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## Using health informatics to address the needs of the endometriosis community

Louise Hull

*Fertility Specialist and Reproductive Endocrinologist, University of Adelaide, Australia*

### Abstract

Endometriosis is an under-recognised chronic pelvic pain condition affecting 1 in 9 women. There are at least 14 co-morbid symptoms in addition to period pain that are not specific to endometriosis and are often not solicited by health providers. Thus, despite its prevalence, people with endometriosis are frustrated by an average of 6.4 years between onset of symptoms to diagnosis. Without a diagnosis, access to medical care is restricted, complications such as complex pain sequelae and infertility can develop, and mental health can deteriorate. As part of the Australian National Action Plan for Endometriosis, we surveyed more than 360 people affected by endometriosis across Australia. Their most important priority was better communication with doctors about endometriosis and pelvic pain. Information about which period symptoms are normal and which should prompt further action was the next most common need, followed by being able to access methods to help people manage pain better. EndoZone is a digital hub designed to primarily address these 3 priorities. EndoZone has a quick test to see if period pain is normal, a printable health report to take to health professionals and pages for clinicians which provide rapid access to resources to care for patients more effectively. Self-care pain management techniques are available as well as descriptions of treatments available from a range of health care providers. A research section outlines projects that develop new diagnostics and treatments for future generations, with opportunities for the endometriosis community to support. Thus, EndoZone is a virtual meeting place for all sectors of the endometriosis community in Australia and internationally. Underpinning the EndoZone platform are health informatic algorithms that are trained over time to personalise individuals experience based on patterns of platform use and user's feedback. This ensures EndoZone responds both to the changing needs of the endometriosis community and to the individual needs of particular subgroups of the endometriosis community. By using co-creation models and health informatics we have designed a responsive digital space to help people with endometriosis have better health experiences. The website [www.endozone.org.au](http://www.endozone.org.au) or [www.endozone.com.au](http://www.endozone.com.au) is being launched on the 29th March 2022.

### Biography

Dr Louise Hull has worked in fertility services since she graduated as a doctor in 1991. During this time she has been delighted to help many couples conceive, as well as promote the development of improved fertility treatments through research and education. Professor Louise Hull works at the Robinson Research Institute, University of Adelaide, Women's and Children's Hospital, Adelaide and in private practice at Embrace Fertility in North Adelaide <https://embracefertility.org/> Professor Louise Hull became an Obstetrician and Gynaecologist (FRANZCOG) after gaining clinical experience working in IVF units in Christchurch, New Zealand, Cambridge, UK and Adelaide, Australia, including Bourn Hall, the fertility centre where the first IVF baby was born. She was awarded the Certificate in Reproductive Endocrinology and Infertility (CREI) sub speciality qualification by RANZCOG in 2006.

*[louise.hull@adelaide.edu.au](mailto:louise.hull@adelaide.edu.au)*