

Towards evaluation of hemophilia therapies in the Netherlands: a nationwide patient registry and digital infusion log.

Goedhart G¹, Fischer K², Driessens MHE³, Van Beurden KM¹, Van der Meer FJM¹ and HemoNED Steering Committee[†]

¹ Dep. of Thrombosis and Hemostasis, Leiden University Medical Center, Leiden, The Netherlands

² Van Creveld Clinic, University Medical Center Utrecht, Utrecht, The Netherlands

³ Netherlands Hemophilia Patient Society, Nijkerk, The Netherlands

[†] Representatives from each hemophilia treatment center, from the hemophilia patient society and from the hemophilia nurse society.

Introduction

Patient registries are crucial in the evaluation of hemophilia therapies, even more in the light of promising innovative products. Additionally, increasing attention is paid to digital personal health environments for patients.

Objectives

- To develop a nationwide registry of Dutch patients with hemophilia and associated disorders.
- To develop a digital infusion log (app) for patients and their physicians.
- To obtain data on number of patients, diagnoses, treatment intensity and outcomes.

Results

HemoNED Registry

Starting December 2017 patients were included in the HemoNED registry after informed consent; by the end of November 2018 1153 patients were included. Severe hemophilia patients were prioritized for inclusion; 75% of them (n=542) were included by November (figure 1; table 1). The mean age of the patients was 39 (range 0-88) years.

Digital infusion log (app)

Since April 2018 'VastePrik' is available as a mobile and a web application (figures 2 & 3). On the webpage both patient and care takers find an overview of infusions and bleeds entered. By November 2018 924 patients had received a personal account; 304 patients started to use the app.

Conclusion

- ✓ The Dutch hemophilia registry was successfully implemented in all six hemophilia treatment centers.
- ✓ The 'VastePrik' app and webpage are a first step towards a digital personal health environment for hemophilia patients. Bleeds and treatment are increasingly being entered in the app, although starting problems are recognized.

Future plans

- ✓ Treatment plans and side effects of treatment will be entered in the registry from 2019; side effects will be centrally reported to national and international (e.g., EUHASS) safety registries.
- ✓ In 2019 scanning the barcode of factor concentrates will be implemented in the VastePrik app to improve infusion registration.

Methods

From 2015 on in the Netherlands the hemophilia treaters society together with the hemophilia patient organization developed and implemented a nationwide hemophilia patient registry ('HemoNED') and a digital infusion log ('VastePrik'). The start-up phase took 2 years and included the set-up of a legal entity, developing project governance, gaining (financial) support and legal (e.g., privacy law) and ethical approvals.

Figure 1 Timeline: # patients included in HemoNED registry

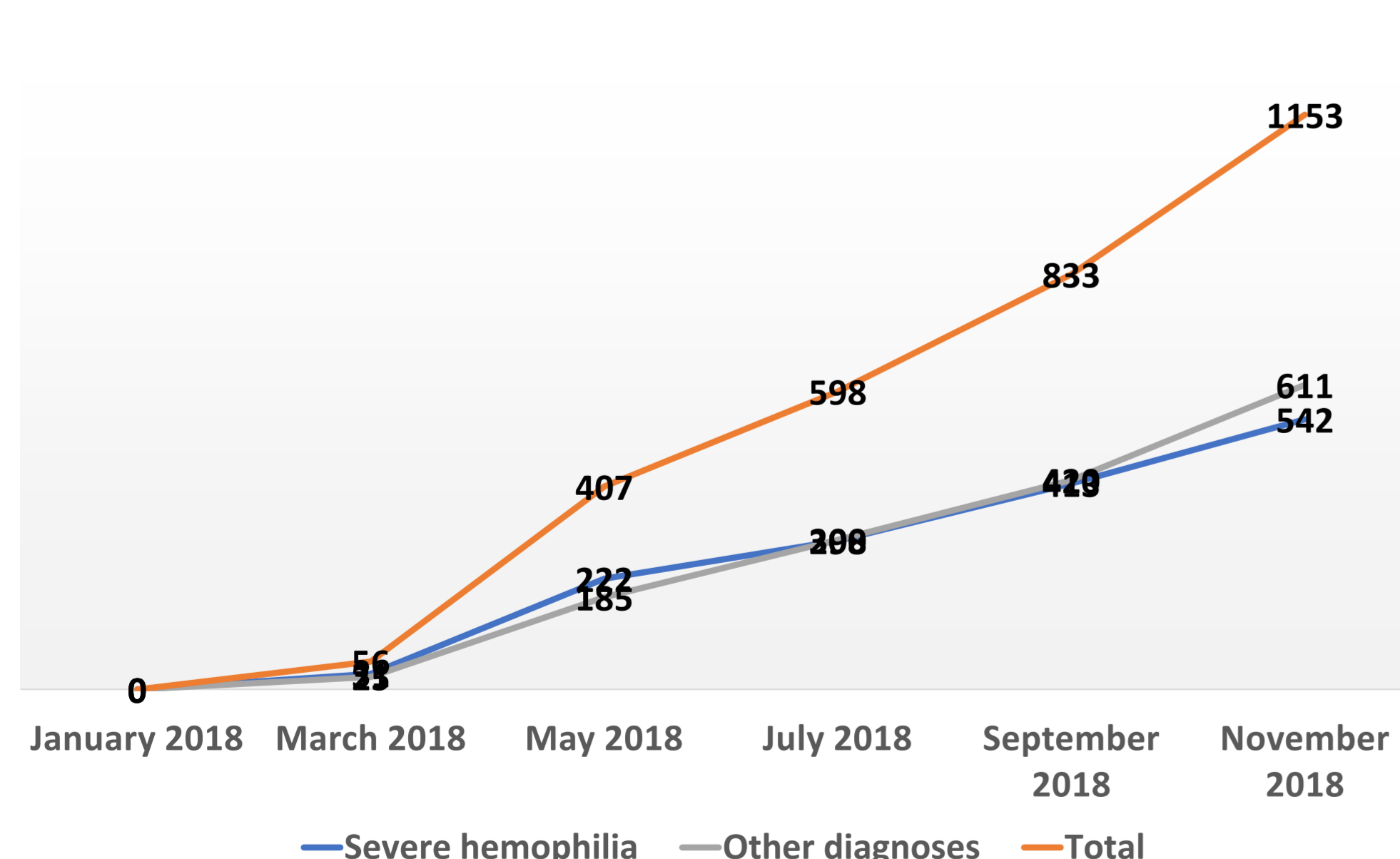


Table 1 Diagnosis of patients included in HemoNED registry by half November 2018

Diagnosis	# patients	%
Hemophilia A	752	66
Severe	435	58
Moderate	107	14
Mild	206	27
Missing	4	1
Hemophilia B	101	9
Severe	61	60
Moderate	17	17
Mild	23	23
Hemophilia B Leyden	14	1
Von Willebrand Disease	126	11
Type I	63	50
Type 2A	17	14
Type 2B	19	15
Type 2, other subtypes	6	5
Type 3	18	14
Missing	3	2
Other Bleeding disorders	33	3
Factor VII deficiency	9	27
Factor XIII deficiency	7	21
Other	17	52
Acquired Bleeding disorder	2	0,5
Carrier	28	2,5
Hemophilia A	19	68
Hemophilia B	9	32
Total Diagnosis known	1056	93
Missing	83	7

Figure 2 Digital infusion log: the 'VastePrik' webpage

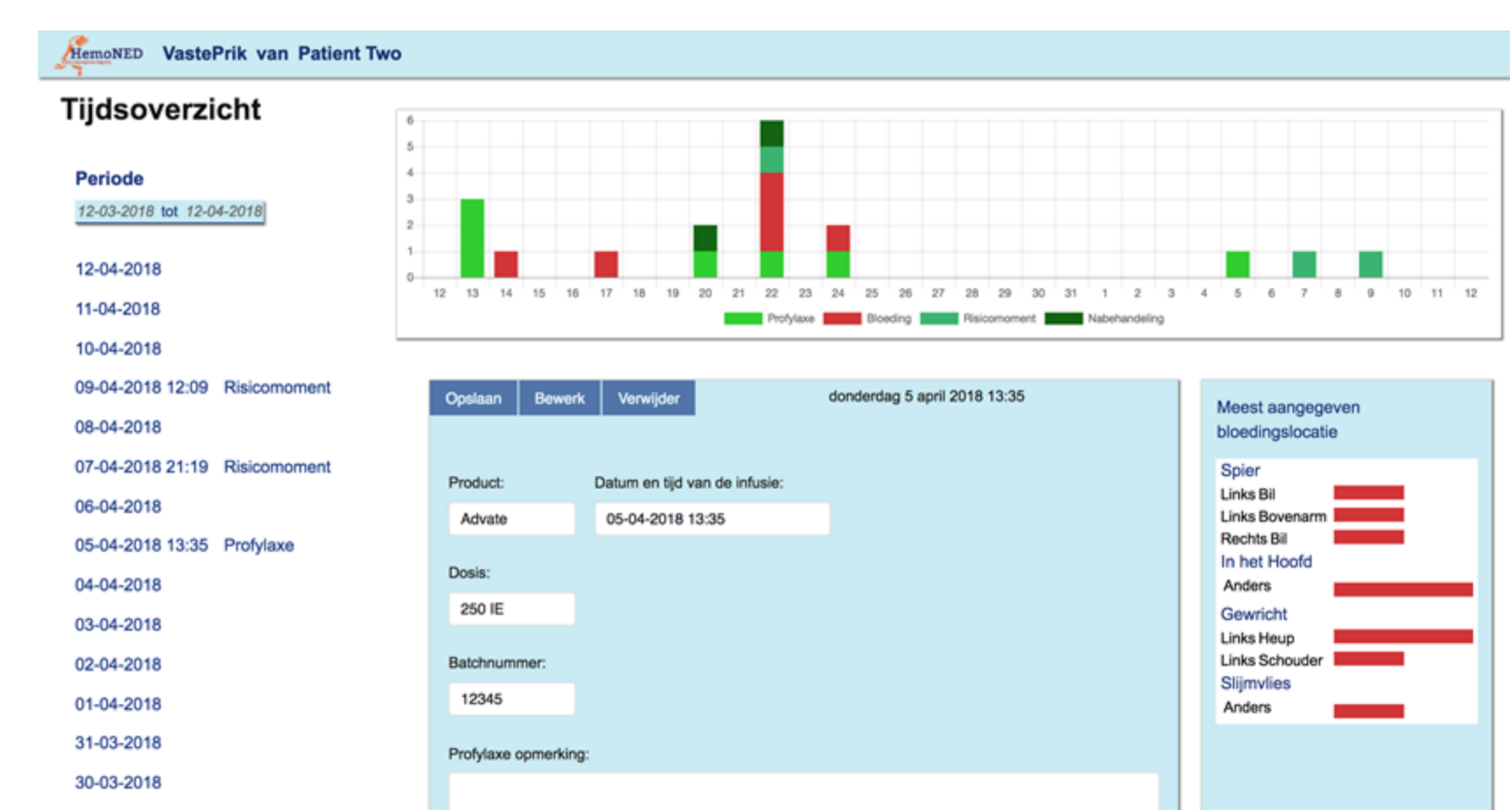
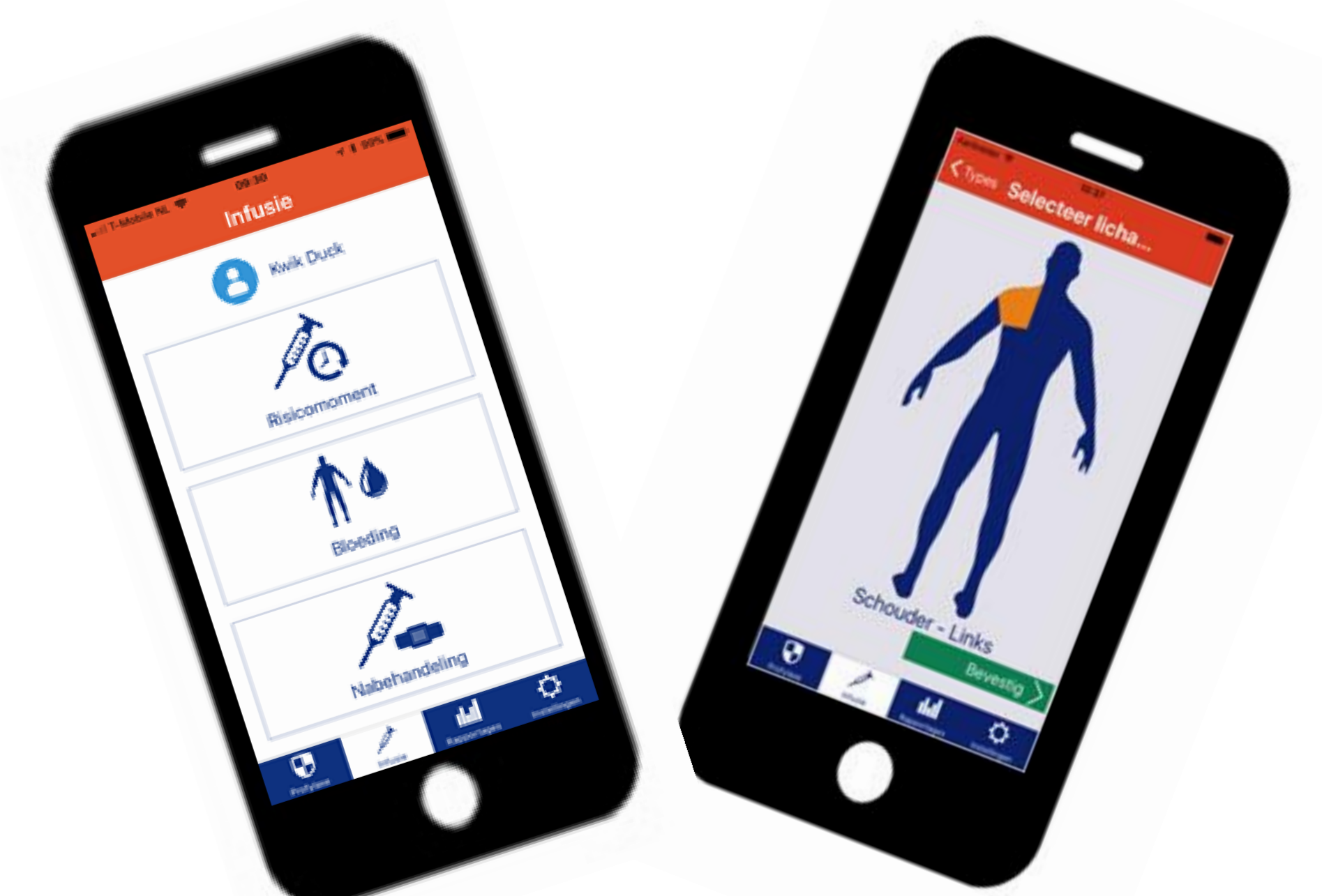


Figure 3 'VastePrik' app



<https://hemoned.nl/en>

Contact

HemoNED Foundation
Leiden University Medical Center
Staff Thrombosis and Hemostasis (C7-Q)
PO BOX 9600, 2300 RC Leiden, The Netherlands

Project coordinator: Mrs. dr. G. Goedhart
Phone: +31 71 526 1893
Email: info@hemoned.nl
Website: <https://hemoned.nl>

Grant/Research support

Netherlands Organization for Health Research and Development (ZonMw), Bayer, CSL Behring, Novo Nordisk, Shire, Sobi and Pfizer.