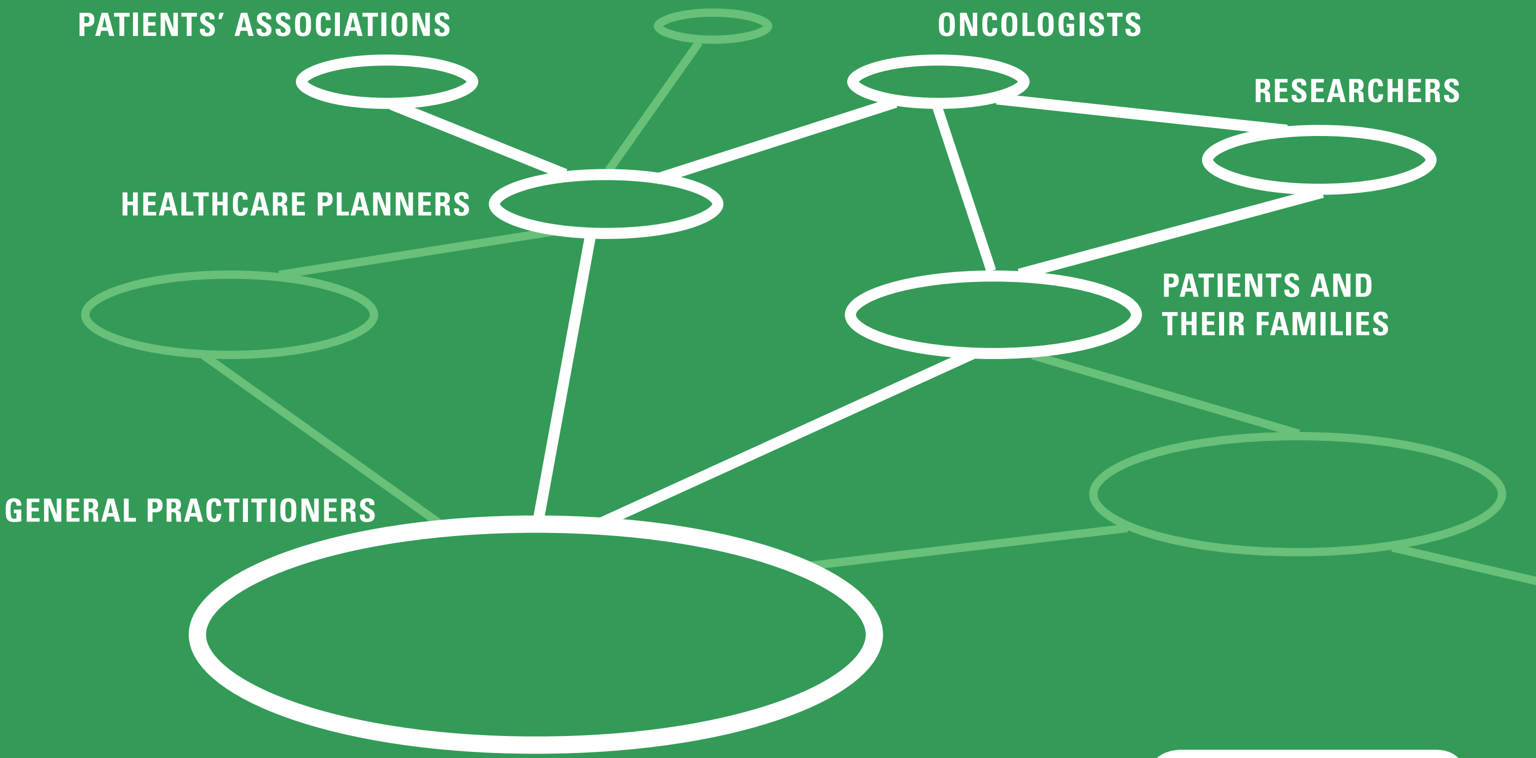
RARECAREnet

What can be done about rare cancers?

12th August 2016



PATIENTS' ASSOCIATIONS

ONCOLOGISTS

RESEARCHERS

HEALTHCARE PLANNERS

PATIENTS AND THEIR FAMILIES

GENERAL PRACTITIONERS

EUROPEAN CANCER PATIENT COALITION

WHAT ARE RARE CANCERS?

Rare cancers are defined as having an incidence of less than 6 per 100,000 people per year.[1]

Rare cancers are often associated with poor survival.[2,3] Due to the small number of cases, diagnosis is often delayed or inaccurate, doctors may not be familiar with available treatments or guidelines, and patients face many challenges finding healthcare practitioners with the necessary expertise to treat their rare cancer. Also obtaining reliable data on the type and number of rare cancers is challenging.

Rare cancers represent 22% of all new diagnoses of cancer in Europe.[3] Therefore, identifying ways to improve the quality of care for patients with each type of rare cancer should be considered a public health priority.[3]

HOW CAN WE IMPROVE CARE FOR RARE CANCER PATIENTS?

As part of the RARECAREnet project, meetings gathering patients, European and national experts on rare cancers, representatives from national cancer programmes and Ministries of Health were organised in Belgium, Bulgaria, Slovenia and Ireland. The aim of these meetings was to discuss how to best address the challenges posed by rare cancers within each country.

Countries were chosen to cover a range of national contexts and population sizes, and the lessons learnt in each of these countries are widely applicable across many contexts.

Summary recommendations and key lessons learnt from these meetings are summarised in this document.

How can quality care be achieved?

- Political commitment
- Guidelines and standard clinical pathways
- Translation of research into practice
- National and international scientific societies for professional development
- Monitoring and evaluation for centres of expertise
- Population-based cancer registries
- Increased patient involvement in treatment decisions
- Collaboration between specialities
- Research networks
- European Reference Networks to enable international collaboration

What is quality care for rare cancer patients?

Ensure that primary treatment is planned at a multidisciplinary meeting

Set minimum standards of quality for all services

Designate centres of expertise to which rare cancer patients can be referred

Implement national and international pathways for rare cancers around centres of expertise

Define a pathway for second opinion for diagnosis/treatment

Ensure that second opinions are reimbursed

Standardise pathological reporting at diagnosis and after surgery

LESSONS LEARNT FROM THE COUNTRY MEETINGS

BELGIUM

Rare cancers:

13,700
new cases
per year

24%
of the total
cancer diagnoses

Survival rates are higher
than the European average

Lessons from Belgium...

Encouraging centralisation of care and developing networks between hospitals are key to improve outcomes for patients

A rare cancer patient can be treated in any hospital with an oncology care programme in Belgium – and not all patients may receive the highly experienced and specialised care necessary for rare cancers as a result.

The development of hospital networks between centres of expertise for rare cancers and other oncology care services or programmes may improve collaboration, centralisation of care and knowledge sharing, ultimately improving outcomes for rare cancer patients.

BULGARIA

Rare cancers:

9,500
new cases
per year

23%
of the total
cancer diagnoses

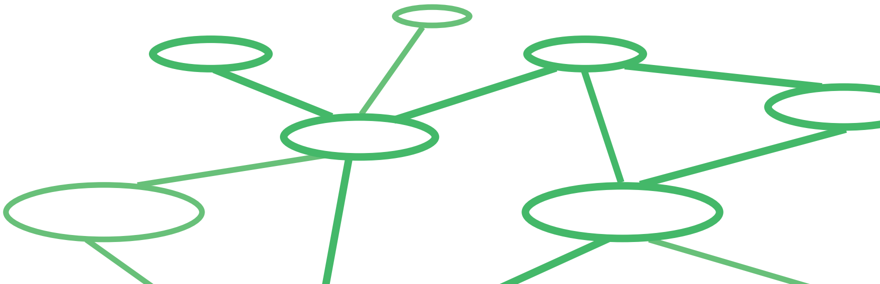
Survival rates are lower
than the European average

Lessons from Bulgaria ...

Inadequate pathology facilities and training pose challenges to timely and accurate diagnosis

It was noted in Bulgaria there were inadequate facilities and capacity to diagnose many complex rare cancers. Investments in pathology laboratory facilities, training of pathologists, translation of WHO Blue books into Bulgarian may all enable a more timely diagnosis for rare cancer patients.

Additionally, defining national and international pathways for second opinions from expert pathologists will help facilitate an accurate diagnosis. European Reference Networks may also create opportunities to improve pathologist training in Bulgaria through dedicated training programmes and fellowships across Europe.



LESSONS LEARNT FROM THE COUNTRY MEETINGS

SLOVENIA

Rare cancers:

2,600
new cases
per year

27%
of the total
cancer diagnoses

Survival rates are equal
to the European average

Lessons from Slovenia...

Delays in diagnosis and treatment must be reduced to improve outcomes

There are often delays in access to diagnostic procedures and radiotherapy, challenging the provision of adequate and timely care. Reducing these waiting times is critical to improve outcomes for patients.

Additionally, there is sometimes limited access to new systemic treatments for very rare cancers in Slovenia. Greater utilisation of European Reference Networks may help improve access to all new drugs developed for rare cancers.

IRELAND

Rare cancers:

4,600
new cases
per year

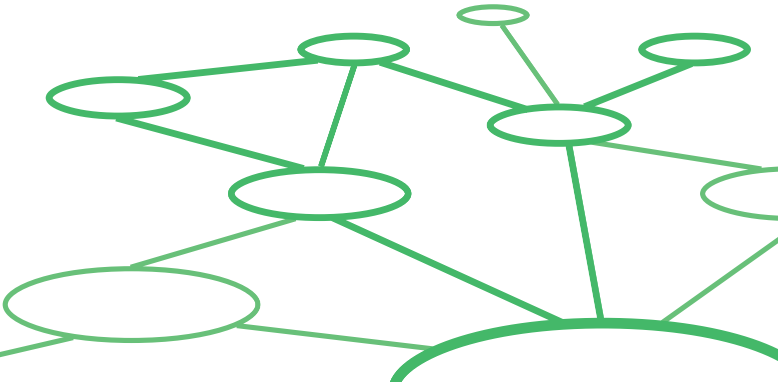
23%
of the total
cancer diagnoses

Survival rates are equal
to the European average

Lessons from Ireland...

Political commitment is important to ensure centralisation of care

Centres of expertise have been identified in Ireland, yet patients do not always receive referrals to these centres, challenging the provision of quality care. Political commitment and legislation are key to implementing care centralisation, ensuring all rare cancers are treated at centres of expertise and enabling all rare cancer patients to receive the highest quality of care.



References

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