

EUROPEAN CANCER CONTROL SUMMIT

Cancer Registries for better cancer control in the EU:

Unity and diversity in reporting risk and outcome

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Anita Waldmann

INTRODUCTION:

High-quality information on cancer in Europe is vital. This meeting and the EUROCOURSE project is vital in terms of the development, analysis, optimal use and exchange of European cancer registry data and I thank you very much for inviting me to provide the all-important patient perspective at this conference.

My name is Anita Waldmann and I am a patient advocate, currently the President of the Myeloma Euronet (ME), Chairwoman of Leukaemihilfe RHEIN-MAIN e.V. (LHRM) since 1991 and honorary Chairwoman of the German Leukemia and Lymphoma Patient's Association (DLH) e.V.. I am also a member of the European CanCer Organisation (ECCO) Patient Advisory Committee and the scientific working group "Quality of life & symptoms of the European Haematology Association (EHA).

I am very committed to the importance of cancer registries.

Cancer registries are the only source of reliable, population-based information on cancer, and they provide a high-quality cancer intelligence service. Knowledge is power, and - I believe that registries play an essential role in the improvement of health and healthcare and can truly help us fight this huge cancer burden in Europe.

As IARC said in a report on epidemiology, cancer registries encourage us not only to ask who has what, when and where, but also - why are some cancers at higher risk than others?

And this questioning is to examine an association between exposure and disease needs to be encouraged.

I think it was Marie Curie who said: What we have learned to understand, we don't have to be afraid of.

SURVIVORSHIP

More than ever before, European citizens are surviving cancer.

Significant work still needs to be done on the late and long-term effects of having survived cancer and its treatments.

Survivors of cancer continue on an emotional journey that is not so straight forward as 'being cured'.

Financial worries, including insurance, acquiring a loan or mortgage, employment issues,

- coping the anxiety of potential recurrence,
- the importance nutrition and exercise, personal relationships,
- fertility (particularly for survivors of paediatric cancer)
- it is a complex and difficult journey often.

An important survivorship issue is the number of paediatric and adolescent cancer survivors and the numerous long-term effects they can have due to the intensive treatment they receive in their youth.

Emotional support is very important. The right emotional support can have a significant impact on the quality of life for survivors, and often reduce troublesome symptoms and improve health.

Patient advocates can truly help to encourage survivors to participate in advancing essential cancer survivorship research.

DATA PROTECTION

Data protection needs to be considered obviously when discussing this subject and I am happy to see that this will be debated in this Summit.

Cancer patients often have a different view of data-protection than the Governments and Ethic-commissions.

Cancer registration is complex and registry programme-owners recognise the sensitivity and huge responsibility they have when dealing with patient information to ensure it is correctly recorded and ensure strict policies are in place governing the handling, processing and transfer of patient data to uphold patient and carer confidentiality.

However not only public but also medical staff awareness of the importance of cancer registries needs to be improved if we are really going to move and gain the support to truly advance in this area.

Patient advocates can and are willing to help you with this process.

PATIENT PARTICIPATION

Patient groups should be included in all this discussions. Partnering with us can help both: the scientific and policy community to prioritise and optimise research and deliver a coherent strategy that puts the patient at its centre.

RARE CANCERS

Rare cancers already face many challenges, where regulatory practices penalise patient populations.

And here I can mention the haematology cancers with all its varieties: Lymphomas and the subtypes like Myeloma, Waldenstroem or Mantelcell.

If you look at the Robert-Koch-Institute Cancer registry report, there is mentioned only: Leukaemia, Non Hodgkin Lymphoma and Hodgkin, but this does not show all the differences.

Network-based clinical databases and tissue banks should be developed

INEQUALITIES

There is a strong socio-economic gradient to the burden of cancer in Europe.

And not only between West and East, but also in several regions of Germany:

The region NORTH RHINE WESTPHALIA for example with the highest population only collect data's from a city called "Muenster" (without Cologne, Duesseldorf e.g. -2006 report).

CONCLUSION

Today cancer causes more deaths than any other disease – even more than AIDS, Malaria and Tuberculosis combined.

And this is set to continue: Healthcare providers have a huge challenge in the future when dealing with the ageing population.

This crisis, as it is and will be a crisis, will be difficult to control unless research is able to improve the outcomes or prevention of the disease.

I believe that support for large epidemiological studies needs to be improved substantially if we can truly make progress.

As EU Commissioner for Research and Innovation, Maire Geoghegan-Quinn, stated at the Oncopolicy Forum 2011, "cancer is everybody's business, touching everyone's family".

My slogan always is: Only all together - we can break barriers!

Thank you very much for your attention.