Other modalities included newspaper advertisements and broadcasting on local radios. As our recruitment strategies were modified after the release of our survey, we did not have a specific ‘newspaper’ or ‘radio’ option to our ‘How did you hear about our survey question?’. In the free text section of the survey, three respondents indicated they were recruited via the newspaper, and five participants through the radio adverts.

The timeline of participant numbers can be tracked across the recruitment period of different media types to

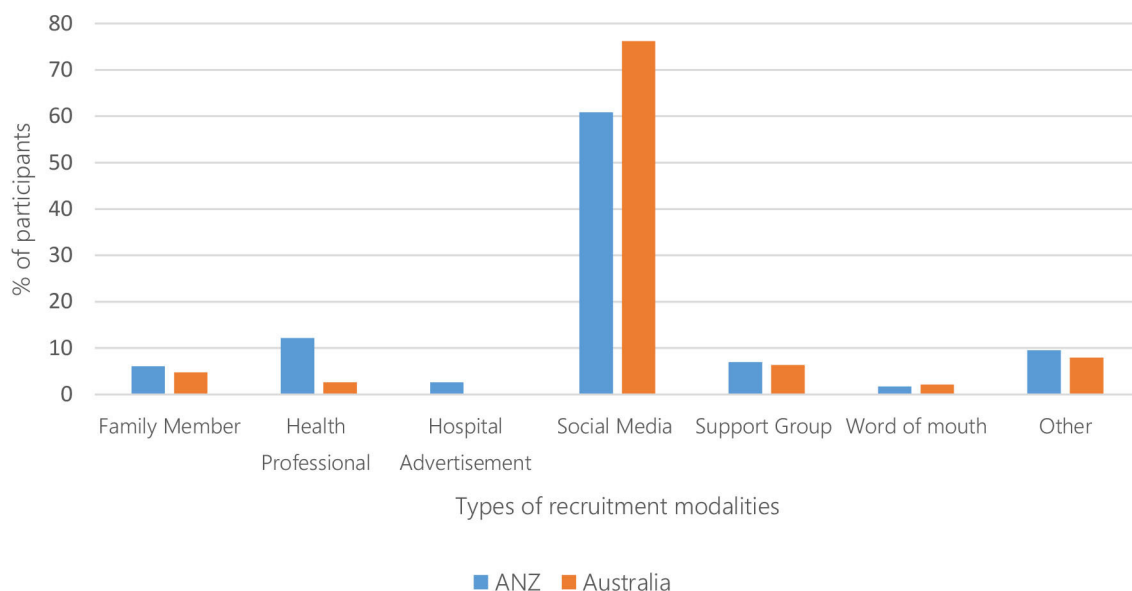


Figure 2 The percentage of participants recruited to the PERT survey per modality.

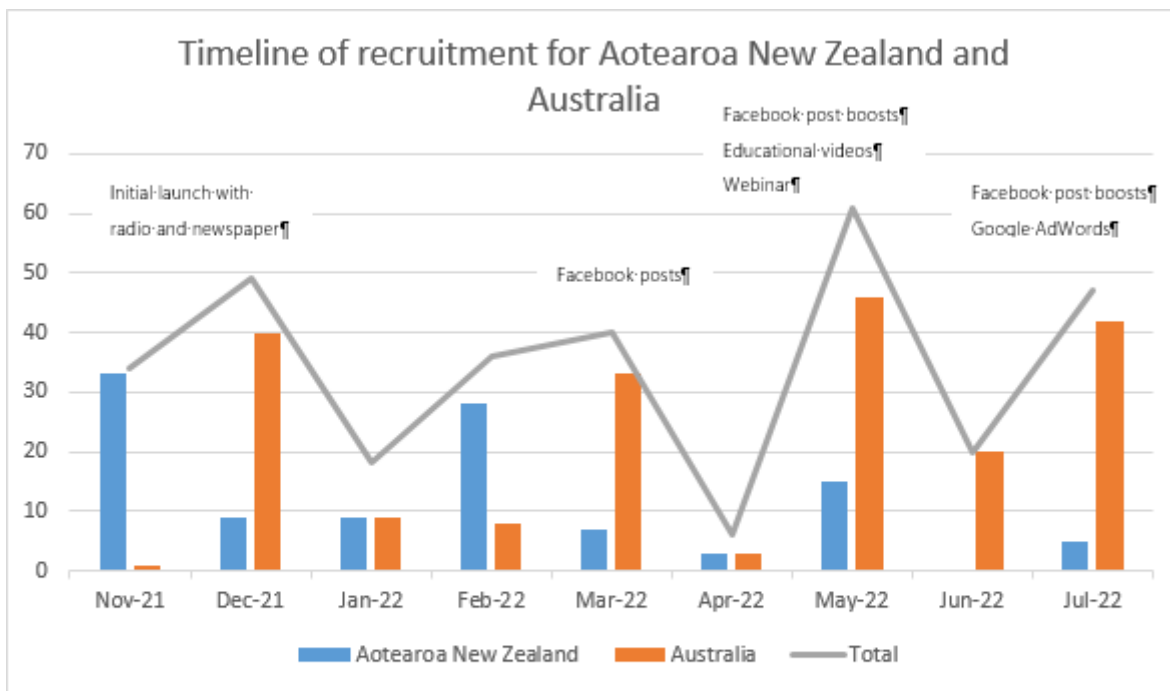


Figure 3 Timeline of recruitment of participants to the PERT survey across Aotearoa New Zealand and Australia

Figure 3 Timeline of recruitment of participants to the PERT survey across Aotearoa New Zealand and Australia.

record what modality was the most effective (figure 3). There was an initial boost as the campaign was launched and research member networks disseminated the information. The numbers of recruits dropped off in January so Facebook posts were created and social media was boosted. The large increase in Australian participants in May was due to the webinar hosted by PanKind, the Australian national consumer group for pancreatic cancer.

A cumulative total of 333812 individuals were shown ASPERT ads or boosted posts resulting in a total of

18790 clicks. Analysing the data, the conversion rate of individuals that clicked on the advertisement who then proceeded to complete a survey was estimated to be 1.5%

Cost analysis

The research team spent a total of \$7209.85 on advertising, with \$3994.40 across Facebook, Instagram and Google AdWords. The total cost per click was \$0.21 across all these formats (total of 18790 clicks). Using this data the team found that it cost \$14.17 on average per survey

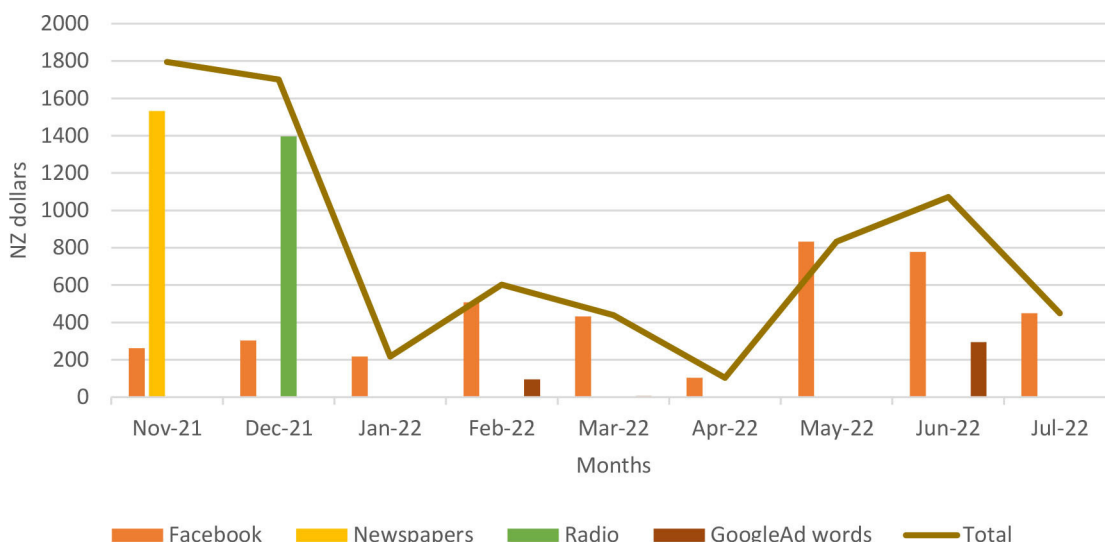


Figure 4 Timeline of costs associated with each media modality in recruitment across Australia and New Zealand.

response for participants who heard about the survey through social media.

Early in the campaign, the ongoing Facebook advertisements cost per click was on average lower (at around \$0.12), while later in the campaign, this was higher (at around \$0.25). This may be because, by the end of the campaign, people had already seen the advertisement and eligible participants had already clicked. The most cost-effective marketing strategy (lowest cost per link click) was the ongoing Facebook ads which had an average cost per click overall of \$0.17. In comparison the boosted posts had an average cost per click of \$0.44, and the Google AdWords cost per click was even more expensive at \$0.91. Overall, \$482.53 was spent on advertising through Google AdWords. The advertisement was displayed 11 268 times and 529 clicks were made to the survey link. This would support that a low daily budget long-term advertisement on Facebook was the most cost-effective format for advertising (figure 4).

Overall, on post 'boosts' we spent \$653.74 and reached 36 216 people, with 1472 link clicks. The purpose of these posts was primarily to recruit participants for the survey, but they were also educational, and the research team hoped they would inform and increase awareness of pancreatic cancer and PERT.

Throughout the mixed media campaign, the research team advertised an email address participants could contact for feedback on the study, or requests for support. Numerous emails were received with patients and their families sharing their stories, requesting advice about symptoms and PERT use. The team were able to link people with support groups, provide information about where to find help and suggest ways to educate their own clinicians.

DISCUSSION

Using a mixed media methodology, this study has demonstrated that the use of social media is a more successful and cost-effective approach than the use of radio or print media in recruiting people with pancreatic cancer to participate in survey research, in both ANZ and Australia. The research team included a member with graphic design skills and another with communication expertise which was invaluable to the flexible media strategy required to reach a small number of eligible and diverse participants across two countries.

Comparison with current literature

The use of media to recruit patients for medical research studies has been used since the late 1970s, first seen in the large aspirin trials.²³ Forty years later, social media was launched into the world, reshaping the communication landscape and changing the way healthcare is accessed and delivered.²⁴ In 2016, Topolovec reviewed the use of social media in medical research recruitment.²⁵ This review reported that only 12 out of 30 eligible studies in the literature reported social media to be the most

effective method for reaching potential recruits. However they also reflected that social media was superior in observational studies and for locating hard-to-reach populations. The recruitment of people with pancreatic cancer, a relatively rare malignancy, could be classified as a difficult-to-reach population.²⁶ There is little literature describing how palliative care research teams have navigated the usage of social media for recruitment to studies, including hard-to-reach populations.

Our research team initially favoured traditional forms of media secondary to the perception that older people, who have higher rates of pancreatic cancer, do not use social media. However, research demonstrates that the elderly population are accessing health information more frequently on social media sites²⁷ and will engage with research projects through this medium.¹⁵ Our study revealed two thirds of the participants were over 60 years old, all of the questionnaires were completed online, and social media was the most popular recruitment method. However, few in the older age groups were reached by this method.

Participant characteristics also revealed our study reached both genders, rural/remote regions and the indigenous peoples of ANZ at a rate close to the national average, with less success in Australia. Previous studies have recruited an over-representation of European females to these types of studies.²⁸ This study had a relatively low average cost per click (\$0.21) in comparison to other studies, with a similar to lower cost per survey (\$14.17).²⁸

The successful use of social media platforms to recruit people with pancreatic cancer may reflect the changing behaviours of the public in relation to their own health and treatment.

Conclusion

The use of mixed media to recruit patients with pancreatic cancer to complete a survey study appeared to be successful. Social media was the most efficient and cost-effective method for reaching the target audience. Hard-to-reach populations were also engaged in the study, in representative numbers across ANZ and Australia. Research teams undertaking this type of study should consider including team members with graphic design and communication skills.

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Contributors AL, HB, MA and VY conceptualised and designed the study. AL, CC, PM, HB and AK were extensively involved in the media strategy and communications. AL, CC, PM and AK conducted data collection. AL, CC, CM, PM, KC, JW and AK analysed participant and recruitment data. AL, CC, VY, MA, JW and PM drafted the preliminary manuscript. All authors contributed significantly into manuscript drafts and approved the submitted version. AL is the guarantor of this study

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Patient consent for publication Not applicable.

Ethics approval This study involves human participants and was approved by University of Otago Ethics Committee (Human). Participants gave informed consent to participate in the study before taking part.

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