Supplementary material for the publication titled: Perspectives of Patient and Public partners on their involvement in Research; a qualitative study

This supplementary material is intended to provide an overview of the Patient and Public Involvement process on which interviews with the PPI partners were conducted and reported in the main paper. This overview is not intended to give a detailed reproducible account of the PPI process but is included to understand the background and context for the conducted interviews.

Purpose of the PPI process

The PPI process was initialized to improve the written patient information material for a clinical study already including patients ("Fatigue, Quality of Life, Cognitive Function and Physical Ability in Patients Suspected of Colorectal Malignancy" - ClinicalTrials.gov ID NCT04749589). The preexisting written patient information material was created solely by the professional medical researchers conducting the study. The PPI process was undertaken to improve the presentation and understandability of study information for future potential participants.

PPI partners

To qualify as a PPI partner, individuals who had a previous diagnosis of colorectal cancer or had just undergone a diagnostic colonoscopy due to suspicion of colorectal cancer, but without any malignant findings, were considered eligible for collaboration. The partners were recruited from the Department of Surgical Gastroenterology at University Hospital of Southern Denmark, Esbjerg in January 2022. Potential partners who had difficulties speaking or understanding the Danish language were excluded from collaboration. As a result of the inclusion process both former patients having experienced the actual disease of interest in the clinical study as well as members of the public with a prior negative colonoscopy were included as PPI partners [9]. No additional criteria concerning age, sex or socio-economy were imposed on eligible Patient and Public partners for collaborating in the PPI process.

Structure of the PPI process

The PPI process was a collaboration between research professionals and PPI partners. It was conducted as group meetings. Facilitation and structure of the PPI group meetings was inspired by

the INVOLVE principles [10], and by guidance from the "Research Centre for Patient Involvement" [11]. Following the INVOLVE framework the PPI process of designing patient information material is contained in the "Designing and Managing" phase of the study.

Originally, 11 individuals were recruited and divided into two groups with either five or six members. Unfortunately, one woman from group one was unable to attend resulting in a final of ten PPI partners. By chance more men than women were identified and included.

Group 1 consisted of 4 PPI partners, age 53-75 years (1 female/3 men) and group 2 consisted of 6 PPI partners, age 52-77, (2 female/4 male).

Each group met twice with a three-week interval. The meetings were facilitated by the first and last authors and supported by an internal consultant who took notes and provided the facilitators with a report on the proceedings.

In preparing for the first meeting, Group 1 had received the existing patient information material for inspiration while Group 2 received only a general information about the content of the research project. Both groups were asked to consider:

- How can we increase the likelihood that prospective patients have read the participant information material before we contact them by phone?
- What is needed for the participant information to be understandable/readable?

The PPI partners did not receive any financial support for their collaboration.

Outcome from the group meetings

Following the first meetings, drafts of the new/revised patient information material of each group were prepared by the authors and sent out so that all PPI partners received a version of both drafts. One draft based on their own group´s session, and one based on the other group´s work. During the second meeting, participants reviewed and provided feedback on both drafts.

Subsequent to the second group meeting, the final patient information material was designed without additional PPI input. The final patient information material was based on the ideas from both groups, striving to maintain fidelity to their input (Figure 1).

The participants' suggestions for changes to the patient information resulted in a material markedly different to the original (Figure 1).

Main changes were:

1. Smaller format: An A5 leaflet replaced the original material, which consisted of standard A4 paper pages.
2. Less text: The content of the written patient information material was significantly reduced to make the material more comprehensible.
3. Illustrations: Images were introduced to substitute text parts in explaining parts of the study visit.
4. Digital media: The new material included a QR code who provided a video featuring the first and last authors explaining the study.

Immediately following the final composition, the PPI-improved version of the information material substituted the original version and was used throughout the remaining part of the clinical study.