News & Views

Patient organisations aim for greater collaboration

Emma Wilkinson

In April, delegates at the European Cancer Patient Coalition summit in Brussels heard from several formidable speakers on measures that need to be taken to tackle inequalities within and between European countries on cancer detection, diagnosis and treatment. One specific goal of the meeting was to identify ways of sharing available best practice and encouraging more research across EU member states.

But just how much of a role do patient organisations have in directing research priorities?

The short answer seems to be an ever-increasing one.

EUROCAN – a scheme set up in 2005 to map national cancer initiatives, identify areas for collaboration and establish future research priorities – has identified a specific need for patient involvement.

The project’s aim is to encourage closer cooperation of EU in determining cancer research strategies.

In a report published earlier this year on the feasibility of bringing national cancer strategies together the project concluded it was "essential to include the patients’ voice in the establishment of priority areas in cancer research".

It is a position reiterated by Dr. Janez Potocnik, European Commissioner for Science at the ECPC summit who said the response from EU member states to the proposals were so far “encouraging”.

Hildrun Sundseth, head of EU policy at the ECPC said the prominence of patient groups in cancer research policy was “slowly improving” although too many organisations still only pay “lip service” to patient groups.

“First of all patient groups had to prove that they were serious stakeholders,” she said.

“In the past researchers have been approaching patient groups at the very last moment when most of the project has already developed, almost as an afterthought or because it was a funding requirement.”

“This is changing now and we are increasingly consulted and considered as partners.”

This assertion is perhaps underlined by the speakers organisers of the ECPC summit were able to attract, including Professor Tanja Cufer, EORTC Board Member who also talked about a new model of collaboration between industry, academia and patient groups and European health commissioner, Androula Vassiliou (Figure 1).

Ms Sundseth, said the breakthrough for the ECPC – set up more than four years ago with funding from the European School of Oncology and now representing 250 member organisations – was getting the European Parliament on board with their cause.

“We approached Members of the Parliament for their political support to help us make cancer control once more a priority in the European Union.”

“As a result they set up a cross-party forum of MEPs who support patients and EU citizens in their fight against cancer. MEPs against Cancer, or MAC for short, now has 67 MEPs from across the 27 EU member states.”

“Increasingly more and more patients may not have access to the full range of services. Cancer treatment and care is extremely complex and expensive. Politicians and health policy makers will be faced with difficult decisions of how resources are allocated,” said Ms Sundseth.

“Cancer patients advocacy groups need to be involved in these debates to ensure that that decisions are not taken behind closed doors but in a transparent consensual manner.”

Even the best cancer control strategy will not serve its purpose if the patient is not put at the centre, she added.

“This is why it is important that the patient voice is heard at all levels of decision making, implementation and monitoring of policies that concern health and healthcare.”

“Our healthcare systems have to become more patient-friendly and strive to ensure equity.”

EUROCAN is by no means the only example of attempts to increase patient organisations at the planning stage of cancer strategies.

The French cancer plan has a patient committee and the plan includes psychosocial care for patients.

The UK Government outlined plans to involve patient groups in medical research in its Best Research for Best Health report.

And the European Medicines Agency (EMEA) has a Working Party of Patient and Consumers’ groups that meet on a regular basis, which the ECPC welcomes as giving patient groups the opportunity for involvement in medicines regulation.

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And at the other end of the spectrum the ECPC is lobbying to make clinical trials information more transparent and accessible to patients in addition to including them in the designs of the clinical trial – a factor they see as a crucial step in the development of ‘personalised medicines’.

Ms Sundseth explains it has been other areas of disease advocacy which have opened the doors for cancer patients to become more involved.

“The HIV/AIDS advocacy community has pioneered the way, campaigning for research funds to be allocated to their disease, getting involved in drawing up protocols for clinical trials, etc.”

“Cancer used to be a disease surrounded by despair and fatalism. In some European countries the cancer patient would not even want to mention a diagnosis of cancer to his nearest and dearest, but more and more cancer survivors are showing the way, by example, that it is possible to survive cancer and to take this experience to help others take courage and lobby for change,” she says.

The ECPC is at the forefront of lobbying for change in Europe but smaller organisations have also noticed recent changes in attitude and have able to shape local decision-making.

Helle Viola Haugaard, president of the Danish Breast Cancer Organization – a society with just over 2000 members – said the opinions of larger groups such as the Danish Cancer Society are most certainly taken into account by researchers, funding bodies and politicians but the smaller ones like themselves are starting to have an impact.

“We have successfully influenced public policy on a few specific issues of significance to breast cancer patients,” she said.

“And yes we have noticed an increased interest in patient experience and in the views of patient organisations in recent years.”

Patient groups are also becoming more organised, she believes.

One example she gives is the participation of Danish Breast Cancer Organization members in a working committee preparing guidelines for the physical rehabilitation of breast cancer patients.

Laura Gibson, spokesperson for the UK-based organisation Breakthrough Breast Cancer points to the aforementioned Best Research for Best Health strategy published by the English government this year as evidence of changing attitudes towards the role of patients in research.

Within five years time, the government report calls for fairness of access across the country for patients taking part in multicentre clinical trials and for more patients to take part in high quality health research with early access to new intervention and prevention strategies.

“There is a clear steer by the government to involve patient groups in medical research,” Ms Gibson says.

And she adds politicians are not the only ones starting to take patient views into account.

“Many funders do ask for patients’ opinions and involvement, for example ‘consumers’ are included in most Clinical Studies Groups of the National Cancer Research Institute (NCRI), a partnership of major UK cancer research funders and are tasked with the development of national cancer clinical trials.”

She says without patient involvement in setting the research agenda, organisations such as Breakthrough Breast Cancer, that fund research would be unable to make sure their work is relevant to their needs.

“Patients tell us that they want to know that research is taking place into issues that are important to them and there is a clear demand from them to be involved in helping to direct research policies.”

“As beneficiaries of research, patients can bring a unique perspective to the table and it is important that our work is informed by their opinions,” she adds.

In the UK and other countries, tables and projects have been set up specifically to explore and assess the impact of patient and public involvement, such as the Natural Ground project by the Association of Medical Research Charities (AMRC).

And it’s not just in Europe where strides have been made in involving patient organisations, Ms Gibson points out.

“In America, the breast cancer charity, Susan G. Komen for the Cure involves advocates in the scientific peer review process to enable a better assessment of disease impact in their funding decisions,” she says.

Breakthrough Breast cancer took views from a range of ‘stakeholders’ when putting together their research strategy including scientists, doctors, policy makers, health professionals, pharmaceutical industry representatives and “importantly” patients.

“All of the above views informed the final decision, which resulted in new research priorities, in particular, the establishment of three new Breakthrough Research Units in England and Scotland,” she says.

She did, however, point out that a ‘Listening Study’ carried out by Macmillan Cancer found there are still generally gaps between the research priorities of researchers and patients.

But added: “There has been a marked increase in the number of research organisations making a strategic commitment to user involvement in research, as highlighted in the NCRI Strategy 2008–2013.”

“Organisations such as the James Lind Alliance are pioneering research into patient priorities in order to identify gaps between patient and scientific research agendas.”

But where and how patient involvement is useful may still be open to debate.
“More evidence is needed about what constitutes good practice in user involvement and what the consequent benefits and impact are.”

“Where benefit is demonstrated, patients and their advocates should also be given more opportunities in helping to decide research priorities alongside researchers, funders and politicians and provided with necessary support mechanisms such as lay briefings,” says Ms Gibson.

Jude Watson, programme development manager at Myeloma UK has a somewhat less optimistic view.

She said patient groups will feel varying levels of engagement but her experience was that researchers, funders and politicians do not take patient views into account, at least that is, some patient views.

“There is limited proactive engagement with the groups that represent rarer or less common diseases,” she said.

“Due to a lack of recognition and awareness of myeloma, government research funding is difficult to come by.”

“Research in myeloma is usually pharmaceutical-led – incentivised by European orphan drug legislation – or led by patient groups themselves.”

“Myeloma UK, for example, funds a sizeable amount of research ranging from basic science to health services research.”

Ms Watson said the voluntary sector can help to bridge the gap between research and patients.

“Patient groups have the expertise, knowledge and knowhow to understand the barriers to, for example, participation in clinical trials and can inform prioritisation of research.”

“Patient group involvement is helpful, for example, in the design of surveys to inform needs, recruitment of patients and knowing the most effective methods of targeting different groups,” she added.

Myeloma UK do not share the view of some other patient organisations that their involvement in strategic decisions has improved dramatically in recent years and this once again is probably due to some areas of cancer medicine getting more attention than others.

“The Cancer Reform Strategy has gone some way to state an intention for better engagement with patient groups, but in our opinion not far enough for rarer diseases,” she says.

But she does believe there are ways to for smaller organisations to make their mark – through coalitions of cancer charities or building up rapport and credibility with MPs.

In the future, Myeloma UK want to see patient groups as a standard part of research decision panels and collaboration between all research stakeholders to help prioritise research and improve and focus outcomes for patients.

In addition, a commitment from government and research bodies to work with the voluntary sector, patients and carers in the development and delivery of a research strategy.

The EU presidency is currently under the leadership of Slovenia and cancer is at the top of the agenda (Figure 2).

Speaking at the ECPC summit, Dr Marija Seljak, Slovenian director general of public health, representing the Slovenian Minister said their goal during the Presidency was to highlight the gaps in cancer care and encourage everyone to take the necessary steps towards making improvements.

“Patients have an important voice informing all of us how best to do that.”

“In the realm of prevention, we need to engage the help and of our citizens in order to combat cancer.”

A spokesperson for the Slovenian Ministry of Health added patient groups had become stronger in the European health policy arena, increasingly involved in shaping cancer prevention and control policies and increasingly more professional and sophisticated in their organisation and lobbying efforts.

It is a view echoed by the Cancer Patients Association of Slovenia who say although there is not yet an established role in policy decision for patient organisations in the country there has been a move in recent years in patients taking on a much greater advocacy role as well as new legislation such as the National Cancer Control Plan and laws on patient rights which have promoted the patient agenda.

Last year the organisation made the serious attempts to present patient groups priorities to those making decisions regarding biological medicines research.

“Ideally, in the future, we would like to see the systematic participation of patient representatives in all major decision making processes,” they said.