

Patient Involvement in the development of a psychosocial cancer rehabilitation intervention – lessons learned

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The present project

Internet-delivered Mindfulness-Based Cognitive Therapy for symptoms of depression, anxiety and stress among women treated for breast cancer and men treated for prostate cancer

- Psychological distress among cancer survivors
 - Effective treatment: Mindfulness-Based Cognitive Therapy (MBCT)
 - Use of MBCT is limited because:
 - Lack of educated instructors
 - Practical implications for patients
- Internet-delivered MBCT (I-MBCT)



Why patients as collaborators?

- Developing the I-MBCT program
- Preparation of the Randomized Controlled Trial (RCT)
- Network: "Patients Putting Researchers to Work" under the Danish Cancer Society

→ A *"single case study"* with some overall reflections





Patient and Public Involvement in Research (PPI-R)

Shared Working Group

Collaborators



3 women treated for breast cancer
2 men – treated for prostate cancer
5 researchers

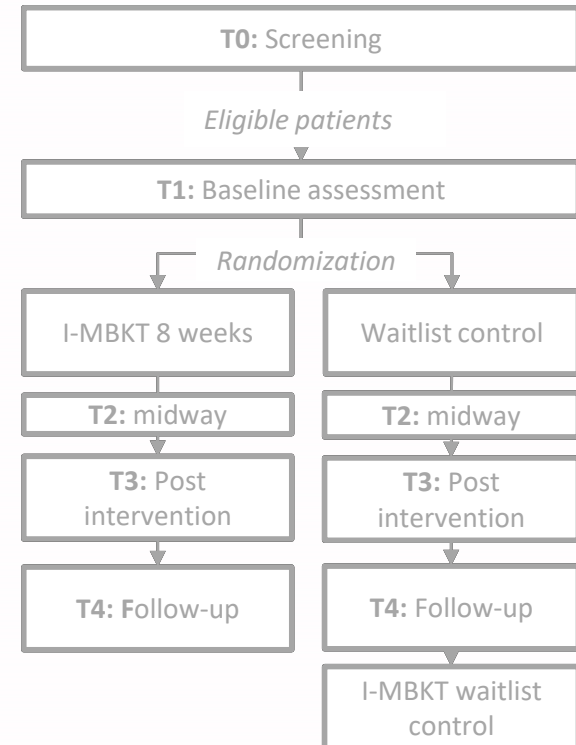
Interviews

Informants



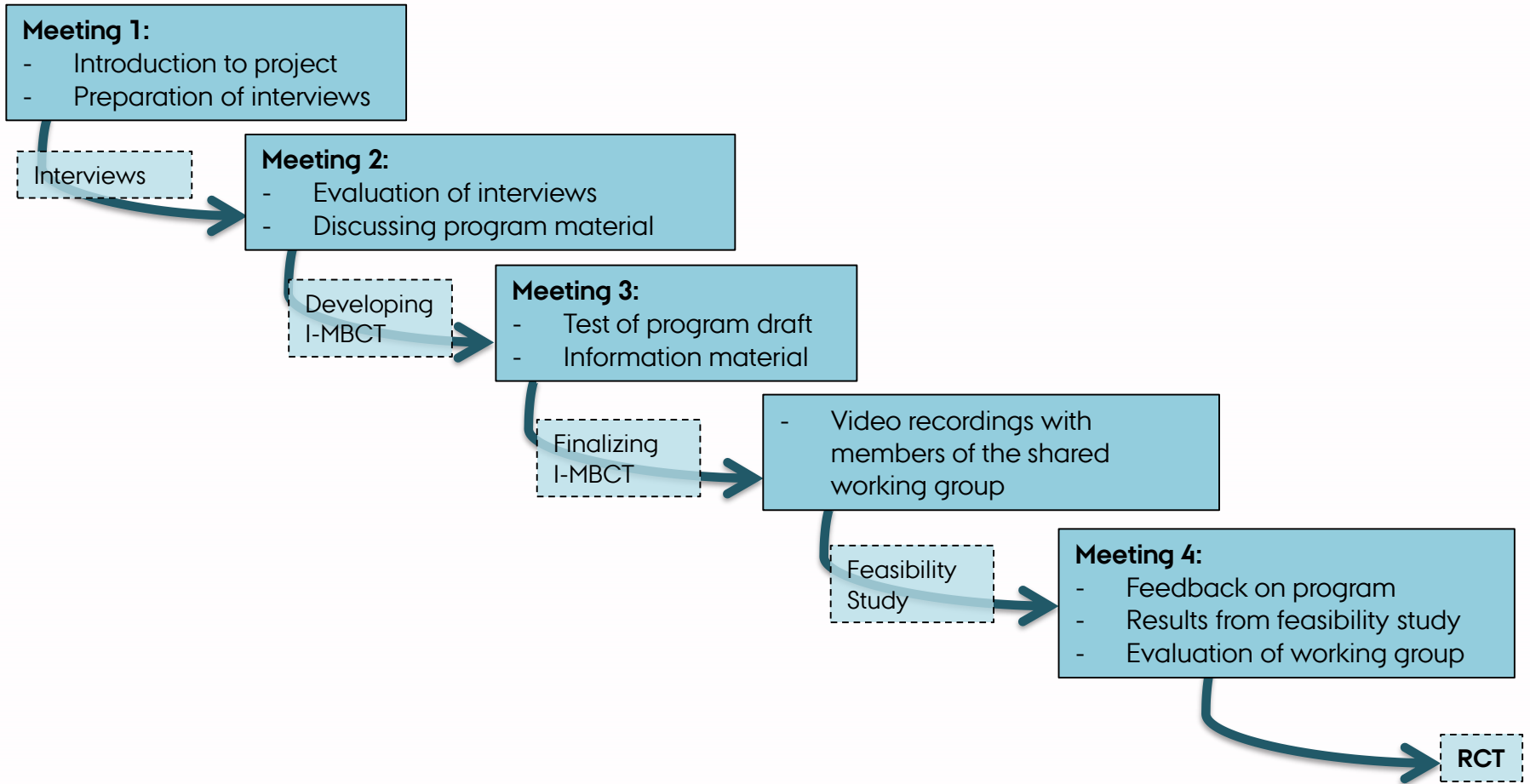
Randomized Controlled Trial

Participants





What did we do?



Material

- Meeting documents
- Transcriptions of interviews with 2 patient representatives and 3 researchers
- Primary investigator's field notes

Method

- Sandelowski's Qualitative Description Strategy
- Focus on process and impact



I-MBCT program

- Text
- Cases
- Visual structure
- Video examples

RCT

- Interview guide
- Recruitment procedure
- Information material
- Outcome measures





General trends

- Diverse socio-economic status
- Pools of trained patient representatives

What we did

- Previous study participants
- Local patient organization
- Ethical and practical challenges



www.invo.org.uk, www.propa.dk, Sacristan et al. (2016), Damholdt et al. (2016), Zachariae et al. (2017)



EPoS

Education

General trends

- Patients undergo general research training

What we did

- "Quick start"
- Facilitation of tasks
- Limiting time spent

www.invo.org.uk, Sacristan et al. (2016)



What we did

- Atmosphere
- Meal
- Introduction round
- Name tags
- Sense of equality
- Facilitation of tasks

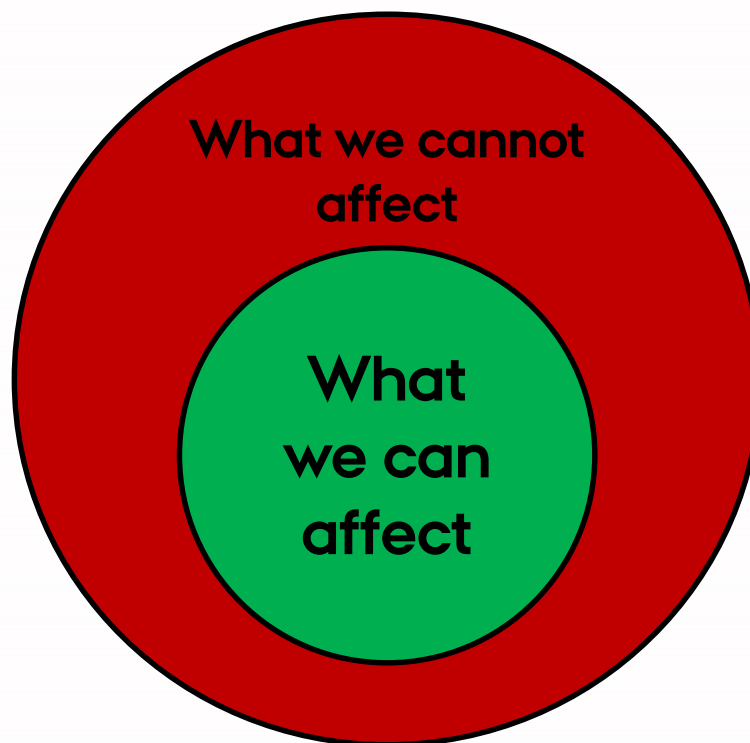


Nissen et al. (under review)



Matching expectations

”Circle of control”



Nissen et al. (under review)



EPoS

Time

General trends

- Any part of the research project

What we did

- Development phase
- Evening meetings
- Time consuming



www.invo.org.uk, Domecq et al. (2014)

General trends

- Avoid tokenistic involvement

What we did

- Differentiating work
- Home work
- Number and duration of meetings



www.invo.org.uk Domecq et al. (2014)

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 - Prof. Kirsten Lomborg
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