



Putting Patients First

BERLIN
18 May 2018

Haus der Wirtschaft
Am Schillertheater 2

CONFERENCE REPORT



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bringing healthcare together



'I give my tissue and my blood to medical research but no one tells me the results of this research or invites me to meetings where my data is being presented'
—patient delegate at 'use MY data' patient workshop



Discussions surrounding healthcare tend to be academic, complicated and rather dry. This tendency comes as no surprise given the vast and complex nature of medicine as a field, which is in constant flux and development. There is a real problem with approaching medicine from this angle; the patient—the reason for the discussion in the first place—is alienated and unable to join the conversation, meaning their valuable, experience-based insights cannot influence healthcare developments.

Neglecting patient perspectives is a problem that has been identified in the past. Nonetheless, there is much work yet to be done to remedy this oversight. Thus, the European Health Innovation Collaborative (EuHIC) 2018 conference, *Putting Patients First*, was born. Second in a series, this provocative and controversial conference focused on gaining the perspectives of patients, patients' families, carers, patient organisations, healthcare professionals, and representatives from across pharma and academia. The conference featured enlightening sessions, delivered by a multidisciplinary host of speakers, that sparked debate across an array of topics. The sessions focused on bringing the patient onto centre stage and highlighting the value of patient-centric, participatory medicine.

Topics covered included:

- Communication in healthcare
- Harnessing patient experience in science, healthcare and policy, and the value of patient collaboration
- Patient perspectives on managing chronic disease
- Common frustrations of patients and doctors
- Palliative care and the psychology associated with coping with illness

This meeting was designed to give patients a voice, to highlight the fact that patients are not just data for clinical trials and that their experiences are valuable. EuHIC 2018 wasn't a run-of-the-mill medical conference. To make the event stand out from the crowd, proceedings were followed by a down-to-earth networking reception. Music was provided by Berlin-based jazz musician Kelly O'Donohue, and Tony Pickering displayed an art series, *The Art of Being a Patient*, which explores his journey as a patient.

This report will provide overviews of the EuHIC 2018 sessions and key messages that were raised during discussion. A conclusion will then summarise the topics from the day and provide thoughts for the future.



Our programme was developed by an eminent group of patient leaders under the banner of the European Health Innovation Collaborative (EuHIC). The conference was delivered on a pro bono basis by Stgilesmedical London & Berlin.

Achim Kautz (Cologne): Joint EuHIC president and patient, manager of Leberhilfe Projekt gUG, Cologne, Germany.

Dr. med. Adrian Tookman (London): Palliative medicine consultant and clinical director, Marie Curie UK.

Birgit Bauer (Abensberg): Patient lead, social media and digital health expert, and avid blogger.

Prof. Dr. med. Carlos Lifschitz (Houston, Texas): Emeritus associate professor of pediatrics at Baylor College of Medicine, Houston, Texas, and associate physician at Hospital Italiano, Buenos Aires.

Dr. med. Christina Gerlach (Mainz): Consultant, lecturer, and clinical scientist at the Department of Interdisciplinary Palliative Care of the University Medical Centre, Mainz.

Dr. Esther Murray (London): Health psychologist at Queen Mary University.

Katharina Kolbe (Meerbusch): Health economist, medical writer and freelance market access consultant.

Len Starnes (Berlin): Independent digital healthcare consultant and founding member of Patients Included.

Prof. Dr. med Rajan Somasundaram (Berlin): Head of the Department of Emergency Medicine at Charité, Campus Benjamin Franklin, Berlin.

Richard Stephens (London): Joint EuHIC president, patient/consumer lead, chair of the Consumer Forum at the National Cancer Research Institute, and joint editor-in-chief of BioMed Central's Research Involvement and Engagement.

Ronny Allan (London): Patient activist and 8-year survivor of metastatic neuroendocrine cancer.

Dr. med Ros Crooks (London): Consultant radiologist at Royal Free London NHS Foundation Trust.

Presidents' welcome; special guest address

Attendees were welcomed by EuHIC presidents Richard Stephens and Achim Kautz along with special guest Roger Wilson. The main topics for the day's proceedings were introduced.

An enlightening short video was delivered by Former BBC presenter Roger Wilson. The acronym Variation in Actual Life and Usual Experience (VALUE) was proposed. VALUE is only measurable by patients and is subjective and unquantifiable.

Key messages

- Emphasising patient individuality is of utmost importance. The needs of each patient should shape the nature of the healthcare they receive.
- Patient participation in healthcare decision-making and strategy is valuable. The following question was posed: how can we further involve patient representatives in decision-making and what can we learn from patients?
- Novel methods for gathering real-world evidence would allow patient data to be obtained at convenient times as opposed to at predefined end points.

What patients want

While there are certainly overlaps, what patients want and what patients need are two distinct concerns. Session chair Richard Stephens provided his own views on what patients truly want from their treatment.

Following Richard's talk, patients Max Williamson and Katerina Tsekoura provided perspectives on the wants of patients based on their own experiences.

Key messages

- Patients are often keen to support research to help other patients avoid unnecessary suffering.
- Patients should be urged to provide feedback on medication, but not pushed. Involving patients in research requires care and close attention.
- Fundamentally, patients just wish to be cured and to have their rights fulfilled. Improved patient education facilitates patient engagement.
- Max Williamson, who was diagnosed with testicular cancer at age 15, described unmet patient wants from the point of view of a young adult. The following ideas were suggested:
 - A focus on personalised, patient-centric care with flexible regulation
 - Cross-platform peer-to-peer support packages
 - Stronger dialogue about the future from the healthcare provider, e.g. fertility, late effects and palliative care
 - Increased recruitment of young adults for clinical trials and wider health research



SESSIONS

Let's talk: better communication in healthcare

The profound importance of patient-doctor communication was underlined by Berit Eberhard, with an anecdote that described her late partner's experience with stage 4 renal cell cancer. He had been told that he was cured following treatment but was not consulted about the high rate of recurrence associated with this type of cancer. He passed away as a result of his disease. The story highlighted the dissatisfaction and dangers associated with short consultations and that communication is a fundamental expectation of patients.

The session was developed with help from Doris Schmitt and chaired by Prof. Dr. med. Carlos Lifschitz, with talks by Berit Eberhard, Dr. med. Friedrike Siedentopf and Dr. med. Steven Walker.

Key messages

- Strong patient-doctor relationships are a cornerstone of successful treatment. Improved communication and an emphasis on patient-participatory decision-making can have a direct and positive impact on clinical outcomes.
- Physicians should develop their communication skills. Patients often prioritise trust and empathy over medical competence in developing good patient-doctor relationships.
- There should be a shift in focus towards 'talking medicine'.
- In contrast, the capacity for already stretched healthcare systems to provide patients with both high-level communication and specialised care is a challenge. There are insufficient resources and time for physicians to provide both in a short consultation.

Harnessing patient experiences for science, healthcare and policy

Chaired by Achim Kautz, this session focused on the untapped potential in patient experience for guiding developments in healthcare. The requirements for effective patient involvement were also addressed.

Providing insights into this discussion were Kai Ruenbrink, Ingo van Thiel, Richard Stephens and Dr. Diane Langenbacher.

Key messages

- Through patient engagement, Scotland achieved a 30% reduction in cases of hepatitis C between 2005–2015.
- Patient-doctor collaboration is invaluable in the development of care guidelines. By comparing experiences, contrasting opinions may arise that can be illuminating and provide vital guidance. Patient opinion can become scientific fact!
- Many patients are eager to be involved in trials and surveys but are not approached. The UK government must conduct more surveys into non-cancer-related disease areas, such as diabetes and heart-related conditions.
- Patient feedback is vital at all stages of research from both a pharma and patient perspective. Pharmaceutical companies can bolster patients' voice by:
 - Considering patient perspectives in all activities
 - Collaborating with patient groups on patient empowerment initiatives
 - Supporting patient communities to generate evidence





My uninvited guest: perspectives on chronic disease in the young and old

Living with chronic disease can feel like sailing against the wind for some patients. Confusion about chronic disease arises through miseducation and can complicate disease management. The importance of the patient voice and strong communication between the patient and doctor is particularly relevant in the case of chronic disease.

Joining chair Ronny Allan to provide their insights on chronic disease were Max Williamson, Prof. Dr. med. Carlos Lifschitz and Bastian Hauck. Support was provided by Colleen Shannon in the development of this session.

Key messages

- Patients should be encouraged not to define themselves by their condition and to keep a positive attitude.
- Patients should be careful of what they ask of their doctors. Often, patients will receive the treatment they push for, even if it is not in their best interest!
- There is a gap in the provision of care between paediatrics and adult care. Young patients usually do not start to involve themselves in decision-making until age 16–18.
- Young people may rebel against their illness and refuse treatment. Doctors must be aware of this reaction and engage in open conversation with young people about their illnesses.
- Some conditions, such as HIV, are associated with social stigma. Open communication between patients and doctors can help resolve these cases of miseducation.

What should participatory medicine look like?

Dr. med. Ros Crooks chaired this discussion on the nature of participatory medicine. Patient groups tend to support the adage ‘No decisions about me without me!’. But what does this mean? Does this approach lead to better outcomes?

Joining Ros to address these questions were Dr. med. Michael Nnaji and Dr. Seun Omolade.

Key messages

- ‘No decisions about me without me!’ means placing the patient at the centre of healthcare decisions.
- Participatory medicine is associated with optimised care, accelerated recovery and improved emotional health. Reduced costs are also an outcome due to fewer referrals and diagnostic tests.
- Patient-centred care is a double-edged sword: despite its benefits, it can also cause misleading information to emerge, prompting misdiagnosis and ill-suited decisions.
- With medical information—often misinformation—being available to patients at the click of a mouse, clinicians must guide the choices patients make using careful dialogue to avoid misguided decisions.

Debate: What annoys us? The patients’ and doctors’ views

The healthcare journey is complex and littered with hurdles that both patients and healthcare professionals must overcome. Discussion and experience sharing between both parties may help make the journey smoother.

To address what frustrates patients and healthcare professionals, a debate was held at lunch time. The session was moderated by Prof. Dr. med. Rajan Somasundaram, with Ronny Allan offering the patient’s view and Dr. med. Christine Oesterling providing the healthcare professional’s perspective.

Key messages

- Listening skills are crucial. An astute healthcare professional can derive important details from conversations with a patient. Even small talk can reveal red flags.
- While listening is important, transparent communication is also vital. Details that may clarify the situation should not be withheld by physicians.
- Humility is key in any healthcare setting. Physicians and patients must both acknowledge that sometimes physicians do know better, and sometimes they do not.
- The patient must not lose sight of the broader perspective. A healthcare system would not function if every single complaint were thoroughly investigated.



SESSIONS

Partnering with the industry: how should patients and the industry effectively collaborate?

In this Q&A session, a panel of experts representing the pharma industry and patients was questioned on how best to approach collaboration between patients and the industry.

Chair of the session, Len Starnes, questioned Richard Stephens, Bastian Hauck and Dr. med. Pooja Merchant, giving rise to conflicting views.

Key messages

- While chief patient officers can be helpful in forging pharma-patient relationships, they can also take the onus off other individuals in the industry to interact with patients and develop relationships.
- It is mutually beneficial for pharma companies to collaborate with patients at all stages of research, as opposed to just at later stages.
- Patients being employed by pharmaceutical companies may provide benefits due to proximity; however, the laws surrounding pharma's employment of patients is blurry and conflicts of interest may arise.
- Patients must be aware that industry collaboration can at times be disguised attempts at marketing.

III health in women: a special case?

Women's health is a hot topic in healthcare. But do women's medical requirements necessitate a distinct branch of medicine? Do women experience inequality in healthcare?

Birgit Bauer, patient representative, chaired this discussion, with talks by Katerina Tsekoura, Elisabeth Robson, Dr. med. Christine Oesterling and Dr. Esther Murray.

Key messages

- Women with disabilities experience pay disparity and difficulty finding work as they are considered potentially high-risk employees.
- Many of the diseases women face are invisible from the outside and so may not be regarded as equal to other more obvious diseases.
- Some drugs are not available to women of reproductive age.
- Focusing on women with disease is important, as many fall through social cracks and do not receive the treatment they require.
- It is important for doctors to adapt their approach to communication on a person-to-person basis as opposed to generalising based on gender.



The changing face of palliative care

Palliative care (or 'The P Word') is a term that carries some frightening connotations.

Chronic disease is on the rise as people in the West are living longer, meaning most people will require palliative care at some point in their lives. With an increased demand for palliative care, it is important that language surrounding the therapy area is addressed so that patients don't feel uncomfortable discussing it.

To discuss palliative care's branding and what it really entails, session chair Dr. med. Adrian Tookman was joined by Dr. med. Christina Gerlach, Dr. med. Faye Gishen, Ronny Allan and Dr. med. Anne Letsch. Dr. Gerlach presented an insightful poster at the conference that described a palliative care instrument for improving QoL in multiple myeloma patients with significant symptom burden. The instrument was shown to be effective, clinically relevant and suitable for everyday life.

Key messages

- There needs to be a shift in emphasis away from terminality towards improving quality of life and survival rates.
- Both the patient and their family benefit from early integration of palliative care. Establishing connections early on leads to improved care on a case-by case basis and a deeper understanding of the patient journey.
- Changing the face of palliative care would open patients up to early integration.
- However, rebranding and restructuring palliative care would be complicated and may not be feasible. In the meantime, patient education is essential.



The psychology of illness: how to cope better

As stated by session chair Dr. Esther Murray, 'Coping isn't internal, nor is it a feeling. It is sharing, thinking and observing. Coping is doing'. Coping with a new diagnosis or day-to-day complications of a disease are challenges faced by all patients. The psychology surrounding coping is complex, and communication is key to developing effective strategies.

Present to discuss the psychology behind coping were session chair Dr. Esther Murray, Sheena Nixon and Prof. Dr. Babette Renneberg.

Key messages

- Patients should feel comfortable voicing disease-related concerns so doctors can guide them to literature that will help form coping strategies.
- Mental health, exercise and healthy eating are fundamental to disease management and well-being.
- Optimism, a strong social support network and healthy behaviour form a firm foundation for coping with a disease.



Patient-centred healthcare: can we afford it?

To round off the meeting, a session was held to discuss the feasibility of patient-centred healthcare. The evidence spoke for itself: the patient's voice is pivotal in revolutionising healthcare. However, patient-centric healthcare can be time consuming. At a time when healthcare services are stretched due to an increasingly elderly population, do the resources exist to support patient-centred healthcare?

Chair Katharina Kolbe was joined by Prof. Dr. Jürgen Zerth, Dr. Christoph Bischoff-Everding and Dr. Patricia Ex to discuss this topic. As this meeting was based in Berlin, the discussions centred around the German healthcare and insurance system.

Key messages

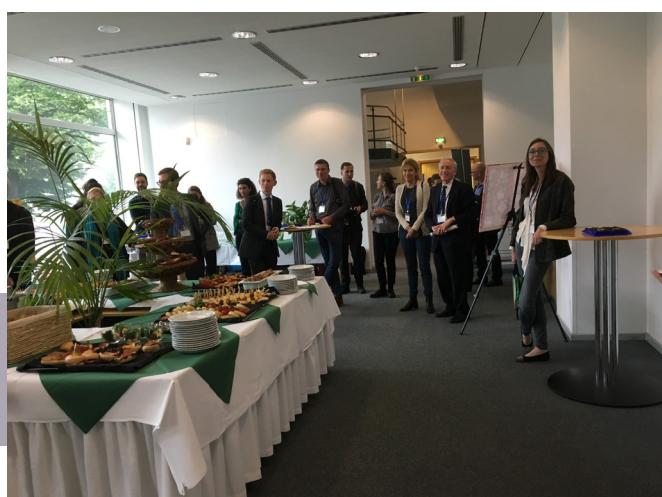
- In Germany, 80% of healthcare costs are covered by 20% of insurance policies, indicating stretched resources.
- Patient-centric care allows the patient journey to be monitored, providing insights into treatment patterns that allow care guidelines to be streamlined.
- Real-world data helps justify prices to payers and identifies growth potential.



The EuHIC 2018 *Putting Patients First* meeting provided a platform for productive debate on patient-centric participatory medicine, taking into consideration the views of representatives from every corner of the healthcare spectrum. A topic that was raised frequently was the importance of patient-doctor communication. Both parties can derive great benefit from frank and open discussion during consultations. Another topic that sparked great debate was patient involvement in medical science and practice. Industry and healthcare providers alike would gain from working closely with patients at all stages of developing medical guidance.

Fundamentally, this meeting showed that the patient's voice is an untapped resource of colossal significance. Future developments in healthcare would benefit significantly from the medical community paying close attention to the voice of the patient.

The EuHIC 2018 presidents and Stgilesmedical would like to thank all meeting participants and attendees for their insightful input.



ORGANISATIONS INVOLVED



NHS
National Institute for
Health Research



Care and support
through terminal illness



Our next EuHIC event
is planned for
Thursday 16 May 2019
in Berlin.
We would be pleased
if you could join us.

www.euhic.com