

## LETTERS

## INFORMATION ON THE INTERNET

## Should clinicians edit Wikipedia to engage a wider world web?

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The “parents’ perspective” in the clinical review on the diagnosis and management of haemophilia highlights the responsibility of clinical teams to “coach and guide” people with a newly diagnosed rare genetic condition.<sup>1</sup> The requirement for specialist teams to provide up to date information resources for the public is increasingly challenging, with the expectation of immediate availability, as offered online.

We simulated 30 opportunistic internet searches for information on haemophilia in the top three search engines using term permutations: haemophilia or hemophilia (with or without A or B); carrier; information; child; treatment.<sup>2</sup> Wikipedia was the most commonly found top 10 site in all search engines. The top 10 appearance of other websites depended on combinations of search engines and terms. The UK National Haemophilia Society website was found in 26 searches in Bing, 21 in Yahoo, but only three in Google. The many bespoke haemophilia websites rarely appeared in top 10 search results.

Analysis of editorial authorship of the Haemophilia Wiki for four weeks found 39 edits by 25 editors, only nine of whom had a profile, and none of whom were experts in haemophilia. Could the public’s thirst for detailed knowledge be better served by medical professionals engaging with Wikipedia? Given the

evolving debate about open access to data, should publishers and authors be mandated to place reviews and key studies, such as that of Nathwani and colleagues,<sup>3</sup> in a public domain like Wikipedia? Currently, Wikipedia references only the *New York Times*’ report of the Nathwani trial’s publication.<sup>4</sup>

Wikipedia provides open access to information for patients everywhere, their families, students, teachers, and those who are impossible to pigeon hole for more bespoke portals. However, as a professional group, we are not sure whether we wish to engage with Wikipedia more constructively.

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- 1 Fijnvandraat K, Cnossen MH, Leebeek FW, Peters M. Diagnosis and management of haemophilia. *BMJ* 2012;344:e2707.
- 2 Experian. Data center—top sites and engines. [www.hitwise.com/uk/datacentre/main/dashboard-7323.html](http://www.hitwise.com/uk/datacentre/main/dashboard-7323.html).
- 3 Nathwani AC, Tuddenham EG, Rangarajan S, Rosales C, McIntosh J, Linch DC, et al. Adenovirus-associated virus vector-mediated gene transfer in hemophilia B. *N Engl J Med* 2011;365:2357-65.
- 4 Wade N. Treatment for blood disease is gene therapy landmark. *New York Times* 2011 Dec 10.

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