A quarter of cancer patients who could benefit from radiotherapy do not receive it. As head of policy and partnerships, Chiara Gasparotto is positioning the European Society for Radiotherapy to make the case for better access and to alert policy makers and the public to the unmet need in their own countries. Peter McIntyre reports.

Radiotherapy has a compelling story to tell about its potential in cancer treatment and about significant unmet need across Europe.

Almost half of patients diagnosed with cancer would benefit from treatment that includes radiotherapy, yet almost a quarter of these patients do not receive it. As the number of European citizens diagnosed with cancer rises, the number of patients who would benefit from radiotherapy will also rise, reaching around 2 million by 2025 – a 16% increase in demand since 2012.

And with improvements in skills and technology and imaging now allowing more personalised and precise treatment that can target tumours more effectively, while doing less damage to healthy tissue, the need to improve access to radiotherapy is ever more urgent.

As Director for Policy and Partnerships at the European Society for Radiotherapy ESTRO, Chiara Gasparotto has responsibility for getting that story heard by people who can deliver on the needed investment in skills and technology. For the past seven years, she has been helping the Society to become more outward looking and to build partnerships that strengthen understanding of the potential for radiotherapy among policy makers and within the cancer community.

When she started in that role, says Gasparotto, it was clear that ESTRO lacked the level of public visibility that other oncology societies enjoyed. “For sure there is no difference in importance within the disciplines, but historically the other disciplines started to grow in terms of public knowledge much earlier than radiotherapy.”

The turning point came in 2012, she says, when the then ESTRO President Vincenzo Valentini launched the Society’s vision for 2020, with the aim that “Every cancer patient in Europe will have access to state-of-the-art radiation therapy, as part of a multidisciplinary approach where treatment is individualised for the specific patient’s cancer, taking account of the patient’s personal circumstances.”

The vision was that other specialities would recognise radiation oncology as a major contributor to cancer cure and ESTRO as a strategic driving force in the multidisciplinary fight against cancer. As part of that, ESTRO aimed to become the pre-eminent educational and scientific society in radiotherapy and oncology.

Gasparotto, who had been managing courses at the ESTRO School for the previous three years, was tasked with establishing the public affairs unit and became its director. With her help, ESTRO began to focus attention on translating clinical and epidemiological data into information that health policy makers can understand and use. And it used facts about unmet need, costs and benefits to achieve greater recognition among the cancer community of the contribution of radiotherapy to curing and palliating cancer.

“When the process started of looking into ESTRO’s place with other stakeholders then yes, you did feel a difference,” says Gasparotto. “The Society began to feel a growing interest in partnership and in reaching out towards external stakeholders, including other oncology societies. We started to look into what it means for ESTRO to engage in public affairs.”

Making the economic case

One of her roles has been to support the HERO project (Health Economics in Radiation Oncology), launched by ESTRO to develop a European knowledge base and a model for health economic evaluation.

“The role of the HERO project was of paramount importance looking at the health economics of radiation oncology. It started to look into the availability of radiotherapy in terms of staffing, machines and guidelines. Then it looked at the need for radiotherapy – how many patients need the treatment and how many patients are not getting the treatment. It was really looking at the whole healthcare system. We were sitting on data that were and still are extremely important from the point of view of organisation of care.”

HERO has delivered a cost-accounting programme as an online tool for use by country-level societies to support data driven decision making.

Changing public perceptions

The Marie Curie Legacy Campaign was launched in 2018 to change public perceptions. An initiative of the ESTRO Cancer Foundation (ECF), developed by ESTRO and corporate partners, it promotes a clear message that radiotherapy could save one million more lives a year by 2035 if used to its full potential.

“The Marie Curie campaign was and still is a beautiful adventure,” says Gasparotto. “For the first time we decided to talk a sort of different language and reach out to media and lay public and include decision makers as well.
“We started this adventure without knowing what would be the level of response from the media and we were positively surprised that it caught on. It means there is a hunger for information and understanding more and better what kind of treatment patients can have.”
Gasparotto worked with colleagues to draw out essential data from the HERO project and distil it into media friendly messages while retaining the confidence of doctors and scientists. “Science definitely has a different pace from media – much slower,” she notes. “It is not always easy to keep up the attention of the media and to make sure that what you are telling them is always newsworthy and relevant.”

The Marie Curie Legacy Campaign has been embraced by ESTRO national societies, which added their own data and backed national media campaigns, notably in Belgium, Poland, Spain, Germany, Italy and Portugal. “The role of the national society was extremely important to be the bridge towards what ESTRO is developing and the different national circumstances,” says Gasparotto.

Advocating on the European stage

This initiative was quickly followed by a White Paper, ‘Radiotherapy: seizing the opportunity in cancer care,’ which makes a pitch for governments, policymakers, healthcare professionals, patients and professional societies to become ‘radiotherapy ambassadors’.

The White Paper, presented at the EU Parliament in Brussels in January 2019, highlights a need to deal with inequalities and presents a five-point plan to close the gaps in radiotherapy provision across Europe. The report cites shortages of equipment, variations in training, insufficient integration of radiotherapy into treatment plans, lack of investment in research, lack of general understanding of radiotherapy, and misconceptions about safety as contributing to radiotherapy’s poor image and underuse.

Gasparotto believes these initiatives have started to make a difference. “The campaign and meetings at the European parliament allowed ESTRO as a society to be more visible and to start entering into discussions and debates with decision makers we would not have had a few years back.”

The European Commission has put cancer high on its health agenda and is receptive to new ideas for promoting treatment. At national level there has been more readiness to include radiotherapy societies in partnerships and networks. “It is a positive circle. You start a campaign and thanks to the campaign you get attention and start building bridges and those bridges might lead to another wave of campaigning.”

A voice in the wider cancer community

The links are also stronger with other European-level cancer societies. Yolande Lievens, President of ESTRO, chairs the Value Based Healthcare project established by the European CanCer Organisation (ECCO) to examine ways of measuring the value of different types of cancer treatments to determine the real benefit to patients. Radiation oncologist Cai Grau, who chairs the HERO project, is also a member of the value-based healthcare expert core group.

With Yolande Lievens, ESTRO Past-President and Chair of the HERO project

In March 2019, ESTRO launched its new strategy for 2030: ‘Radiation Oncology. Optimal Health for All, Together,’ which puts still greater emphasis on partnerships and on looking outwards. It calls for the creation of more multidisciplinary practice guidelines in which the oncology societies would work together to promote evidence-based combination treatment, with an enhanced role for radiation therapy. It proposes greater collaboration with GPs, carers and patient support groups.

ESTRO is also playing a wider global role, and in 2018 established an ‘ESTRO meets Asia’ congress, now held annually in Singapore, to share experiences and plan future collaboration. It also partners with the International Atomic Energy Authority, which works to make the case for radiation oncology in parts of the world, in Africa for example, where around half the countries have no radiotherapy services.

Marrying sociology and oncology

When Gasparotto joined ESTRO in January 2009 to manage courses at the ESTRO School, it was the match of skills that attracted her, rather than the oncology. “I’ve always liked to understand connections and relationships between people and between groups, she says. “What inspires me most today is the sociology of organisations – to see the dynamics between people and the values and behaviours within organisations.”

In fact she had reservations about working alongside clinicians. Her father was a radiographer and her mother a hospital secretary (both now retired). Her uncle is a doctor and hospital manager and her aunt is a nurse. As if this was not enough her sister is a biologist.

“I was panicking a bit because I did not know anything about oncology and because everyone in my family works in a hospital. I was kind of proud that I was the only one who escaped from a healthcare environment … but then you see that things happen for a reason.”

She concludes that her choices were probably not by chance. “Very often you are in the right place at the right time. There is a *fil rouge* that connects all my steps.”

Born and brought up in north-east Italy, Chiara Gasparotto did her first and second degrees at the University of Udine in Gorizia, close to the border with Slovenia. Her Masters is in European public relations, concerned with European public affairs and international relations.

Between her two degrees she took part in the Erasmus exchange programme, studying social science at Göttingen University in Germany, after which she went to live and work in Brussels, partly because she wanted to travel and partly "because of love".

She took an internship with a consultancy dealing with financial services, where she found herself in charge of organising events, and then worked with a consultancy concerned with EU financing for university education and research.
That experience prepared her for her first job with ESTRO, as their School contact point for professional development courses. In that role she developed a strong insight into the needs of young specialists and into the workings of a European medical society. She also got to understand the value of the 'volunteers' – the specialist radiation oncologists, physicists and radiation therapists who build the organisation, run its influential committees and share their expertise. "The volunteers are extremely motivated and it is motivating to work with them. You feel this energy and commitment they put into the society and that is amazing. I had this when I was working with the School and I still have it today."

The next decade

With so much going on, it is perhaps not surprising that ESTRO is one of the fastest growing professional medical societies in Europe. A 30% increase over the past five years has seen membership grow to more than 7,800 radiation oncology professionals, just over half of whom are radiation oncologists, about a quarter are medical physicists and 10% are radiation therapists and dosimetrists, who deliver the treatment, or radiobiologists, who study how radiation affects the biology of cells.

Gasparotto talks of the need to "time-proof" the future of the organisation by anticipating the need for changing services. "The vision looks at how to empower the radiotherapy community. You listen to the communities, you understand what they need, and then you respond to those needs."

"If you look at the goal of ESTRO and all the other medical associations, it is to ensure that patients do have the best care, and patient treatment by definition is multidisciplinary. So making sure that we are going to work together and collaborate is somehow in the DNA of what cancer care is today. The feeling that I get is that we have much more dialogue with patient societies, organ specific societies and other medical societies."

> "You feel this energy and commitment the volunteers put into the society, and that is amazing"

She says that ESTRO has greater potential to make use of the data that emerges from their research projects, both internationally and by supporting national level societies which are gatekeepers for information about radiation therapy in their countries.

Gasparotto is also focused on the challenges of complexity and effective governance that accompany growth and greater visibility. "We need to make sure we have the governance appropriate to get to our goals in 2030," she says. "My personal and professional endeavour is to learn to face this

complexity. Personally I am a fan of simplicity, but if problems are complex you cannot expect always to find a simple solution. I would like to learn how to do that a bit more."

She is as enthusiastic about her job today as when she joined ESTRO. "The radiotherapy community is growing stronger and more confident over the years, with a clear standpoint that the role they play in oncology care is central. The professionals ESTRO represents – clinicians, physicists, radiation therapists and radiobiologists – are the main reason why we work for ESTRO. They are brilliant, very bright (they understand this complicated technology) and at the same time humble and down to earth, and very sociable too. They love to party! I think the radiation oncology community is a very joyful one."