

The emerging concept of neglected cancers: a definition based on literature data and population-based indicators, and core clinical variables needed to describe pancreatic cancer patients pathway



TYPE
STATUS

Implementation is complete and program is ongoing

LAST
UPDATE

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EUROPE • HEALTH SYSTEMS
Diagnostic, Treatment and Research

PROBLEM & OBJECTIVE

PROBLEM One of the aims of the Innovative Partnership for Action Against Cancer (iPAAC) is to provide better efficacy for dealing with “neglected cancers”, through the development of new key indicators useful to assess clinical cancer pathways and health-related costs, with focus on pancreatic cancer (PC). However, a common understanding of the definition of “neglected cancer” is yet missing.

OBJECTIVE The Fondazione IRCCS Istituto Nazionale dei Tumori (INT) aimed to (1) reach a scientific definition of “neglected cancers”, and (2) to provide a list of variables which are useful to describe the care pathway of PC patients and to investigate their outcomes.

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KEY COMPONENTS / STEPS

To reach a scientific definition of “neglected cancers”.

- Systematic literature review searching PubMed and Scopus databases to systematically explore the use and the meaning of the term “neglected cancer” in international literature.
- Analysis of the population-based indicators on solid cancers to quantify the health impact as identified by the systematic literature review and to identify cancers sharing these characteristics to be included in the “neglected cancers” group.
- Incidence (I) and mortality (M) data for cancer patients diagnosed up to 2012, and projected up to 2018, were accessed from the online ENCR-JRC (Joint Research Center) database.
- Relative survival (RS) estimates for cancer patients diagnosed in 2000–2007, and followed-up to the end of 2008 were accessed from the online EUROCARE database.

To provide a list of variables to describe the PC patients care pathway and their outcomes.

- Analysis of the past data collection experiences (ENCR, EUROCARE, HR studies), ESMO clinical practice guidelines, and meetings with iPAAC teams on pain management and palliative care (WP8.5 and WP8.6).

KEY CONTEXTUAL FACTORS

- In Europe, PC carries higher incidence and mortality than elsewhere.
- From 2000 to 2007, PC incidence and survival increased slightly, particularly among the elderly and among women, with persisting low survival thus highlighting an emerging public-health problem.
- Improvements in prevention, detection, and treatment are urgently needed.
- A description of the PC care pathway, from diagnosis to terminal care, may provide useful information to better understand deficiencies in diagnosis and treatment that impact quality of care and quality of life.

MAIN IMPACTS / ADDED VALUE

- When we started this WP8 task, the term “neglected cancer” did not have a uniform meaning in the literature, but the various definitions share the same characteristics, thus consenting to define “neglected cancers” as those cancers bearing a high health impact due to (modestly) high incidence and mortality and, low survival due to either tumour biological aggressiveness, late diagnosis, or lack of effective treatments.
- The analysis of the three indicators at the population level was needed to quantify the “modestly high” incidence and mortality rates, and the “low” survival.
- Neglected cancers are tumours with a high health impact in terms of incidence, mortality and survival. They are non rare cancers with (i) incidence and mortality rate <20 per 100000, (ii) high (≥ 0.7) M/I ratio, (iii) low survival (RS $\leq 40\%$ at 1 year, $\leq 30\%$ at 3 or 5 years after diagnosis).
- Tumours of the pancreas, gallbladder and biliary tract, stomach, liver, and brain and central nervous system fall under the above definition. Of these, PC is the most important and most representative, due to the highest M/I ratio and the lowest survival at 1, 3 and 5 years after diagnosis.
- A list of defined variables (distinguishing between core and additional variables) was agreed. They are related to patients and tumour characteristics at diagnosis, surgery and systemic treatments, palliative care and care at the end of life, as well as clinical and life-status follow-up.

LESSONS LEARNED

- An extensive list of variables was proposed in order to investigate and compare PC care pathways and patients outcomes, both at population- and hospital-based level. If population-based registries, hospital-based registries and administrative registries were better connected, data collection would be easier and data more complete.

REFERENCES & DOCUMENTATION

- iPAAC Report
- ECIS - European Cancer Information System
- ENCR - European Network of cancer registries
- ESMO - European Society for Medical Oncology
- EUROCARE - EUROpean CAncer REgistry based study on survival and care of cancer patients
- HR studies - European High Resolution studies on patterns of care and adherence clinical guidelines across Europe

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