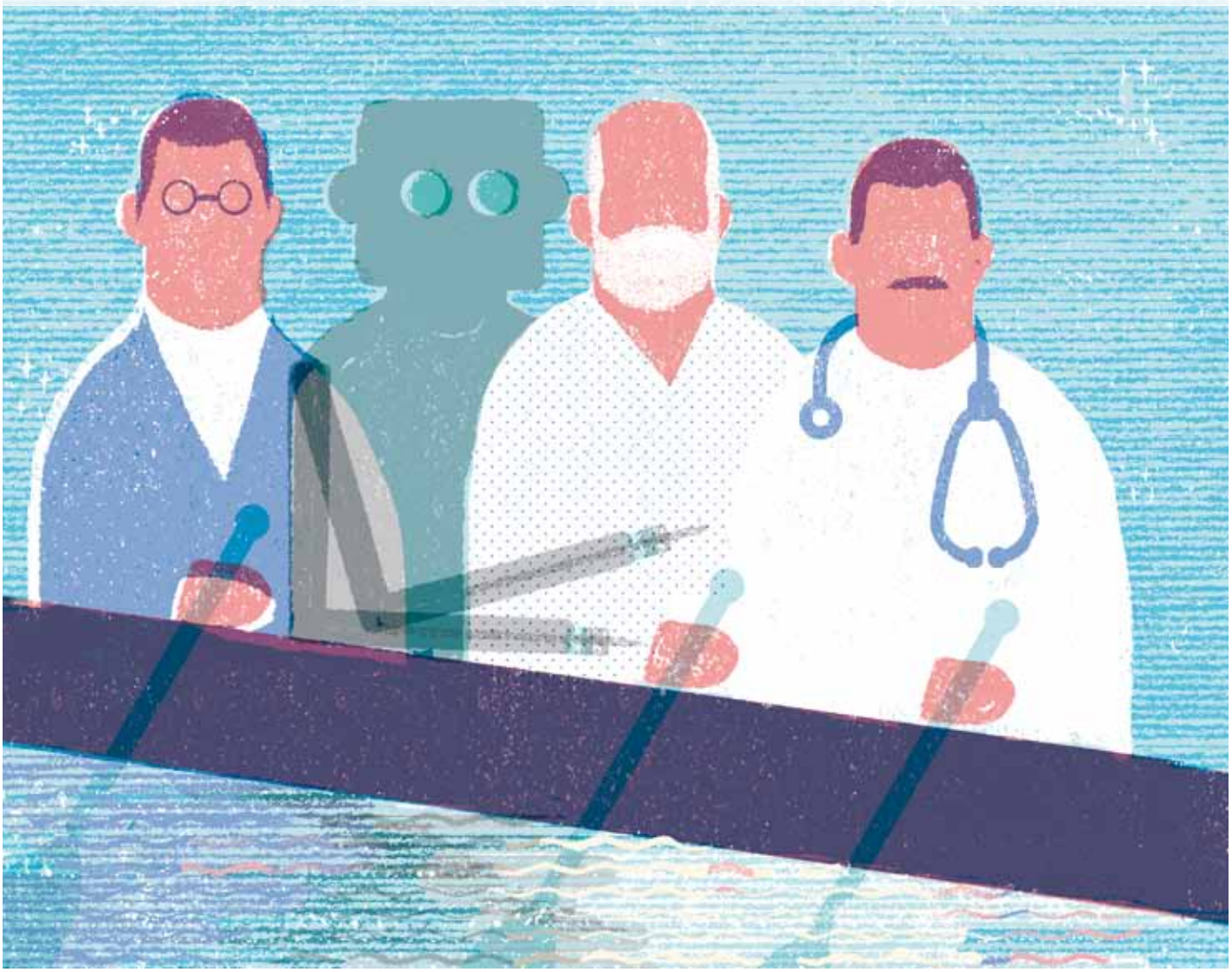
Pulling together: the case for prostate cancer units

People with cancer need their care managed by a team of specialists who work together and learn and improve together. **Simon Crompton** reports on efforts to achieve such a collaborative approach in delivering prostate cancer care.



There are few easy decisions in prostate cancer. Many men's experience of diagnosis, treatment and beyond is characterised by lack of clarity about the best management options, worry about potentially life-changing side effects, and enduring uncertainty about prognosis. A 2014 review in *BMJ Open Oncology* found that anxiety reached clinical levels in more than one in four men on diagnosis, one in seven during treatment, and more than one in six after treatment.

But it wasn't like that for Jobst Plog, a 74-year-old retired director of a broadcasting company, who has little bad to say about his cancer journey while at the Martini Clinic in Hamburg, Germany. Before having a nerve-sparing radical prostatectomy, he was advised about options, offered his choice of treating physician and treatments, and was then given the opportunity to attend a pre-treatment multidisciplinary conference.

"Physicians and the entire staff at the clinic work as a team, using their range of experience and specialisations in an organised process," he says.

A diagnosis of prostate cancer brings choices, which take careful explanation because each option is based on uncertainty and involves a complex risk–benefit analysis. Treatments such as surgery and radiotherapy may bring a greater likelihood of cure, but they produce hugely varied side effects from patient to patient. Some men are left with life-changing complications such as incontinence and impotence.

Around two in ten men have long-term urinary incontinence following prostatectomy, but the likelihood varies according to age, physical fitness, surgical technique and where the surgery is conducted. The Martini Clinic, for example, claims its database shows that more than nine in ten of its patients are fully continent after treatment, compared to a German average of between five and six in every ten (Harvard Business Case Collection 2014, case 714-471).

Less aggressive approaches such as active surveillance, which rely on careful monitoring, reduce the risk of side effects and overtreatment – but leave the risk of cancers growing and becoming harder to treat.

Whichever way you look at it, patients can often be left with an anxiety-inducing gamble. Finding the right option for them requires clear understanding and impartial expert advice from the sum of the professionals involved in their care – not just a single urologist or radiation oncologist. And it was the multidisciplinary pooling of expertise at the Martini Clinic that helped Plog weigh the pros and cons, and left him confident he was doing the right thing.

Finding the right option requires impartial expert advice from all the professionals involved

He was told about the treatment options and also provided with detailed printed information. And he was involved in all the joint decision-making about the type of treatment he should receive.

"There were no surprises during my treatment because I was well informed and prepared," he says.

Specialist, multidisciplinary, audited units

What distinguishes the Martini Clinic, and 96 other centres in Germany, from the vast majority of units treating cancer in Europe is that they are certified prostate cancer units – centres characterised by specialisation, multidisciplinary collaboration and independent audit.

It is a model that a range of opinion leaders, led by the European School of Oncology and Europa Uomo – a coalition of prostate cancer patients' groups – see as the future of prostate cancer care in Europe. Its over-riding principle is that no surgeon, radiation oncologist or other professional should treat prostate cancer unless they specialise in it, and no single professional should be directing treatment on their own. The patient should be informed, involved and supported.

It is the logical way to go, according to Riccardo Valdagni, Director of the Radiation Oncology 1 and the Prostate Cancer Programme at Milan's Istituto Nazionale Tumori and also coordinator of ESO's Prostate Cancer Programme.

"If we look at the experience with breast cancer, it is clear that our evolution will be towards a system of certified and accredited prostate cancer units," he says. "That means independent bodies checking the quality of services."

As Valdagni suggests, the idea of the prostate cancer unit hasn't come out of the blue. A similar model has been promoted – and gradually implemented – for breast cancer care across Europe. Responding to evidence of widely varying survival rates, two European Parliament resolutions in 2003 and 2006, and declarations on the fight against breast cancer in 2010 and 2015, called on member

Exploring all the options. Patients seen by the Prostate Cancer Unit at Milan's Istituto Nazionale Tumori have an initial consultation with the full range of specialists, including a urologist, radiation oncologist, medical oncologist, psychologist and nurse

states to ensure that all women in the European Union have access to treatment in specialist breast units, certified according to quality criteria set down by the European Society of Breast Cancer Specialists.

There is evidence that five-year survival is around 18% higher among women treated in a specialist breast unit (*BMJ* 2012, 344:1e9). Indeed, research in breast and other cancers shows that such specialist multidisciplinary centres produce the highest treatment success rates and best patient experience. High concentrations of specialists and a high volume of patients develop skills and quality. And multidisciplinary care brings quicker treatment, better individualised care and support, and better adherence to evidence-based guidelines.

The case for prostate cancer units

Multidisciplinary specialist management has become widely accepted as the best means to optimise experience and outcomes for patients for many years. But the argument to have it at the heart of prostate cancer care is particularly strong.

Here, the 'best' means of diagnosing and treating localised disease can attract intense debate: the benefits and drawbacks of different diagnostic tests; the relative merits of surgery, brachytherapy, radiotherapy and surgery; the right time for active surveillance and watchful waiting; the role and timing of new drugs. All need to be carefully balanced to meet each individual's needs and priorities.

Multidisciplinary prostate cancer units provide a structure where urologists, radiation oncologists, medical oncologists and psychologists specialising in prostate cancer collaborate to decide the best treatment and care options.

Germany has been encouraging cancer centres with this specialist multidisciplinary approach since 2003.

Requirements for a European Prostate Cancer Unit

A multiprofessional task force of internationally recognised opinion leaders, representatives of European scientific societies and patient advocates gathered to set criteria and standards for prostate cancer units. The result, published as a position paper in *Critical Reviews in Haematology & Oncology* last year, describes the relevant, feasible and applicable core criteria for defining prostate cancer units, and represented a consensus on 40 mandatory and recommended standards and items, including the following:

European Prostate Cancer Units

- are structures, with on-site interdisciplinary and multiprofessional teams and infrastructures, that are able to provide interdisciplinary and multiprofessional curative and supportive care for patients from newly diagnosed through to follow-up, rehabilitation and care of patients with advanced disease
- must manage a minimum volume of patients (set at 100 patients/year for the unit, 50 radical prostatectomies/year for surgeons, 50 radical or adjuvant treatments for radiation oncologists and a patient load of 50 for medical oncologists)
- need not be a geographically single entity, but patients must be managed and followed up under the guidance of a single interdisciplinary and multiprofessional team, for all immediate and deferred treatments and observational protocols (active surveillance, watchful waiting)
- should be allowed to network and outsource services, including adjuvant and palliative therapies as well as psychological support, to entities formally collaborating with the prostate cancer unit, to complete the path of care.

Education and research

- Prostate cancer units should provide interdisciplinary and multiprofessional continuous education on all aspects of prostate cancer care, including research.
- They should actively aim to enrol patients in clinical trials and research.

Guidelines/protocols

- Evidence-based written guidelines used for diagnosis and management of prostate cancer at all stages should be clearly identified.
- Protocols should be agreed by the core team members; new protocols and protocol amendments should be discussed in the core team.

Documentation and audit

- A minimum set of variables should be recorded electronically in a database: diagnosis, pathology, surgical treatments, radiotherapy, brachytherapy, adjuvant treatments, observational strategies, palliative treatments, clinical outcomes and follow up, including side effects and complications.
- Data must be available for audit.
- Minimum outcomes for mandatory quality indicators should be achieved.
- Performance and audit figures must be produced yearly and set alongside defined quality objectives and outcome measures.
- Internal audit meetings should be held at least twice a year to review quality indicators and amend protocols as necessary.

The full list of standards and requirements can be seen in Critical Reviews in Haematology & Oncology *vol 95, pp 133–143.*

It has done it through a system of certification administered by Deutsche Krebsgesellschaft, the German Cancer Society – first for breast cancer, then for colorectal cancer and then, in 2008, for prostate cancer. By 2014, one-third of all prostate cancer patients in Germany were treated at a certified prostate cancer centre.

Each centre needs to fulfil a catalogue of requirements and publish quality indicators to receive certification. The requirements were developed by a commission of experts from professions and disciplines specialising in prostate cancer and German patient advocacy groups. They were taken into account when ESO's Prostate Cancer Units Initiative in Europe developed 40 new standards for prostate cancer units, which were published last year in *Critical Reviews in Haematology & Oncology* (see box).

The German framework, then, is providing inspiration for the new European evolution of prostate

cancer treatment. But what insights does it provide into the experience and effectiveness of specialist, multidisciplinary units?

An analysis of the German Cancer Society's 2014 annual report of 92 urology departments certified as prostate cancer centres shows that all treat more than 100 primary cases of prostate cancer each year: throughput is an important quality indicator. The number of radical prostatectomies has decreased over time, indicating that approaches aiming to minimise overtreatment are increasingly valued.

Between 2010 and 2013, the proportion of patients on active surveillance increased more than six-fold, from 2.5% to more than 16%. And the proportion of patients receiving psycho-oncologic care more than doubled, from 8% to 17%.

"We defined our measures to reflect quality," says Simone Wesselmann, head of the certification department of the German Cancer Society. "An auditor from the independent OnkoZert institute visits each centre, examines processes there, speaks to all the people involved and discusses the results of the quality indicators. This gives you a means of judging."

It is this constant measurement and reporting that most distinguishes prostate cancer centres

Certification, she says, is all about transparency for the patient – making quality of care visible, and providing a basis for national and international comparison. The main criterion for comparing centres will never be length of survival, says Wesselmann, even if it were possible to measure.

"That's not the aim of certification,"she says. "If you want to gain the trust of the patient, you must be able to say that within this year, this doctor achieved these high-quality standards.

"You cannot say that if one patient dies after 13 years and another dies after 15 then the difference is down to the quality of their surgery, or the care they received. For certified centres that would be a superficial measure. We want to be trusted by the patient – to be able to tell him that we know what this doctor did last year, that he's had so many re-sections for a particular operation, or so many critical events."

These are the things that matter for patients, says Wesselman. "It's about being totally transparent."

No one claims that the German system is perfect. Wesselmann acknowledges that patients' own reports of outcomes for different therapies could be included in the indicators: the German Cancer Society is investigating this as part of a new study into the patient experience, which will be funded by the men's health charity Movember. And a recent paper in *Der Urologe* reviewing the 2014 report of German prostate cancer centres noted that data about potency and continence following all treatments was lacking.

Patient groups have, however, been a driving force behind certification of German prostate cancer centres, and representatives do believe that the patient experience is improving as a result of certification.

Günter Feick, chairman of the German prostate cancer patients' organisation Bundesverbandes Prostatakrebs Selbsthilfe, is also a member of the certification commission for German prostate cancer centres. He says that around a quarter of the total number of hospitals treating prostate cancer in Germany are now certified. The important differences between the certified and non-certified centres, says Feick, lie in management systems, structural requirements, audit, and collaboration with prostate cancer patient groups.

"The multidisciplinary organisation is very important to us," he says. "The patient always has the oncologist, the urologist, the radiation oncologist, the pathologist, the psychological team, the social management team all together as one organisational unit, all following a certain path of treatment and communication together, in a procedural flow described in the requirements.

"It's important that, three years after their initial certification, centres are visited by an independent team of experts, including a patient representative, to see on-site whether what they are doing still fulfils the initial requirement.

"Each of the centres is required to be in cooperation with a prostate cancer patient support group. Because of this, not only are we part of the certification process, but we also have representatives within the centres.

"Patient representatives are also involved in the annual audit. So this is a system where the patient has maximum influence, where the patient is treated in a structure, process and reporting system which you find in no other clinical organisation."

It is this constant measurement and reporting that most distinguishes prostate cancer centres from the rest, according to those involved with the

"What's measured improves"

The German Cancer Society certifies prostate cancer units on the basis of their performance, on a wide range of indicators, including the following measures of interdisciplinary collaboration:

- Case presentation in pre-treatment conference — through urology (primary cases)
- Case presentation in pre-treatment conference — through radiotherapy (primary cases)
- Participation of core disciplines in post-therapy conferences — urology (diagnostic + surgical)
- Participation of core disciplines in post-therapy conferences — radiotherapy
- Participation of core disciplines in post-therapy conferences — urologist or medical oncologist
- Participation of core disciplines in post-therapy conferences — pathology
- Presentation at post-therapy conference — primary cases
- Presentation at post-therapy conference — all patients with initial manifestation of a recurrence and/or distant metastasis
- Psycho-oncologic care (at least 30 minutes) (primary cases)
- Social service counselling (primary cases)
- Participation in research study

The full list includes indicators of interdisciplinary collaboration, specialism and adherence to clinical guidelines.

German certification system. Once you do that, how good (or bad) you are becomes transparent – and the force to improve becomes irresistible. As Feick says: "What's measured improves."

This amounts to much more than the vague commitment to involving and informing patients that might come from non-certified centres, he says. The certification requirement that patients should be present, if they wish, at the pre- and post-treatment conferences with the entire multidisciplinary team, makes decision-making without patient involvement virtually impossible.

The German Cancer Society's report of indicators from all prostate cancer centres shows that 98% of patients who initially presented to a urologist attended a pre-treatment conference in 2013.

The challenge of change

Specialist centres where men with prostate cancer are managed through a multidisciplinary team have been established in some countries besides Germany, and some are now applying the ESO criteria. Their experiences are pointing to some of the challenges, as well as some of the opportunities, that come with introducing prostate cancer units.

In the Netherlands, for example, the official ending of national health insurance in 2006 enabled insurance companies to centralise treatments in specialised centres to increase efficacy and quality. The Prostate Centre at the Erasmus Medical Centre in Rotterdam started in October 2010, and is the first organised multidisciplinary prostate cancer unit in the Netherlands.

There is as yet no authoritative evidence that abiding by the requirements outlined in the ESO initiative (*Crit Rev Haematol Oncol* 95:133–143) improves patient experience or outcomes, says Chris Bangma, Professor and Chairman at the Department of Urology at the Erasmus Medical Centre. "Of course, our questionnaires show we have high patient satisfaction," he says. "We also know that we are reducing unnecessary biopsy by 30% because of risk-reducing protocols agreed between specialists. It's the result of close collaboration and agreed procedures. But there is as yet is no comparable data to show that it is better."

What is clear, says Bangma, is that setting up a truly multidisciplinary expert system is no minor undertaking. Re-organising structures, funding, working methods and professional

hierarchies, takes time. For some professionals, it involves letting go.

"It's all about creating trust," says Bangma. "Some people think they're working towards something, other people want their income or salaries or patients or whatever. That is what you have to avoid."

Elsewhere, there have been concerns that traditional urology structures in some countries are a barrier to the multidisciplinary outlook of prostate cancer units. Last year, the long-serving Secretary General of the European Association of Urology (EAU), Per Anders Abrahamsson, told *Cancer World* that urologists – traditionally surgeons – could no longer work independently of other specialists in the cancer field and had to work as part of multidisciplinary teams. He expressed EAU support for the concept of prostate cancer units.

Re-organising structures, funding, working methods and professional hierarchies takes time

Investing in nurses

But the concept of true multi-disciplinary working, with skilled and specialist nurses at the heart of clinical care, is still a challenge to some, according to Lawrence Drudge-Coates, a urological oncology nurse specialist at King's Hospital London and Chair of the European Association of Urology Nurses.

"If prostate cancer units are to be a reality throughout Europe," he says, "there has to be a recognition from urologists that there needs to be investment in specialist urology nurses – and an agreed skill mix where nurses are not just part of a support team, but actively, clinically involved in patient care. It's about a change of attitude, realising that nurses have to be engaged on an equal level."

In the UK, specially trained urology nurse specialists form part of a multidisciplinary urology cancer team, and see all newly diagnosed patients. This is a mandatory requirement, laid down by the standard-setting National Institute for Health and Care Excellence (NICE). The NICE requirements, concentrating prostate-specialist professions, means that the UK effectively has a system of prostate cancer units.

For the patient, says Drudge-Coates, there are enormous benefits. "In the UK model, nurses are pivotal in ensuring continuity in patient care, from the point of referral when prostate cancer is first suspected, and then all along that patient pathway. They have more contact with the patient than any other individual in the team, and have the skills to tackle many aspects of patient care, patient questions, follow-up, and also providing key clinical input."

Research conducted at King's College Hospital found that a nurse-led assessment clinic for suspected cases of prostate cancer cut waiting times to further tests from eight to four days. And nine out of 10 men said they were very satisfied at having nurses involved at this early point of contact, saying they gained a clear understanding of the diagnosis process.

However, there are huge variations in nursing skills, status and autonomy in Europe. In some countries, such as the UK, Ireland, Scandinavian countries and the Netherlands, specialist nurses have clinical autonomy and work alongside urologists. In others, their clinical input is virtually zero. In the absence of any European directives for standards in urological cancers – as there have been for breast cancer – it is hard to see nurse specialists in urological cancers becoming widely available, says Drudge-Coates.

"Prostate cancer units may be able to function without them, but in those countries that don't have nurses working at that level, you have to ask what can we can do to raise skill levels so that centres can call themselves prostate cancer centres."

In setting down its 40 requirements for prostate cancer units, ESO's Prostate Cancer Units Initiative in Europe acknowledged the need to set standards at an "attainable medium level" to make them applicable across Europe.

The prostate cancer unit skill mix requirements specify, as part of the core team, "one or more nurses dedicated to or specialised in urology", where "dedicated to" is defined as devoting at least 75% of their working time to genito-urological oncology. Among their specified roles, they are required to be available at clinics for people who are newly diagnosed, "to provide additional information and support as required". Candidates for accreditation as Prostate Cancer Units will therefore have to show their nurses have the knowledge and skills to fulfil that role.

Making it happen

The example of breast units in Europe, though inspiring for prostate cancer, is not necessarily encouraging. The target set by the European Parliament was that all

women in Europe should have access to a specialist breast centre by the year 2016. But according to Europa Donna, the European breast cancer patients coalition, that was instrumental in gaining EU guidelines on specialist breast units, progress has been slow. And the need to improve breast cancer services through specialist units has not been accepted by all stakeholders.

"There are still many countries where no breast units exist that in any way conform to the guidelines and there is a risk that there are now entities calling themselves breast units without meeting many of the standards outlined in the guidelines," said Susan Knox, Europa Donna Chief Executive Officer, in an article in *Breast* last year.

She told *Cancer World*: "We continue to advocate for the implementation of specialist breast units across Europe. We are now working on highlighting the need for specialist breast unit implementation at the upcoming European Breast Cancer Conference, where a survey will be presented indicating the status of implementation today and a manifesto addressing this issue will be released."

The next steps for the Prostate Cancer Unit Initiative in Europe, then, look to be deliberate ones. Gathering support for the concept, gaining wide agreement for the quality indicators, and establishing an independent accrediting body won't happen overnight.

"Putting together the actors could take a while," says the Chair of the Prostate Cancer Unit at Milan's Istituto Nazionale Tumori, Riccardo Valdagni. "But we understand the process and the nature of our evolution is that, if people support the idea of multidisciplinary working, the rational way to go will be someone independent accrediting prostate cancer units."

The prostate patients' coalition Europa Uomo, which has supported ESO's European prostate cancer unit initiative from the start, now sees the main challenge as inequalities in Europe. "We absolutely support prostate cancer units as the gold standard," says current chairman Ken Mastris.

"From the patient point of view, the current experience is that the professional you first see is the person who controls your treatment. And in some countries the urologist is still regarded as God. It's important that we break down that kind of barrier to a multidisciplinary approach. At the same time, you have to recognise that the gold standard may not be easily achievable for the next five to ten years."

"In some countries the urologist is still God. We need to break that barrier to a multidisciplinary approach"

Following the example of breast cancer, Mastris believes that EU guidelines for prostate cancer services are essential. Europa Uomo's Call to Action on prostate cancer across Europe, published in 2013, called for prostate cancer care to be coordinated and managed by a multiprofessional team within a certified centre or network of excellence. Europa Uomo sent a copy to every Member of the European Parliament, asking for support. So far, the response has been thin.

"We want to see the issue addressed more in the European Parliament," says Mastris. "The priority should be: don't treat the cancer but treat the patient. We need more personalised medicine, more communication, patients being guided through their journey – before, through and after treatment. Communication between professionals is so important for that."

Prostate Cancer Units Network

In January 2016, ESO and the patient advocacy coalition Europa Uomo launched a new network designed to help those centres working on the prostate cancer unit model share information and spread understanding. The objective is to gather a European consensus about the need for prostate cancer units, and then build an international system to accredit them. More information about its aims and how to join can be found at www.prostatecancerunits.org.