ACT EU Call for topics for MSP AG meeting on 4 July 2024
CDDF proposal 1/3 “Enabling CTIS Public Data Use” (scientific/operational)

Enabling CTIS Public Data Use 1/3. Problem:

- CDDF acknowledge the excellent work by EMA to update the CTIS transparency requirements and launch these in CTIS as of 18 June 2024 when data on 4,000 trials was made available and is now being updated on an ongoing basis.
- Discussions and presentations during CDDF workshops from patient representatives and healthcare professionals/researchers constantly call for public information on the trials that are ongoing and available for recruitment –information used has tended to come from US sources.
- There is very little public information that can describe the scientific aspects of trials, ongoing or completed, and allow them to be analysed
- Patient representatives in particular discuss own initiatives to develop and make use of a range of tools and information sources, investing time and money in these, to enable patients and healthcare professionals to be aware of opportunties to join clinical trials and of the nature of the protocols and location of trial sites with contact details. This energy and commitment in time and money would be better placed in working with data furnished by CTIS rather than trying to make up for its absence.

Enabling CTIS Public Data Use 2/3. Possible actions – patient groups:

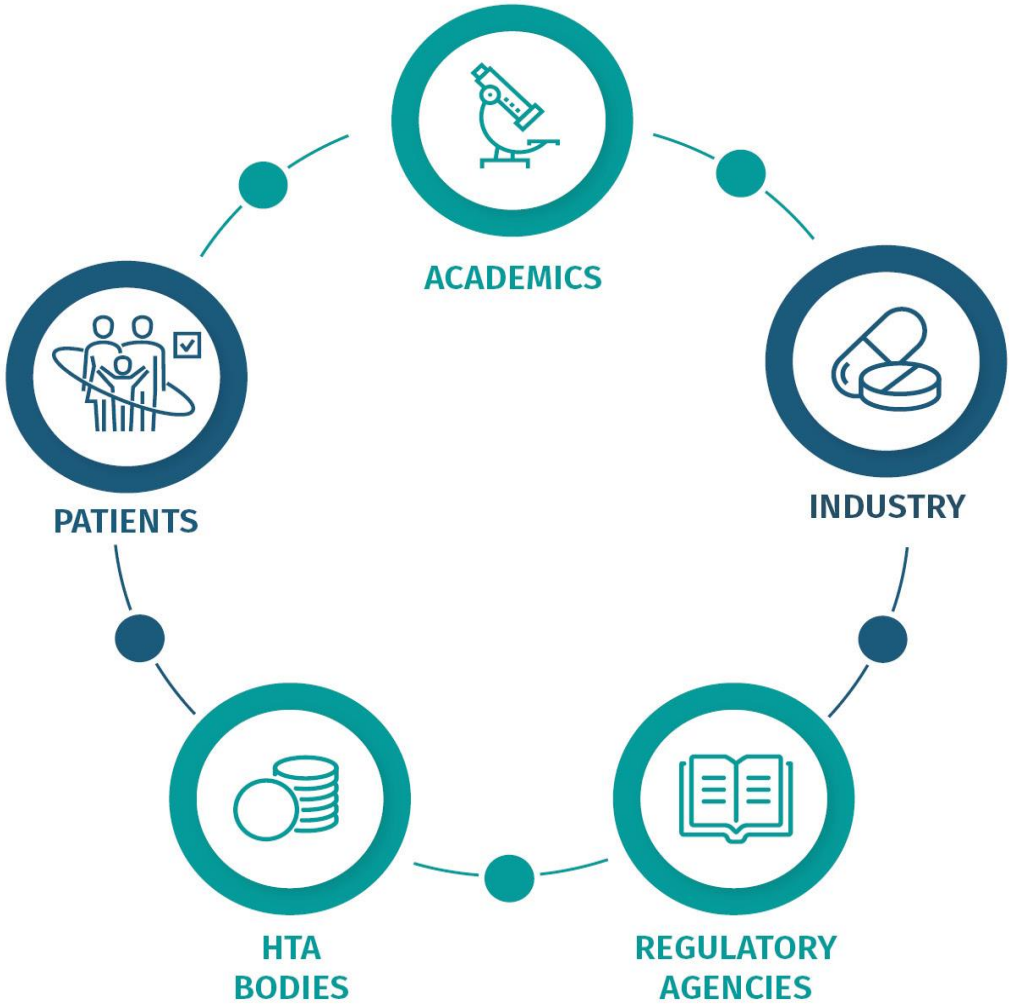
- Enabling patients, carers and healthcare professionals to find and identify clinical trials of interest to specific patients using CTIS public information.
- Work with patient groups to ensure disseminated information on what is available, what is planned and to agree on priority information and how it is made available for use.
- Work with patient groups to ensure that data is available for automated access to enable patient groups or other parties to build systems that can export and use data to provide information in a form useful for individual patient groups (e.g. focusing searches on certain diseases, geographic areas, patient populations, languages), and enabling such systems to update in real time

Enabling CTIS Public Data Use 3/3 Possible actions – researchers, academia, policy makers:

- Using CTIS (and EudraCT) public data to describe the oncology research landscape in EU and to help build and expand networks for multistate clinical trials in oncology and specific priority areas within oncology.

- As for patient groups, work with researchers, academia, policy makers and others to make data available in a downloadable form useable directly by third party systems to carry out research, link CTIS (and EudraCT data) with other information in order to enable third parties to optimise the use of this data without additional burden on the public authorities. Data source should enable third party systems to use and update in real time, once the data is publicly available.

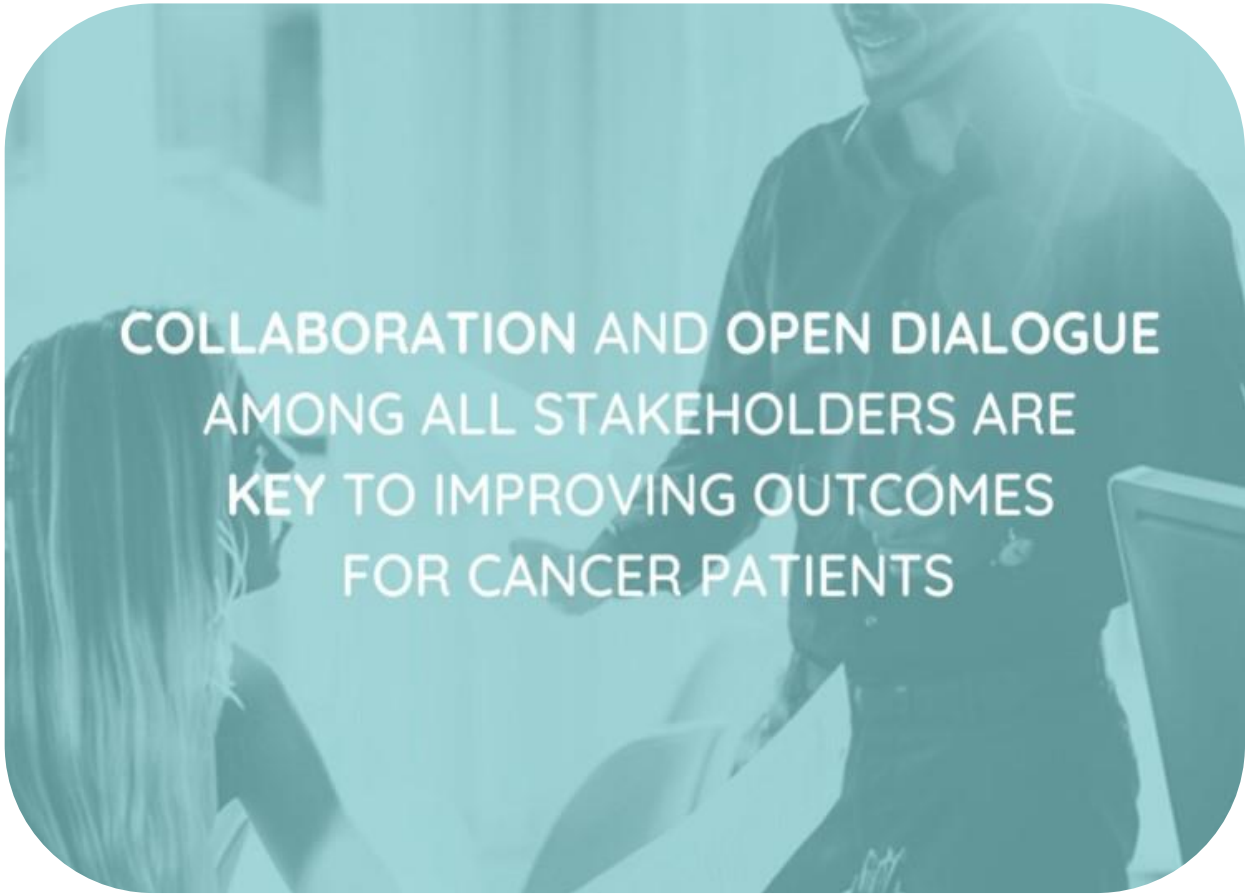
What is the CDDF?



- The Cancer Drug Development Forum (CDDF) is **a non-profit organization,** registered in Belgium, that provides a **neutral, non–competitive platform** for **multi-stakeholder discussions** and **collaboration** in the **development of cancer drugs.**

- The CDDF's mission is to **facilitate collaboration** between **stakeholders**, to **increase efficiency** in cancer drug development and **accelerate the delivery of effective oncology treatment** to **patients**.

actors by the European Medicines Agency



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