



# “Who will help me?”

People suffering from serious illnesses are turning to unproven and risky stem cell therapies in growing numbers. Researchers are trying to understand why—and how to provide better information and support.

Stem cells have been saving lives for decades, largely through bone marrow and cord blood transplants treating leukaemia and other blood diseases. Unproven treatments are booming, however, with clinics in Australia and around the world spruiking cures for conditions from osteoarthritis and MS to dementia and diabetes.

Associate Professor Megan Munsie and her colleagues in Stem Cells Australia’s Engagement, Ethics and Policy Program have heard many tales of patients spending thousands of dollars on treatments that often have no benefit and may be harmful or even deadly.

“While some providers sincerely believe they can help patients, what’s often advertised can have the hallmarks of the perfect con,” says University of Melbourne health sociologist Dr Claire Tanner, who has teamed up with Megan and sociologist Professor Alan Petersen at Monash University to come to grips with the problem.

“If the treatment fails, patients blame themselves or think their body has failed them.”

The team set out to gather evidence by talking to people who had considered or tried stem cell treatments, as well as their families.

The stories of patient harm, exploitation and confusion they collected formed a key part of Stem Cells Australia’s submission to the Therapeutic Goods Administration review of regulations for stem cell treatments.

## What’s the harm?

**Alistair, a father with a teenage son with a spinal cord injury, had placed a \$12,000 deposit with a clinic in Mexico before hearing of fraud allegations with the clinic’s doctor. He told researchers of his frustration with the lack of warning from medical professionals in Australia.**

“Our interviews with patients provided solid evidence for policymakers. We showed that there really is a problem,” Claire says.

The research also uncovered less obvious problems, such as unscrupulous clinics coaching patients on crowdfunding to meet exorbitant prices and how some health professionals are wary of advising patients on stem cell treatments because they feel they are not well informed themselves.

The team are working with doctors and patient groups such as Musculoskeletal Australia, MS Australia, MND Victoria and the Chronic Illness Alliance to understand how best to support patients. Support might include resources for GPs and other healthcare professionals, as well as tailored patient information provided through community groups and via websites and phone services.

Navigating the space where science and medicine overlap with regulations and social forces has required a wide range of skills.

“That’s the strength of our interdisciplinary collaboration. Megan has a strong scientific background, as well as experience in bioethics, science communication and public engagement. Alan’s expertise is in sociology and mine is in gender studies and health sociology.”

Along with their collaborators Chinese Studies scholar Dr Jane Brophy and anthropologist Dr Casimir MacGregor, this group recently received a prestigious prize for their book on stem cell tourism.