HRQOL in monitoring the quality of health care interventions in Europe: the point of view of patient advocate associations

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node hub core

overview

- hrQoL- a comment on the tools
- hrQoL tools and their usage

hrQoL tools

- external, not just internal validity important
- new therapeutic modalities might require new hrQoL tools- e.g. immune therapies
- early Phase trials important space for qualitative research
- interesting new developments: modularity, broader scope of usage

EORTC item library

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ITEM LIBRARY

The new QLG strategy: core + module + Item Library

Development and validation of a quality of life measure takes a long time. Thorough testing ensures validity and reliability, but requires resources and time. In order to answer the needs of clinical research and build on what the Quality of Life Group has already developed and tested, the Item Library was created, offering researchers new possibilities.

In the past, the standard model of use was the core + module, which involved use of the QLQ-C30 supplemented with a disease-, site, or population-specific module from the EORTC's portfolio. However, it quickly became evident that a given module might not include problems and symptoms of novel treatments that were not common when the questionnaire was initially being developed.

Now, with the new strategy, these missing symptoms or problems can be added to the module as an item list created with the help of the Item Library. This means that the current model is based on the core + module + item list, which includes questions from the Item Library. This new strategy offers users much more flexibility by allowing them to capture a wider range of symptoms and events, which in turn makes it easier for patients to describe their experiences more fully.



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quality of life impacted by

- therapy
- disease itself potential to more accurately define unmet need
- environment's reaction to disease, e.g. job loss potential for targeted interventions
- the quality and burden of care improvement of care delivery

Cancer Mission Call

Programme

Horizon Europe Framework Programme (HORIZON)

Call <u>Research and Innovation action</u> <u>2021-CANCER-02)</u>	See budget overview		
Type of action HORIZON-RIA HORIZON Research and Innovation Actions		Type of MGA HORIZON Action Grant Budget- Based [HORIZON-AG]	Closed
Deadline model single-stage	Opening date 22 December 2021	Deadline date 26 April 2022 17:00:00 Brussels time	



Cancer Mission Call

Proposals under this topic should aim for delivering results that are directed and contributing to all of the following expected outcomes

- Cancer patients, survivors and caregivers will benefit from enhanced quality of life, more effective and less burdensome treatments with better supportive care and counselling approaches.
- Health care professionals, supportive workers, counsellors and industry will be better aware of the (unmet) needs, expectations and preferences of cancer patients, survivors and their relatives and be compelled to address them.
- Regulators and institutions will have a set of metrics, which they can include in decision making about risks and benefits of new health interventions.
- Health Policy Makers will have a set of metrics at their disposal, which they can include in their health information and performance measurement systems.
- Labour market and social protection policy makers will benefit from additional evidence to consider in the design of labour market and social protection policies that are facilitating return to work and active participation in society.

what I'm excited about

Meeting Abstract | 2017 ASCO Annual Meeting I

PLENARY SESSION

Overall survival results of a randomized trial assessing patient-reported outcomes for symptom monitoring during routine cancer treatment.

Check for updates

Ethan M. Basch, Allison Mary Deal, Amylou C. Dueck, Antonia Vickery Bennett, Thomas Michael Atkinson, Howard I. Scher, ...

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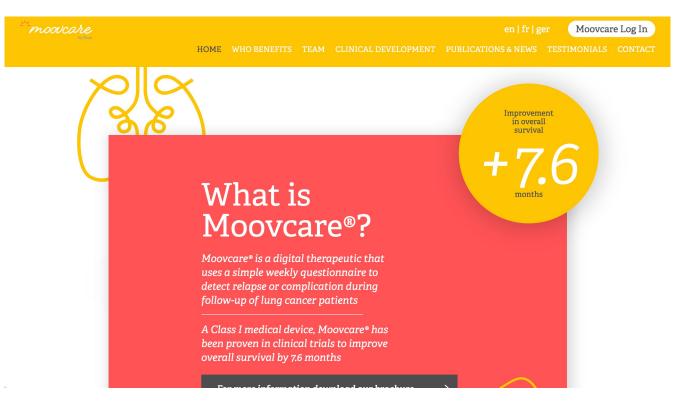
Abstract Disclosures

Abstract

LBA2

The full, final text of this abstract will be available at abstracts.asco.org at 7:30 AM (EDT) on Sunday, June 4, 2017, and in the *Annual Meeting Proceedings* online supplement to the June 20, 2017, issue of the *Journal of Clinical Oncology*. Onsite at the Meeting, this abstract will be printed in the Sunday edition of *ASCO Daily News*.

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because

- digital tool with valid value proposition for patients
- addressing situation of high unmet need and high psychological burden
- potential for monitoring at a distance and long-term, e.g. in primary care and long-term- potential for quality improvement outside tertiary care setting
- interesting space for innovation (digital Europe, DiGAs, EHDS...)
- opportunity for tackling vexing problem of uncertainty but
- vertical integration critical

summary

- hrQoL tools- external, not only internal validity
- usage beyond classic trial setting
- promising digital tools for personalisation of care and follow-up
- potential for better, less burdensome cancer follow-up in periphery

Thank you

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