

Feasibility of short message service (SMS) to document bleeding episodes in children with haemophilia



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Background

Whilst the shift from hospital-based treatment to home-based treatment has improved quality of life for many children with haemophilia, it has made accurately documenting bleeding episodes more difficult. Currently paper-based bleeding diaries are most commonly used however there may be poor compliance resulting in an under-estimation of the number of bleeds and a delay for health professionals in retrieving these diaries¹.

Aim

The aim of this study was to assess the feasibility of using a short message service (SMS) to monitor incidence of bleeding episodes in children with haemophilia.

Methods

One hundred and four children with moderate and severe Haemophilia A or B took part in a one-year prospective study between 2008 and 2010². Children or their parents received a weekly SMS asking whether they had had a bleeding episode in the preceding week. If no reply was received, follow up messages were sent 24 and 48 hours later. Response rates were calculated. Back-up reporting methods in the form of a toll-free telephone number and bleeding diaries were also used.

Table 1: Response rate by place of residence (classified according to Australian Standard Geographical Classification³)

| Code | Classification | n | Median response rate (%) | Range of response rates (%) |
|------|---------------------------|----|--------------------------|-----------------------------|
| RA1 | Major Cities of Australia | 72 | 94.2 | 19.2 - 100 |
| RA2 | Inner Regional Australia | 20 | 94.2 | 36.5 - 100 |
| RA3 | Outer Regional Australia | 11 | 100 | 5.7 - 100 |
| RA4 | Remote Australia | 1 | | |
| RA5 | Very Remote Australia | 0 | | |

References

- Walker I, Sigouin C, Sek J, et al. Comparing hand-held computers and paper diaries for haemophilia home therapy: A randomized trial. *Haemophilia* 2004; 10 (6): 698-704.
- Broderick CR, Herbert RD, Latimer J, Barnes C, Curtin JA, Monagle P. Estimation of transient increases in bleeding risk associated with physical activity in children with haemophilia. *BMC Blood Disorders* 2008; 8: 2.
- Australian Standard Geographical Classification (ASGC) Remoteness Structure (RA) Digital Boundaries In: Statistics ABo, ed., 2006. Access date 14/02/2012 <http://www.abs.gov.au/ausstats/abs@.nsf/productsbytitle/9A784FB979765947CA25738C0012C5BA?>

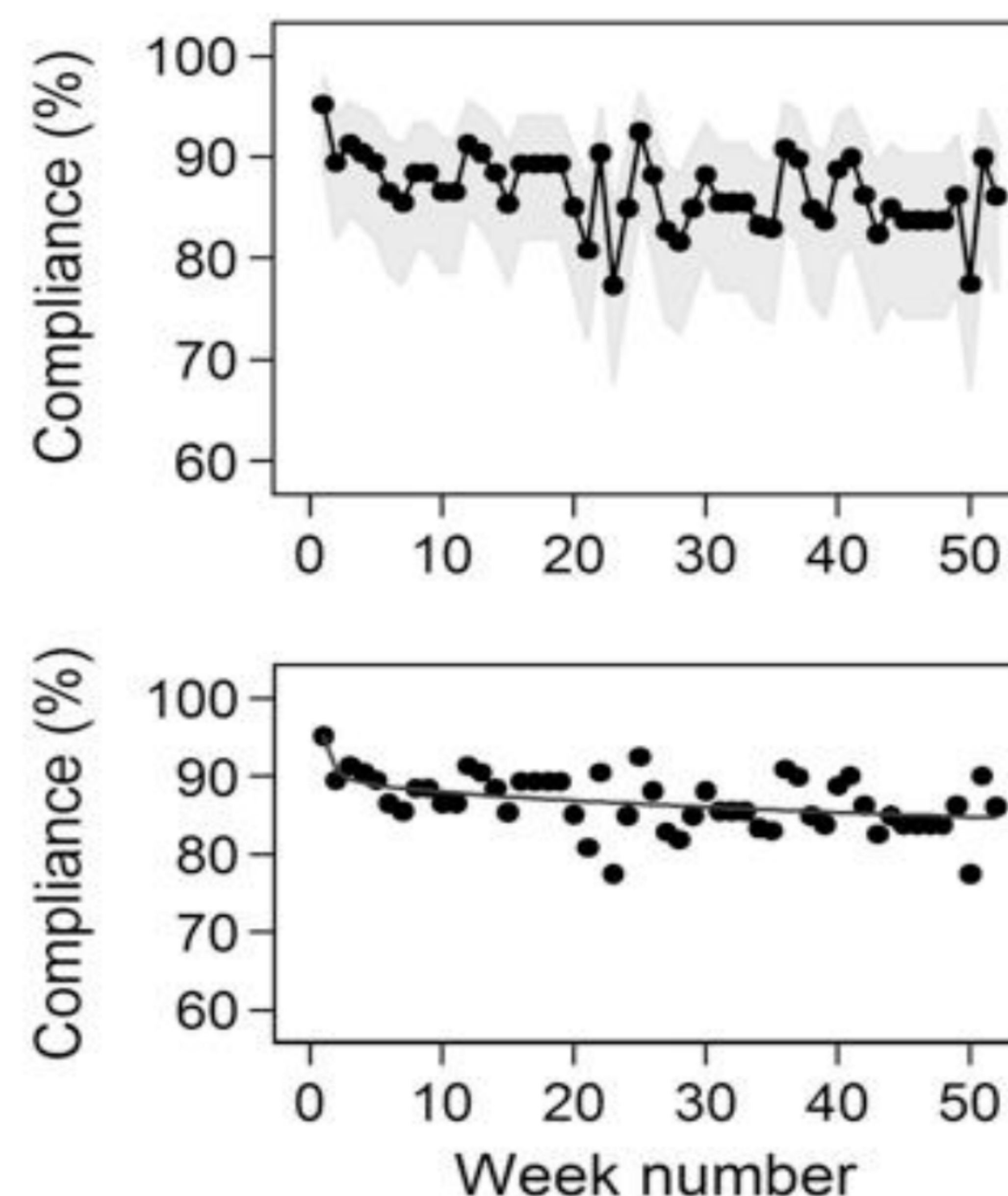


Figure 1: SMS compliance by weeks in study. In the top graph shaded regions are 95% confidence intervals. In the bottom graph a fractional polynomial regression line has been fitted.

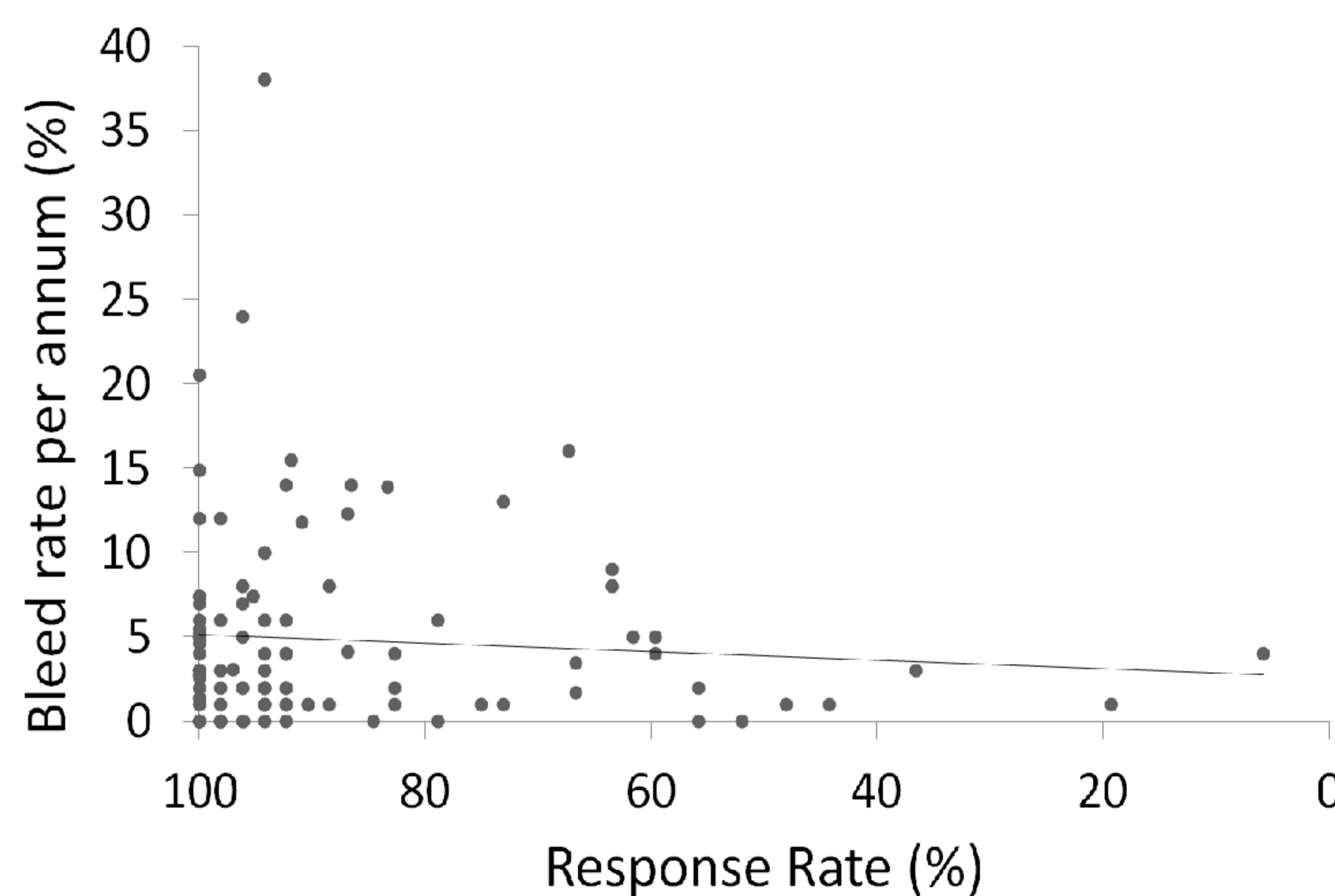


Figure 2: Bleeding rates versus response rates

Results

Children were followed for a total of 4839 person-weeks. SMS replies were received for 4201 weeks. Thus the rate of follow-up was 86.8%. Median responses rates were 94.2% (IQR 86.1%-100%). Response rate by place of residence is shown in Table 1. Figures 1 and 2 show response rates varied little over time and were unaffected by the number of bleeds a child experienced.

Conclusions

SMS is a feasible tool for collecting data related to bleeding episodes in children with haemophilia. The use of SMS could be extended to encourage compliance to prophylactic treatment, particularly in adolescents with haemophilia.

