

Using Closed Loop Reporting to Change Patient Behaviour: Case Report

Robyn Shoemark¹; Zirke Wiid²

¹The Kids Factor Zone – Haemophilia Treatment Centre, The Children’s Hospital, Westmead, Australia;
²Global Innovative Pharma, Pfizer Australia, West Ryde, Australia

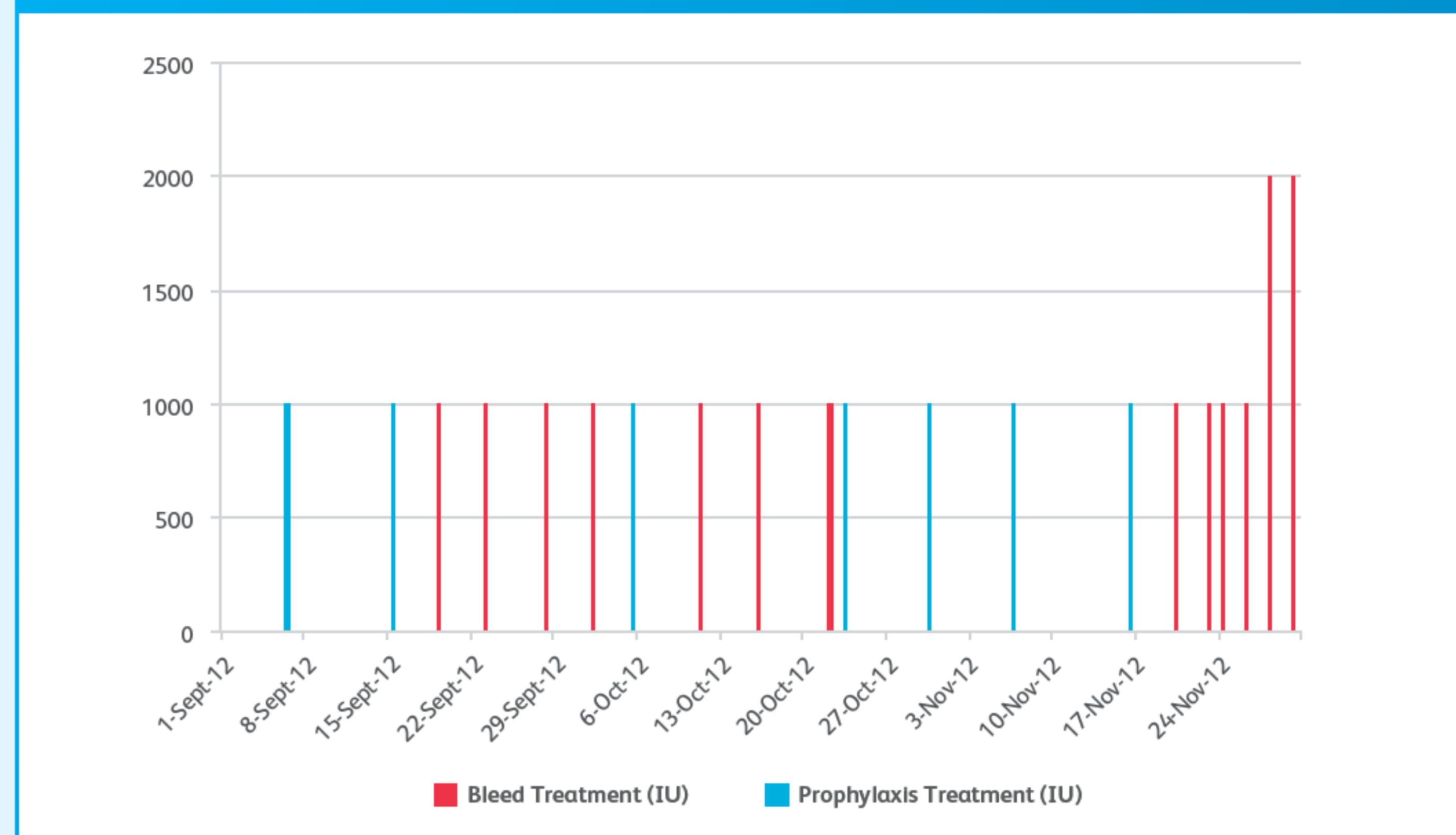
INTRODUCTION

- Adherence to prescribed treatment, particularly with chronic conditions, is a widely reported area of concern in healthcare.¹
- Adherence is often reported to be worst in teenagers who struggle with the impact of adolescence in addition to the limitations that treatment regimens may impose on their lives.²
- While information about bleeds and factor usage is pivotal to the management of haemophilia patients, paper-based diaries pose challenges to the interpretation of longitudinal data and detection of trends in the absence of graphical representations.
- In Australia, clinicians at haemophilia treatment centres (HTCs) have access to a haemophilia telemonitoring tool, pfusion (Fig. 1), that allows real time reporting of bleeds and factor usage by patients.

Figure 1. Pfusion



Figure 2. Recombinant FVIII Infusions Prior to Patient Education



Intervention and Outcome

- The pfusion graphs were used by the treating clinician to educate the patient about the association between bleeds and infusions.
- The graphs were used to demonstrate to the patient that the number of infusions administered each month on-demand to treat bleeds was similar to the number of infusions prescribed as part of the prophylaxis regimen.
- The patient realised that by using the same number of infusions prophylactically instead of on-demand, the pain and potential joint and muscle damage associated with bleeds could be prevented.
- In the 9-month period following the patient education session, adherence to regular prophylactic factor replacement gradually improved (Fig. 3).
- During the final 8 months of observation, prophylaxis was administered more regularly and only one injury-related bleed occurred.

OBJECTIVE

- Describe the impact of using patient-reported bleed and factor usage data to improve adherence through education in an adolescent patient.

CASE REPORT

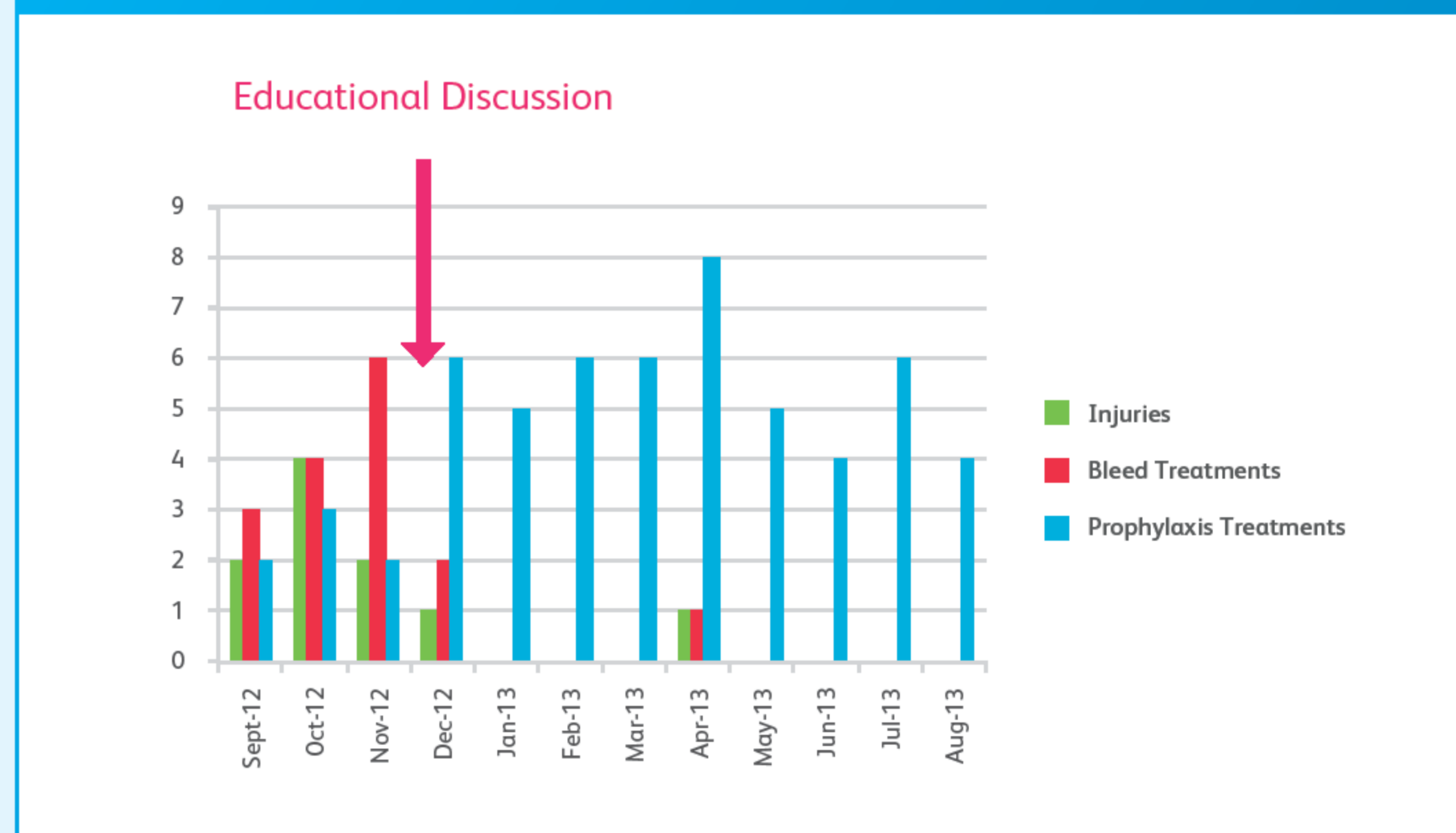
Patient Profile

- A 12-year old male patient, JT, was diagnosed less than 5 months after birth with severe haemophilia A (FVIII 1%) due to an intron 22 mutation.
- His mother and sister are carriers and there is no family history of haemophilia.
- JT has no target joints and participates in sport, including soccer and swimming.

Treatment and Medical History

- JT received treatment on-demand for bleeds during the first 4 years following diagnosis.
- At the age of 4 years when he started preschool, JT commenced on prophylaxis, initially once weekly and was subsequently switched to alternating once or twice weekly prophylaxis depending on the sport season.
- JT started self-infusing at the age of 12 years through venepuncture only.
- At the time his prescribed prophylaxis regimen consisted of 1000 IU rFVIII twice weekly.
- Subsequent pfusion reports indicated that JT was experiencing 2 to 4 injury-related bleeds per month, some bleeds requiring multiple treatments. (Fig. 2)
- Patient-reported information in pfusion indicated that poor adherence with the prescribed prophylaxis regimen was contributing to the bleeding pattern.
- Factor replacement was generally administered on-demand to treat bleeds.

Figure 3. Number of Bleeds and Infusions



CONCLUSIONS

- This case illustrates how closed loop reporting can be used to educate patients and improve patients’ insights about the impact of poor adherence.
- With the necessary education and guidance from clinicians, patients are able to use the reported information to their advantage to minimise the impact of the condition on their daily activities.
- The report is consistent with published literature that suggests teenagers are able to understand and make complex treatment decision about treatment schedules that offer protection from bleeds and facilitate participation in normal daily activities.³

References

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Conflicts of Interest

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