

## Towards informed decisions in colorectal cancer screening

Benefits of population-based colorectal cancer (CRC) screening using a faecal occult blood test (FOBT) have been well recognised. Screening using FOBT has been shown to reduce CRC mortality by 16%<sup>1</sup>. In addition, early detection of certain risk factors can prevent a more advanced disease stage. In Flanders, population-based CRC screening started in 2013, offering all eligible individuals a free FOBT (immunochemical type) which is sent to individuals' home addresses, thus no transportation required. However, CRC screening can also cause potential harms such as stress and anxiety due to false positives, a false sense of safety due to false negatives and complications of a follow-up colonoscopy<sup>3-5</sup>. Compared to benefits, drawbacks of screening are much less communicated to the CRC screening target population. This is also the case in Flanders, where there is a drive to increase screening participation, resulting in motivating campaigns that emphasize the advantages of participation (through slogans such as "deal with it before it deals with you"). As a result, an individual participates in screening based on "informed motivation" rather than "informed choice". In Europe, few studies<sup>6</sup> are working towards improved informed decision making in cancer screening whereas there is an increasing international recognition that the target screening population need to be fully aware of both benefits and harms of screening to make an informed choice about participation<sup>7-8</sup>. In Belgium, the Kom op tegen Kanker organisation has been clearly advocating for such a right to be well-informed<sup>9</sup>. However, in all regions of Belgium, there is currently no informed choice tool for CRC screening. Communication instruments have been developed for breast cancer and prostate cancer screening but have not achieved the desired effect (e.g. [www.dekeuzemaken.be](http://www.dekeuzemaken.be), a decision-aid for prostate cancer screening that does not function).

In this project, a **CRC risk stratified Shared Decision-Making (SDM) tool will be developed and formally tested in General Practitioner (GP) practices to enhance communication between GPs and vulnerable patients about CRC screening**. The aim is to provide the target screening population with balanced information about both the benefits and risks of CRC screening and ensure that their possible participation is one through an informed choice, based on evidence and in line with their values, preferences and personal risk factors.

**Active involvement of the GP** in a person's decision-making process has been shown to increase screening participation and follow-up rate in CRC screening<sup>10-11</sup>. The American Cancer Society 2018 guideline update for CRC screening places great emphasis on the importance of communication between health care providers and their patients to understand patient preferences and decisions about CRC screening<sup>12</sup>. Such decisions depend greatly on the magnitude of the potential benefits, harms, patients' values, preferences, risk perception and prior experience<sup>13-15</sup>. GPs could (1) **provide** their patients with **balanced and personalized information** to increase informed decision-making and (2) **support** patients with psychological effects of false positives/negatives results<sup>16</sup>. GPs (3) are also a gateway to better reach the **vulnerable population** and (4) influence their informed choice about CRC screening participation<sup>17</sup> by providing **logistic support**, tackling issues of language barriers, health literacy, costs, technical problems, etc).<sup>18</sup> An evaluation by Domus Medica (personal communication, 22/02/2021) showed that GPs in Flanders are willing to support their patients in making an informed choice about CRC screening participation, but **lack the right instruments** to do so. In cancer screening discussions, GPs provide information about the screening test and CRC, and their patients provide information about their risk factors<sup>19</sup>, values and preferences. In this context, an SDM tool is not meant to select a certain test for an individual or to replace practitioner consultation. Instead, it equips patients with sufficient knowledge to make informed, values-based decisions with their GPs.

Nonetheless, providing the needed information and weighing all relevant factors is a challenging task<sup>20</sup>. Although eliciting patient preferences in the context of SDM has been advocated for CRC screening, GPs often fail to comply with patients' preferences that differ from their own<sup>21</sup>. In this project, we **combine a sophisticated machine learning (AI) prediction model with a SDM tool**, which enables GPs to inform patients in a much more tailored way.

While a limited number of initiatives have started to derive and validate clinical risk prediction algorithms and SDM tools for CRC<sup>21</sup> and risk stratification in a SDM tool was perceived to be useful, GPs often failed to comply with patient's preferences, which negatively impacted patients' satisfaction with the SDM process, screening intention and participation rates. This implies the importance of developing and formally implementing such a tool, considering inputs from GPs and patients. Moreover, most of the existing risk stratification instruments have been developed for recommending a screening or follow-up strategy but less for SDM purposes.

To warrant usability, GP- and patient-friendliness and sustainability, the development of our tool will focus on:

- 1) **Co-creation:** Apart from the research team and experts, GPs and vulnerable patients will also participate in the development of the SDM tool, both on content and layout. All their needs, preferences as well as concerns will be considered during this process and the tool will be adjusted accordingly.
- 2) **Artificial intelligence (AI) and personalized risk communication:** A machine learning (AI) prediction model to predict an individual's risk of CRC based on the person's risk factors will be developed and incorporated in the SDM tool. According to IMECs 2021 e-health report, Flemish GPs (46,6%, young and old) support the use of technology and AI in their practice.
- 3) **Vulnerable population:** People with low socio-economic status and migrant background will be the centre of this project. Compared to the average population, this group participates much less in CRC screening due to language issues, 'feeling healthy' and embarrassment talking about CRC screening<sup>22</sup>. Our research will help to gain more insights into the knowledge, perception, need, preference and concerns about CRC screening of these people.