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Patient Perception, Preference and Participation

Innovating information-delivery for potential clinical trials participants. What do patients want from multi-media resources?

Catherine Shneerson *, Richard Windle, Karen Cox

University of Nottingham, School of Nursing, Midwifery and Physiotherapy, Queens Medical Centre, Nottingham, United Kingdom

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ABSTRACT

Objective: To discover whether the provision of clinical trials information via a multi-media platform could better meet the needs, preferences and practices of potential cancer trial participants.
Methods: A mixed qualitative and quantitative questionnaire was delivered to 72 participants from cancer support groups to elicit views on the provision and design features of multimedia resources in delivering clinical trials information.
Results: Perceived lack of information is an expressed barrier to clinical trials participation. Multimedia resources were viewed positively as a way to address this barrier by most potential clinical trials participants; in particular by helping to align information to individual needs, promote active engagement with information, and by allowing more control of the learning experience. Whilst text remained the most valued attribute of any resource, other highly rated attributes included the resource being simple to use, easily accessible, having a clear focus, incorporating examples and visual aids, and being interactive. Provision of support for the learning resource was also rated highly.
Conclusion: As in other areas, such as education, multimedia resources may enhance the delivery and acceptance of information regarding clinical trials.
Practice implications: Better alignment of information may have a positive impact on recruitment and retention into clinical trials.

1. Introduction

Although participatory clinical trials are the mainstay of research within many areas of oncology, recruitment of sufficient participant numbers remains problematic. Whilst recruitment has increased over the decade, a recent study found that only a small proportion (10%) of patients become involved in clinical trials [1]. Furthermore less than one third of trials reached the number of individuals required by their statistical design [2], making their results less valid and limiting the quality and impact of cancer research [3]. Reasons for low clinical trial recruitment are multifaceted. Some relate to resourcing, such as include staffing levels, time-constraints, and attitudes [4,5]. However, the major issue identified by patients themselves is a perceived lack of information about the purpose, procedures and value of clinical trials that they have been asked to contribute to [4–6]. Consequently there is a need to re-appraise how clinical trials information is delivered to potential participants and find methods that allow greater alignment of information to the participants' requirements and preferences.

Emergent technology has transformed information delivery in nearly all aspects of life including health [7]. Indeed, there is evidence that patients are already using the Internet as a primary source of information about their conditions [8] and its reporting of clinical trials has raised their profile [9]. Therefore, it is possible that well targeted electronic resources could improve knowledge of clinical trials and consequently have a positive effect on trial participation. Where technology has been used in other areas such as education, industry and the workplace to support learning [10], key factors for success have emerged regardless of the specific media used. Firstly, the need for careful instructional design to align materials to the learners' needs and preferences. Secondly, the need to give learners a sense of control and ownership of their learning [10–14]. Research has shown that involving learners in the design of technology-enhanced provision from the outset can help to ensure that resources meet these criteria [15].

The benefits of e-learning have been shown in a number of previous studies [10,22,23], indicating that aspects of interactive multimedia technology appear beneficial for learning, especially

* Corresponding author at: Room 121/122 Primary Care Clinical Sciences, School of Health and Population Sciences, University of Birmingham, Edgbaston, Birmingham B152TT, United Kingdom. Tel.: +44 0121 414 5483; fax: +44 0121 414 6571.
E-mail address: CLS104@bham.ac.uk (C. Shneerson).

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alongside other multimedia resources [10,11]. However, although parallels can be drawn from examining multimedia in facilitating learning, a lack of consistent literature exists surrounding multimedia technology in improving delivery of clinical trials information. As a result the study reported here investigated the expressed and inherent preferences of potential cancer-trial participants about the design of technology-delivered clinical trials information to support clinical trial participation.

2. Methods

2.1. Questionnaire design

A mixed qualitative and quantitative questionnaire was designed (Appendix 1, see Supplementary material). Quantitative questions rated agreement with a specified statement on a four point-Likert Scale e.g. '*Strongly Agree*', '*Agree*', '*Disagree*', '*Strongly Disagree*', or selected/ranked a series of responses from a given list. Open-ended qualitative questions invited participants to give details, examples or reasons from their own experience. Sections of the questionnaire examined respondents' demographics, preferred learning modes, views of clinical trial participation, familiarity with multimedia technology and design preferences for multimedia and paper-based resources.

Face-validity was addressed by piloting the questionnaire with eight individuals aged 40–65 who were not part of the subsequent study to gain feedback on usability. Content validity was reviewed by a technology-enhanced learning expert. Questions in each section were randomly ordered to minimise likelihood of responder bias.

2.2. Ethics

Ethical approval was granted from the University of Nottingham Medical School Ethics Committee. All personal data were treated confidentially and stored securely to uphold ethical principles of research protecting participants' rights to confidentiality and anonymity [16].

2.3. Participants and data collection

In order to gain a representative population of likely clinical trial participants, the study recruited from a number of cancer support groups in and around Nottingham. The support groups were chosen to reflect the average age recorded for people with a cancer diagnosis, which is in their sixties [17]. Both men and women aged 18 or over were recruited to the study. All support group members including those with a cancer-diagnosis, carers, friends and family were included in the study. Although a cancer diagnosis may affect the way people view information transmitted to them, carers are themselves often recruited to clinical trials in similar ways to patient groups. Therefore their views on multimedia design were relevant.

The key contacts of six local cancer support groups were sought, via the Self-Help Nottingham website, to explain the study purpose and seek permission to access the sample population by attendance at meetings. All six support groups agreed to participate. The total sample size of the six support groups was 143, and as the study aimed to recruit 50 participants a 35% response rate was required. Individuals were invited to participate through attendance at support group meetings between April and May 2011, where a short presentation outlining the study purpose was given and information sheets distributed. Individuals willing to participate were asked to provide written informed consent. Respondents could either complete the questionnaire at the meeting, or return it by post.

2.4. Data analysis

Quantitative data were used to generate frequency and mode response rates. These results were used to examine differences in the way participants attributed importance to different design features of potential resources.

Aspects of three different health behaviour models, the Health Belief Model, the Theory of Reasoned Action, and the Theory of Planned Behaviour were used to provide a qualitative framework for the study, as they are concerned with risk perception and factors influencing behavioural intentions [38–40]. Multimedia use in raising clinical trial awareness illustrates a method for challenging health behaviours, providing people with information to make informed treatment choices based on their risk perception [40]. Qualitative responses were analysed using a thematic analysis approach. This was conducted by two researchers (CS, RW) to ensure greater reliability of findings. Identified themes were developed into categories and data extracted were used to support and challenge quantitative findings, aiding understanding.

3. Results

3.1. Demographics

Questionnaires were distributed to approximately 80% of individuals in each group, and the response rates are shown in Table 1. In total 72 questionnaires were returned giving an overall response rate of 50%, and a range of 23–88% (Table 1). There was a 5:9 response rate between men ($n = 25$) and women ($n = 45$), representative of the total ratio of men to women in the support groups (Table 2). The most common age bracket was 60–69 years ($n = 22$), representative of the demographics for these types of cancer (Table 2).

3.2. Knowledge and participation in clinical trials

When asked about the importance of clinical trials to healthcare 100% of respondents strongly agreed with the statement that '*clinical trials are crucial to healthcare*'. Twenty-seven percent of respondents indicated that they had previously taken part in clinical trials and 79% of these would consider future participation. Whilst 63% indicated that they had not previously taken part, a similar proportion (75%) indicated they would consider future participation. However, every individual indicated that they would expect to have full understanding of what a clinical trial involved before taking part (Fig. 1A), and 94% agreed that receiving prior clinical trials information would make them more likely to participate (Fig. 1B). Despite this obvious need for clear trials information and the generally expressed desire to take part in clinical trials under these conditions, 12% of respondents still disagreed or strongly disagreed with the statement '*I know what clinical trials are*' (Fig. 1C), which may have influenced their response regarding consideration of future participation in clinical trials.

Table 1
Participant response rate.

Support group	Group size	Responses, *n* (%)
A	40	9 (23)
B	30	7 (23)
C	25	19 (76)
D	8	7 (88)
E	25	18 (72)
F	15	12 (80)
Total	143	72 (50)