

# Assessing the quality of hemophilia care: how suitable are patient-centered outcomes to compare hospital performance?

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## BACKGROUND

Patient-centered outcomes provide valuable measures of treatment effectiveness in hemophilia trials, but their suitability for comparing hospital performance, a prospective route to improve quality of care, remains uncertain.

## METHODS

- Data:** 807 adults with hemophilia registered at six treatment centers (questionnaire-based study 2018-2019)
- Evaluated outcome indicator:** five clinical and seven patient-reported outcomes
- Evaluation criteria**
  - Validity → Spearman's rank correlation between case-mix adjusted and unadjusted hospital scores (*high correlations indicates minimal case-mix influence*)
  - Reliability → rankability percentage or proportion of between-hospital variation not attributable to chance (*higher rankability indicates greater reliability*)

### AIM

To evaluate the suitability of patient-centered outcomes as quality indicators for comparing hospital performance

### CONCLUSION

Clinical outcomes outperform patient-reported outcomes as quality indicators for hospital comparisons

## RESULTS

Outcome indicator	Spearman's CC (95% CI)	Rankability (95% CI)
<i>Clinical outcomes</i>		
Zero-treated bleeds	0.89 (0.50-1.00)	0.16 (0.00-0.65)
Zero-treated joint bleeds	0.89 (0.40-1.00)	0.10 (0.00-0.65)
Annual bleeding rate	0.94 (0.40-1.00)	0.55 (0.00-0.96)
Annual joint bleeding rate	0.94 (0.50-1.00)	0.67 (0.00-0.90)
Joint score	0.77 (-0.50-1.00)	0.48 (0.00-0.82)
<i>Patient-reported outcomes</i>		
General physical functioning	0.03 (-1.00-1.00)	0.10 (0.00-0.56)
Hemophilia-specific physical functioning	0.37 (-0.80-1.00)	0.12 (0.00-0.56)
Social functioning	0.89 (0.00-1.00)	0.03 (0.00-0.44)
Pain	0.43 (-0.50-1.00)	0.17 (0.00-0.72)
Anxiety	0.94 (0.50-1.00)	0.00 (0.00-0.27)
Depression	0.94 (0.40-1.00)	0.00 (0.00-0.27)
Hemophilia-specific treatment satisfaction	0.77 (0.20-1.00)	0.31 (0.00-0.80)

Case mix: age, education, income, severity, inhibitor, hypertension, hypercholesterolemia, DM type 1 and 2, COPD, psychological complaints, hepatitis C

## AFFILIATION

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## FURTHER INFORMATION

SYMPHONY consortium aims to orchestrate personalized treatment in patients with an inherited bleeding disorder. This research was funded by NWO-NWA consortium (NWA.1160.18.038; Principal Investigator: Prof. Marjon H. Cnossen; project manager: Dr. Simone H. Reitsma). More information: [www.symphonyconsortium.nl](http://www.symphonyconsortium.nl).

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