

# Five-year follow-up in haemophilia care comparing real life data from electronic documentation smart medication™

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## Background:

Electronic diary has shown to be a valuable tool for analysis of annual joint bleeding rate (AJBR) and annual factor VIII/IX consumption (AFC) in real life setting. What has changed over a five-year period?

## Methods:

AFC and AJBR among 358 patients with haemophilia A/B from 13 haemophilia centers in 2018 were compared to data to prior years (277 patients from 9 centers in 2017 and less in prior years) according to electronic documentation smart medication™.

## Results:

Looking at five consecutive years, the average AFC (IU/kg BW) was 2442, 2701, 2575, 2670 and 2924 the average AJBR 2.1, 2.5, 2.3, 2.2 and 1.9 between 2014 and 2018, respectively. Four groups, comparing above or below average AFC and AJBR, were compared between 2014 -2018: The majority (45%/40%/44%/45%/40%) had an AJBR of  $\leq 2$  with less than average AFC, followed by a group (31%/35%/32%/32%/29%) with  $\leq 2$  AJBR but above average AFC. A minor group (14%/11%/15%/15%/14%) had an AJBR  $> 2$  and more than average AFC. Only few (10%/14%/8%/8%/17%) had an AJBR  $> 2$  but less than average AFC.

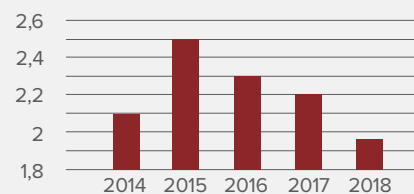
## Conclusion:

In 2018 the AJBR was slightly lower, the AFCR slightly higher compared to prior years. Whether this reflects changes in treatment or is due to an increasing number of participating patients and centers needs to be further analyzed. With the introduction of extended half-life products the future bleeding and factor consumption may change, demonstrating the necessity for ongoing electronic surveillance in hemophilia care.

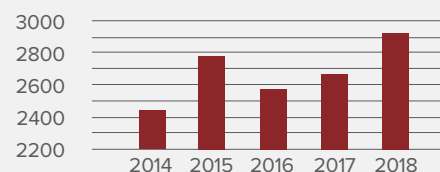
**TABLE. 1** NUMBER OF PATIENTS, ALL BLEEDS, JOINT BLEEDS AND AVERAGE UNITS/BODY WEIGHT/YEAR ACCORDING TO GROUP AND YEAR

	Patients	all bleeds	joint bleeds	IU/kgBW/y	IU
A	144 (40,22%)	372	32	1549	18,9 Mio
B	104 (29,05%)	158	24	4689	33,2 Mio
C	49 (13,69%)	529	319	5055	18,5 Mio
D	61 (17,04%)	639	326	1450	7,2 Mio
SUM	358	1698	701	-	-
Average				2924 ( $\pm$ 2700)	

Annual Joint Bleed Rate



Annual factor VII/IX consumption between 2014 and 2018



**FIG. 1** MEAN AS LIMIT FOR BLEEDS AND FACTOR CONSUMPTION

