



Identifying the care pathway for young children with hemophilia at three hemophilia treatment centers in the Netherlands.

E.S van Hoorn¹, C.M.A. Mussert², M.E. Jansen³, H.L. Hooimeijer ³, S.C. Gouw⁴, S.H. Reitsma², M.H. Cnossen² and H.F. Lingsma¹, for the PARTITURA consortium

- 1 Erasmus MC, University Medical Center Rotterdam, Department of Public Health, Rotterdam, The Netherlands
- 2 Erasmus MC Sophia Children’s Hospital, University Medical Center Rotterdam, Department of Pediatric Hematology and Oncology, Rotterdam, The Netherlands
- 3 UMC Groningen Beatrix Children’s Hospital, University Medical Center Groningen, Department of Hematology and Oncology, Groningen, The Netherlands
- 4 Amsterdam UMC location University of Amsterdam, Department of Pediatric Hematology, Amsterdam, The Netherlands

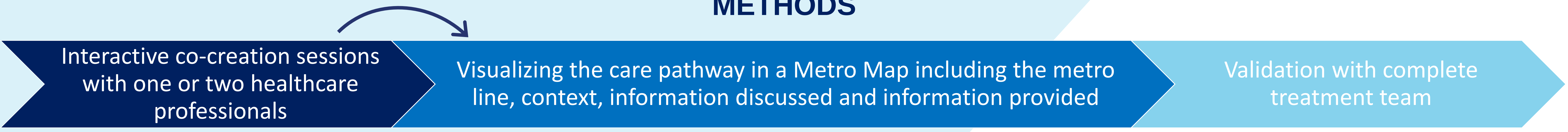
BACKGROUND & OBJECTIVE

- To identify possible improvements within hemophilia care provision, it is essential to gain insights into how care is currently provided.
- This study aims to identify the care pathway for young children (0-8 years) with hemophilia in Dutch hemophilia treatment centers.

CONCLUSIONS

- Slight differences were found within the care pathways. These differences may be explained by variation in organizational structures, culture and team composition.
- Identification and visualization of the care pathway guides patients and their caregivers more transparently through the healthcare process and stimulates improvement of care.

METHODS

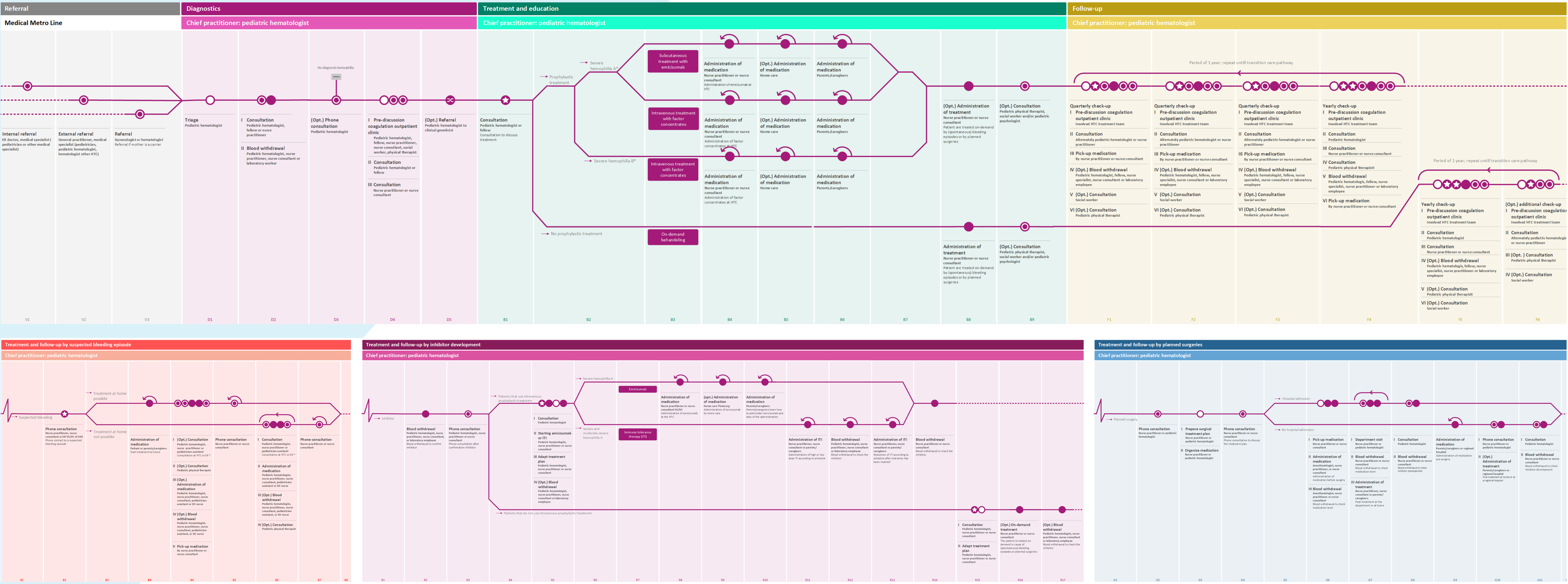


- Healthcare professionals involved in the care process for young hemophilia patients.
- Erasmus MC - Sophia Children’s Hospital, Amsterdam UMC - Emma Children’s Hospital & UMC Groningen - Beatrix Children’s Hospital.

- Modified Metro Mapping methodology for co-designing care pathways in a holistic, iterative way with active involvement of healthcare professionals¹.
- Documentation of the current care process, including the different steps that patients and their caregivers follow within the hospital and the role of the healthcare professionals.

(INTERIM) RESULTS

Hemophilia care pathway of Erasmus MC Sophia Children’s Hospital



- Multiple interactive co-design sessions with one nurse practitioner/consultant and one pediatric hematologist at each hemophilia treatment center (HTC).
- Depending on available documentation approximately 5-15 hours are needed to create a Metro Map.
- Seven phases of the care pathway identified.

- Differences between HTCs:

 - Consultations in follow up phase
 - Organization of outpatient clinic
 - Delivery of medication
 - Home care to administer prophylactic treatment and to educate caregivers when necessary
 - Ultrasound to diagnose bleeds in joints and muscles

ACKNOWLEDGEMENTS

We would like to thank Ilse Hoogendijk and Charlotte Schmidt for their contribution to the Partitura project. Partitura is a multicenter side project of the SYMPHONY consortium which aims to orchestrate personalized treatment in patients with an inherited bleeding disorder. This research was funded by Roche and the SYMPHONY NWO-NWA consortium (NWA.1160.18.038; Principal investigator: Dr. M.H. Cnossen; project manager: Dr. S.H. Reitsma). More information: www.symphonyc consortium.nl.

REFERENCES

1. Stiggelbout A, Griffioen I, Brands J, Melles M, Rietjens J, Kunneman M, et al. Metro Mapping: development of an innovative methodology to co-design care paths to support shared decision making in oncology. BMJ Evidence-Based Medicine. 2023;bmjebm-2022-112168.

CONTACT INFORMATION

Questions or comments?
Come and find me!

Or send an e-mail to
e.vanhoorn@erasmusmc.nl

