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Public involvement in the development of leaflet for colorectal cancer screening

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Purposes: To improve the participation rate in cancer screening programs, the target population needs to be appropriately informed. Although cancer screening guidelines have been published, no leaflets for the public that explains these guidelines in an easily understood manner have been developed. We attempted to develop a leaflet for the colorectal cancer screening guideline with public involvement.

Methods: Based on public/patient involvement in other clinical guidelines, an original method, unique to the Japanese cancer screening guideline, was established for the cancer screening guideline leaflet.

Results: The leaflet development process is as follows: recruitment through the website, selection of committee members, meeting including a lecture on basic knowledge for cancer screening and specific issues related to colorectal cancer screening, planning the content for the leaflet, having a professional writer write the leaflet, external review by another person through a web-based questionnaire survey, focus interview survey involving the public and a medical professional group, feedback of the results of the survey to the development committee, re-evaluation and improvement, and publication.

Discussion: Although there are several clinical guidelines targeted at patients, guidelines developed with patient involvement have been limited in Japan. There are differences between the public and medical professionals with respect to the necessary information related to cancer screening programs that need to be considered. Given our experience, there are several problems that need to be solved for the development of leaflet for cancer screening with public involvement including: the selection method for committee members, the support system for development of the leaflet, and understanding balance of benefits and harms among committee members.

Conclusion: We formed a unique method to develop the leaflet for cancer screening guideline with public involvement. By virtue of this method, other leaflets based on the Japanese cancer screening guidelines will be developed.