

Use of Data and Reporting to Improve Haemophilia Care

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INTRODUCTION

- In New Zealand, a consistent approach to the collection and analysis of information about bleeds and factor replacement among haemophilia patients has not yet been established.
- Launched early 2012, the CARE FACTORY telemonitoring tool allows real time reporting of this information by haemophilia patients and facilitates analysis and reporting by haemophilia treatment centres (HTCs).

STUDY OBJECTIVE

- This research assesses the current and potential uses of reports generated from the data captured in CARE FACTORY to help improve patient care.

METHODS

- Data was obtained from bleed and factor usage reports received by one HTC through the FACTORY digital platform over a 12-month period.
- Through analysis of the reports, the utility of the data in the management of haemophilia patients is identified and described.

RESULTS

- During the 12-month period, 23 patients recorded 210 bleeds and 2,082 infusions.
- Most (57%) of the bleeds were spontaneous (Fig. 1) and 111, 83 and 16 bleed reports were classified as mild, moderate and severe, respectively.
- The use of pain relief was reported for 117 of the 210 bleeds.
- The number of infusions and average dose by reason for treatment (Fig. 2) indicate that prophylaxis and ITT were the most common reasons for treatment accounting for 57% and 29% of all infusions, respectively.
- The overall average dose per infusion was 827 IU with surgery accounting for the highest (2,421 IU) and ITT for the lowest (633 IU) average dose per infusion.
- The number of infusions varied between 1 and 613 by patient while the average dose per patient varied between 261 IU and 2,520 IU per infusion (Fig. 3).
- The bubble chart gives a three-dimensional overview of patient-level data providing a snapshot of number of bleeds, number of infusions and average dose per infusion (size and colour of bubble) per patient (Fig. 4).

DISCUSSION

- The reports provide clinicians with the ability to view and analyse bleed and infusion reports objectively for individual patients or patient cohorts.
- The differences in bleeds and factor usage between patients can be explained to some extent by varying bleeding phenotypes and differences in weight, however the reports may identify opportunities for reviewing patients' treatment schedules to help optimise outcomes.
- Some findings are expected such as high number of infusions associated with ITT, while other findings such as high number of bleeds with low number of infusions may indicate an opportunity for patient education regarding the importance of adherence to prescribed prophylaxis regimens.
- In addition to patient-level analysis, the reports provide a means for identifying trends across patient cohorts.

CONCLUSIONS

- This report suggests that opportunities exist for clinicians at HTCs to use longitudinal data reported by patients to identify and respond to trends in patient groups and to educate individual patients with the aim of improving patients' insights about their disease and its treatment.

Conflicts of Interest

This paper was supported by Pfizer New Zealand, the developer of CARE FACTORY. Associate Medical Director of Pfizer New Zealand is a co-author of this abstract and assisted with its preparation.



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Figure 1. Causes of Bleeds

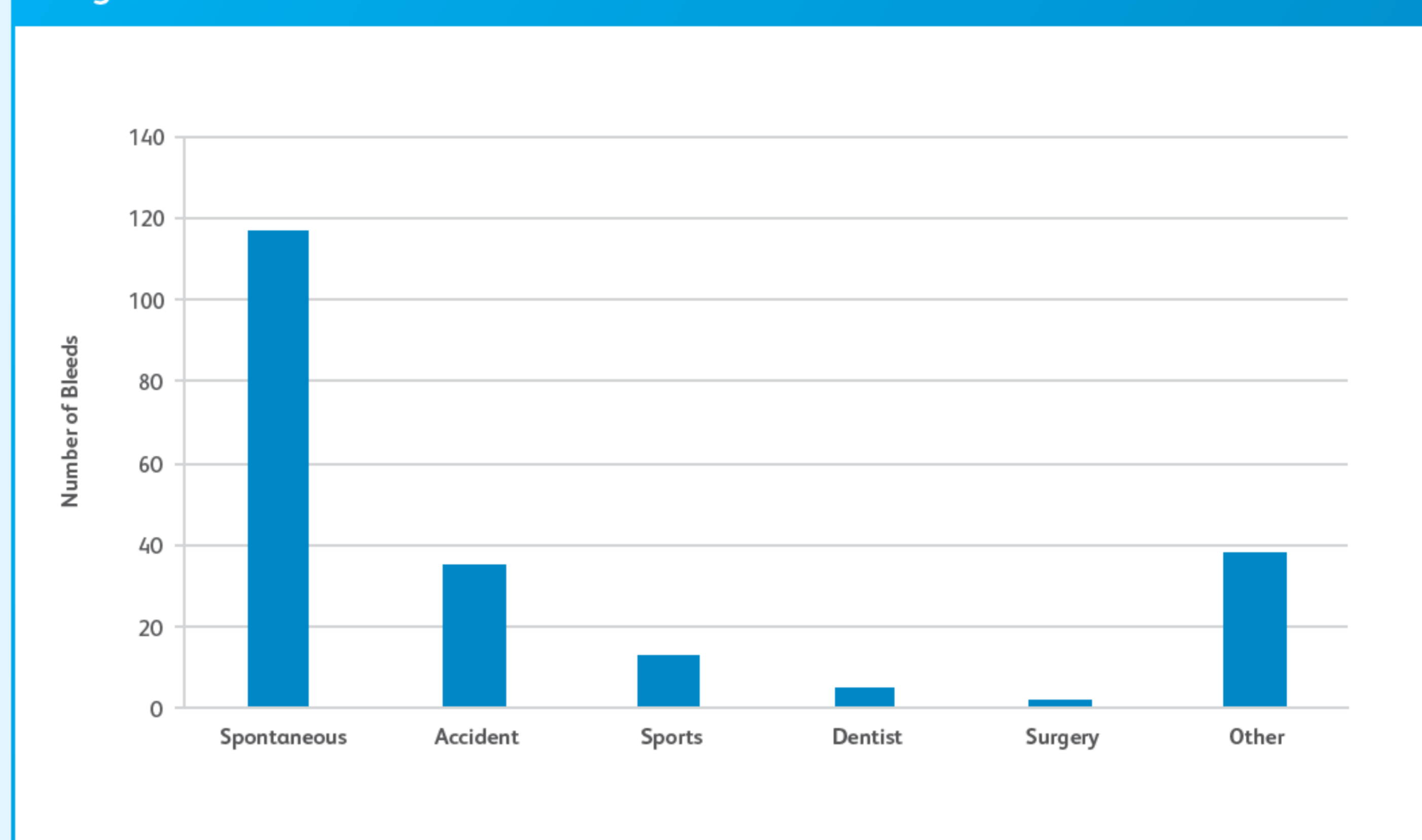


Figure 2. Number of Infusions and Average Dose by Reason for Treatment

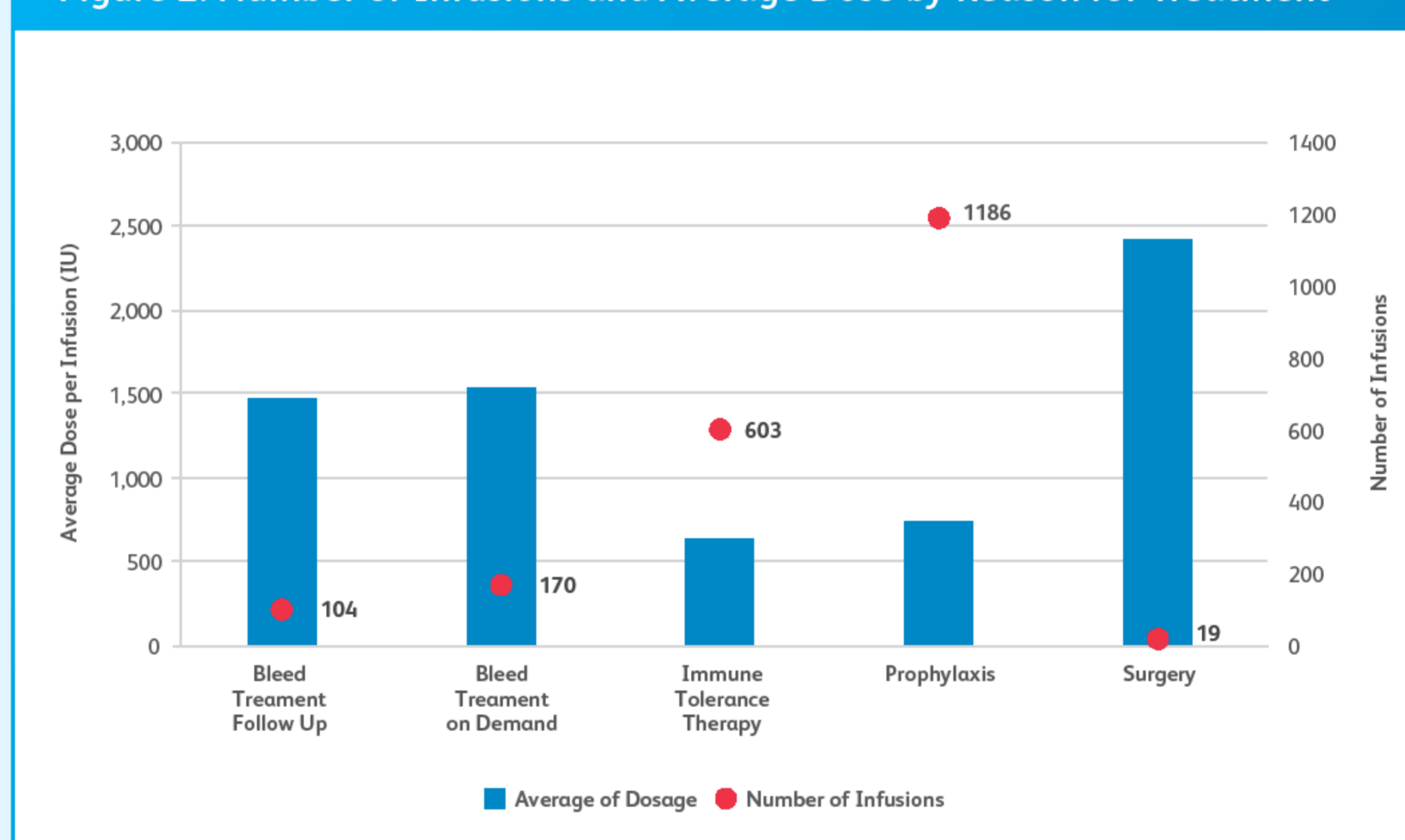


Figure 3. Average Dose and Number of Infusions per Patient

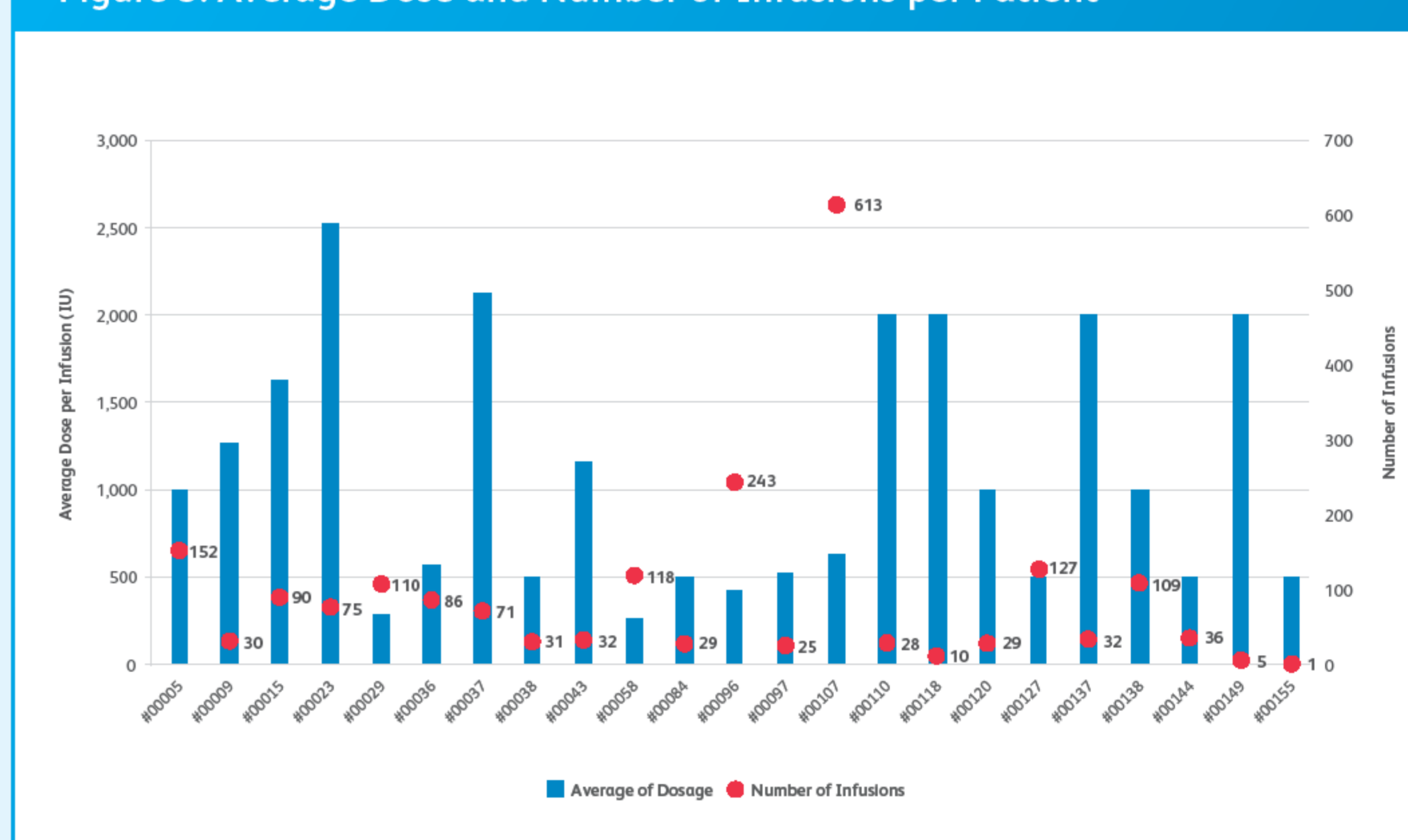


Figure 4. Number of Infusions, Number of Bleeds and Average Dose per Patient

