

# Shared decision making and decision aids in Colorectal Cancer Screening: a “mixed method” project

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## BACKGROUND

Over the past decades there has been a great interest in involving and empowering people to take care of their own health. The Ottawa Charter (World Health Organization, 1986) transformed the definition of health promotion encouraging a shift towards lifestyle and life condition changes that combined personal election with social responsibility. Since then, care models have been shifting from paternalistic approaches to **participatory models** in which patients are considered responsible and autonomous agents. People's participation can improve not only satisfaction with health care services but also quality of health indicators.



Colorectal cancer (CRC) screening offers different clinical scenarios that require active participation of the population during the decision making process. Offering increasing information based on Evidence Based Medicine (EBM) is not enough to ensure patient involvement in screening if it is not integrated in their own meaning of health and care. **Empowerment** requires a better understanding of the complex process of affective and practical aspects of screening and the resources involved.

For the implementation of the patient empowerment approach, emerges the **Shared Decision Making (SDM) model**. In SDM, healthcare professionals involve patients in a two-way flow of information, sharing comprehensive scientific evidence about the possible preventive, diagnostic and therapeutic options. Meanwhile, patients share their expectations, health and life objectives. The aim is to reach an agreement between healthcare professionals and patients after a joint assessment of the possible options and alternatives.

**Mixed methods** are specially attractive for translational research as they allow to understand interventions in the actual context of application. Participating in healthcare decisions involves clinical, organizational, social and individual aspects that ensure a broad and deep research scope that avoids fragmentation of the phenomena.

## THE PROJECT'S OBJECTIVE AND DESIGN

The aim of the project is to increase population's knowledge about CRC screening and informed participation. To accomplish this, our team employs a mixed method approach framed within the model of Shared Decision Making and Decision Aid tools that will conclude with the development of a Web Services Platform.



### Phase 1: Systematic Review of predictors of participation in CRC screening

The systematic review seeks to identify modifiable and nonmodifiable factors influencing populations' participation in CRC screening. The focus is put in **factors modifiable through interventions**, such as knowledge in CRC and CRC screening, perception of risk of suffering CRC, intention to undertake the screening, recommendations and reminders from primary care professionals, etc. The results of this phase is intended to help in the design of the following phases.

### Phase 2: Collecting patients' experiences

**Semistructured in-depth interviews** are being conducted to collect the diversity of experiences in CRC screening and prevention and the experience of patients diagnosed with CRC. The aim is to collect the diversity of trajectories in CRC prevention regarding received information, sources of information, participation motivation, clinical follow-up, motivations for adherence or abandonment, perceptions of the screening program and information needs. In the same session, participants complete to a quantitative questionnaire that collects sociodemographic variables, personal and relatives health history, CRC knowledge levels (EUROPACOLON, 2009), previous participation in screening programs and the preferences for that participation (Pignone et al., 2012). This first phase ends with **focus groups** that explore barriers and facilitators for screening both with healthcare professionals and targeted population.

**Phase 3: Development and evaluation of a Decision Aid for Shared Decision Making in CRC screening**  
A Decision Aid (DA) tool will be designed for CRC prevention, presenting the potential benefits and drawbacks of each of the different CRC screening techniques to help decision making based on personal values and preferences. Its development consist of 3 steps:

- 1. Content Development.** The preliminary content of the DA is decided with the inputs of previous phases
- 2. DA design.** The content is reviewed and assessed through focus groups with screening population and health professionals. The instrument is then modified according to the results of this assessment.
- 3. DA evaluation.** The DA is used in a real scenario and eligible people to screening are asked to answer an 8 items questionnaire with 5 Likert-scale responses evaluating: quantity, clarity and usefulness of the information, new knowledge about CRC acquired, screening, diagnosis and treatment options, risk and benefits, new questions for their healthcare professionals and DA recommendation to other people. Finally, patients are asked through 2 open questions what issues they would remove from or add to the DA.

The consolidation of the tool requires effectiveness evaluation as well. A **multicenter randomised controlled trial** in which usual screening is compared with the use of the DA is conducted.



### Phase 4: Research needs in prevention and treatment of CRC from screening population perspective

Phase 2 interviews identified population's concerns regarding screening and CRC, which will be used to uncover needs or demands for health care/service, information and research. Those identified will be consensually prioritized by a group of CRC experts, Screening Administrators, Patients' Associations members and screening participants through two online Delphi panels.

### Phase 5: Development of a Web Platform of Digital Services in CRC

The results of the previous phases will be integrated in an existing online platform, PyDeSalud, as a new module for CRC module. It will be divided in three sections: **1)** basic information and experiences in CRC screening, early detection, diagnosis and treatment; **2)** the developed DA for decision making in CRC screening; and **3)** the prioritized research needs.



Patient experiences' section is built with clips from the interviews. The clips collect the experiences and stories about CRC screening, diagnosis and treatment covering the following aspects: information, support, relationships, storytelling, disease perception and affected behaviour. The second section contains the DA, which can be downloaded. In the third section, the web presents the prioritized research themes. This section is oriented to help decision making at policy, research and health management levels and thus contributing to the define SNHS research agenda.

## THE TEAM

Formed by psychologists, anthropologists, sociologists, epidemiologists, healthcare professionals, nurses, health services researchers, and designers, this multidisciplinary team acts as the **Promoter Group** of the research and its application in the Web Platform. Their main role is to manage the research process, including the editorial control and the relationship with the rest of the participants.

The **Advisory Group** supports the development of the research during all phases of the project. This group is formed by healthcare professionals involved in CRC screening, Administrators from Regional Screening Programs, Patients' Associations and other organizations related to cancer prevention, and Public Health researchers. Some of them participated in the financial proposal as co-applicants. They provide their expertise in the screening programs by providing the policy setting, the implementation and dissemination strategy, up-to-date information on screening participation and organizational problems. The Advisory Group also participates in the research project by assessing initial research needs, identifying the profile of participants for the interviews and questionnaires, helping recruitment using their formal agendas and reviewing the web contents.

The **Scientific Reference Group** comprises healthcare experts in CRC research, members of the Colon Prev Study. The research experts are consulted by virtual means in several occasions during the research project and the web development. They collaborate assessing the initial protocol, providing relevant bibliography and reviewing the evidence presentation for the Web Platform, and they evaluate the DA once it is developed.

**Patients and screening population participants** are involved in different phases of the project in what is both an empowering process, as their expertise in CRC and screening grows, and a rich source of information and knowledge. They engage in interviews, questionnaires, in evaluating the DA and answering to the research needs Delphi and in reviewing the selection of their experience for the web.

## CHALLENGES

Partnership development and maintenance is crucial for this project. Coordinating and managing stakeholder participation requires an important methodological investment. A multidisciplinary team facilitates interdisciplinary practice that stimulates dialogue, exchange and combination of different methodological expertise. Coming from different theoretical, methodological and epistemological traditions and cultures, the groups' approach is to rely on the disciplinary contributions recognising their contributions, limits and specificities. The empowerment and SDM theories provide a common framework and the focus is put in the pursuit of the project's objectives. Tensions between disciplinary frameworks in SDM and patient empowerment, between, for example, more individual and collective approaches to participation are shared and discussed.

## SO FAR...

- The mixed methods design of the project has been sent to a journal and is under review.
- The Systematic review has been finished and the article is in process.
- We have accomplished all but one of the interviews.
- The online Web Services Platform is being prepared to integrate the CRC screening module and preliminary contents are being developed.