European Atlas on Clinical Trials in Cancer & Hematology

(EuroACT)

What it is?

EuroACT is a research project initiated by WECAN and the European Hematology Community. The project aims to generate evidence on clinical trial landscape and use of PROs.

Who?

Why?

Inequality in the clinical trial landscape is obvious and the use of meaningless PROs in clinical trials is also a high burden patients' face. Hence gathering evidence across diseases and also disease specific data on what can be improved is crucial in order to have facts and data to compare and strengthen our advocacy claim for change.

Objectives

- To understand the clinical trial landscape and inequalities in research on cancer and hematology across WHO Europe and the differences between countries over the last 5 years
- To collect evidence on the use of PROs in clinical trials and to identify patterns in PRO / HRQoL data collection over the last 5 years, listing most and least frequently used instruments
- To summarise and present the results, using the data to evidence or refute specific concerns or beliefs of the patient community, assess and critique current practice and trends in practice, and identify gaps in knowledge and practices.
- To develop community- and disease-specific conclusions to be utilised in advocacy.

Hypothesis

Hypothesis 1.
Trials are not run in all European countries and this might cause inequalities in access to trials that exist between regions

Hypothesis 2.
When trials do take place, the collection of PRO data might not always take place, and if it does, the tools used are not meaningful to understand patient reality on disease and treatment

Hypothesis 3.
PRO data might not be used or published

Methodology

Phase 1
Foundation: Data collection

Phase 2
Analytics: Targeted Research

Phase 3
Conversion: Data is Evidence

Phase 4
Publication: Targeted Advocacy

Phase 1 in detail

Literature review of **SLR** and **MA** publication on PROs in each disease area

Database search of clinical trials in **Clinical Trials.gov**

Database search of clinical trials in **EU Clinical Trials Register**

List of PROs identified through targeted literature review also reviewed by patient organisations

Identification of **relevant studies** from merging both datasets and identification of PROs used in the clinical trials

- Identification of PROs used in each disease area and the patient perspective which are the most used and what is most relevant for them.
- Identification of clinical trials that have happend in the last 5 years in each disease area in all WHO Europe countries

Expected outcomes

Evidence on :

- Clinical trial operations, trial site location and infrastructure and characteristics.
- Difference between trials in terms of country and region footprint
- HRQoL on primary, secondary or other endpoint
- PRO / HRQoL instruments / PRO data collection used in clinical trials
- Reporting and publication of PRO data
- Inequalities around where (countries and sites) trials are run across Europe / disease areas
- Key issues, gaps regarding the use of PRO / HRQoL data in clinical trials across Europe / disease areas
- Benchmarking and “gold standard” of PRO / HRQoL tools in clinical trials per disease area
- Practical and meaningful use of PRO / HRQoL measurement and tools in clinical trials across Europe / disease areas

Phase 1 and Phase 2 sponsors:

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