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Development of a core data set for individual treatment plans for patients with congenital bleeding disorders

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HemoNED Nederlands Hemofilie Register

PO159

INTRODUCTION

- In the Netherlands, there was no national consensus on the content of an individual treatment plan for congenital bleeding disorders
- Each of the 6 hemophilia treatment centers (HTC) uses their own plan, with different data items & answering options
- These plans are not fully adherent to (inter)national standards for reporting and exchanging health data.
- This hampers data exchange between treatment centers and with the Dutch quality registry HemoNED
- A standardized treatment plan could:
  - Reduce administrative burden
  - Facilitate shared care
  - Aid quality assessments
  - Facilitate clinical research
  - Improve the quality of care

AIM

- Establish a standardized treatment plan for children and adults with a congenital bleeding disorder in the Netherlands

METHOD

The plan was developed by hematologists, specialized nurses, data managers and HemoNED representatives. Consensus had been reached by all groups involved.

To draft a core data set:

- FAIR (Findable, Accessible, Interoperable, Reusable) data principles were adopted
- National treatment guidelines and Dutch Health and Care Information models were used as guidance to capture information
- (Inter)national standards were applied
  - The Dutch G-Standard to register medication
  - LOINC to register test results
  - the Diagnosethesaurus (Dutch interface terminology based on SNOMED CT codes) to register diagnoses

RESULTS

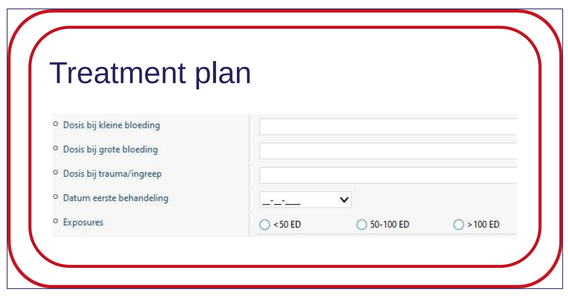
- Consensus was reached on the following data set:

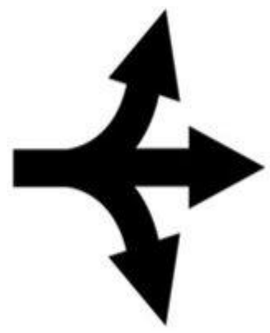
Item	Variable
Diagnosis	If Hemophilia A or B: mild, moderate, severe If Von Willebrand: type If other platelets disorder or factor deficiency: please specify
Most recent length & weight	Date last weight
Relevant laboratory parameters	Depending on diagnosis: • Lowest measured FVIII or FIX • FVIII T ½ or FIX T ½ • FVIII or FIX after 1 hour and 4 hour • VWF Act after 1 hour and 4 hour
History of gene therapy	If yes: • Most recent factor level and • Date of measurement
Inhibitor status and titer (for hemophilia)	• Last measured inhibitor titer • Date of measurement
Allergies/contra-indications for relevant treatments	If yes: for which coagulation product
The presence of an extreme fear of injections	Yes; No
Date last change treatment plan	Yes; No
Home treatment	Yes; No
Use prophylaxis	If yes: product; dose; frequency
Optional: Inhibitor in past	Yes; No
Optional: Shared care	Yes; No. If Yes: Name Hospital
In case of a bleed	
Mild	Product (including DDAVP); Dose
Severe	Product (including DDAVP); Dose
Life-threatening	Product (including DDAVP); Dose
Dose (remark)	If product = Haemate-P or a different VWF-concentrate: describe dosage instructions

CONCLUSIONS

- National consensus had been achieved on a treatment plan for people with a congenital bleeding disorder
- Implementing this plan in the Electronic Health Record of all Dutch hemophilia treatment centers has started

Registration in Electronic Health Record by health care provider





Reuse of data

Treatment plan letter for patient

Value Based Health Care

Personal Health Record

National Hemophilia Registry HemoNED Nederlands Hemofilie Register

Reports Zorginstituut Nederland

Research

REFERENCES

Visit the HemoNED website

Treatment plan

ACKNOWLEDGEMENT

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