
Blood and Beyond

Rethinking Blood Use

Webinar

Thursday 26th of March 2020
10:30-12:00

SUMMARY NOTE

The policy webinar marked the launch of the multi-stakeholder initiative Blood and Beyond and its first publication the “Rethinking blood use in Europe to improve outcomes for patients” report. The webinar brought together over seventy participants from EU institutions, EU and national authorities, patient groups, medical professional societies, allied healthcare professionals, industry representatives and other interested stakeholder groups.

The webinar was initially planned as a conference but converted into a webinar as a result of the COVID-19 pandemic.

Opening

The webinar opened with a short introduction by the moderator, Tamsin Rose, who introduced the initiative and noted the importance of rethinking blood use, particularly in the context of the COVID-19 crisis. Member of European Parliament (MEP), Manuel Pizarro, stressed that a well-functioning blood system is a vital component of every health system and highlighted the role of the European Union in the field. In a written message read by Lee Baker from Interel, MEP Dr Cristian-Silviu Buşoi noted that the current pandemic highlights the importance of proper blood use and of ensuring a sustainable blood supply.

Why we need the Blood and Beyond initiative

Dr Androulla Eleftheriou, Executive Director of the Thalassemia International Federation (TIF), explained the relevance of the initiative from the patients' perspective and in the case of thalassemia. She shared information on thalassemia syndromes including data on their prevalence in Europe and noted that the most severe form of thalassaemia is dependent on life-long blood transfusions for survival, while other forms have variable transfusion requirements. The annual blood requirements for thalassemia patients are huge, she said. Blood and Beyond is needed to highlight the impact of blood transfusions for patients, to address the challenges in the blood supply and to identify and rectify policy gaps and unmet needs. Multi- stakeholder collaboration strengthens and augments the patients' voice.

Presentation of the science policy report

Following a brief overview of the aims and contributors by Tamsin Rose, Dr. Axel Hofmann¹ presented the report "Rethinking blood use in Europe to improve outcomes for patients", being launched today. He gave insights on the current role of blood transfusion in chronic diseases, pointing that transfusions are one of the most common invasive procedures in hospitals, and summarized the blood supply ecosystem in Europe. The report provides a summary of the priority challenges and unmet needs, and outlines the need for a collaborative, patient-centered approach to rethink and optimize blood use in chronic diseases care in Europe. With a focus on red blood cell (RBC) transfusions, it presents recommendations to safeguard and optimize Europe's blood supply; to reduce transfusion dependency and to facilitate innovation. It formulates ideas of overarching EU policy mechanisms to take the recommendations forward. The report and summary infographic, as well as many other collaterals are available on the Blood and Beyond website: www.bloodandbeyond.com also launched today.

1. Visiting Professor of the Institute of Anesthesiology, University Hospital Zurich, and Adjunct Associate Professor, School of Medicine, University of Western Australia

Patient Testimonial

Bergit Kuhle² shared her experience as a patient and patient advocate. Diagnosed with MDS in 2005, she has received 646 blood transfusions throughout her life to date. Bergit explained how the disease, the regular transfusions – despite being life-saving - and hospital visits impact her quality of life. She highlighted that in between transfusions, she is often suffering fatigue, shortness of breath, muscle and bone pain. This made her quit her job and had a significant impact on her social life. Bergit described how she manages her condition, her daily life and the side effects of transfusions such as iron overload and the necessity of chelation therapy.

Panel: Forward-thinking solutions and policy responses to improve outcomes for patients and address the impact of blood transfusions while safeguarding Europe's blood supply

Moderated by Tamsin Rose, the panel discussion focused on solutions and policy changes. Tamsin Rose explained that unfortunately, Ms Stella Pelteki, representing the patient organisation DEGETHA & FRIENDS, could not join the webinar due to health issues, and her colleague could not replace her as he had to undergo his regular blood transfusion at the same time.

Dr Esther Oliva³, explained the importance of harmonised, evidence-based and multi-disciplinary clinical guidelines to ensure appropriate use of blood and good management of anaemia. Such guidelines should be patient-centred and allow to take into consideration multi-morbid patients and support an individualised approach. Clinical guideline developers from different specialities should collaborate to develop and implement such guidelines, which should be developed with patient organisations.

2. MDS Patients Interest Group (MDS-Patienten Interessengemeinschaft); Leukemia Relief Rhein-Main (Leukämiehilfe Rhein-Main) and Steering Committee Member, MDS-Alliance

3. Department of haematology, Grande Ospedale Metropolitano Bianchi-Melacrino-Morelli di Reggio Calabria; Reggio Calabria, and Board member, European Hematology Association (EHA) Scientific Working Group on Quality of Life

Dr Guy Rautmann⁴ explained the current work of the European Committee on Blood Transfusion (CD-P-TS), a steering committee reporting to the Committee of Ministers of the Council of Europe, to ensure the quality, safety and appropriate use of blood transfusions in Europe. He shared insights on the guidance provided by the CD-P-TS on optimal use of blood and on the protection of both donors and patients. One of the main outputs of the CD-P-TS is the so-called “Blood Guide”, a set of harmonised recommendations for blood establishments, which is updated every second year and currently under review. Dr Rautmann noted the relevance of the Blood & Beyond initiative. He highlighted that the EDQM works closely with the European Commission; and that the Good Practice Guidelines published in the Blood Guide are part of the EU legislation.

Dr Gilles Folléa⁵ shared learnings from France and reflected on good practices. Currently, national guidelines are more blood product-oriented than patient-oriented. A national Patient Blood Management (PBM) policy would help to focus efforts. He noted that more focus on optimising blood transfusion use in onco-haematology and cancer patients would probably help, as more than 50% of blood components are used in these patient groups. In light of the COVID-19 pandemic, the EFS wrote to all concerned French scientific societies to encourage clinicians to closely evaluate patients’ blood needs and to postpone non-urgent interventions that require transfusion support. These efforts led to a significant decrease in blood components delivery and use in France over the past week. Dr Folléa presented data depicting this evolution, noting a 13% decline in RBC use. Further decreases were expected in the next days (and confirmed). At national level, greater involvement of patient organisations in policy making would help advance change. Dr Folléa also informed about the flagship initiative of the EFS to help in further developing and implementing PBM in France, through transfusion advising and training, which is fully supported by the Health Ministry. He expressed support to the recommendations developed by Blood and Beyond and added that after the pandemic, there will be a need to design ways to implement PBM in the context of global crises to ensure appropriate responses for the patients.

4. Secretary of the European Committee of Blood Transfusion, EDQM, Council of Europe

5. Advisor Campus, French Blood Establishment (EFS)

Dr Androulla Eleftheriou shared further suggestions from the viewpoint of thalassemia patients on how to improve adequacy and safety and improve the clinical use of blood. She called for access to appropriate care, innovative therapies and increased research efforts to improve the health and quality of life of thalassemia patients. She welcomed the developments and potential changes in the context of the EU blood directive which could inform the revision of transfusion guidelines for thalassemia patients.

Participants raised the issue of blood shortages in Greece resulting from the current pandemic. Dr Oliva further explained the impact of the pandemic on the perception of the requirements of transfusions in elderly patients with haematological malignancies. She noted how the protection measure of social distancing and “stay at home” generates fears for patients with MDS. She suggested that the implementation of home transfusion would represent a very important improvement in the quality of life and the burden of transfusion for patients.

Participants highlighted that many guidelines focus on blood transfusion regimes and neglect iron overload which is often responsible for the worsening of the health status of chronically transfused patients. It was noted that this is not considered enough in existing recommendations for blood transfusion and not sufficiently acknowledged by clinicians; although work is undertaken to improve the situation. Prof Hofmann stressed that guidelines should be patient-centered and problem/disease-centered, not treatment nor intervention-centered as is currently often the case. He brought up the case of Australia as the first country which changed the perspective: with the development of Patient Blood Management guidelines, clinicians are focusing on the patient’s underlying problem first, i.e. detecting and correcting the causes of anaemia and blood loss, thus optimizing and conserving the patient’s own blood rather than resorting to donor blood in the first place. He called for a reengineering of how guidelines are produced following a similar approach.

Other topics discussed include the fear of patients to experience a lack of transfusions due to the current pandemic and risk of shortages, and challenges in the sustainability of blood supply. Prof Hofmann informed about the upcoming publication of a paper on the benefits of PBM in times of pandemics and crises. He noted that as most non-urgent interventions are being postponed, there still seems to be a balance in the demand and supply at present. Dr Folléa noted that in France, blood use has decreased, and the blood establishment has adapted blood supplies to the same level to avoid wastages. All agreed on the importance that the quality of care for transfusion-dependent patients is not affected.

In light of the epidemic, Dr Rautmann noted that the CD-P-TS engaged with blood establishments to monitor the measures taken by Member States to prevent contamination by the SARS CoV-2 during blood donations. Results of this survey will be available soon. Bergit Kuhle noted that home transfusion could reduce the risk for patients to be exposed to COVID-19 but very few countries have guidelines for this. Dr Rautmann informed that Italy and Germany successfully started targeted activities to raise awareness on the importance of blood donations in the context of the crisis. Both countries already reported an increase in donation rates - up to 20% of blood donations for Italy.

The topic of prenatal diagnosis of thalassaemia as part of prenatal care was also discussed in the context of changes in demographics in Europe. TIF suggested that early screening, awareness and information should be strengthened.

Closing

Many stakeholders are working on making blood transfusions a safer, easier and better treatment and discussing how to optimise blood use through sharing ideas and developing consensus on the way forward. This report presents additional ideas, with the overarching goal of improving outcomes for patients. It is acknowledged that some of the improvements are reliant on policy changes, including a potential reopening of the EU Blood Directive, and others need further stakeholder collaboration to become a reality.

Concluding the meeting, Tamsin Rose invited stakeholders to engage with the Blood and Beyond initiative and share perspectives or interest in contributing to the next steps towards the implementation of the recommendations. Participants are encouraged to communicate about the new report. All materials and collaterals are available on the Blood and Beyond website: www.bloodandbeyond.com. Tamsin closed the meeting by wishing everyone well and to stay safe; and with expressions of gratitude to frontline healthcare professionals.



About Blood and Beyond

Blood and Beyond is a multi-stakeholder initiative developed and funded by Celgene, now part of Bristol Myers Squibb, involving experts from the fields of haematology and blood management, nursing, patient advocacy, health economics and hospital management.

The aim of the initiative is to raise awareness of the impact of blood transfusion on patients, support networks, healthcare systems and society at large; with the overarching goal to help advance policies and practices that improve patient outcomes by optimising blood management and supporting innovation across Europe

www.bloodandbeyond.com