

Event report

Patient-Clinician Education Models

Tuesday 27 October 2020, Virtual event

EXECUTIVE SUMMARY

The objective of this EHC Roundtable was to outline the necessity of integrating a patient-clinician education approach into healthcare models, and give an overview of the benefits of a patient-as-partner engagement in disease and healthcare management.

The event featured presentations and discussions which put forward the following key takeaways:

1. The patients-as-partners approach, as demonstrated in the Montreal model, provides key tools for patient empowerment and education.
2. A new strategy for integrated care is needed in order to build a more engaging relationship between physicians and patients.
3. Patients need to be empowered to engage with their own treatment process, and therefore the physician must be equipped with skills to facilitate this process. By acknowledging the patient's competence and expertise, this would not only benefit on an individual case basis, but would also help the general improvement of the healthcare service.
4. Patient-clinician partnership should be included into the European principles of Haemophilia care.

The event also featured two interventions by MEPs Stelios Kypouropoulos and Alex Agius Saliba who expressed their support with helping the haemophilia community at a European level.

I. ABOUT THE EVENT

On Tuesday 27 October 2020, the European Haemophilia Consortium (EHC) organised a virtual roundtable entitled *Patient-Clinician Education Models*. Moderated by Thomas Sannié, EHC Steering Committee member, the event brought together a variety of participants from research, industry, patient and academia fields. MEPs Stelios Kypouropoulos and Alex Agius Saliba were also in attendance, expressing their support to the haemophilia community.

The event's agenda is provided in the final part of this report.

II. WELCOMING REMARKS

Guest speakers: MEP Stelios Kypouropoulos; MEP Alex Agius Saliba

Dr Kypouropoulos opened the discussion by stating that the design and implementation of patient-centred interventions offer promising results for healthcare, enabling patients to have control over their own life. Moreover, a more coordinated European response is crucial to enable such models, and

through the EU4health programme, research and health access can be modernized. In conclusion, Dr Kypouroupolos stated that a European Policy on Health is essential to support the best available expertise, which can be additionally supported through the establishment of European networks for cross-border contexts.

In view of his heavy involvement in the Digital Services Act, MEP Agius Saliba stated that digital services have great potential in integrating patient experiences into disease management as well as into the education of the medical community. Whilst advocating the inclusion of patients in the digital discussion, Mr Agius Saliba emphasised that digital tools could provide key solutions that place patients at the heart of EU policy.

III. FROM “PATERNALISM” TO “PATIENT- CENTRED” TOWARDS “PATIENTS AS PARTNERS” – AN ONGOING EVOLUTION

Alexandre Berkesse, Strategic Advisor at the Center of Excellence on Partnership with Patients and the Public (CEPPP)

Mr Berkesse presented the Montreal model – an approach that acknowledges the need to combine patients’ experiential knowledge of the disease with medical expertise and provides guidelines on improving stakeholders’ interdependence in healthcare. In this regard, the integration of environmental factors faced by patients could help in their emancipation process towards individual and collective autonomy to make choices and act, thus establishing a cooperative mind frame to improve one’s health. Noting that 50 to 70% of patients suffering from chronic illnesses are considered non-compliant, the solution advanced by the Montreal model would be to build a common ground between patients and professionals, where both are co-accountable. To that end, the main postulation of the model is to acknowledge that patients should be perceived as key partners and actors of care in the healthcare system. According to the Montreal model, there are numerous and different cooperation possibilities through which healthcare professionals would access the reality of the patients.

CEPPP YouTube channel for further information :

https://www.youtube.com/channel/UCE_3vdtDyc4NxDzhHYKIH6A/featured

IV. CHANGING THE PARADIGM OF CARE FROM REACTIVE TO PROACTIVE – CAREGIVER EDUCATION

Cédric Hermans, Saint-Luc Clinics, Brussels; Catholic University of Louvain.

Professor Hermans delineated the importance of patient involvement in the education of healthcare professionals. Outlining the expectations from patients with haemophilia and from medical professionals in the field, it was noted that adherence to prophylaxis and proper outcome data can only be achieved through strong patient collaboration. Haemophilia treatment landscape and goals

have constantly been evolving and with every patient being different and unique, patients play an increasingly important role in both their own healthcare and others', where they can readily contribute to advocacy activities, auditing processes of Haemophilia Treatment Centres, the development of study designs or clinical trials, amongst others. In view of this, Professor Hermans notes that it is fundamental for more patients to transition from passive care-recipients to care partners.

Cédric Hermans concluded that Patient-doctor partnership in haemophilia care is a critical determinant of the quality of the disease management, therefore this collaboration should be addressed and included in the European principles of haemophilia care. Zero bleed goal is only achievable with major collaboration of the patient and his family. Efforts are required from all the stakeholders.

V. JOINING-UP PATIENT-CLINICIAN PERSPECTIVES

Ivan Šebest, haemophilia patient and advocate; Christoph Königs, clinician at University Hospital Frankfurt; Kate Khair, nurse and Director of Research at Haemnet

From a patient perspective, Mr Šebest stated that patients should not just be recipients of care, but rather participants of care in order to optimise their own health outcomes. Having a good patient-clinician relationship is the basis for a haemophilia management programme, and therefore, the patient should be educated to participate in the treatment process. This requires a good preparation to achieve readiness to become active. Not all the patients are well equipped, therefore we need to empower them. In current situation, haemophilia patients are usually very well taken care of and might not necessarily feel the need to get involved in their treatment – this also requires some education and information. Dr Königs highlighted the importance of engagement and interaction with his patients, especially with teenagers and young adults. Prophylaxis and follow-up cannot take place without patient involvement. Communication is also key; so is the language we use. Providing perspective on the impact of haemophilia on people, Dr Kate Khair stressed the importance of understanding the lifestyle of the patient as opposed to simply jumping into a more biomedical approach, since the bleeding disorder only constitutes a small part of the individual and do not define who the person is.

VI. KEY QUESTIONS AND CONCLUDING REMARKS

The roundtable discussion sparked significant interest in further understanding the application of patient-clinician education models at grassroots level. Key concerns encircled around the lack of awareness observed amongst physicians in Europe on engaging with patients through this approach. Moreover, promoting patient engagement to the patients themselves was also foreseen as a hurdle, since they may not realise their full capacities and competencies within disease management and healthcare improvement. Considering these points, all participants agreed that a pragmatic and effective implementation of patient-partnership education models is needed to mobilise patients' perspective into care. In summary, the following important points were highlighted during the event:

- The Montreal model provides a framework of co-accountability between patients and professionals with respect to disease management and improvement of healthcare services. Such an approach integrates the experiential knowledge obtained from patient-clinician partnership, and mobilises it for better treatment outcomes.
- Education models need to facilitate the transition of patients as passive care-recipients to care partners, which should be done through the proper dissemination of information to educate both physicians and patients alike
- Patient-doctor partnership in haemophilia care is a critical determinant of the quality of the disease management, therefore this collaboration should be addressed and included in the European principles of haemophilia care.
- It is essential for physicians to go beyond the patients' medical diagnosis and treatment regime and perceive the patients' lifestyles as a key components of disease management. Patients on the other hand, should realise the value of cooperating with the medical community in order to improve their own health. Efforts are needed on both sides.

European Haemophilia Consortium Round Tables of Stakeholders

Tuesday 27 October 2020

Virtual event

Patient-Clinician Education Models

AGENDA

(CET)

10.55 – 11.00	Opening & Instructions <i>Thomas Sannié & Nastassia Kisialeva</i>
11.00 – 11.05	Welcome and introductions <i>MEP Stelios Kypouropoulos & MEP Alex Agius Saliba</i>
11.05 – 11.40	From “paternalism” to “patient-centred” towards “patients as partners” – an ongoing evolution Patients empowerment and education <i>Alexandre BERKESSE</i>
11.40 – 12.00	Changing the paradigm of care from reactive to proactive – Caregiver education New strategy for holistic and integrated care; involvement of patients in the education of healthcare professionals <i>Cédric HERMANS</i>
12.00 – 12.10	Q&A
12.10 – 12.40	Joining-up patient-clinician perspectives - Panel discussion Patient perspective – <i>Ivan ŠEBEST</i> Clinician perspective – <i>Christoph KÖNIGS</i> Healthcare provider – nurse perspective – <i>Kate KHAIR</i>
12.40 – 12.55	Q&A and discussions
12.55 – 13.00	Conclusions
