

Format and readability of an enhanced invitation letter did not affect participation rates in a cancer registry-based study: a randomized controlled trial

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Abstract

Objectives: To assess the effectiveness of an “enhanced” invitation letter in increasing participation in an Australian cancer registry-based study and assess the representativeness of the study sample.

Study Design and Setting: Eight hundred hematological cancer survivors, diagnosed within the last 3 years and aged 18–80 years at recruitment, were selected from one Australian state-based cancer registry. Half were randomly allocated to receive the standard invitation letter (control group). The remaining half received a modified invitation letter, incorporating content and design characteristics recommended to improve written communication (intervention group).

Results: Of the 732 eligible survivors, 268 (37%) returned a completed survey. There was no difference in participation between the intervention ($n = 131$, 36%) and control groups ($n = 137$, 38%; $P = 0.53$). Participants were representative of the population for characteristics assessed, except for age group at diagnosis. Survivors 50 years or older at diagnosis had higher odds of returning a completed survey, 50–59 (odds ratio [OR]: 2.53; 95% confidence interval [CI]: 1.47, 4.35), 60–69 (OR: 2.69; 95% CI: 1.58–4.58), and 70–80 (OR: 1.90; 95% CI: 1.07–3.35), than survivors aged 15–39 years at diagnosis.

Conclusion: An enhanced invitation letter was not effective in increasing participation of hematological cancer survivors in an Australian cancer registry study. The study sample was moderately representative on variables assessed, with age group at diagnosis the only variable associated with participation. Research should evaluate strategies to increase participation in registry studies and focus on tailoring techniques to patient's age. © 2013 Elsevier Inc. All rights reserved.

Keywords: Patient information; Patient recruitment; Cancer registry; Patient letter; Patient communication; Randomized controlled trial

1. Introduction

In Australia and many other countries, it is a legal requirement that all cancer diagnoses are notified to the relevant cancer registry [1–3]. Population-based cancer registries collect demographic and disease information relating to all

cancers diagnosed in a defined location [2,4]. Cancer registries thus provide an opportunity to recruit large, representative, and unbiased samples of cancer patients for empirical research [2,5]. However, studies have reported low response and participation rates when using cancer registries for recruitment [6–8].

1.1. Why use written communication to increase participation rates?

Written communication (i.e., invitation letters and information sheets) is used in most research studies to inform and invite potential participants. Despite a number of

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What is new?

Key findings

- An enhanced invitation letter did not affect participation rates, with a similar percentage of survivors who received the standard invitation letter (38%) returning a completed survey as those who received the enhanced letter (36%).
- However, low response rates may not have substantially affected study representativeness, with age at diagnosis the only variable assessed, which differed between participants and nonparticipants.

What this adds to what was known?

- This study emphasizes the difficulties in recruiting patients from cancer registries.

What is the implication and what should change now?

- Strategies that effectively increase study participation, which can easily be adopted into standard registry recruitment methods, should be identified.
- The representativeness of a study sample should be assessed on as many variables as possible to allow for identification of potential bias, particularly when faced with a low response rate.

guidelines and recommendations on how to improve written communication, health-related information is often written above an eighth-grade reading level [10–13] (approximately 13 years [9]) which has been suggested as an appropriate reading grade level for written health communication [14]. Study materials, such as consent forms, used for health research have been shown to be complex and difficult for patients to understand [15]. Their length and complexity has been suggested to be, in part, influenced by the regulations and requirements set out by institutions relating to the level and type of detail that must be included in these documents [10,16]. This may also be true for standard invitation letters that are sent from cancer registries to patients. In an unpublished analysis performed by the authors, it was found that the patient invitation letters designed for a larger study using the standard template of several Australian state-based cancer registries had an average reading grade level of 12.8 (more than 17 years [9]), included long sentences with a mean of 22.1 words and did not contain headings. Patient communication needs to be coherent and comprehensive to ensure that it is easily understood by the intended population. If communication is not understood by the target audience, they may be less likely to pay attention to the material [17], to understand key points of the research, and therefore may be less likely to agree

to participate. Consequently, altering the content and/or presentation of written communication sent to potential participants may help to increase participation rates.

1.2. Does “enhanced” written communication influence behavior?

Certain design and content characteristics of written information have been suggested to increase readability and comprehension [17–23]. Design characteristics are those that relate to document design such as layout, font, and use of visual material [23,24]. Content characteristics include the use of active voice, short words, and sentences, and are argued to reduce the complexity of written materials [18,23].

Questions still remain as to whether the design and content characteristics of written communication influence people’s behavior [17]. Studies investigating the influence of written communication on behavior in real-world settings have produced mixed and often unfavourable results [10,25,26]. For example, several studies attempting to increase cancer screening behavior by providing participants with enhanced or simplified brochures have been unsuccessful [10,26]. However, we are aware of only a few published studies that have examined the effect of incorporating such design and content characteristics to improve the readability and comprehension of study invitation letters on study participation rates [27–31]. None of these identified studies have been conducted in the area of health.

1.3. Are high participation rates the only thing to consider when recruiting from population-based cancer registries?

In theory, population-based cancer registries should offer access to an entire population of cancer survivors; however, certain subgroups of cancer patients, including younger patients, older patients, men, and racial and ethnic minorities, have been underrepresented in previous studies [7,8,32]. Regardless of the response rate if a study sample is not representative of the population being researched, the validity and generalizability of the study results to the wider population are reduced. Although a high response rate increases the chance of obtaining a representative sample, it is not a guarantee. For example, several cancer registry-based studies that have recorded modest response rates above 60% have evidence of potential response bias, with differences found between some responder and nonresponder characteristics [32–34]. Therefore, in addition to trying to increase response rates to cancer registry-based studies, it is important that researchers strive to obtain a representative sample. Although this is not always possible, studies should attempt to assess the representativeness of their sample on as many characteristics as possible. Doing so will provide an understanding of the limitations of the data and allow for appropriate conclusions to be drawn.

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