



EURORDIS' activities on EU and National Policies

Rare Cancer Perspective in the EUCERD

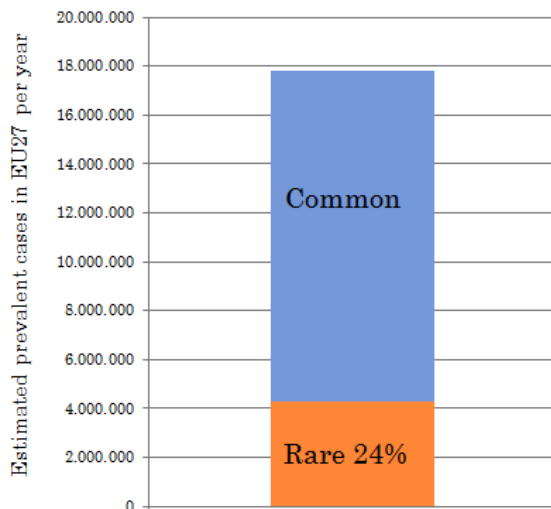
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Hype or hope: success stories only for small number of cancers

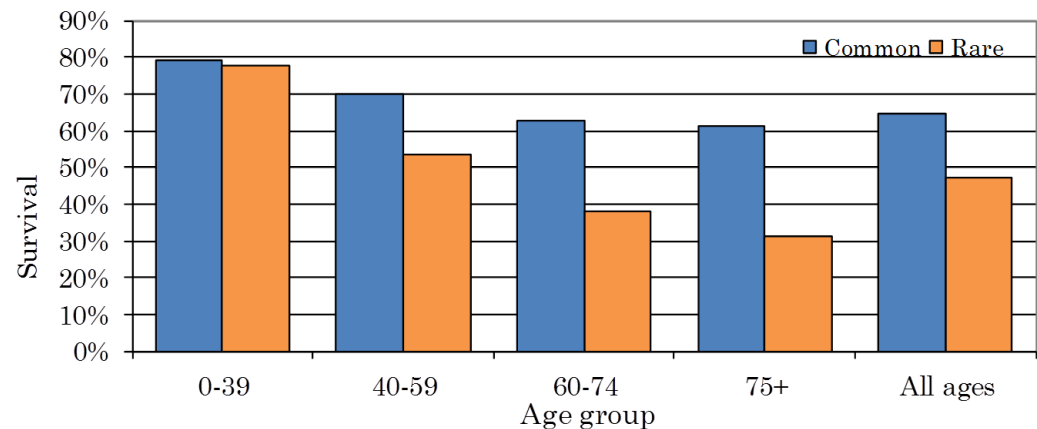


- Main attention is on common cancers
- Only small number of rare cancers have effective treatments



Source: RareCare (2012)

5 YEAR RELATIVE SURVIVAL FOR RARE AND COMMON CANCERS IN EU27 BY AGE GROUP



Patients with rare cancers share common problems with rare diseases



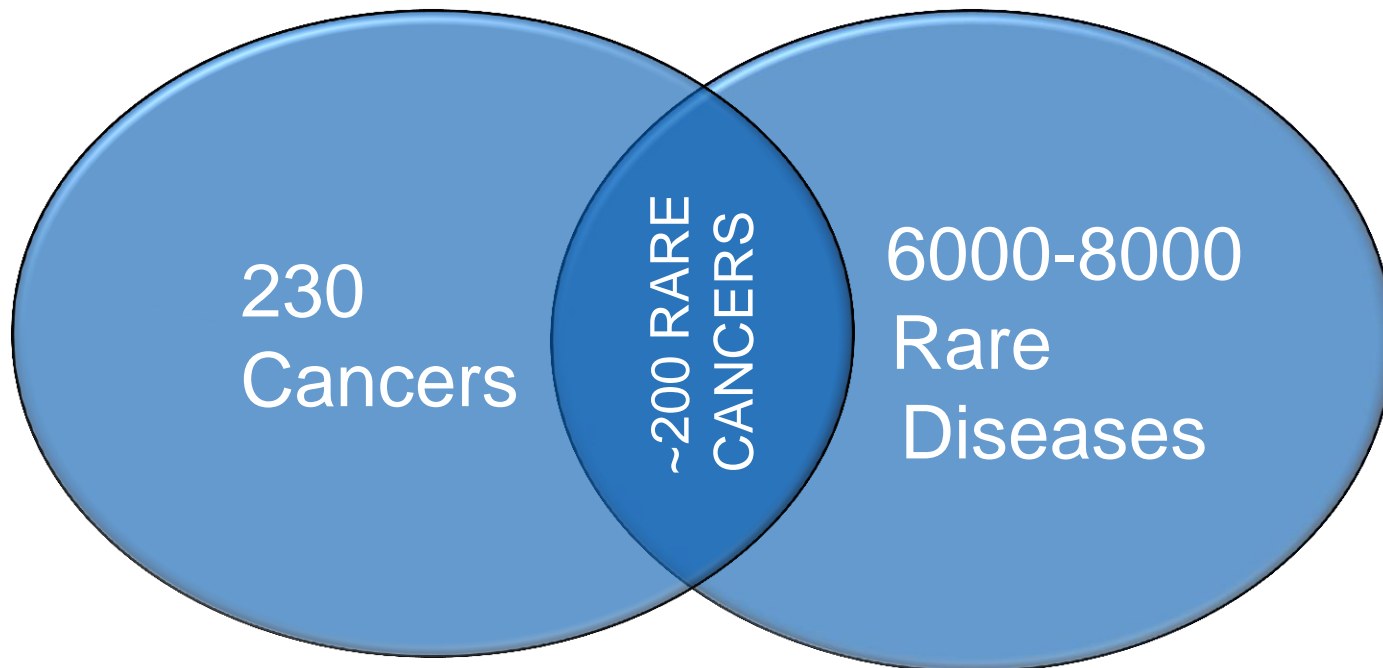
1. Prevention/screening mostly not relevant
2. Late or incorrect diagnosis
3. Experienced doctor not available locally
4. Lack of access and referral
5. Few centres of expertise, few networks of excellence
6. Slowness of research, lack of funding
7. Stigma and inequity
8. Lack of harmonisation in health policy
9. Limited data on the burden of RC/RD



Rare diseases and rare cancers: Unite, not divide



- Rare Cancers are often lost between common cancers and rare diseases
- Contradictions in RD/Onc health policy, in RD plans and national cancer plans might not be beneficial for any side



On the Commission level, there are two „Joint Actions“



- Reduce cancer incidence by 15% by 2020
- Make better use of limited resources, avoid duplication
- Integrated cancer plans in MS
- Cancer registries, health promotion, NoE/CoE, research coordination
- 126 partners



- Facilitate implementation of national rare disease plans
- standardization of RD nomenclature
- mapping the provision of specialised social services for RD
- integration of RD initiatives and mapping of national initiatives
- 51 members (incl 27 MS, POs, ...)

Suggested: Joining forces between EUCERD and EPAAC!



On initiative by the EURORDIS team in EUCERD + the Istituto Nazionale Dei Tumori Milan to consider:

- Mapping of national **cancer plans** (EPAAC WP10) and national **rare disease plans** (in Europlan)
- Harmonisation of **stakeholder views** on rare disease/cancer policy
- Alignment of **criteria for accreditation** of centres of excellence, and criteria for ERN
- Harmonization of framework for **Clinical Guidelines**
- Bridging EU pre-marketing authorization and MS-level post-market authorization
- Alignment on methodologies for **disease registries**
- Evaluate **ongoing EU initiatives** on cancer/RD on health equity impact



Under
discussion!

Thank you!



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European Partnership for Action Against Cancer: Structure and Process



Forum
Representatives from Member States, academia, cancer societies, health professionals, NGOs, patient groups, civil society & industry

WP4: Secretariat, Open Forum

WP1: Coordination & Management

WP 10 National Cancer Plans

WP5: Health Promotion and Prevention

WP6: Screening and early diagnosis

WP7: Healthcare

WP8: Research

WP9: Information & data

WP2: Dissemination, Virtual partnership

WP3: Evaluation

Partnership Secretariat



National Cancer Plan - NCP

A public health programme designed to:

reduce the number of cancer cases and deaths and improve quality of life of cancer patients, through the systematic and equitable implementation of evidence-based strategies for:

- prevention,
- early detection,
- diagnosis and treatment,
- rehabilitation,
- palliation and
- research to search for innovative solutions and evaluate outcomes.

Work Organisation

Work on NCPs will be organised on 3 levels

- **First level:** Partners from WP 10 (Belgium, Ireland, Italy, Malta, Slovenia)
Preparation of the background documents, questionnaires, analyses..
- **Second level:** Working Group on the NCPs
Review of the work done on first level
- **Third level:** SC of the Partnership
Review of the work done on second level and adoption of decisions

New Working Bodies

Working Group (WG) for NCPs

- Representatives of all MSs
- WHO Europe
- EUREGHA
- EOHSP

Steering Committee (SC) of the Partnership

- Members of the WG
- Members of the SC of the JA EPAAC
- Representatives of IARC, the EOHSP, ECPC, ECCO
- Representative of an industry association
- Individual renowned experts
- Workpackage leaders

Specific Objectives



- **To obtain an overview of the current state regarding NCPs in MSs, Norway and Iceland**
- **To obtain a review of the content of NCPs from all MSs, Norway and Iceland**
- **To identify benefits of every existing NCP**
- **To define areas to be respected in NCPs**
- **To finally evaluate the effectiveness of WP 10 regarding the outcome indicators**
- **To prepare guidelines for a high level standard NCP which includes the listed areas**
- **To define specific indicators for each area listed in the high level standard NCP**