

ComPaRe Endometriosis: how to improve care for patients

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Driven by researchers and academic staff from the Centre for Clinical Epidemiology (AP-HP), the Centre for Research in Epidemiology and Population Health (CESP - Inserm)/Université Paris-Saclay/UVSQ/Gustave Roussy) and the Centre for Research in Epidemiology and Statistics (CRESS - Inserm/Université Paris Cité), ComPaRe, the AP-HP Community of Patients for Research, has conducted a citizen science study to gather ideas from patients suffering from endometriosis with a view to improving their care. The 1,000 study participants answered the following question: "If you had a magic wand, what would you change about your health care?". Some 2,487 ideas were put forward, categorised into 61 areas for improvement. Led by Solène Gouesbet, PhD candidate at Université Paris-Saclay, and supervised by Dr Viet-Thi Tran, epidemiologist and co-investigator at ComPaRe (Université Paris Cité/AP-HP), the study was the subject of a scientific publication in the *Journal of Women's Health* on 19 January 2023.

Endometriosis is a gynaecological disease that can cause a number of disabling symptoms (pelvic pain during menstruation or sexual intercourse, digestive problems, fatigue, etc.). The disease affects around 10% of women of reproductive age, but despite its high prevalence, it is estimated that it takes around seven years from the onset of symptoms to diagnosis.

Treatment options are limited, and many women live with unresolved pain. Few studies in literature¹ consider the patient's point of view.

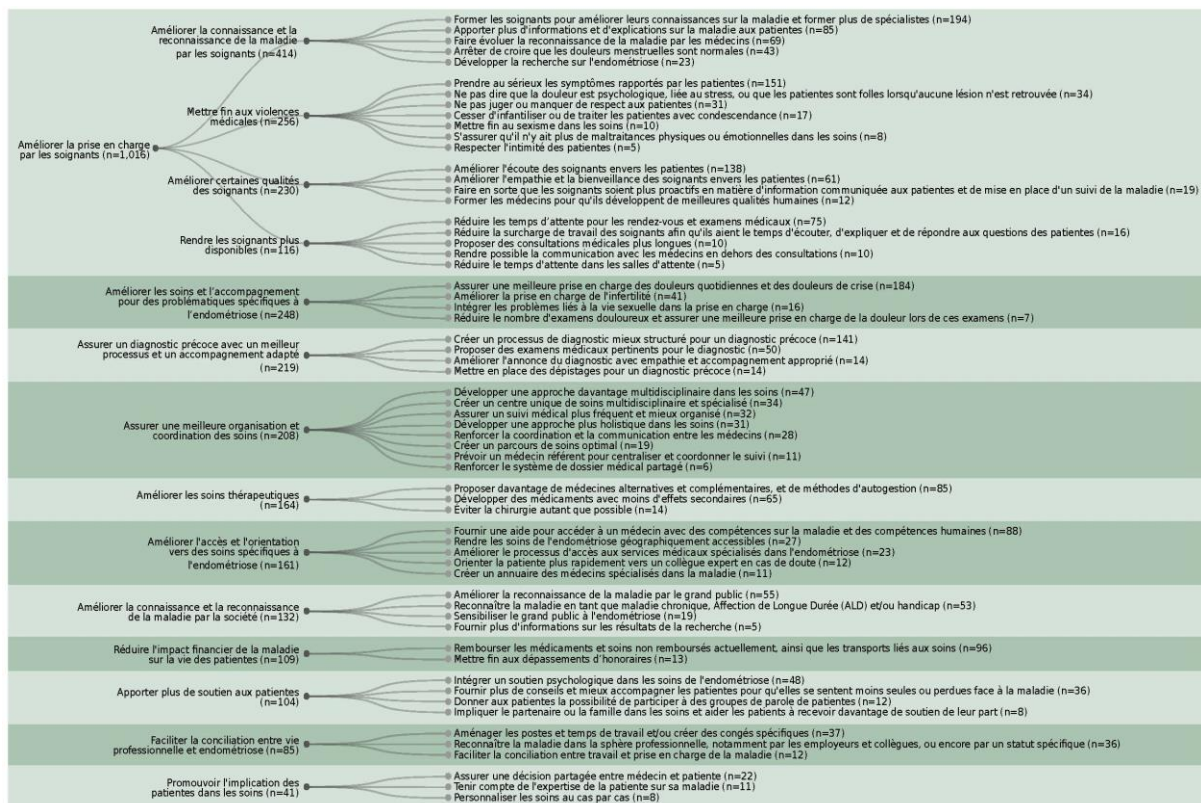
1,000 patients from the ComPaRe Endometriosis cohort were selected at random. They were asked the open-ended question "*If you had a magic wand, what would you change about your health care?*" via a questionnaire in their personal ComPaRe account. The data was analysed by a group of researchers, caregivers and patients. Thanks to the study's participants, nearly 2,500 ideas were identified, categorised into 61 areas for improvement.

Patient suggestions for improvement included better knowledge and recognition of the disease by caregivers (41%), improved care and support for endometriosis-specific issues (25%), and ensuring an early diagnosis with an improved diagnostic process and appropriate support (22%).

"I would have liked to have been diagnosed earlier, so that I could have started amenorrhea quickly. It would have saved me many days of suffering, of not being able to attend classes (...)" said one patient.

The collective intelligence of the patients captured through this study will enable a model of care to be defined that is better adapted to patients' experiences. Once again, ComPaRe is making patients key players in the research into their disease.

On the occasion of this publication, ComPaRe Endometriosis would like to thank all participants and renews its call for participation. By registering with ComPaRe (<https://compare.aphp.fr/endometrioise/>), patients can contribute to the advancement of public medical research into their disease, and make their voices heard.



Created in 2017 by AP-HP, ComPaRe, the Community of Patients for Research, currently brings together over 50,000 patient volunteers throughout France. They contribute to the advancement of research into their chronic disease(s) by regularly responding to researchers' online questionnaires, on the secure <https://compare.aphp.fr> platform.

Patients participate in the general cohort and/or one of the fourteen cohorts dedicated to diabetes, Verneuil's disease, vitiligo, chronic low back pain, kidney disease, vasculitis, arterial hypertension, endometriosis, neurofibromatosis or Marfan syndrome.

Reference: *Solène Gouesbet, Marina Kvaskoff, Carolina Riveros, Élise Diard, Isabelle Pane, Zélia Goussé-Breton, Michelle Valenti, Marie Gabillet, Camille Garoche, Philippe Ravaud, and Viet-Thi Tran.* **Journal of Women's Health**

[1] <https://www.aphp.fr/contenu/etude-compare-si-vous-aviez-une-baguette-magique-que-changeriez-vous-dans-votre-prise-en>