



EPICS

THE VALUE OF THE PATIENT PERSPECTIVE IN ONCOLOGY HEALTH CARE

September 2019

- > On 11 September 2019, Aptitude Health gathered in Brussels, adjacent to the European CanCer Organisation (ECCO) Cancer Summit, a group of patient advocacy experts and cancer supportive care experts to attend the closed-session Emerging Paradigms in Care Series (EPICS) meeting, The Value of the Patient Perspective in Oncology Health Care
- > The goals of the meeting were to broadly discuss a number of topics relevant to all cancer patients and to stakeholders involved in their care and treatment, and identify points of common interest, to be able to draw conclusions and provide a roadmap for future next steps
- > The topics discussed were patient empowerment, disparities in cancer care in Europe, patients and patient-reported outcomes (PROs), and the role of patients in the drug life cycle

Time	Topic	Speaker/Moderator
18.00 – 18.05	Welcome and introductions	Matti Aapro and Ian Banks
18.05 – 18.15	Presentation: Where do we stand with patient empowerment in Europe?	Bettina Ryll
18.15 – 18.45	Discussion	All
18.45 – 18.50	Conclusion and key takeaways	Matti Aapro and Ian Banks
18.50 – 19.00	Presentation: Patient access to medicines – variations and inequalities across Europe	Ian Banks
19.00 – 19.30	Discussion	All
19.30 – 19.35	Conclusion and key takeaways	Matti Aapro and Ian Banks
19.35 – 20.00	<i>Dinner break</i>	
20.00 – 20.10	Presentation: Patient-reported outcomes – patient perspective in the value of PROs	Florian Scotté
20.10 – 20.40	Discussion	All
20.40 – 20.45	Conclusion and key takeaways	Matti Aapro and Ian Banks
20.45 – 20.55	Presentation: Incorporating the patient perspective in the drug life cycle	Pietro Presti
20.55 – 21.25	Discussion	All
21.25 – 21.30	Conclusion and key takeaways	Matti Aapro and Ian Banks
21.30	Meeting close	Matti Aapro and Ian Banks

Co-CHAIR

Matti Aapro

ECCO and Genolier Cancer Center
Switzerland

FACULTY

Sarper Diler

Lymphoma Coalition Europe
Turkey

Teodora Kolarova

International Neuroendocrine Cancer Alliance
Bulgaria

Nicoleta Mitrea

Lung Cancer Europe
Romania

Jana Pelouchová

Leukemia Patient Advocates Foundation and ECPC
Czech Republic

Co-CHAIR

Ian Banks

ECCO and European Men's Health Forum
United Kingdom

Pietro Presti

European Cancer Patient Coalition (ECPC)
Italy

Bettina Ryll

Melanoma Patient Network Europe
Sweden

Florian Scotté

Hôpital Foch
France

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Where do we stand with patient empowerment in Europe?

BETTINA RYLL

WHERE DO WE STAND WITH PATIENT EMPOWERMENT IN EUROPE? (1/3)

- 1. **Current status of patient empowerment in Europe**
 - 1.1. **Legal framework**
 - 1.2. **Implementation of patient empowerment**
- 2. **Challenges and opportunities**
 - 2.1. **Challenges**
 - 2.2. **Opportunities**
- 3. **Recommendations**
 - 3.1. **Policy level**
 - 3.2. **Healthcare provider level**
 - 3.3. **Healthcare system level**
 - 3.4. **Healthcare professional level**

WHERE DO WE STAND WITH PATIENT EMPOWERMENT IN EUROPE? (2/3)

Country	Key Findings
Germany	High patient awareness and engagement, strong emphasis on shared decision-making.
France	Increasing patient participation, but still a gap between awareness and actual involvement.
Italy	Focus on patient education and empowerment through digital health tools.
Spain	Significant progress in patient empowerment, particularly in chronic disease management.
UK	Well-developed patient empowerment programs, with strong emphasis on patient choice and control.

WHERE DO WE STAND WITH PATIENT EMPOWERMENT IN EUROPE? (3/3)

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EPICS

Discussion

- 1. The patient empowerment movement is a response to the increasing complexity of health care and the need for patients to be more active in their health care decisions.
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- 10. The patient empowerment movement is a response to the increasing complexity of health care and the need for patients to be more active in their health care decisions.

- 1. The patient education program is designed to be comprehensive, continuing, and available to all patients and families in the hospital setting.
 - The program includes written materials, audio, video, and interactive materials.
 - The program is designed to be available to patients and families at all times.
- 2. The patient education program is designed to be available to all patients and families.
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- 4. The program is designed to be available to all patients and families at all times.
- 5. The program is designed to be available to all patients and families at all times.

- 1. The patient education program is designed to be comprehensive, covering all aspects of the patient's health and well-being, including physical, mental, and social health.
- 2. The program is designed to be patient-centered, focusing on the patient's needs and preferences, and involving the patient in the decision-making process.
- 3. The program is designed to be evidence-based, using research and best practices to inform the content and delivery of the education.
- 4. The program is designed to be accessible, using a variety of formats and languages to reach all patients, including those with limited health literacy skills.
- 5. The program is designed to be evaluated, using a variety of methods to measure the effectiveness of the education and to make improvements as needed.

CONCEPT OF EDUCATION



PERSONALISED MEDICINE

- 1. Personalised medicine is the use of information about an individual's genes, environment, and lifestyle to tailor medical treatment to that individual.
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EPICS

Patient access to medicines – variations and inequalities across Europe

IAN BANKS

PATIENT ACCESS TO MEDICINES: VARIATIONS AND INEQUALITIES ACROSS EUROPE (1/2)

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PATIENT ACCESS TO MEDICINES: VARIATIONS AND INEQUALITIES ACROSS EUROPE (2/2)

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EPICS

Discussion

ENABLING ACCESS TO MEDICINES: HARMONISATION (1/2)

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ENABLING ACCESS TO MEDICINES: EUROPEAN CANCER PLAN

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ENABLING ACCESS TO MEDICINES: CHALLENGES IN EASTERN EUROPE

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ENABLING ACCESS TO MEDICINES: EDUCATION

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CONCEPT OF CANCER HARMONISATION ACROSS EUROPE



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Patient-reported outcomes – patient perspective in the value of PROs

FLORIAN SCOTTÉ

PATIENT REPORTED OUTCOMES (1/2)

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PATIENT REPORTED OUTCOMES (2/2)

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EPICS

Discussion

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PATIENT-REPORTED OUTCOMES: QUALITY OF LIFE

- 1. **PROVIDER-REPORTED OUTCOMES: QUALITY OF LIFE**
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- 10. **PROVIDER-REPORTED OUTCOMES: QUALITY OF LIFE**

PATIENT-REPORTED OUTCOMES: FORMATS

- 1. **PROVIDER-REPORTED OUTCOMES (PRO-RO)**
 - PRO-ROs are reported by the provider, typically through a patient portal or a dedicated provider interface.
 - They are used to track patient outcomes and are often used for quality improvement and research purposes.
- 2. **PATIENT-REPORTED OUTCOMES (PROMS)**
 - PROMS are reported by the patient, typically through a patient portal or a dedicated patient interface.
 - They are used to track patient outcomes and are often used for quality improvement and research purposes.
- 3. **PROVIDER-REPORTED OUTCOMES (PRO-RO) AND PATIENT-REPORTED OUTCOMES (PROMS)**
 - These are combined to provide a comprehensive view of patient outcomes.
 - They are used to track patient outcomes and are often used for quality improvement and research purposes.
- 4. **PATIENT-REPORTED OUTCOMES (PROMS) AND PROVIDER-REPORTED OUTCOMES (PRO-RO)**
 - These are combined to provide a comprehensive view of patient outcomes.
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- 5. **PATIENT-REPORTED OUTCOMES (PROMS) AND PROVIDER-REPORTED OUTCOMES (PRO-RO) AND PROVIDER-REPORTED OUTCOMES (PRO-RO)**
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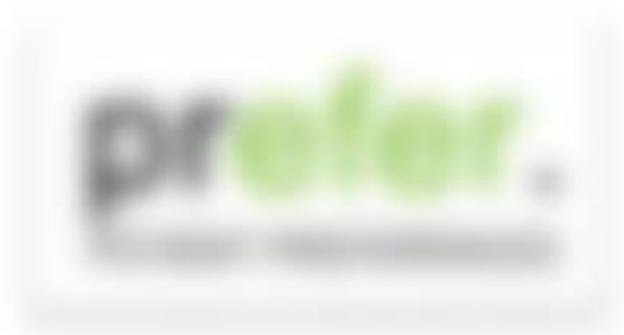
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Incorporating the patient perspective in the drug life cycle

PIETRO PRESTI

PROGRAMMES ON PATIENT INVOLVEMENT IN DRUG LIFE CYCLE

EUROPEAN COMMISSION COMMUNICATION ON PATIENT INVOLVEMENT IN DRUG DEVELOPMENT



- Focus on patient involvement in drug development
- Emphasis on patient involvement in the development of medicines for rare diseases, orphan drugs, and generics
- Emphasis on patient involvement in the development of medicines for chronic diseases
- The European Commission is committed to patient involvement in drug development
- The European Commission is committed to patient involvement in drug development

- 1. **Identify the patient groups that will be affected by the technology.**
- 2. **Engage patients in the process from the start.**
- 3. **Use patient input to inform the development of the technology.**
- 4. **Use patient input to inform the development of the evaluation process.**
- 5. **Use patient input to inform the development of the implementation process.**
- 6. **Use patient input to inform the development of the monitoring and evaluation process.**
- 7. **Use patient input to inform the development of the dissemination process.**
- 8. **Use patient input to inform the development of the sustainability process.**

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Discussion

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THE EPICS GROUP HAS A COMMITMENT TO THE PATIENTS AND SCIENTIFIC ADVICE

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Key Takeaways

KEY TAKEAWAYS

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KEY TAKEAWAYS

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