



FRED LAHACHE

2022 AUSTRALIA FRANCE ENDOMETRIOSIS COMMUNICATION FORUM: DIAGNOSIS INNOVATION

AUSTRALIAN FRENCH ASSOCIATION FOR INNOVATION & RESEARCH (AFRAN)

CONTEXT & RATIONALE

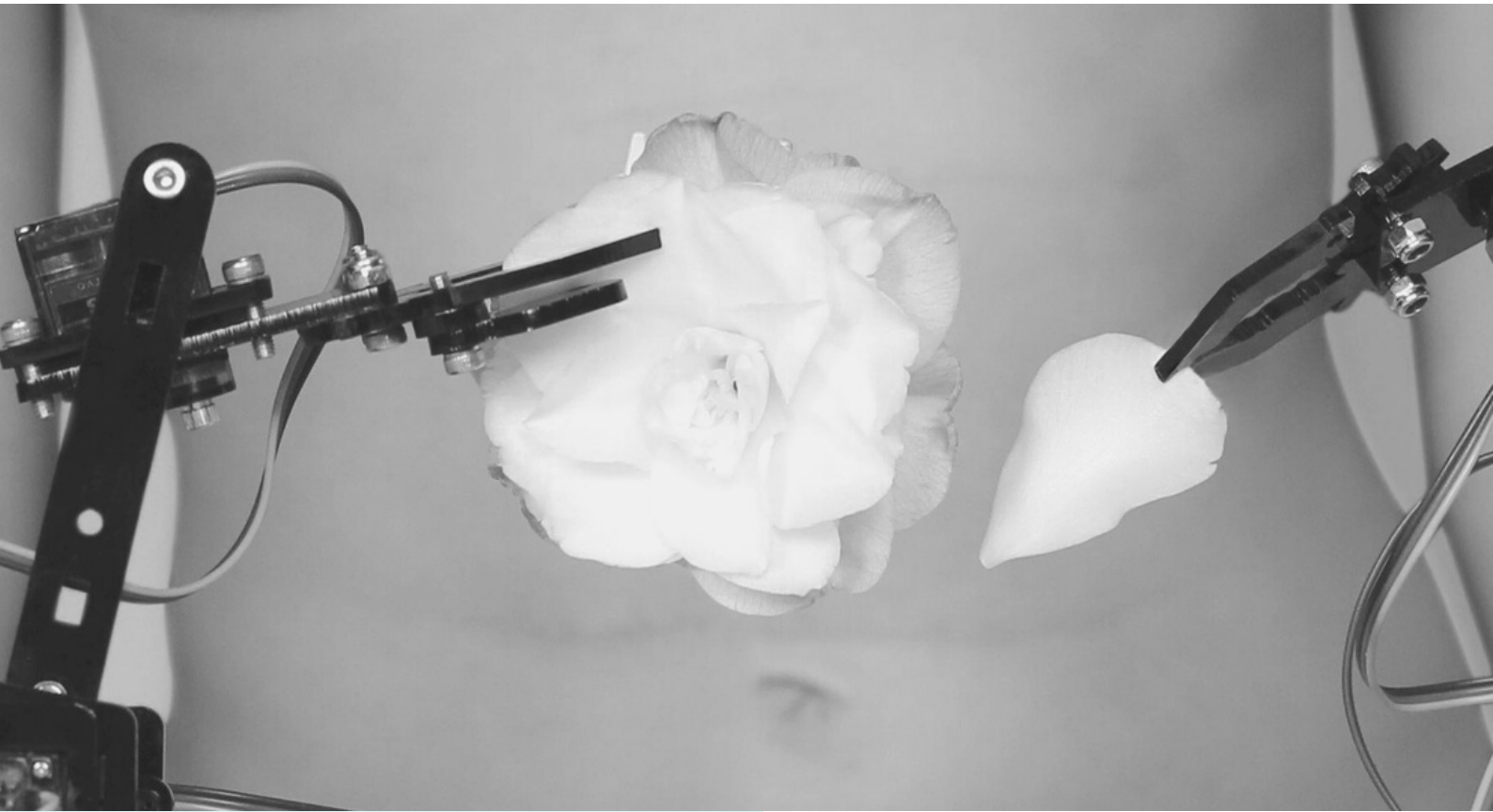
Endometriosis is an invisible illness with an average diagnosis time of 7 years, despite affecting many people with uteruses worldwide. One of the most significant challenges is the communication of endo-like symptoms, where stigma and medical challenges disempower patients on their diagnosis journeys. The Australia France Endometriosis Communication Forum focusing on Diagnosis Innovation seeks to compare best cases in research, innovation, and care in France and Australia.

Australia and France are the world's first two countries to implement a national strategy for endometriosis. Although funding and interest in increasing, patient care still requires radical improvement. This forum followed Jess Coldrey's artist residency in France, comparing patient experience and symptom communication across the two countries.



GENEROUSLY SUPPORTED BY THE
AUSTRALIAN FRENCH ASSOCIATION
FOR INNOVATION AND RESEARCH





OBJECTIVES

The forum aimed to bridge the gaps between patients and practitioners across countries, including representatives from high-profile universities and the nationally regarded endo organisations QENDO (Australia) and EndoFrance. This event, generously supported by the Australian French Association for Innovation and Research, focused on stimulating discussions about key endo issues and opportunities while creatively grounding conversations in patient experience. The Australia France Endometriosis Communication Forum was also intended to catalyse future international collaborations and knowledge sharing initiatives.

SUPPORTED BY AFRAN

SESSION ORGANISER

Jess Coldrey | Australian Artist, John Monash Scholar and Laureate of the Australian French Association for Innovation and Research

LIST OF SPEAKERS

- Jess Coldrey
- Josepha Goetz-Collinet
- Arounie Tavenet
- Amanda Grogan
- Dr Susanne Ischner
- Mary Xu
- Dr Arnaud Fauconnier



Australian
National
University



KEY MESSAGES

Increasing the consistency of pre-diagnosis care is a key concern

- Solutions involve an algorithm to predict patients' likelihoods of having endometriosis using a standardised questionnaire (e.g., <https://arnaudfauconnier.shinyapps.io/shinyDEVA/>)
- Seeking biomarkers to indicate if a patient has endometriosis based on fluids
- Recognising, managing, and providing support for symptoms in cases of undiagnosed but suspected endometriosis

Patient's voices need to be sought out

- EndoFrance is consulting patients as members of expert research circles in the development of the National Endometriosis Strategy
- Artists and creative researchers across Australia and France are investigating how mark-making, symbols, and unconventional visual ways of exploring symptoms can aid patients in communicating their experiences with others

Trauma-based approaches to patient care could benefit many with diagnosed or suspected endometriosis

- PTSD can be closely linked with pelvic pain, and dealing with chronic pain symptoms for years can drive anxiety and depression
- Trauma education could be integrated into medical courses or supported through professional learning programs for GPs (see resources provided below)

RESOURCES ON TRAUMA-INFORMED PRACTICE

- *Book: Pain and Prejudice* by Gabrielle Jackson
- *Documentary: The Wisdom of Trauma*
- *Community: Blue Knot Foundation*

PRESENTER SUMMARY

ENDOFRANCE

Endometriosis has been emerging in the national dialogue for two decades, with a 2022 announcement from President Emmanuel Macron on the establishment of the national endometriosis strategy. The primary goal of EndoFrance's research activity is to help reduce the delay of diagnosis and create clearer medical pathways for patients.

Several current projects are searching for biomarkers of the illness in menstrual blood. A key future focus will be structuring collaborations between the public and private sectors. EndoFrance seeks to match members and researchers through round tables and symposia.

Primary care providers often resist referring patients, leading women to feel ignored or disbelieved.

More experienced sonographers are required to interpret scans to provide more accurate recommendations for or against a laparoscopy procedure.

Measuring symptoms in children and adolescents will help build longer-term understandings of the signs and progression of the illness. People should not be left alone in their pain, and support in managing life with pelvic pain should be channelled through local support groups.

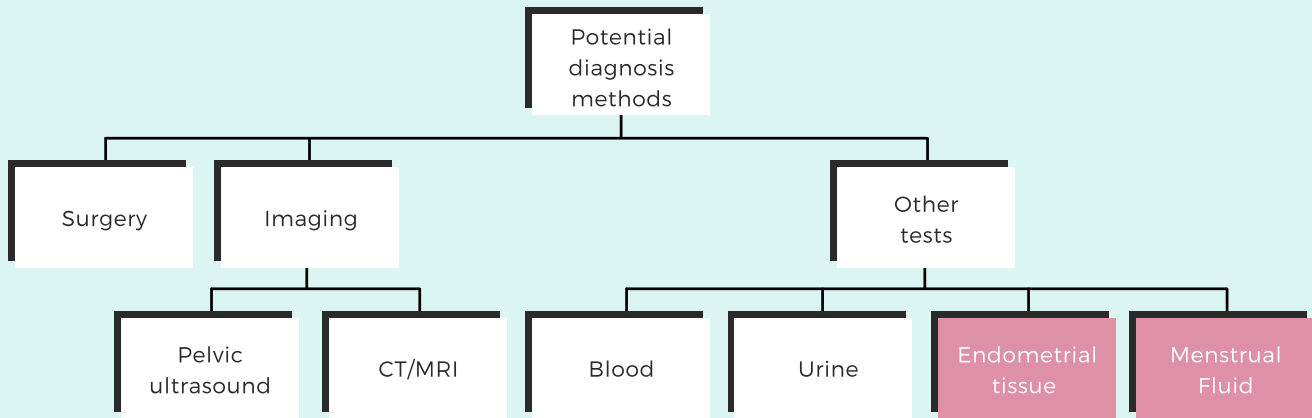
QENDO

For many patients, it is important to have a mental health care provider who is aware of their illness and can contribute perspective through lived experience. Focusing on patient care through a wellness perspective can help improve lifestyle and health management more holistically than exclusively medical care.

Mental health issues such as PTSD can drive higher inflammation and affect people's ability to cope with their illness. Factors like body image, alienation, and perceived power dynamics with doctors can contribute to patients' experiences and willingness to adhere to recommended medical management practices. This will affect many areas of their life.

HUDSON INSTITUTE

Patient care would be radically improved if endometriosis diagnosis was possible without surgery. The Hudson Institute is working on the diagnostic potential of menstrual fluid, looking for biomarkers and new ways to model the illness.



AUSTRALIAN NATIONAL UNIVERSITY

The turbulent experience of navigating a chronic illness raises many socio-political and interpersonal issues for patients and health carers. As researchers and clinicians,

"we need to understand the relationship between suffering and dignity".

Neither suffering nor caring for the unwell should be considered undignified, as they are both essential processes of human society. Seeing the patient as a needy object, as well as historical habits of dismissing women's pain, hinder effective communication in medical practices.

Practitioners must both look at the visible evidence that patients 'present' and listen to their verbal descriptions and reasoning, especially regarding their invisible symptoms and details about how they are experiencing their pain.

When medical professionals lead patients to feel frustrated, misunderstood and ignored, an emotional 'battle scene' can evolve between patients and clinicians.

The one-word diagnosis of endometriosis can open doors to improved treatment and sometimes reduce impact on work and social life. However, many endometriosis patients then wish for a co-constructed care plan including honest evaluation of alternatives, and respect for individual circumstances and context.

AUSTRALIAN FRENCH ASSOCIATION FOR INNOVATION AND RESEARCH

Australia and France have many similarities and shared research interests in improving communication and endometriosis patient care. Coldrey's project spanning Melbourne and Paris has shaped new collaborations and public outcomes, creating a new dialogue that enables patients, researchers, and practitioners to step outside of their own experience and share their insights openly with others.

DISCUSSION SUMMARY

DIAGNOSIS

*should not be seen as the holy
grail of endometriosis care.*

SYMPTOMS

*need to be recognised at the
primary care level, and
adequate care must be provided
regardless of the diagnosis
status of patients.*

SILOS

The body is not divided into separate, discrete parts; hence the medical practice should not be carved into siloed and discrete parts. Endometriosis management often requires an interdisciplinary approach, which incorporates wellness and lifestyle factors.

TRAUMA

The presenters and participants were receptive to learning about trauma-informed practices through work with hospitals and universities.

COLLABORATION OPPORTUNITIES

The Australian French Association for Innovation and Research provides small annual grants for initiatives (up to AUD 2000) and funds some international presentations in the scientific community. They also keep a directory of funding opportunities across Australia and France at <https://www.afran.org.au/funding-opportunities>

The Academy of Social Sciences in Australia runs an Australia-France Collaborative Research Program supporting the fostering and reinforcement of social science collaborations between Australia and France (up to AUD 5000)

The FASIC Researchers Scheme supports researchers' mobility from France (French overseas territories included) to Australia to develop scientific and technological exchanges of excellence between laboratories in both countries. They also run a workshop and PhD schemes, although matching funding from a partnering Australian research institution is mandatory.