iPAAC
INNOVATIVE PARTNERSHIP
FOR ACTION AGAINST CANCER

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Framework for the implementation of Patient Reported Outcome Measures (PROMs) in routine cancer care

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Abbreviations

EORTC	European Organization for Research and Treatment of Cancer
ICHOM	International Consortium for Health Outcomes Measurement
iPAAC	Innovative Partnership for Action Against Cancer
ISOQOL	International Society for Quality of Life Research
PROM	Patient reported outcome measure

Set of Recommendations for PROM Collection in routine Care

To enable providers to better serve individual patients (e. g.: treatment of impaired quality of life) and to enable cancer centers to compare their own patient reported outcomes data with that of others (benchmarking), the task 4 working group of IPAAC work package 10 developed ten recommendations for PROM implementation. The recommendations were deduced from the literature review undertaken by the same working group, existing manuals on PROM implementation issued by ISOQOL and the EORTC Quality of life Group, as well as expert opinions. The recommendations are meant to support Comprehensive Cancer Care Networks in implementing PROMs in routine care. They do not include recommendations related to necessary earlier steps, like the development and psychometric testing of PROM instruments.

1. Plan an initial meeting to clarify the main objective of PRO assessment (screening/ monitoring vs benchmarking, or both) as well as the exact group of cancer patients (e.g., kind of cancer, tumor stage and setting of care).
2. Involve at minimum one PROM coordinator per comprehensive cancer care center and preferable also an administrative support team that is for example responsible for reminding patients to complete questionnaires.
3. Organize a meeting with all relevant stakeholders to discuss which PROs are important and at what time of cancer treatment PRO information are needed. Taking the main objective of PRO assessment into account, all stakeholders are involved in the decision which questionnaires are used and when PROs are collected and evaluated. Carefully decide which data need to be collected to allow for case mix adjusted comparisons. Consider using an established standard data set, like those developed by ICHOM. Also consider joining an existing PROM collection program.
4. Decide how PROs should be presented to patients and providers (e.g., paper-based or integrated in the electronic health record; literal, numerical or graphical).
5. Choose the mode of data collection and data capture dependent on the personnel and infrastructural resources, patient abilities and the possibility of integration in the clinical workflow. Avoid a change from a paper-based collection to an electronic presentation and vice versa as it requires additional resources. Make sure additional providers can join later in the process, i. e. once the program is established.
6. Ensure that data collection and data recording is in accordance with data security issues and consult other regulatory or quasi-regulatory bodies (i.e. IRB, ethics committee) in advance.
7. Allow for flexible data access in daily clinical routine and benchmarking as well as data usage for clinical trials and research purposes.
8. Decide who is responsible for which task in data collection, recording and evaluation and train all stakeholders in their specific tasks.
9. Develop strategies for responding to issues identified by the questionnaires, for example use decision tree pocket-cards.
10. Continuously monitor the implementation process, even in the maintenance phase.