

Delivery of survivorship

Assessing the needs of cancer survivors



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and problems, professionals can provide tailored support, education and intervention for their patients. If patients are physically and psychologically supported, educated and learn to cope and manage the after effects of their treatment and disease they will feel more empowered to self-manage and will want to live a more healthy and active life.

Recovery package

Three key areas of the recovery package we have focused on in our hospital are the following:

Holistic Needs Assessments

A Holistic Needs Assessment (HNA) is a questionnaire that is completed by patients affected with cancer, and identifies the patient's physical, emotional, spiritual, practical and social needs and concerns. The aim is to address these unmet needs within an acceptable timeframe by sharing these unmet needs amongst the multidisciplinary team to improve patient's management and care.

In the UK, HNAs are recommended to be completed at the following points of the patients pathway; start of treatment, during treatment, end of treatment, diagnosis of recurrence and transition to palliative care.

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Health and Well-Being Events

Health and well-being events are events aimed at supporting patients through their treatment by

Health services are continuously being put under pressure to deliver five-star service; with patient demand increasing and the lack of financial support and resources, this proves more and more difficult.

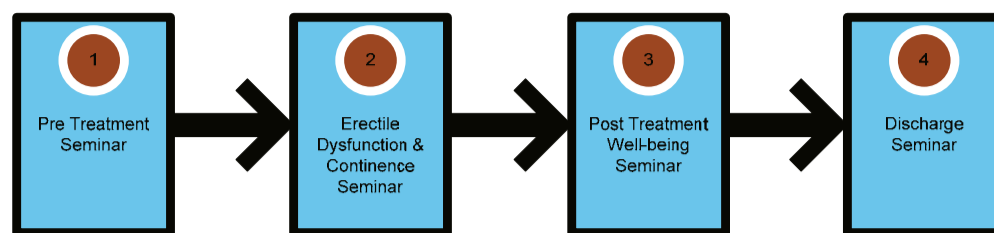
The only way to meet such demands is by radically changing how we currently practise, and revisit our patient treatment pathways to make them more efficient and effective for both patient and hospitals.

We know more people are surviving cancer because of early diagnosis and improved treatments. However, from patient satisfaction surveys and National Patient Reported Outcome Measures (PROMs) many cancer survivors are living with moderate to severe unmet needs (Macmillan, 2014). Marsh (2014), states "We have achieved most as surgeons when our patients recover completely and forget us completely." The question we need to ask ourselves is this: If patients are experiencing unmet needs how can they move on with their lives and put their cancer care behind them?

The UK has implemented the 'Recovery Package' as a national recommendation from The National Cancer Survivorship Initiative (2007). The aim is to implement key interventions to identify the unmet needs of patients in specific tumour sites. By gaining this knowledge and understanding of patients' concerns

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Figure 1: Prostate Cancer Survivorship Pathway:



Designed and Implemented by Paula Allchorne

involving different members of the multidisciplinary team to actively provide education, support or signposting people to the appropriate resources or support services. The events are tailored to your patient's clinical and tumour specific needs and concerns. Patients' biggest concerns or unmet needs are identified from the HNA questionnaires, which devised the content of what should be included in the health and well-being events.

Treatment Summaries

A treatment summary is a letter sent to the commissione medica locale or primary care doctors. The aim is to provide information on what treatment the patient has had in hospital and to give instructions on any interventions, for example, on-going medication or clinical observations. The treatment summaries also help the patient to understand what to expect in the future including; late side-effects and possible treatment toxicities, future management plan and the contact details for health professional to answer any future concerns.

These key elements of the recovery package aim to support and encourage self management.

Survivorship pathway for prostate cancer patients

In a busy urology unit in the UK, in 2014/15 we treated 1,500 prostate cancer patients. The only way to deliver these three elements of the recovery package we needed to devise a new survivorship pathway for prostate cancer patients. We ran several focus groups; for patients, specific ethnic groups and health professionals to establish what patients wanted from us. Also establishing what was feasible from the multidisciplinary team regarding time and commitment as there is currently no extra finances or resources associated with the recovery package. The following pathway was blueprinted:

Four seminar sessions have been embedded in to the prostate cancer survivorship pathway.

Seminar 1 Pre Treatment Seminar

This seminar is compulsory for all patients that are going to have prostate cancer treatment at our hospital. The pre-treatment seminar session physically and psychologically prepares patients for their pending treatment and enhances self management, educating them on their disease, side effects or complications they may experience during or after their treatment. There is also a key focus on healthy eating and physical exercise to promote life style changes. Each seminar session is tailored to the different treatments.

Seminar 2 Post Treatment Erectile Dysfunction (ED) and Continence Seminar

The erectile dysfunction and continence seminar is compulsory for all patients who have had robotic surgery. They attend this seminar four weeks after their catheter is removed to be educated on pelvic floor exercises, ED and a demonstration for using the vacuum erection device (VED).

The HNAs highlighted that ED and continence were among the biggest concerns and unmet

needs for our patients which is why this seminar was implemented.

Seminar 3 Post-Treatment Well-being Event

This is the only seminar we have not made compulsory based on the feedback from patients. Patients felt seminars 1 and 2 informed and taught them self management and coping techniques for their side effects and signposted them to other resources if they required any further interventions. However, we do still run a post-treatment well-being event for patients that have expressed any concerns that need more support physically or psychologically.

Seminar 4 Discharge Seminar

The discharge seminar is also compulsory for all patients that are being discharged back to their commissione medica locale or primary care doctors for follow-up. This seminar is aimed to encourage and empower patients to take back responsibility for their own health and future follow-up appointments. The seminar is designed to show patients what resources are in the community, help provide peer support and ensure they understand their future follow-up regime with their commissione medica locale or primary care doctors.

Evaluation

The new pathway has been successful not only for patients but also more cost efficient and effective for healthcare professionals. Delivering interactive group seminars has opened communication channels between patients, healthcare professionals and community services. All patients who have attended a seminar have completed a feedback questionnaire, and the majority of the patients found the seminar beneficial.

A total of 97% of patients who attended the seminars felt they benefited and gained more knowledge and coping strategies and 100% of patients were satisfied with the seminars. One of the biggest impacts to the group seminars was peer support; patients found it comfort in knowing other people were in the same situation and there were resources that could help them cope. The seminar sessions encouraged patients to ask questions about personal problems and also helped patients who were too embarrassed to ask personal questions as the group discussions were reported back as having a relaxed atmosphere and put people at ease. One patient said: "All the questions I wanted to ask but was too embarrassed to were either addressed by the nurses or another patient asked the question."

The seminar sessions have also been more efficient and effective for the healthcare professionals. Conducting one to two-hour group sessions has reduced the waiting list in the outpatients clinic because the nurses can now see up to twenty-five patients at once. This new survivorship pathway has also reduced the number of outpatient's appointments for patients, and has allowed healthcare professionals more time to provide efficient service to their patients.

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Urology nurse gains practical insights on caring for PCa patients



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I am a New Zealand urology nurse specialist with a special interest in prostate cancer. Fifteen years ago I established a small company which gave me the opportunity to develop a nursing service intended to identify and meet the needs of patients undergoing urology surgery.

I practice in Tauranga, a stunning seaside city in the aptly named region 'Bay of Plenty.' We have a large public hospital and a smaller more intimate private hospital called "Grace" which strives to be a centre of excellence in urology. The surgical treatments offered for men with prostate cancer are robotic-assisted laparoscopic prostatectomy, radical prostatectomy, brachytherapy and cryotherapy. We also have a brand new state-of-the-art Radiation Oncology Unit.

In August 2015, with the support of the (PCFNZ) Prostate Cancer Foundation of NZ, Abbvie and the New Zealand Urology Nurses Society (NZUNS) I attended the Prostate Cancer World Conference in the sunny North Queensland city of Cairns. It was my third conference which is usually convened in Melbourne, Australia. This year the organisers broke with tradition and the balmy Cairns temperatures really did provide welcome respite to those of us enduring a long, cold southern hemisphere winter!

The conference started extremely well with the official welcome being hosted on Green Island, Great Barrier Reef. Networking began in earnest on the boat trip out to the reef with a great turn out of delegates who spent the afternoon snorkelling and diving in the Gin clear water with its stunning variety of sea life and coral readily accessible.

The conference 'proper' began the following day at the Cairns convention centre with the programme offering three streams: Clinical Urology, Translational science, Nursing & Allied Health. The event brought together approximately 650 delegates (from 26 countries) with world leaders in prostate cancer presenting their expertise and current research across all facets of care.

Comprehensive programme

I found the programme of tremendous interest and very relevant to nurses. In this article I would like to focus on lectures of interest to me and share some of "the pearls of wisdom" gleaned.

On Day 1, Prof. Suzanne Chambers, clinical psychologist and author of "Facing the Tiger: Advice for Men and the People Who Love Them" spoke on the latest advances in psychological care for men with localised prostate cancer. Suzanne is a wonderful speaker who opened my eyes further to the prevalence of high levels of distress, depression and increased risk of suicide among men diagnosed with prostate cancer. I was surprised to learn that eight years after diagnosis, 30-40% of men had ongoing health-related distress, worry, low mood and insomnia. Almost half (47%) also reported at least some unmet sexuality support need.

Prof. Chamber's talk galvanised me into action and I returned home to establish a database of counsellors and psychologists with a special interest in caring for prostate cancer patients. Recognising that high levels of early distress predict later ongoing distress, I now ask all men to complete a "Distress Thermometer" (DT) as part of their rehabilitation assessment. The DT is a



validated tool designed to predict cancer distress (the prostate cancer version of the DT and associated validation data is available from Prostate Cancer Foundation of Australia).

Another Day 1 highlight was a workshop which offered the audience many tips on networking in a conference environment. The speaker urged the audience to avoid looking at how contacts can benefit them, instead recommending they be the person that connects other people together. We were encouraged to practise asking questions (but not 'closed' ones), not fill awkward silences (you end up oversharing) connect people to one another, and ask "How can I help you?" rather than look to how people can help me. This workshop achieved its desired outcome with everyone conversing freely by the end of the session. Strangers were prepared to approach others and start a conversation based on commonalities. There was wonderful interaction and this set the tone for getting people together for the rest of the conference.

On Day 2 I particularly enjoyed the lively and informative panel on "Challenging prostate cancer cases." The multidisciplinary panel included a urologist, radiotherapist, medical oncologist, psychologist, nurse specialist, exercise physiologist, general practitioner and the president of Prostate Cancer Foundation of Australia. This panel discussion highlighted the importance of a team approach in caring for men with prostate cancer, with each panellist lending their perspective on the best approach for care. It takes a skilled team to provide holistic support to men on a

prostate cancer treatment pathway. Treatment often starts, but does not end solely with a skilled surgeon!

Role of physiotherapy

A highlight from Day 3 was the presentation by Continence physiotherapist Dr. Irmina Nahon titled "Prehab physiotherapy – the best practice." Her presentation highlighted the benefits of pre-prostatectomy assessment and a change in thinking in the way we teach men pelvic floor exercises. She described a new hypothesis: that training the urethral sphincter will improve continence outcomes for men having radical prostatectomy. She stated that health professionals need to move away from giving 'anal cues' when delivering pelvic floor muscle training, instead focussing on instructions which selectively recruit the urethra. In summary the correct verbal cues for teaching men are to perform pelvic floor contractions that will shorten the penis, lift the testicles and stop the flow of urine.

A subject close to my heart, Dr. Favil Singh presented a wonderful talk titled "Pre-Surgical exercise programming to improve outcomes for men undergoing prostatectomy." He said that if we could squeeze all the benefits of exercise into one pill, it would be the most prescribed pill in the world. Exercise has been shown to counteract the negative side effects of treatment, shorten recovery times and improve quality of life. Preliminary investigations by Dr. Singh and his team at Edith Cowan University show that targeted pre-surgical exercise intervention is well tolerated by prostate cancer patients and results in considerable improvements in neuromuscular strength and cardiovascular fitness. Despite the numerous adverse effects of prostate cancer treatment, exercise has the potential to provide a buffering effect in preserving functional capacity.

The 2016 Asia Pacific Prostate cancer conference will return to the Melbourne Convention Centre, Victoria, Australia from 1 to 3 September. Make sure you save the date.

European Association of Urology Nurses

EAUN fellowship report

Expert insights at nurse-led clinic in the UK



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My fascination with all that is related to the nursing profession goes back beyond 2004, the year of my registration as a first-level Nurse. Soon after qualifying, I was given the opportunity to join the Operating Theatres Scrub Team at St. Luke's Hospital, a few years before our migration to the new Mater Dei Hospital.

I initially trained in General Surgery followed by Urological and Neuro Surgery. Excluding Theatre Nurse Specialists, all the rest, are obliged to be proficient in three specializations, not just for flexibility's sake, but also in case of a national disaster. My main specialisation, however, is urological surgery and I am working my way to become the second Urology Theatre Nurse Specialist here in Malta. Our urology unit is a specialised dynamic environment, where innovative techniques are the norm with the patient as the ultimate beneficiary.

EAUN Fellowship

My interest for the EAUN fellowship was fuelled by my pursuit of knowledge on how other prestigious urological facilities are being conducted and managed by competent nurses. Such first-hand experience will surely boost my understanding, helping me in my main goal to reach a competence level to that of a urological nurse specialist. I can say now that the knowledge I gained from this fellowship also exceeded my expectations and I am convinced that there is always room for improvement.

My primary objective was to witness first-hand the way experienced urology nurses perform and deliver. Unfortunately, such nurse-led clinics are still in their infancy in Malta and this fellowship helped me realise the potentials if we have the same experience and standard in Malta in the future. This is now more relevant than ever, especially with the upcoming Maltese Nurse Specialist Register that will be activated soon.

Host institution

Homerton University Hospital provides general hospital services and full range urology services. It is well known that this hospital supports the development of nursing. The hospital works closely with four other hospitals and includes top nurse-led clinics like Prostate Biopsy, PSA surveillance, haematuria and Intravesical therapy, among others. The support that the aforementioned clinics get from their healthcare institution is second to none.

The team I worked with was made up of a Nurse Consultant Urology and Uro-oncology, a Clinical Nurse Specialist Uro-oncology, a Clinical Nurse Specialist Urology and a Urology Staff Nurse.

The unit has a welcoming environment with a highly competent and friendly staff and made me feel part of a competent team. On my arrival, I was greeted by the urology staff nurse with whom I had corresponded. He showed me around the clinics and their respective setup. Though small, the clinics were well equipped with the necessary facilities. All medical equipment was well placed and ergonomically efficient. The competent staff was very knowledgeable in using the equipment and made difficult tasks look easy.

My fluency in English helped me follow the procedures done by the multi-disciplinary teams and their interaction with their respective patients. My mentors were highly qualified and experienced, and were motivated and very professional. Patients in Homerton are treated in a holistic approach, including the relatives in their care. The staff helped patients to turn from passive spectators into active role players in their healthcare plan and delivery. Reassurance,

courage and assistance were always on the nurses' agenda, with care plans presented to patients in a friendly and understandable way.

The unit nurses were helpful and went out of their way in explaining and sharing their knowledge on how to run such clinics in an efficient and cost-effective way. Treatment was always given in a friendly manner and with a smile despite the hectic workload. Although I had set out for myself a somewhat loaded and optimistic schedule plan, I was able to observe and participate in many of the clinics in my list, which helped me gain an overview of nurse-led clinical services.

The nursing staff communication skills were commendable and definitely contributed to the effective and speedy manner in which they perform their tasks. As a team they helped each other when problems arise. They back up each other well and efficiently such as when a team member is unavailable, enabling them to attend to all patients and avoid delays in delivering proper care.

The schedule was as follows:

Monday 21st	TWOC and Prostate Biopsy Clinic
Tuesday 22nd	MDT meeting and Prostate cancer follow up
Wednesday 23rd	Prostate Assessment and Haematuria Clinics
Thursday 24th	Intravesical Therapy
Friday 25th	Urology telephone clinics

I believe that I have not only reached my objectives but also surpassed some of them. From this experience I witnessed first-hand the way my European colleagues deliver exceptional service to urology patients. These experiences also helped me to fine tune and hone my mentoring skills. Sharing professional experience with colleagues and students is of paramount importance in our demanding profession. My goal was to return to my practice better-informed in providing a cost effective and efficient service to patients. This objective was



reached and the experience gained helped me improve my performance as a team player and motivator at our multi-disciplinary urological surgery team at Mater Dei Hospital in Malta.

Recommendations for future EAUN fellowship beneficiaries

It is an absolute must to plan well ahead for this fellowship, irrespective of one's choice of venue and with clear goals and expectations. One should research well beforehand the costs of accommodation and flights when submitting one's application. Applicants must also have a realistic comprehension of the costs when booking since London is no exception to high commuting costs.

Taking part in this EAUN fellowship truly boosted my nursing career. The experience gained will help me provide a high level of nursing care in Malta while still striving to improve my skills, knowledge and commitment.

I thank Bruce Turner, Sasha Ali, Clare Smart and Clifford Astwood for their patience in mentoring me. I felt at home from Day 1 and will not hesitate to have this experience again with such a great team. Finally, my special thanks to the EAUN Board for their commitment to this fellowship programme.

European Association of Urology Nurses

2nd ESUN Course takes place in Rome, Italy

Neurogenic detrusor overactivity & overactive bladder



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be able to deliver the course in their clinical areas as part of a developmental training and educational commitment.

The course is open to 25 nurses from all across Europe, who will arrive on Friday, 4 November in the morning and attend the first half of the course in the afternoon. On 5 November, the second part will take place in the morning. Thanks to a grant from Astellas, the participation fee is just €100; hotel rooms and the dinner for Friday 4th will be booked by the EAUN, so the delegates will only need to book their flight ticket, which will be covered by the grant as well. This ESUN course has been created and organised by the EAUN, with logistic support from AIURO, the Italian Association of Urology Nurses.

The scientific programme includes the aetiology of bladder control and neurophysiology of the lower urinary tract, pathophysiology and management of OAB and neurogenic detrusor overactivity with similarities and differences, and evidence-based nursing. The course will be interactive: the participants will discuss clinical cases and focus on decision-making, with help from a faculty of experts. The final goal is to give nurses a clear understanding of how to manage these patients with a multidisciplinary team. We are committed to offering a high-level international course, with a practical approach based on clinical reasoning and the best available evidence.

The course will be entirely held in English, so the participants are requested to be proficient in

understanding and speaking, in order to ensure the highest level of interaction.

Don't miss the opportunity to attend an important course in such a wonderful city; for all details regarding the course and registration, please contact Susan Brenninkmeijer, s.brennickmeijer@congressconsultants.com

See you in Rome!

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The European School of Urological Nursing (ESUN) is proud to announce a brand-new course on neurogenic detrusor overactivity and the overactive bladder syndrome complex. The course will take place in Rome, Italy, on 4 and 5 November, 2016, and will provide the participants an overview of the pathophysiology of lower urinary tract dysfunction in idiopathic overactive bladder (OAB) and neurogenic detrusor overactivity, relating to neurophysiological mechanisms.

In addition, the current evidence base for management will be discussed. Upon completion of this course, the participants will be able to describe the anatomy, physiology and pathophysiology of overactive bladder. They will also be able to describe and discuss the methods used for diagnosing and treat neurogenic and non-neurogenic overactive bladder. In addition they will

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Neurogenic detrusor overactivity and Overactive bladder

2nd Course of the European School of Urology Nursing
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17th International EAUN Meeting

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Lawrence Drudge-Coates,
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Stefano Terzoni,
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The 17th International EAUN Meeting: Join us in Munich!

The 17th EAUN Meeting will take place in Munich, Germany, from March 12 to 14, in conjunction with the 31st Annual EAU Congress. The brand-new nursing programme includes many interesting thematic sessions such as *Urology issues during transition to adulthood* (with Winnie Nugent, UK and Hanny Cobussen, NL), *Sexuality and cancer* (chaired by Paula Allchorne, UK), *Tobacco and cancer* (Susanne Vahr and Thordis Thomsen, DK), *Painful bladder syndrome, Self-care in urostomy patients, Perspectives in prostate cancer care* (with Franziska Geese, CH), Marie Anne Van Stam, NL, and Michael Kirby, UK), *Primary challenges in urology* (Jerome Marley, IE, Ian Banks, IE, Michel Kirby, GB) and many more.

State-of-the-art lectures on *Probiotics* (Lidy Van Driel-Rooks, NL) and *Genital mutilation*, two 2-hour EAUN-ESU courses, one on Sunday on *Instillations for non-muscle invasive bladder cancer* (Bas Van Rhijn and Willem De Blok, NL) and another one on Monday *Discussing cutting-edge management of Urinary stones* (Oliver Traxer, FR, Bhaskar Somani, GB, Hendrik Oussoren, NL) and hot-topic sessions will provide comprehensive overviews of fundamental topics, like *Nurse-led cystoscopy and urodynamics* (with Peter Rosier, NL), *Neoadjuvant treatments for bladder cancer* (with Paula Allchorne, GB, Bas Van Rhijn, NL, Jonathan Borwell, GB). *Ethical issues in urology* will be discussed in a dedicated lecture by Marinane Rabe, DE, with interesting cases and inputs for debate.

A session of videos submitted by the delegates will be held on Sunday, as well as a *Marketplace* session, which has the advance

that in a small group you can truly interact with the speaker, which is always well-appreciated by the participants, and it has therefore over the years become a milestone of our congress. The theme this year will be the *Preparations for major urological surgery*.

This year we received a lot of high quality abstracts from the delegates, with the top numbers coming from the UK, Italy and Japan; two poster sessions will be held on Saturday and Sunday, in which selected speakers will present their own work and run for a valuable prize. The delegates will also be involved in the popular difficult cases session, in which unusual nursing cases submitted by delegates will be presented and discussed e.g. on *Complications after cystectomy, autonomic dysreflexia and encrustation uropathy*.

The EAU is launching patient information for patients with bladder cancer, which will be presented on Monday, while a special session on Saturday will introduce the new evidence-based EAUN guideline developed by a nursing panel on Male External Catheters. Our association is always committed to producing and updating high level guidelines, which will be available at no cost in the printed version at the EAUN booth (Room 2) (as well as in PDF format on the EAUN website: <http://nurses.uroweb.org/nurses/guidelines/>).

The debate about the direction of urological nursing, started in Madrid last year, will go in-depth in the plenary session, as new

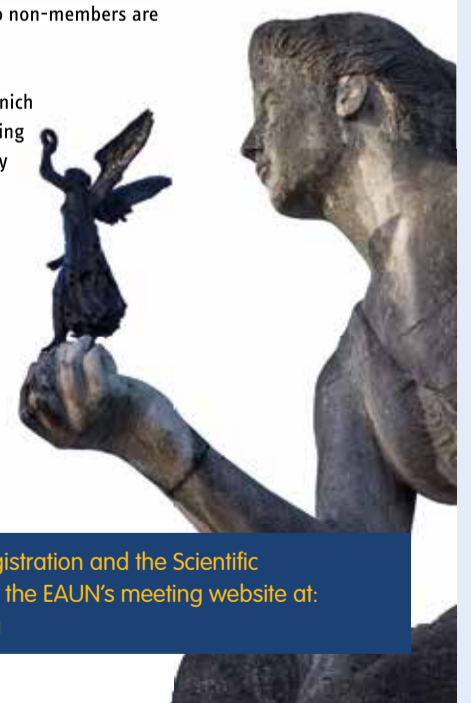
developments are going on across Europe. Finally, important announcements about upcoming educational initiatives of the EAUN will be made during the General Assembly, held on Monday, at 12.15 h. Also non-members are welcome to attend.

The programme for Munich is rich and has something for everyone, with many updates and sessions involving the delegates directly; don't miss the opportunity of taking part in this important educational event!

See you in Munich!

Stefano Terzoni

For details on registration and the Scientific Programme, visit the EAUN's meeting website at: www.eaun16.org



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