Informed Decision Making in Colorectal Cancer Screening

A computer-based decision aid for individuals with varying health literacy levels

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Dutch CRC screening programme

Ages 55-75
Invitation sent to invitees’ homes every two years
Fecal Immunochemical Test (FIT) → Colonoscopy

Informed decision making: Knowledge, Values & Behaviour

Challenging for individuals with low health literacy
Health Literacy

The ability to **access**, **understand**, and **use** health information to make appropriate health decisions
Aim research project

To develop and pilot-test a computer-based decision aid to support informed decision making in CRC screening that is usable, acceptable and comprehensible for individuals with low and adequate health literacy.
Methods

Development prototype

Alpha-testing

To assess the usability, acceptability & comprehensibility

Beta-testing

To assess changes in outcome variables after use of the decision aid
Decision aid prototype

Simple webpage
External internet agency
Built on information from the National Institute Public Health and the Environment
Based on International Patient Decision Aids Standards (IPDAS) checklist

- CRC
- Decision options
- Risk information
- Benefits and Harms
- Values Clarification
Decision aid prototype

Decision options

Emphasis on:
- It’s a personal choice
- Decision to participate or not participate
Alpha-testing

**Interviews** with individuals with low health literacy (n=15) & adequate health literacy (n=10)

Think aloud method

Thematic analysis
Beta-testing

Before/after study design

Population: Individuals eligible for CRC screening (n = 81)

Health literacy (Newest Vital Sign and or SAHL-D)
  • Low (n = 35)
  • Adequate (n = 46)

<table>
<thead>
<tr>
<th>Outcomes</th>
<th>Pre</th>
<th>Post</th>
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<tbody>
<tr>
<td>Knowledge</td>
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<tr>
<td>Attitude</td>
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<tr>
<td>Decisional Conflict</td>
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<tr>
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<tr>
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<tr>
<td>Usability</td>
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Results
Alpha-testing

Low health literate participants:
• Purpose of decision aid not always clear
• Decision to not participate not always recognized
• Difficult medical words
• Risk information difficult
• Preference for spoken text and videos
• Values Clarification Exercise difficult

What does DA mean exactly?

Some cons are not cons [for me]

So I am misled [by the information]?

The last bit [VCE] is really difficult. I would really quit, yes
Adaptations

Beslissingshulp
Bevolkingsonderzoek darmkanker

Wat houdt het bevolkingsonderzoek darmkanker in?

- Wat is darmkanker?
- Hoe voert u de ontsluitingstest uit?
- Wat betekent de testuitslag?
- Wat houdt het vervolgonderzoek in?
- Test uw kennis

- Met het bevolkingsonderzoek kan darmkanker worden voorkomen of vroeg worden ontdekt.
- Bij het bevolkingsonderzoek wordt gekeken of er bloed in de ontsluiting (poep) zit.

Meer lezen over het bevolkingsonderzoek? Klik hier.
Satisfaction with the decision aid

- Attractiveness
- Comprehensibility
- Emotional support

Low HL (n=35) vs Adequate HL (n=46)
Usability and Decision making preparation

**Usability**
- Low HL (n=35)
- Adequate HL (n=46)

**Decision making preparation**
- Low HL (n=35)
- Adequate HL (n=46)

* P value < 0.05
** P value < 0.01
*** P value < 0.001
Mean knowledge score before and after the DA

- Low HL (n=35)
  - Pre Knowledge: 12.9
  - Post Knowledge: 13.4
  - P value < 0.001

- Adequate HL (n=46)
  - Pre Knowledge: 13
  - Post Knowledge: 14.6

* P value < 0.05
** P value < 0.01
*** P value < 0.001
Mean decisional conflict score before and after the DA

- Low HL (n=35): Pre decisional conflict 25, Post decisional conflict 55.4
- Adequate HL (n=46): Pre decisional conflict 42.7, Post decisional conflict 20.3

* P value < 0.05  
** P value < 0.01  
*** P value < 0.001
Mean deliberation score before and after the DA

Low HL (n=35)  Adequate HL (n=46)

Pre Deliberation  Post Deliberation

16,7  19,8  15,2  20

***  ***

* P value < 0.05
** P value < 0.01
*** P value < 0.001
No significant pretest posttest differences were observed for:

- Attitude towards screening participation
- Intention to participate in screening
- CRC risk perception
- Anxiety
Conclusion and implications

- Acceptable, comprehensible and usable among individuals with varying health literacy and educational levels
- Significant changes in Knowledge, Decisional conflict and Deliberation
- No significant changes in Attitude, Intention, Risk perception and Anxiety
- Important first step in the development of decision support tools for individuals with lower health literacy
- Further research: Test effects on decision making in Randomized Controlled Trial
Thank you
Stage 1: DA prototype

Core Elements based on IPDAS

- CRC screening
- Decision options
- Read more & aloud
- Values
- Clarification
- Exercise
- Risk presentation formats
Welke uitslagen zijn mogelijk?

van de 1.000 deelnemers ondergaan 50 personen een coloscopie

1.000
50

4 - darmkanker

21 - gevorderde poliepen

12 - beginnende poliepen

13 - geen kanker of poliepen