

THE EAU PATIENT POSTER SESSION EAU21: WHAT HAVE WE LEARNED?

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Introduction

Since 2012, the EAU has sought to meaningfully involve patients and their families in its mission to raise the level of urological care in Europe. Well-informed patients are better equipped to talk about their conditions and treatments and this fosters more meaningful dialogue between the doctor and the patient, leading to better care.

The concept of a Patient Poster Session was developed, supported by an unrestricted grant from Pfizer. The main purpose of the Patient Poster Session was for healthcare professionals to engage directly with patients and to provide a platform (the Annual EAU Congress) where the patient's perspective is heard, to identify any disconnects, improve communications and ultimately, to improve patient outcomes.

EAU Patient Poster Session 2021

Studies have shown that there is often a gap between what the physician recommends, based on scientific evidence combined with experience, and what patients prefer in terms of outcome, side effects and maintaining a good quality of life.

A patient's personal values and opinions may not be taken into consideration or compatible with the recommended treatment. As a result, healthcare professionals (HCPs) may appear to be out of sync with health-related quality-of-life matters that a patient wants to discuss.

The Poster Session theme for 2021 was: *Disconnect between the physician and patient*. The aim of the session was to discuss topics from a patient perspective, to encourage discussion between expert and patient and to identify any patient-physician disconnect. Patients and patient advocates were encouraged to submit abstracts to this session and in March 2021, 13 abstracts were selected for presentation. The top 5 abstracts who received the highest ranking were selected for an award. The selected abstracts were classified under 5 sub-headings: Bladder Cancer, Kidney Cancer, Prostate Cancer, General Oncology, Functional Urology and

COVID-19. Each poster presentation was recorded (webcast) and made available on the EAU21 Resource Centre website within 24 hours: <https://bit.ly/3zJXXpB> . The Patient Poster Session took place as part of the inaugural EAU Patient Day of the EAU21 Virtual Congress on July 9, 2021.

Key Messages

The Patient Poster Session outlined several important messages for clinicians, healthcare providers and the healthcare industry (see table 1). These were around patient involvement and engagement, communication, collaboration, support, finance and procedures. Each set of key messages highlights the clear unmet need for those living with and beyond urological cancer and proposes ways in which healthcare professionals and the healthcare industry can better work with patient advocates to address these.

<p>Patient involvement and engagement</p>	<ul style="list-style-type: none"> - Clear benefits of involving patients and engaging with Patient Advocacy groups when designing products that optimise urological care, designing clinical care pathways and supportive care pathways and in identifying and addressing unmet needs. EAU should consider using patient focus groups in designing EAU Patient Information and patient education. - Patients will participate in clinical research if they see its relevance and the benefits of participation outweigh the risks, however, HCPs generally do not encourage their patients to participate (40%) nor do they inform them about clinical trials and associated benefits and risks, and this is more true so for African American men (80%) - Involvement of patient representatives in development of clinical studies will ensure relevance to patients is incorporated in clinical study designs. - Peer to peer contact is an excellent means of increasing participation in clinical trials - Study participation should aim to have a minimal impact on work, childcare commitments and other critical aspects of their lives and participation should be appropriately costed. - Patient engagement in the design and delivery of care also holds direct benefits for patients e.g. increased emotional well-being, improved physical well-being, and improved self-care in terms of adherence to guidelines and treatment plans.
<p>Communication</p>	<ul style="list-style-type: none"> - Improved communication between the physician and patient lessens a cancer patient’s stress, improves their quality of life, and facilitates better participation in care. - Patients have additional needs that are not addressed by the disease-orientated focus of the physician e.g. quality of life, not just disease specific outcomes, and this involves identifying and addressing unmet needs. Patient-reported outcomes may differ from those reported by clinicians. - There is often a disparity between what information a doctor considers important for patients and what the patient and their families consider important e.g. survival rates, clinical trials. This can lead to poor rates of satisfaction with information about disease diagnosis and management. - Healthcare providers (HCPs) communicating information to patients must ensure that the information is tailored to patients’ needs, takes patients’ goals and aspirations into account, uses simple language, and that it is delivered at a pace that allows them to process information. - Clinicians need to inform patients about clinical trials and HCPs and representative bodies like EAU PI must support clinicians to direct patients to clinical trial websites, or use patient peers, volunteers and advocates to bring the subject up. - Almost 75% of patients continue to prefer Face to Face consultations especially for critical parts of their care pathway, e.g., initial diagnosis, and discussion of treatment options, and where disease recurs requiring second line treatment options. - Although often described as impersonal, telephone consultations are still favoured by elderly patients living remotely from hospitals, or for discussing side effects of treatment

	<ul style="list-style-type: none"> - Healthcare providers need to listen to patients and provide products that work for patients rather than cheaper generic products, e.g. absorbent aids in urinary incontinence.
Collaboration	<ul style="list-style-type: none"> - Organisations advocating for patients with urological disease, also network with other international patient advocacy groups e.g., the Global Cancer Coalitions Network (GCCN). Such links assist the EAU as they attempt to lobby healthcare providers on behalf of patients and Urologists and the EAU has a major role to inform and lobby healthcare providers to address these global needs. - Collaboration is needed to restore cancer services safely and effectively without delay, while a global plan of action for cancer is required to meet the challenges of future healthcare crises.
Support	<ul style="list-style-type: none"> - Almost 100% of patients experienced clinical anxiety at the time of cancer diagnosis, which can persist in almost 50% of responders. This emphasises the need for psychological support. - All patients surveyed wanted supplementary information available to them concerning their disease e.g., web-based support such as EAU Patient Information (PI). Patients also value access to patient advocates and to their family and care givers to help them understand the information and to provide emotional support and report need for a consistent “Go To” person. - Emergency support is needed by patient advocacy organisations and affiliated associations to ensure the needs of cancer patients are met during the pandemic, especially as long delays in accessing treatment reported in a number of countries
Finance	<ul style="list-style-type: none"> - A significant number of patients report financial hardship as result of cancer diagnosis, which increases anxiety and impacts on adherence to treatment; only half of this group of patients are given opportunity to discuss this issue with their doctor. - Some urological diseases need to be recognised as chronic illness by healthcare providers and reimbursed accordingly; the EAU should lobby for improved drug reimbursement.
Procedures	<ul style="list-style-type: none"> - Doctors must improve neobladder surgical techniques to prevent severe incontinence rates reported by patients.

Table 1: Key messages from the Patient Poster Session 2021

Conclusion

In all articles submitted to the EAU for the Patient Poster Session 2021, the patient's voice was expressed in many forms from typical scientific articles to patient stories and even beautiful artwork. All have value. It is hoped the EAU can build on this pioneering initiative which will undoubtedly shape and improve the future management of urological disease.

Strengths and limitations

The session was well attended and there were 110 delegates. This compared favourably to delegate numbers attending scientific presentations by clinicians. The virtual format, however, was a challenge to patient presenters, some of whom had little experience presenting at a major international medical meeting (the EAU21 Virtual Congress). While the session concluded on time, there were some technical difficulties with presentations and answering questions, as well as little time to answer questions. A reduced number of oral presentations in 2022 will allow more time for questions. Submitted abstracts that meet selection criteria but are not presented will be displayed in the Patient Information kiosk for attendees, located adjacent to the EAU Booth on the congress exhibition floor.

Looking ahead: EAU22 Patient Poster Session

The theme for the EAU22 Patient Poster Session will be addressing the unmet needs identified in the EAU21 poster session. EAU PI encourages all patients and patient advocates to present solutions, novel approaches and best practices revolving around:

1. Physical and Psychological well-being
2. Finance and Work
3. Patient involvement in clinical research, and development of care pathways and clinical practice guidelines
4. Patient engagement /advocacy in healthcare policy

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EAU22 will take place 18 – 21 March 2022: <https://www.youtube.com/watch?v=iUof5HRw3Fo>