DR NÚRIA MALATS SPOKE TO PEN ABOUT SOME OF THE CHALLENGES AND SUCCESSES OF THE EUPANCREAS COST ACTION

Action on pancreatic cancer

The application of the rapidly evolving '-omics' technologies to cancer research is a reality. It has been demonstrated that large-scale international collaboration is essential to decipher relevant information in the context of massive-scale interrogations. This is even more important for rare and dreadful diseases like pancreatic cancer, and so the EUPancreas COST Action is designed to create a unique European platform to facilitate the collaboration of a a broad range of European and international pancreatic cancer multidisciplinary research groups to integrate knowledge and experience in a multidisciplinary way.

It is hoped that the Action will develop novel interdisciplinary tools that will improve understanding of PDAC and its control by answering questions related to the aetiology, early detection and evidence-based and personalised treatment to enhance primary, secondary, and tertiary prevention, respectively, as well as on health management.

Pan European Networks asked the Action's chair, Dr Núria Malats, about some of the Action's challenges and successes thus far.

Could you outline the background to the Action as well as perhaps some of your overarching objectives?

Pancreatic cancer is considered to be a rare cancer because incidence rates are not very high. However, mortality rates have been increasing in recent years and this, coupled with the fact that there has been no improvement in the control and/or prevention of pancreatic cancer in the last decade, is a real cause for concern.

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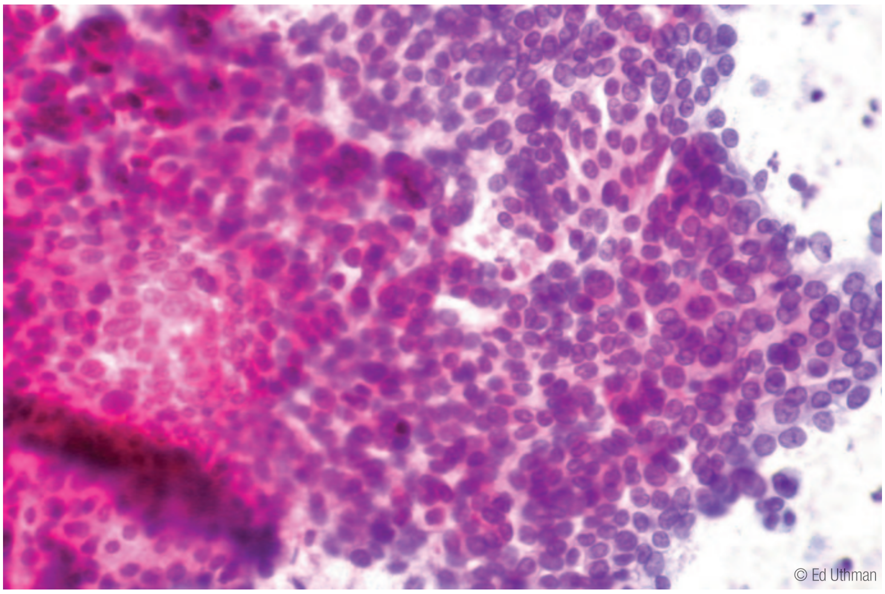
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The five-year survival rate for this type of cancer remains at around 5%, with the average survival time being just six months, and there is evidence to suggest that trends in mortality are set to rise. In the USA, for example, pancreatic cancer is expected to become the second most fatal type of cancer in the country, after lung cancer in the next decade.

Primary prevention – which refers to avoiding the risk factors in order to prevent the development of the disease – is difficult, if not impossible to apply because we simply don't know, with any real degree of certainty, what the causative factors are. Similarly, screening programmes cannot be applied either, because we don't know which population to classify as being high risk. Nor are there any markers for this disease, and the treatments that exist are inefficient. Furthermore, pancreatic cancer can be particularly difficult to investigate – there is a high percentage of misclassification and misdiagnosis for this disease, and it is difficult to obtain tissue sampling. The fact that patients are too sick to participate in the studies poses several obstacles. In addition, there are difficulties experienced when trying to provide care for someone who has this disease. As such, its wider (societal) impacts are clear.

The best way of advancing knowledge of this cancer is by uniting efforts across groups interested in research; this is the idea of our COST Action: to build a platform for collaboration and the sharing of experiences.

This comes at a time when the US Congress has classified pancreatic cancer as a recalcitrant cancer and in 2015 invested more than $5bn (~€4.6bn) for research. This is something we need to mirror in Europe. We must make sure that we raise the awareness of pancreatic cancer not only amongst the public, the researchers, and the healthcare professionals, but also at the policy level because Europe's policy makers need to ensure that pancreatic cancer is placed on their agendas.

What would you say the Action's biggest achievements have been so far?

Perhaps our main achievement is that we have been able to unite ongoing efforts and to identify overlapping interest across groups working on pancreatic cancer research. From this, we have been able to prioritise research and to form collaborative groups that are working towards projects to be submitted under Horizon 2020.

We have also been able to increase the awareness of pancreatic cancer not only through participation in the COST Action, but also in other initiatives – for example, the European Alliance for Personalised Medicine is supporting pancreatic cancer in their agenda, and we also endorse the EU Multistakeholder Platform on Pancreatic Cancer.

These are the overarching achievements, and there are also more specific ones. For example, Working Group One has been able to harmonise the research tools so they can be used by different countries and different groups. Amongst these efforts, there has been work to homogenise definitions when it comes to questions about the pancreas at the pathological level and to establish the key terminology that refers to the pathological diagnosis, which is very important.

This working group has also been able to develop protocols and standardised questionnaires, whether epidemiological or clinical, for the scientific community, whilst also working to standardise the operating protocols for pancreatic fresh tissue collection, for example. All of this aims to standardise defaults in order to be able to build common projects in Europe.


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Working Group Three is building two large cohorts: one refers to intraductal papillary mucinous neoplasm (IPMN) – a type of tumour that grows within the pancreatic ducts – and the other relates to new onset diabetes. These two resources are set to address a gap in pancreatic cancer research and will hopefully identify biomarkers.

Finally, Working Group Four is aiming to identify the barriers for personalised medicine on pancreatic cancer, and then report on these areas. It is now building best practice guidelines that will be transmitted to healthcare systems across Europe.

Amongst these initiatives there is a grander scheme at work: working together with the EU Multistakeholder Platform we are hoping to drive towards a clinical registry for pancreatic cancer in Europe that is also endorsed by the European Commission, and by the European Network of Cancer Registries. These resources are crucial for pancreatic cancer research and to advancing knowledge of this cancer.

Could you comment on the COST Action as a mechanism and the benefits you feel it has lent to your effort 'to create a unique European platform to facilitate the collaboration of a broad range of European and international PDAC multidisciplinary research groups to integrate knowledge and experience in a multidisciplinary way "from cell to society"'?

I strongly believe in interactive research which can serve to integrate not only data but also ideas, hypotheses, and skills of those from other disciplines. This is what we hope to achieve through the COST Action, but it is certainly no easy task.

We have almost 200 members from 22 different European countries (as well as researchers from the USA and Canada) that also participate; we do not only want to include academic researchers but other professionals and researchers from the private sector. We have biotech and pharmaceutical companies already participating, which helps to create synergy.


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Because we have all of these stakeholders in the different activities the Action has prioritised, we have organised the structure of the Action into four working groups (the first refers to the harmonisation of research, the second to the integration of -omics data, the third to the translation research, and the fourth to patient management).

A working group within the Action has developed protocols and standardised questionnaires for the scientific community, whilst also working to standardise the operating protocols for collection, for example

One element of the Action is 'answering questions related to the aetiology, early detection and evidence-based and personalised treatment to enhance primary, secondary, and tertiary prevention, respectively, as well as on health management.' How challenging has this been?

It is important to note that the Action does not fund research itself, which means that all of the projects that the Action prioritises need to apply for funding, which is a challenge. Nevertheless, we continue to build resources, to identify risk factors, and to identify markers for early detection and personalised treatment. As such, it is possible to say that the Action goes some way to creating the necessary environment for researchers to meet and discuss the things such as the prioritised fields and evidence, the places where efforts should be invested, and to build the critical mass.

The Action is thus a way to increase awareness of pancreas cancer and to highlight the fact that we need to spend more time and resources on pancreatic cancer research and that there is a fundamental need to generate a collaborative effort to lobby with other initiatives in Europe to make this a priority at the European policy level.

How well has the combination of young and experienced researchers within the Action worked?

In this regard, the Action could perhaps do a little better. Having young researchers involved is crucial; having young researchers take up the challenge now to work on pancreatic cancer is fundamental when it comes to planning future efforts, and we have found young researchers as crucial peers within the different working groups.

We offer short term scientific missions, mainly for young researchers, to enable them to become immersed in the field and to experience the cross-disciplinary nature of the work that we do. Yet, we have found it very difficult to engage a satisfactory number of young researchers, and so this is certainly something that will need to be re-evaluated.

What are your hopes for the future, and how do you hope to be able to continue this work beyond 2016?

When we started with the Action, four years seemed to be a lot of time to achieve fantastic things and make a lot of advances. Now, however, we have realised that this amount of time is not long enough to achieve everything we've hoped for. It takes quite a while to even become properly acquainted with the COST system, and then to inform and convince our colleagues to participate and to invest their time and efforts to build these resources for the scientific community. Perhaps the key word here is indeed 'invest'; the COST Action is an investment for the future.

The Action will be very useful in the building of a multidisciplinary research base and in enhancing collaborative research on pancreatic cancer, but we need more time to see the realisation of these benefits. Of course, we will be unable to extend the Action, and we are taking this into consideration by looking at mechanisms such as Horizon 2020 as a way of furthering our efforts into the future.

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