

Comment on: Generation and optimization of the self-administered pediatric bleeding questionnaire and its validation as a screening tool for von Willebrand disease

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Abbreviations	
Self-PBQ	Self-administrable Pediatric Bleeding Questionnaire
IV	Intravenously

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1 To the editor: We would like to congratulate Casey et al on the development of their self-
2 administrable pediatric bleeding questionnaire (Self-PBQ) as a screening tool for von Willebrand
3 disease¹. To date, similar screening tools have required expert administration, generally in a clinical
4 setting. The development of a self-administrable tool has many benefits including reducing the time
5 burden on clinicians and the possibility of administration outside of the clinic.

6
7 Although we acknowledge the usefulness of such a tool, we raise a number of concerns with the
8 validity of the Self-PBQ. Namely, we are concerned with the wording of a number of items. One such
9 example is item 1.9 where a possible answer is, “given a medication intravenously (IV) or with a
10 needle into the skin at least once (desmopressin – DDAVP, Octostim or Stimate)”. The reference to
11 *intravenously* and *desmopressin – DDAVP, Octostim or Stimate* is unlikely to be comprehended by a
12 layperson. Agreement demonstrated in the validation of the Self-PBQ with the expert administered
13 version may be influenced either direction due to the wording i.e. if a question is not understood in
14 one version of the tool the participant is unlikely to understand the same question when asked in
15 another version of the same tool. Therefore, the participant’s responses will most likely be in
16 agreement between the tools, despite the limited understanding of the question².

17
18 The authors noted that the tool was converted to a grade 4 level of reading, however the specifics of
19 how this was achieved was not mentioned. It is critical that self-administered tools aimed at children
20 undergo lay translation in consultation with an appropriate expert specialising in educational theory^{2,3}.

21
22 It is fundamental to the utility of any self-administered screening tool that comprehension by the
23 target population is achievable. Without patients adequate understanding of the questions being posed
24 to them, the development of a meaningful and useful tool is unachievable

25 **Conflict of Interest statement**

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1 The authors have no conflicts of interest to disclose.

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3 1. Casey LJ, Tuttle A, Grabell J, et al. Generation and optimization of the self-administered
4 pediatric bleeding questionnaire and its validation as a screening tool for von Willebrand
5 disease. *Pediatr Blood Cancer*. 2017;00:e26588

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8 2. Davis TC, Crouch MA, Wills G, Miller S, Abdehou DM. The gap between patient reading
9 comprehension and the readability of patient education materials. *J Fam Pract*. 1990;31:533–8

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12 3. Davis TC, Mayeaux EJ, Fredrickson D, Bocchini JA, Jr, Jackson RH, Murphy PW. Reading
13 ability of parents compared with reading level of pediatric patient education
14 materials. *Pediatrics*. 1994;93(3):460–468.

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