



CAWRI

Creativity and Wellbeing Hallmark Research Initiative

Stomach Ache: an arts-led exploration of the gastrointestinal system.

Final report

Vanessa Bartlett,
28 February 2023

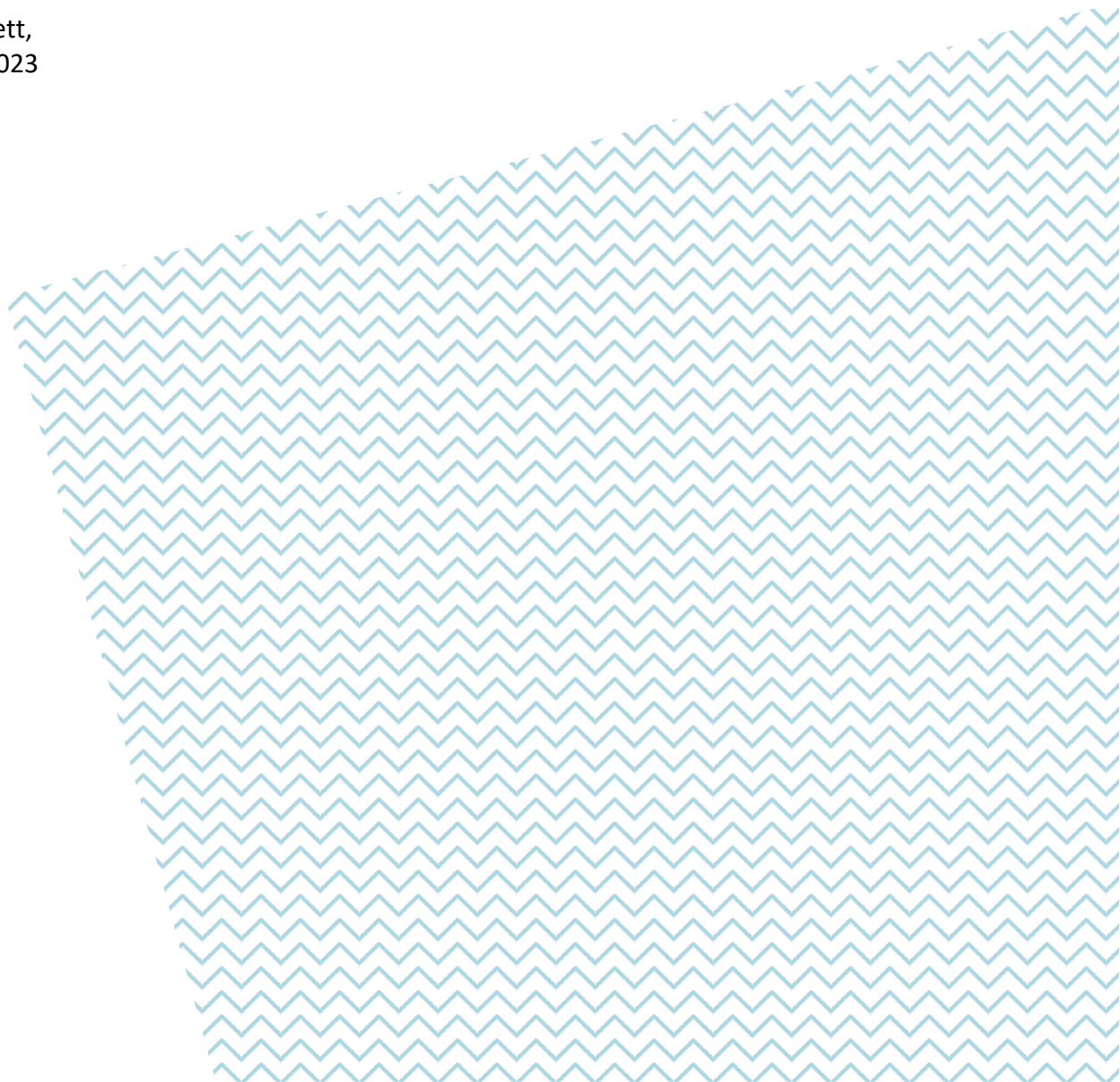


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Stomach Ache: Objects of Digestion workshop, featuring *Dysphagiatic* by Lindsay Kelley 2022.
Image: Julianne Bell

Project summary

This project applies creative practice research to explore an urgent social and economic problem: the exponential rise of complex, chronic gut issues that have major implications for individual wellbeing and economic productivity. Medicine has proven ill-equipped to address this problem alone. Creative practice offers a method for enacting and disseminating research in the public sphere, to illuminate and communicate the wellbeing implications of these common but poorly understood health issues.

Seed funding received from CAWRI was used to support four strands of activity:

1. Interviews with people with lived experience of chronic gut issues.
2. Interviews with artists who explore the gut and gut microbiome in their practice, with a focus on artists creative relationship *with* their guts.
3. A workshop at The Big Anxiety Festival Naarm, which tested the potential of a socially engaged artwork about digestion—Lindsay Kelley’s performance *Dysphagiatic*—as a site of research engagement and dissemination.
4. Development of a new exhibition concept informed by steps 1-3.

This iteration of the Stomach Ache project is now complete. **However, work on our exhibition will continue through 2023-24.** Many of the new collaborations fostered by the project are ongoing.

Research team

Vanessa Bartlett	Faculty of Fine Arts and Music, University of Melbourne
Chamara Basnayake	Medicine, Dentistry and Health Sciences, University of Melbourne
Lindsay Kelley	School of Art and Design, Australian National University
Rachel Marsden	University of the Arts, London
Julianne Bell	School of Historical and Philosophical Studies, University of Melbourne

Partners

Jill Bennett	The Big Anxiety Research Centre, University of New South Wales
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Acknowledgements

This project was funded by the Creativity and Wellbeing Hallmark Research Initiative of the University of Melbourne, and the University of Melbourne McKenzie Postdoctoral Fellowship Scheme.

Thank you to Julianne Bell for her assistance with literature review, interview management and website development, and Associate Professor Claire Hooker (University of Sydney) for her contribution to two of our academic events. We would like to thank our interview participants, particularly artists Kathy High and Judith Walker.

Background

Research context

Gut issues are on the rise globally, (Sperber et al., 2021) and in Australia (Basnakye et al., 2022) and have a considerable impact on individual wellbeing (Black et al., 2020). For many people, chronic and persistent symptoms result in impaired productivity and absenteeism (Basnayake et al., 2022), creating major impacts for the Australian economy. About 40% of people globally report experiences in keeping with a functional gastrointestinal disorder (FGID) and people who fit these criteria are often dismissed by clinicians due to the lack of clear organic or structural causes for their symptoms. **For many people with FGIDs this experience initiates the beginning of self-management practices, where people are forced to supplement their engagement with formal medicine based on a concern that the clinician has simply ‘given up’ up finding the ‘real cause’** (Black et al., 2020, 5).

Innovative forms of research are required to address the alternative forms of agency and social justice implicated by people’s experience of self-managing complex gut issues. Stomach Ache

explores the potential of creative and curatorial practice-based research to illuminate this gap in knowledge. **In the field of creative practice-led research, the creative process is increasingly framed as a way of investigating research questions that produce knowledge equal in value to more traditional forms of qualitative research** (Barrett 2014a, 51). Estelle Barrett identifies the specific contribution of creative-practice research as its ability to generate “tacit and experiential knowledge” (2014b, 3) that arises from sensory interaction with contexts and social situations. Meanwhile, curators and museum professionals increasingly recognise their work as “a collective, inquiry-driven, knowledge-producing practice” that extends beyond the production of exhibitions, toward investigation of research questions (Triscott 2017, 3; Sheikh 2015). In the museum sector, the affordances of creative participation as method for generating and communicating new knowledge about social and emotional wellbeing is an urgent topic (Neal 2012; Chatterjee & Noble 2016). There have already been several major museum exhibitions that have documented the emerging science of the gut microbiome and its impacts on mood, behaviour, and health (Dumitriu 2015; Bencard & Whiteley 2018). Yet little attention has been given to the value of creative practice-led research for illuminating and raising awareness of the lived experience of chronic gut health issues that are poorly served by clinical medicine.

Project aims

The aim of Stomach Ache is to explore how curatorial and creative practice methods might help to investigate, document and raise awareness of the lived experience of complex, chronic gut issues. Interviews with people with lived experience aimed to explore how people are forced to think creatively and experimentally in response to their symptoms, where clinical medicine has been unable to offer clear pathways to symptom management and alleviation. **The initial hypothesis was that these stories would generate important new knowledge and could also provide a compelling curatorial stimulus for an exhibition about the gut’s pivotal role in human health.** Interviews with practicing artists aimed to investigate how artists are responding to the lived experience of gut issues, to advance knowledge about the gut as an increasingly prevalent topic in the visual arts (Bencard & Whiteley 2018; High 2019; Fite-Wassilak 2022).

Methodology

The Stomach Ache project integrated interviews with artists and people with lived experience into its reflexive curatorial process (Muller 2008), placing research data at the fore of conceptual development of a new exhibition. This approach draws on MacLure’s notion of data that “glows”, where **data is imagined as a source of wonder and uncertainty that can enrich research and foster creativity** (2013).

Participants for the lived experience interviews were recruited via relevant online forums, charity webpages, and social media pages. The project website was developed to act as the study landing page with participant recruitment focused on driving traffic to website through social media advertising and events (Lunn et al., 2019). A thorough literature review was conducted to identify artists with lived experience of gut issues working with a variety of different media. All interviews followed a narrative method designed by psychosocial researchers Hollway and Jefferson. A narrative interview poses open ended questions designed to elicit stories that are rich in affect rather than descriptive or analytical (Hollway & Jefferson 2012).

Cross-disciplinary collaborations/connections

Stomach Ache drew on interdisciplinary expertise across curatorial practice, art practice, art history and clinical medicine. Dr Chamara Basnayake from Medicine, Dentistry and Health Sciences at University of Melbourne played an important advisory role for our lived experience interviews. He advised on best practice for creating a supportive interview process, including advising on the development of our participant distress protocol. Claire Hooker, Associate Professor in Health and Medical Humanities at University of Sydney was a respondent at two of our academic events, and provided important critical feedback based on her expertise in public health and bioethics.

Key findings

To date, 21 individuals with lived experiences of gut issues have signed up to participate in the research, with nine interviews conducted. From these sign ups, 20 identified their gender as female and one as other. Although the sample size is small, this weighting toward female participation supports existing studies that suggest conditions like irritable bowel syndrome (the most common FGID) are more prevalent in women (Kim & Kim 2018). Women are also known to be more proactive in seeking help with their mental health (Oliver et al., 2018), suggesting that females may be more likely to volunteer to discuss the social and emotional aspects of gut issues in participatory research or creative arts setting.

Our literature review of artists investigating the lived experience of gut issues identified multiple female identifying artists who explore lived experience in their work: Kathy High (US), Judith Walker (UK), Liz Richardson (UK). Prominent female artists investigating the gut microbiome include Helen Pynor (AUS), Anna Dumitriu (UK) and Jenna Sutela (Finland). Future work will need to either recruit a wider range of genders or develop the project to be explicitly female focused based on an identified need.

The lived experience interviews generated a range of data that support our starting hypothesis: that people with gut issues are often required to self-manage their condition to some degree. Although our recruitment was initially targeted to attract people with functional gastrointestinal disorders, people with other gut conditions such as Crohn's disease and small intestinal bacterial overgrowth also volunteered to participate. Participants with Crohn's described returning to their GP repeatedly for up to ten years before they were diagnosed, **suggesting that the clinical and social factors that precipitate self-management of gut issues could apply across multiple diagnostic categories.**

The most common form of reported self-management was restricting diet, including using the medically endorsed low FODMAP diet, and restricting foods based on personal perception of digestive symptoms after consumption. Participants accessed information about food and diet online, including accessing peer reviewed research and more informal sources such as food blogs. All participants reported at least some experimentation with alternative medicines to manage their symptoms, including Chinese medicine, ayurvedic medicine, kinesiology and naturopathy. However, **attitudes to the validity and usefulness of alternative medicines ranged widely.** One participant described her kinesiologist as her most valuable resource for managing her symptoms, to the extent that she used the kinesiologist to verify and interpret recommendations given by her clinically

referred dietitian. Another described engaging with modalities like functional medicine, but ultimately felt exploited: “I just bought into everything because I was so desperate”.

Interviews with practicing artists showed a mixed attitude to framing their practice as a form of self-management or therapy. **While artists acknowledged coming to terms with their symptoms was part of their motivation for making work, they stressed that the work must have broader cultural relevance beyond their own health.** Artist Kathy High explores her lived experience of Crohn’s disease, but is ultimately most concerned with what the rapidly escalating prevalence of Crohn’s disease implies about modern farming processes and high stress lifestyles (High & Bartlett 2022).

Both interview groups have inspired a **new curatorial concept** that will inform our exhibition (curated by lead researcher Vanessa Bartlett and planned for late 2024/early 2025). **Bartlett has developed *creative collaborations with guts* as a lens for understanding human-gut relations across clinical, domestic and artistic spaces.** This frames self-management of gut issues as a way of *attuning to* and *working with* the gut, as people live alongside complex and enduring symptoms. It is also a response to Kathy High’s practice, which interprets Crohn’s disease as part of her gut’s *adaptation* to our growing ecological crisis and symbiotic relationship with our food and environment (High 2019). Future curatorial work including selection of artists and exhibition design will be guided by the provocation and tag line: *what does art made with guts look like?* Methods are being developed for involving lived experience participants directly in the curatorial process. Bartlett is meeting with potential host galleries in Australia and the UK, and an application for funding from the Australian Research Council in development.



Curatorial development underway in the studio (exhibition mock up) 2023

Project outcomes

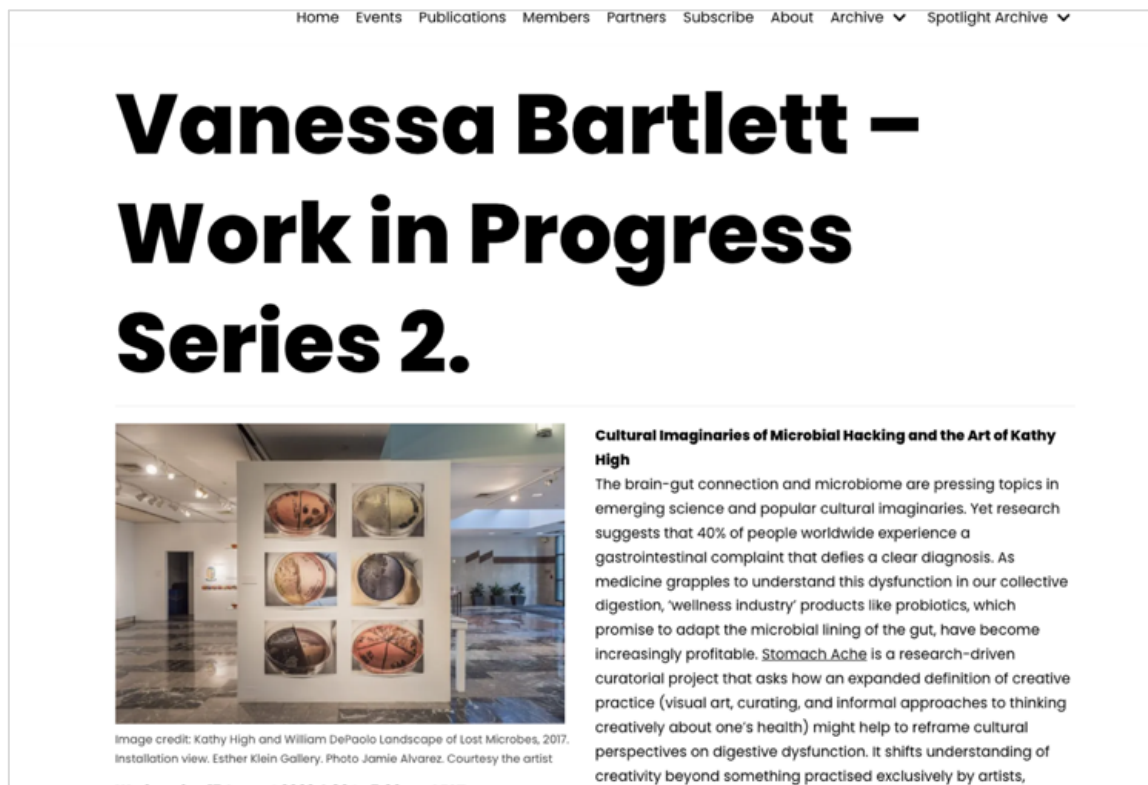
Stomach Ache has generated traditional and non-traditional research outputs.

Invited academic presentations:

Lead researcher Vanessa Bartlett’s work on artist Kathy High has been particularly well received in the field of medical humanities, both in Australia and internationally. Bartlett was the keynote

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speaker at the Australasian Health and Medical Humanities Work in Progress seminar with a presentation titled *Cultural Imaginaries of Microbial Hacking and the Art of Kathy High*.



Promotional material for the Australasian Health and Medical Humanities Work in Progress Series

Bartlett, Vanessa. *Cultural Imaginaries of Microbial Hacking and the Art of Kathy High* (2022)
<https://www.youtube.com/watch?v=oQPVhCqeWGo>

Based on the success of this presentation, Bartlett was invited to curate an online panel for the event series, *Confabulations: Art Practice, Art History, Critical Medical Humanities*. Confabulations is a major international research initiative supported by funding from Durham University's Institute for Medical Humanities, the Social Sciences and Humanities Research Council of Canada (SSHRC), and Leicester Wellcome Trust ISSF. The panel will feature Kathy High and medical humanities scholar Claire Hooker (University of Sydney) alongside Stomach Ache researchers Vanessa Bartlett, Lindsay Kelly and Rachel Marsden.

Vanessa Bartlett, Kathy High, Lindsay Kelley, Claire Hooker & Rachel Marsden. Stomach Ache at Confabulations (2023)
<https://confabulationsdotorg.wordpress.com/current-programme/stomach-ache/>



Creative works

Stomach Ache generated two new creative works, and restaged one existing work in a novel context.

Stomach Ache: Objects of Digestion

<https://stomachacheproject.com/stomach-ache-objects-of-digestion/>

The workshop *Stomach Ache: Objects of Digestion* at The Big Anxiety Naarm used a socially engaged artwork as stimulus for group discussion about digestive dysfunction.



Stomach Ache: Objects of Digestion workshop, featuring *Dysphagiatic* by Lindsay Kelley 2022. Images Julianne Bell

Artist and Stomach Ache researcher Lindsay Kelley led a tasting from her performance *Dysphagiatic*, which responds to the feeding tube as an object that challenges social and sensory relationships with eating.

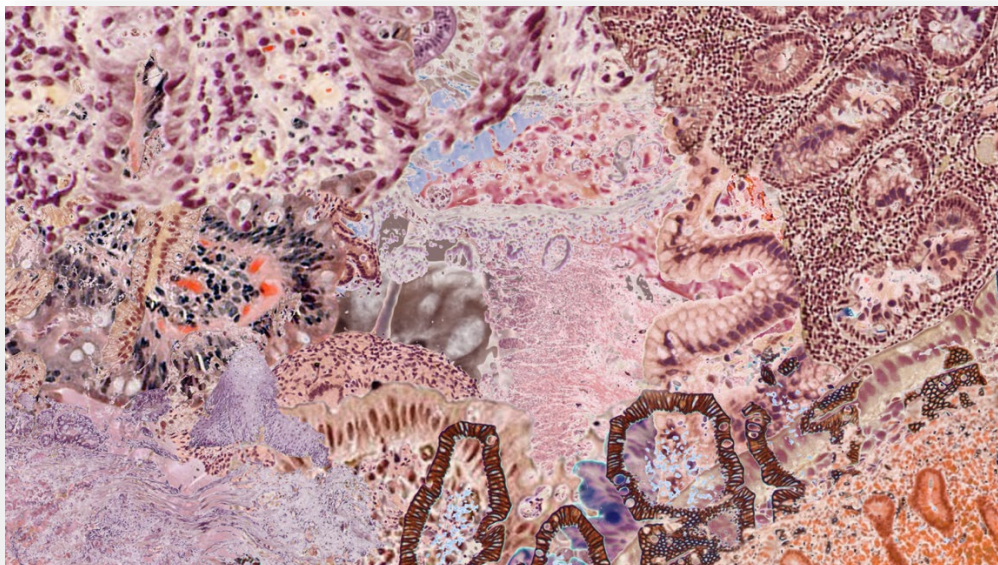
Dysphagiatic is based on Kelley's lived experience of nourishing her grandfather after he lost his ability to swallow. The event was attended by approximately 25 people.



Website

Stomach Ache <https://stomachacheproject.com/>

Artist Amelia Hine was commissioned to produce a new moving image work for our project website. The piece uses images of biopsies taken from different parts of the gastrointestinal system.



Amelia Hine, New Moving Image Artwork commissioned for the Stomach Ache Website

Recording

Stomach Ache researcher Rachel Marsden wrote *Welcome to Nuclear Medicine*, a 500 word text based on her lived experience of an 11 day nuclear transit study. A spoken recording of this was used to close our workshop at The Big Anxiety Naarm.

Blog items

The Stomach Ache project has been featured on several blogs, including the Arts Health Network NSW/ACT blog, and the CAWRI (University of Melbourne) blog.

Interview

Our lead researcher Vanessa Bartlett has been interviewed for a forthcoming article on creativity and wellness to be published in the NSW State Library magazine *Openbook*.

Forthcoming publications

An academic journal article and an article for *The Conversation* are in progress.

Discussion, implications and future directions

This project demonstrates the potential of creative practice-led research to illuminate and communicate the wellbeing implications of common but poorly understood gut health issues.

Further funding is needed to realise the exhibition outcome and to achieve its full potential for communicating with a much larger audience. There is a need to partner with charities such as The Gut Foundation and The Gastrointestinal Society of Australia who could facilitate engagement with a pool of participants with a range of social and educational circumstances. **When asked to reflect on factors that enabled them to self-manage their gut symptoms, most interview participants identified some degree of educational or financial privilege that supported their ability to analyse different sources of health information or purchase non-prescription medicines.** It is crucial that the project works to highlight the clinical and social injustices that play a role in perpetuating the symptoms of chronic health issues for marginalised people. Increased access to resources will allow us to be more proactive in this area.

Our data reflects existing research showing gut issues result in reduced quality of life, reduced capacity to function socially, and out of pocket expenses created by specialised diets and supplementary medicines (Black et al., 2020, 5). These costs for individuals translate into major economic costs: one international study estimated the cost to industry through absenteeism could be as high as \$1300 per patient per year for irritable bowel syndrome alone (Canavan et al., 2014). **While Australia is a world leader in the use of cultural programming to address mental health** (Australia Council for the Arts et al., 2022), **there has been no major body of work addressing the lived experience of complex gut issues. This is surprising given the arts' proven ability to address psychosocial wellbeing.** Lived experience interview participants reflected on this lack of opportunity to acknowledge their lived experience in the public domain:

I've realized that I've got a story and that's what interested me when I approached you [the researcher] because I thought, oh, here's a chance finally, to say something, because there's not, you know, those opportunities are not there.

Future work on the project exhibition may meet this need, providing an opportunity to address the taboo issues of poop and digestive dysregulation and reduce stigma. Popular culture is finally ready for these stories, as demonstrated by the recent popularity of Channel 4 TV show *Know Your Sh!t*, which explores 'poop problems' and gut health through a playful lens.

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More information

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For more information about CAWRI, visit <https://research.unimelb.edu.au/creativityandwellbeing>