

LETTER TO THE EDITOR

Patient public involvement and engagement in thrombosis research: Not just for the intrepid

We commend the American Heart Association and the International Society on Thrombosis and Haemostasis for their statement on venous thromboembolism (VTE) research priorities, developed through a survey across 16 scientific organizations and subsequent expert panel.¹ The authors state, "Collaboration among experts in the preclinical and clinical area will provide optimal insight to the field and to the patients."¹ Regrettably, one important expert group was conspicuous by its absence: the patients. Whereas clinicians and scientists have disease-specific expertise, patients have experience-based expertise, which is important if we want to improve the relevance of the research, increase the stakeholders' trust in the research, and increase research adoption.^{2,3} We could have hoped for a new era in thrombosis research where meaningful patient experience was embedded in the VTE research priorities and not reduced to a passing remark on the need to examine patient-centered outcomes in a population-based study setup.

We do not imply that VTE researchers are without good conscience and motivation to improve patient care through advances in research; however, evidence suggests that patients can have meaningful contributions in all stages of VTE research,³ recognizing that during a project, emphasis and input between individuals in a research group will fluctuate depending on the expertise required, and not all in a research group will be involved in every decision and every part of a project.²

Patient engagement in designing, implementing, and disseminating research has been shown to amplify translation of research into clinical practice.³ Thus, while we agree with the authors' appraisal of translational research, we strongly encourage a broader translational approach throughout the VTE research priorities involving patients themselves.

The inclusion of patient representatives in the development of VTE clinical guidelines is well established,⁴ yet the absence of patient and public involvement (PPI) in the development of these particular VTE research priorities is evident. If we do not engage patients as partners when identifying and prioritizing research, we risk a disconnect between the research priorities and the true needs of patients,^{2,3,5} a concern shared with at least one of the participants in the crowdsourcing survey who, according to the Online Appendix, commented, "Did you engage patients in this

list? Won't the list just reflect researchers' current topics?"¹ The preselected group of topics in the crowdsourcing survey clearly reflects physician-centered research priorities and possibly explains why patient experience is absent in the identified priorities. This potentially impedes the understanding and improvement of areas such as decision making, compliance, and health-related quality of life and the support of grant-funding bodies that have strong PPI.

We respectfully continue the call for increased PPI and engagement in shaping VTE research priorities as well as their design, implementation, and dissemination by supporting our campaign to Innovate Thrombosis Research Engagement with Patient and Public Involvement in Design and Delivery (INTREPID).⁵ We believe such an INTREPID approach would ensure that our research priorities align more closely with our patients.

RELATIONSHIP DISCLOSURE

AH has been on the speakers bureau for Bayer and Pfizer/BMS alliance. SN has been on the speakers bureau for Bayer, Leo Pharma, Pfizer/BMS alliance, and Daiichi Sankyo, and advisory board for Pfizer/BMS alliance, Daiichi Sankyo, and Bayer. The other authors declare no conflicts of interest.

Anette Arbjerg Højten RN, MScN, PhD^{1,2} 

Mette Søgaard DVM, PhD^{1,2}

Kathy Seddon PhD³

Simon Noble MD, FRCP⁴

¹Aalborg Thrombosis Research Unit, Department of Clinical Medicine, Faculty of Health, Aalborg University, Aalborg, Denmark

²Department of Cardiology, Aalborg University Hospital, Aalborg, Denmark

³Marie Curie, Expert Patient Voices, Division of Population Medicine, Cardiff University, Cardiff, UK

⁴Marie Curie Palliative Care Research Centre, Cardiff University, Cardiff, UK

Handling Editor: Dr Susan Kahn.

This is an open access article under the terms of the Creative Commons Attribution-NonCommercial-NoDerivs License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made.

© 2020 The Authors. *Research and Practice in Thrombosis and Haemostasis* published by Wiley Periodicals LLC on behalf of International Society on Thrombosis and Haemostasis (ISTH).

Correspondence

Anette Arbjerg Højen, Department of Cardiology, Aalborg
University Hospital, Sdr. Skovvej 15, DK-9000, Denmark.
Email: a.wind@rn.dk

TWITTER

Anette Arbjerg Højen  @anettehojen

REFERENCES

1. Cushman M, Barnes G, Creager M, Diaz J, Henke P, Machlus K, et al. Venous thromboembolism research priorities: A scientific statement from the American Heart Association and the International Society on Thrombosis and Haemostasis. *Res Pract Thromb Haemost.* 2020;4:714-21.
2. Hickey G, Brearley S, Coldham T, Denegri S, Green G, et al. Guidance on co-producing a research project. Southampton: NIHR Involve; 2018.
3. Duffett L. Patient engagement: What partnering with patient in research is all about. *Thromb Res.* 2017;150:113-20.
4. The American Society of Hematology. The State-of-the-Art Methodology Behind New Venous Thromboembolism (VTE) Guidelines. 2018. <https://www.hematology.org/-/media/hematology/files/clinicians/guidelines/vte/vte-guidelines-development-infographic.pdf?la=en&hash=8CF41C0F738B605B18A2C058E1C214A8>
5. Noble S. Patient engagement in research: are we really worse than orthopaedics? *Thromb Res.* 2017;150:111-2.