Intersecting electronic decision support with user modelling in a web-based consumer decision aid for colorectal cancer screening

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Abstract. Colorectal cancer (CRC) is one of the most common types of cancer. However, its associated mortality can be ameliorated through effective screening tests dependent on high uptake and adherence within a target population of older adults. This paper describes a developmental process to deliver specific tailored information via the web to assist individuals in making a decision to undertake screening. This decision aid aims to adopt behavioural theories to define the psychosocial variables within a user model; such a model could then be utilised to individualise tailored information to initiate and sustain a decision to undertake CRC screening.

1 Introduction

Colorectal cancer is one of the three most common cancers of Europe, North America, Northern Africa, Western Asia, South Eastern Asia and Australia [1]. In the United States, in 2003 it was predicted to account for 10% of all cancer-related deaths [2]. Similarly in the EU, CRC accounted for 13% of new cancer cases and $\sim 10\%$ of cancer deaths in 2004 [3]. In Australia CRC was responsible for 14% of cancer deaths for the year 1990 [4] and is the most prevalent form of newly diagnosed cancer [5]. Despite the prevalence of CRC, research suggests that only 20 to 40% of people in the targeted age group (50/55 to 75 years) actually screen by testing for faecal blood. Moreover, this low uptake level for screening occurs despite the fact that the most commonly used faecal tests, the faecal immunochemical test (FIT) for blood in faeces and the faecal occult blood test (FOBT, non-specific chemical detection) are easy to use, safe and inexpensive [6,7]. Tests are effective with trials indicating a 23% reduction in mortality, as well as favourable shifts towards earlier stage distribution of colorectal cancers in screening groups [8]. Other screening modalities, such as colonoscopies are also effective [9,10,11]. Trials suggest that, implementing biennial screening (and even annual screening) could reduce CRC mortality by 20% over 10

years; dependent on high uptake and adherence to regular screening. Communicating the need for CRC screening and the effectiveness of the screening tests available to the target group is thus a clearly demonstrated need. Paper based delivery of screening messages has improved uptake [14] but a need remains to test whether electronic delivery can achieve similar or improved uptake rates. The potential advantages of web-based delivery include the ability to present information in a way that is more easily navigable than paper; a capacity to use context to enhance relevance through tailoring on key variables, and the ability to provide instantaneous internet enactment of a decision to avoid difficulties that are attached to procrastination i.e. online test ordering or physician booking.

Previous work demonstrates the effectiveness of screening decision aids through improving knowledge, reducing decisional conflict and stimulating more active decision making [15]. Research suggests that this effectiveness is enhanced when information is tailored to an individual and their needs; tailored print communications are read, remembered and perceived as more relevant than non-tailored materials [16]. Recent meta-analyses comparing web- and non-web information interventions show enhanced outcomes among individuals using web-based interventions, in areas of knowledge and targeted behaviour change [17]. The web delivery of tailored information therefore poses unique development challenges; impacting on a user base and their acceptance of information systems that aim to influence screening behaviours using educational and behavioural interventions. This relates to an intended user base of age 50 years and older, with a limited but burgeoning literacy in both computer and internet technologies; ~29% of Australians aged 60 and over are reported as having used a computer in the last 12 months (2003 as reference year), 32% and 42% of those aged 55 to 64 have accessed the internet from home or from any site respectively [13].

The aim of this randomised clinical trial in development, is to determine the effectiveness of tailored electronic information delivery compared to paper-based delivery, focusing on outcomes including screening behaviour (participation, change in stage of readiness to screen), screening modality (FIT/FOBT or colonoscopy), and satisfaction with screening decision, information and delivery mode.

2 Methods

Development of the computerised decision aid will be based on behavioural theory including locus of control, risk perception, self-efficacy, response efficacy and the Precaution Adoption Process Model. It would reflect an individual's set of behavioural determinants that may require change to initiate and sustain the process of CRC screening. The ability to deliver a targeted behavioural intervention to older adults is predicated on achieving an understanding of a community who are presumed to have not benefited from the internet "dividend" (i.e. those that may not have internet literacy), the potential age biases that exist in provisioning of such information [19], and the optimal manner for presenting information to those with

cognitive (e.g. memory) and other impairments [20]. Before developing the web resource it is important to achieve an understanding of factors that describe willingness and motivation to access internet technologies by this cohort of users [21]. The technology of user modeling provides a means of delivering a tailored mix of educational content directed at an individual's specific motivation, beliefs, knowledge and other determinants that affect behaviour. A survey will be conducted in order to identify and measure individual determinants associated with CRC screening beliefs and behaviours and outcomes from this will be used to inform decision support frameworks and an individual's user model. Stage of change (readiness to screen) will also be measured at this point. Frameworks are required to be developed which address the granularity of these user models, impacted against the modes of data acquisition, to develop user models i.e. the value of "tailoring" surveys versus alternate acquisition through end user information system observations. A successful software system implementation would reflect characteristics of interpersonal communication; verbal interactivity equivalence within the individualised user model to act in the capacity of a pedagogical tool [18].

A variety of sources will be used for creating and assessing applicability of educational content and feedback messages (including focus groups, domain experts, the literature, and American Cancer Society plus Australian National Health & Medical Research Council (NHMRC) guidelines). This information will be used to develop text that describes the nature of and risk factors for CRC, the value of screening, and descriptions of testing procedures and the implications of test outcomes. Information will be personalised on the basis of name and basic personal characteristics, and also tailored to meet the specific informational needs of each user.

3 Outcome measures

Outcomes will be compared between the paper and electronic modes. The study will be powered so as to effectively compare screening uptake, but a range of additional outcomes will be included. These consist of:

- Intention to undertake screening and the screening test selected,
- Appropriateness of screening test selected as determined by comparison to clinical guidelines,
- Participant satisfaction with their decision and decision-making process,
- Satisfaction with the information provided and the mode of its delivery,
- Anxiety caused by the intervention,
- Decisional conflict, and,
- Cost effectiveness of the electronic process.

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