RMIT UNIVERSITY

Health <Transformation> Lab

EXTENDING IMPACT OF THE
WRITING THE FUTURE OF HEALTH FELLOWSHIP

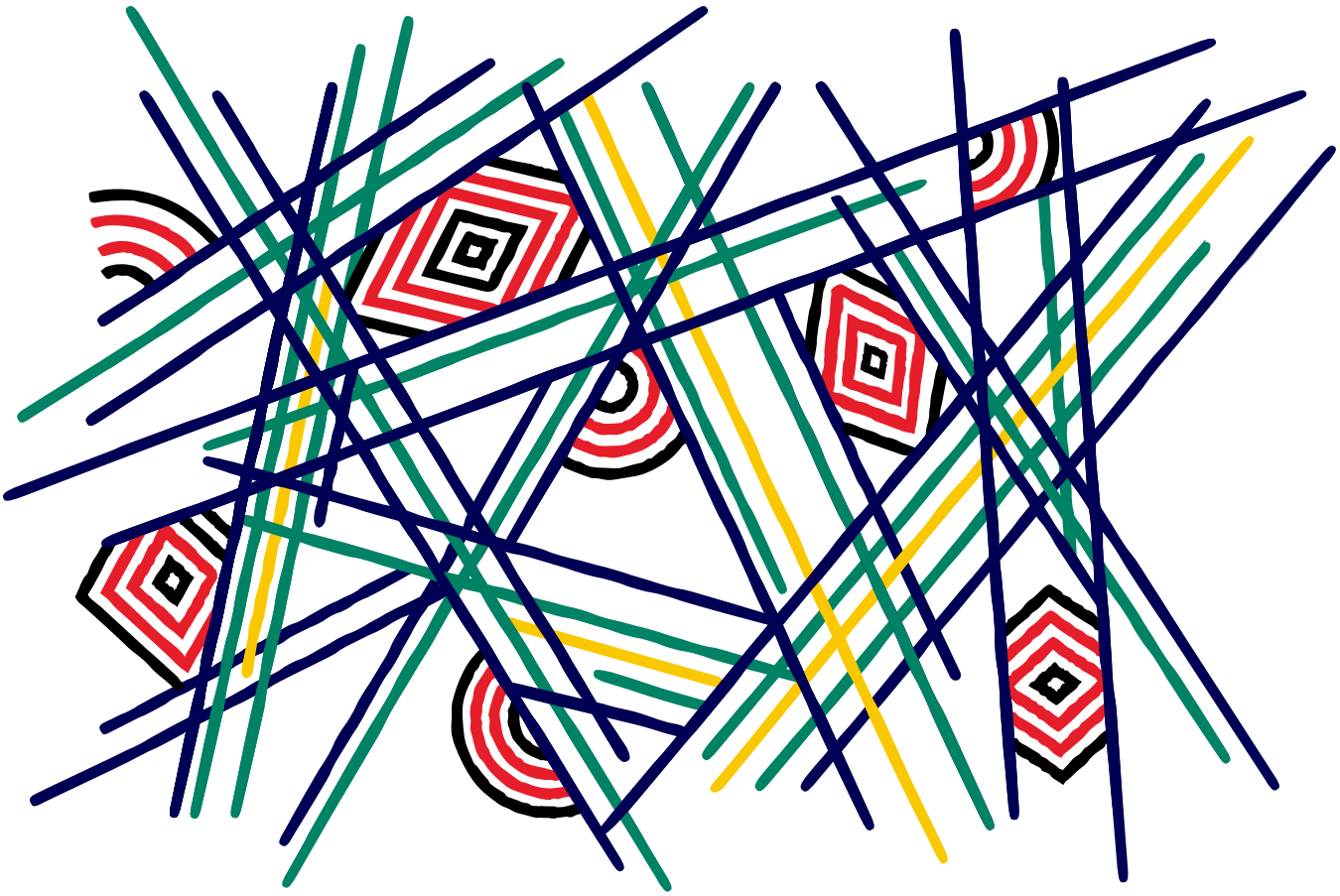
Collab/Oration *In Conversation*

Influencing Health Systems Through Creative Practice

INSIGHTS REPORT

A collaboration between
RMIT Health Transformation Lab, RMIT College of Vocational Education | Creative Industries , College of Design and Social Context, and Andy Jackson

December 2025



Acknowledgement of Country

RMIT University acknowledges the people of the Woi wurrung and Boon wurrung language groups of the eastern Kulin Nation on whose unceded lands we conduct the business of the University.

RMIT University respectfully acknowledges their Ancestors and Elders, past and present.

RMIT also acknowledges the Traditional Custodians and their Ancestors of the lands and waters across Australia where we conduct our business

Artwork ‘Sentient’ by Hollie Johnson

Hollie is a Gunaikurnai and Monero Ngarigo woman from Gippsland who graduated from RMIT with a BA in Photography in 2016.

TABLE OF CONTENTS

1. INTRODUCTION

This section outlines the project's purpose and evolution, from the inaugural Writing the Future of Health Fellowship through to the Collab/Oration in Conversation project. It also introduces the focus of this Insights Report and identifies the audiences who may find it most relevant.

IN THIS SECTION:

- ABOUT COLLAB/ORATION IN CONVERSATION: WHO IS THIS REPORT FOR
- PROJECT OVERVIEW
- IMPACT THROUGH PROVOCATION AND CONNECTION

About **Collab/Oration** *In Conversation*

AUDIENCE

Collab/Oration *In Conversation,* a three-part project building on the RMIT Health Transformation Lab's *Writing the Future of Health Fellowship,* brought together healthcare professionals, artists, and individuals with lived experience of disability and of navigating the health system. The project used the Writing Fellowship's published work to inspire discussion about a reimagined future for healthcare: centring creativity, narrative, and lived experience as essential tools for transformation.

This report captures key insights, provocations, and learnings from the event, as well as the consultation process that informed its design. In doing so, this report can serve as a resource for future dialogue and action toward a more inclusive healthcare practice.

The Health Transformation Lab's role in this project is not to speak for lived experience, but to create the conditions in which lived experience can be centred, heard, and meaningfully inform systems thinking and future practice.

This report is for those working in or interactively with the health system, curious about the relationship between creative practice, health and human experience.

This might include the **organisations** interested in exploring the possibilities, or system-level implications, of creative practice improving health outcomes. It may also include **clinicians** looking to create more inclusive spaces, **health and creative practitioners** curious about the role of creative practice in building trust and empathy with patients, **health leaders** reimagining health models, and **individuals** discovering creativity as fundamental to better health and well-being.

> *"Writers play a central role in shaping our understanding of the past and our expectations for the future. At the Health Transformation Lab, we believe there is a space in academic discourse for more creative visions of the future."*
>
> *– Health Transformation Lab*

Project Overview: from Writing Fellowship to Collab/Oration *In Conversation*

THE WRITING FELLOWSHIP

The *Writing the Future of Health Fellowship '22–23* was created by the RMIT Health Transformation Lab (HTL), driven by a desire to elevate creative modalities in systems change processes.

The Fellowship positioned literary practice as a powerful method for rethinking the future of health. Writing is unique in its capacity to articulate future possibilities with clarity, emotional resonance, and depth. Through this medium, the Fellowship set to test how new futures could be described in ways that others can see, feel, connect with, and ultimately be motivated to realise.

In collaboration with RMIT Vocational Education and Higher Education Creative Writing programs, the HTL awarded the inaugural 2022-23 Fellowship to acclaimed writer and poet, Andy Jackson. Through an unexpected but powerful decision, Andy employed 22 writers with disability, to co-create the resulting work, *Collab/Oration,* responding to the prompt '*What is the Future of Health?'*

This poignant and deeply moving body of work, now published as '*Raging Grace: Australian Writers Speak Out on Disability' (Puncher & Wattman, 2024)*, was showcased in an official public event at State Library Victoria.

Due to the relevance and success of *Collab/Oration*, the work was selected for the Big Anxiety Festival and events at the Wheeler Centre in the same year. Bringing together audiences of health care and literary professionals, innovation specialists, creative arts and medical students, *The Writing Fellowship* model has generated dynamic dialogue about the power of creative practice in designing health futures.

Collab/Oration (now the *Raging Grace* anthology) lays bare the realities of our healthcare system, from the perspective of those who use it, as inspiration for a better future - highlighting that we cannot move forward without fully understanding the present.

Inviting us to explore ideas of 'shared vulnerability' and the wisdom of lived experience, *Collab/Oration* emphasised that more work needs to be done to understand the critical relationship between creative practice and lived experience.

CREATING COLLAB/ORATION *IN CONVERSATION*

Looking for an opportunity to explore what lies at the intersection between creative practice, lived experience and systems change, **the Collab/Oration *In Conversation* project was awarded the RMIT Enabling Impact Platform Strategic Impact *Thought Leadership* grant in 2024**.

The three-part project reflected on the role of lived experience in designing inclusive models of care.

> *"what are we going to tackle today, I think really is, 'health' in a much broader sense, and also collaboration in a much more fluid, individual sense"*
>
> *- Andy Jackson*

The project's three elements included:

Part 1: Lived Experience Consultation:

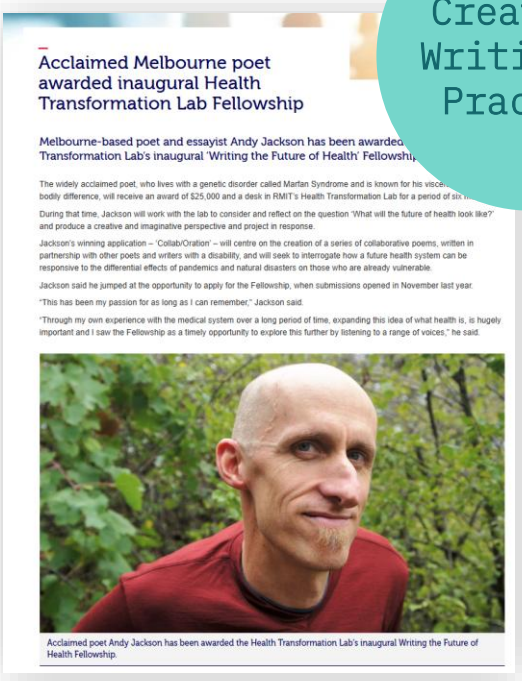
- An engagement series with the writers of *Collab/Oration* focused on a) crafting the event themes and design, and b) designing an inclusive and safe physical and online environment for the event.

Part 2: Interactive Event:

- Including a Showcase, panel discussion and creative experience.

Part 3: Insights Report:

- This report was created to capture and summarise insights from across this project, and to also inform continued work in this space.



Acclaimed Melbourne poet awarded inaugural Health Transformation Lab Fellowship

Melbourne-based poet and essayist Andy Jackson has been awarded
Transformation Lab's inaugural 'Writing the Future of Health' Fellowshi

The widely acclaimed poet, who lives with a genetic disorder called Marfan Syndrome and is known for his visce
bodily difference, will receive an award of $25,000 and a desk in RMIT's Health Transformation Lab for a period of six

During that time, Jackson will work with the lab to consider and reflect on the question 'What will the future of health look like?'
and produce a creative and imaginative perspective and project in response.

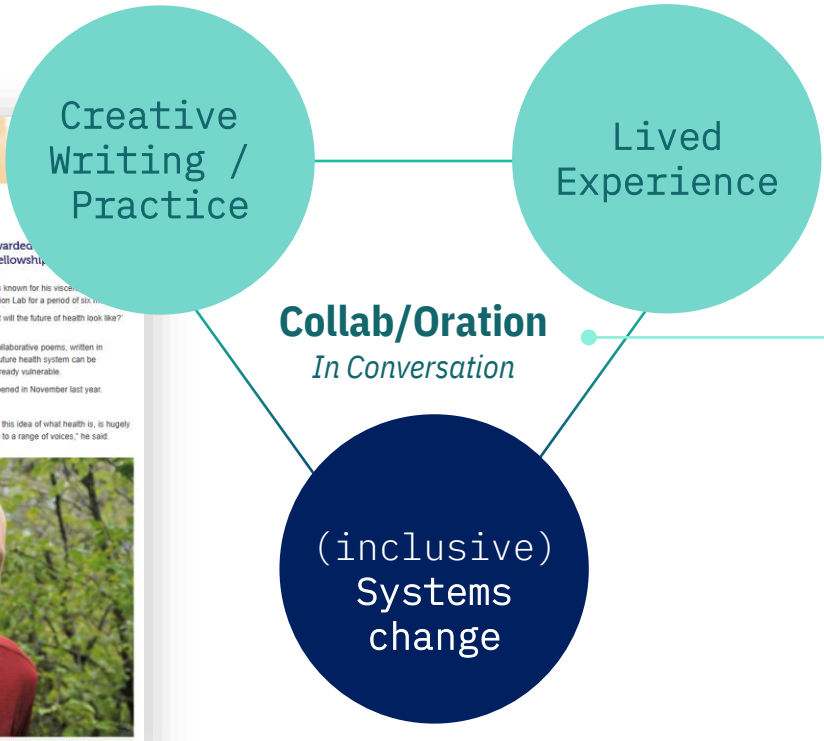
Jackson's winning application – 'Collab/Oration' – will centre on the creation of a series of collaborative poems, written in
partnership with other poets and writers with a disability, and will seek to interrogate how a future health system can be
responsive to the differential effects of pandemics and natural disasters on those who are already vulnerable.

Jackson said he jumped at the opportunity to apply for the Fellowship, when submissions opened in November last year.

"This has been my passion for as long as I can remember," Jackson said.

"Through my own experience with the medical system over a long period of time, expanding this idea of what health is, is hugely
important and I saw the Fellowship as a timely opportunity to explore this further by listening to a range of voices," he said.

Acclaimed poet Andy Jackson has been awarded the Health Transformation Lab's inaugural Writing the Future of Health Fellowship.



INTERACTIVE EVENT

> *In combination, the power of literature, lived experience voice and interdisciplinary thought leadership, create a powerful platform to ignite and inspire new ways of thinking about a future in health, and what it might take to realise it.*

The event, held in February 2025, was co-designed by authors of *Collab/Oration* (now *Raging Grace)*, and offered the unique opportunity for participants to experience, in real-time, the themes explored by expert panellists and artists. Bringing together diverse perspectives in health, Collab/Oration *In Conversation* asked:

- *What can we learn from creative practice- to connect people, experiences and ideas*?
- How can we use this connection to transform healthcare models in ways that *centre humanity, diversity* and *patient self-determination*?

Acknowledging the unique and invaluable perspectives of each of the Fellowship writers, this event highlighted that personal experience is not only intrinsic to creative expression but also essential to conversations about systemic change in healthcare.

The HTL team would like to especially recognise and thank the writers and those with lived experience who were involved in this event. Our heartfelt thanks for sharing your deep insights and lived experience. Any change this project generates will be a direct result of your efforts.

Project Elements

Continuing impact ---------->

Lived Experience Consultation	Interactive Event	Insights Report
Co-design of event, and insights for inclusion	Showcase | Panel | Creative Experience	Learnings to inspire pathways for change
See insights:	**See insights:**	**See insights:**
Key Learnings (p.22)	Panel Insights (p.10)	Discussion (p.29)
Detailed Insights (p.26)	Participant Insights (p.17)	

Impact Through Provocation and Connection

The reflections below are from participants across the Collab/Oration *In Conversation* project, illustrating the potential of creative practice models to inspire ideas and motivate change

CREATING SAFE PLATFORMS
FOR LIVED EXPERIENCE VOICE

"Creativity is trauma-informed care. ***Creativity is accessible care and it's essential.*** *And I think we need to embed it in all of our systems, whatever that looks like"*
- Participant and Panellist

INFLUENCING **HEARTS AND MINDS** through creative experiences

*"**I was really inspired by the process and methodologies** of the broader project - but also the questions it posed"*
- Participant

VALIDATING MODELS
OF CREATIVE PRACTICE AS A SYSTEMS CHANGE INTERVENTION

"There is so much we can learn from First Nations and Indigenous culture and ways of knowing, being and doing - ***where culture and creativity are not separate from health, they are health****"*
- Panelist

DEEPENING COLLECTIVE **UNDERSTANDING**

"This event has made me see real possibilities for creative expression and [related] interactions to ***form more current and relevant health policy****"*
- Participant

CONNECTING A **NETWORK** OF **DISCIPLINES,** EXPERIENCE, EXPERTISE, through collaborative experience

"This event has inspired me to start ***creative writing in my teaching*** *of medicine students"*
- Participant

2. INTERACTIVE EVENT
2.1 INSIGHTS FROM THE PANEL

This section highlights the **8 key insights** from the panel discussion and Q&A session, drawing from their experiences as creative and arts therapy practitioners, researchers, and artists with lived experience of disability and neurodivergence.

IN THIS SECTION:

Panel Discussion

EXPLORING THE INTERSECTION OF CREATIVITY AND LIVED EXPERIENCE

The panel discussion, moderated by Andy Jackson, brought together a multidisciplinary group of creative practitioners with expertise also spanning academic research, social sector, and lived experience of disability and neurodivergence. The themes and guiding questions for the conversation were co-designed by Jackson, in collaboration with writers from the Fellowship, through the lived-experience consultation process.

The discussion explored the role of creativity in shaping how we understand and experience health. Discussion also explored how practices such as writing and music, or neurodivergent perspectives, could serve as tools to understand the nature of care. Panellists reflected on where creativity currently sits within healthcare systems, questioning whether care is experienced as imaginative or collaborative, and how systemic constraints limit these possibilities. Panellists also discussed the role of lived experience in improving health outcomes, both in therapeutic settings and in structural contexts such as research, authority, and system design.

Across the dialogue, panellists articulated what meaningful collaboration between healthcare professionals and patients could look like and identified the reframing or changes that could move health systems toward more inclusive, and responsive models of care for disabled people.

PANELIST BIOS

Andy Jackson - Moderator

Poet | Inaugural *Writing the Future of Health* Fellowship Recipient

Andy Jackson is a poet interested in disability and solidarity. His latest poetry collection '*Human Looking*' (Giramondo, 2021) won the ALS Gold Medal and the Prime Minister's Literary Award for Poetry. Other collections have been shortlisted for the Kenneth Slessor Prize for Poetry, the John Bray Poetry Award, and the Victorian Premier's Prize for Poetry. Andy has featured at festivals and events across Australia, as well as on ABC's Radio National and the 7.30 Report, and at the ceremonial closing sitting of the Disability Royal Commission. He was the inaugural RMIT *Writing the Future of Health* Fellow, is a co-editor (with Kerri Shying and Esther Ottaway) of *Raging Grace: Australian Writers Speak Out on Disability* (Puncher & Wattman, 2024) and is on the editorial team for disability poetry journal, Sunder. Andy is a creative writing teacher at the University of Melbourne, a Patron of Writers Victoria, a book reviewer for The Saturday Paper, and he writes and rests on Dja Dja Wurrung country.

Dr Anthea Skinner – Panellist

Ethnomusicologist | Australian Research Council Early Career Industry Fellow

Anthea is an ethnomusicologist who specialises in disability music culture and education, organology and heritage archiving. She is currently an Australian Research Council Early Career Industry Fellow in the Faculty of Fine Arts and Music. Anthea's research into disability music focuses on professional musicians with disability, their creative output and career pathways, as well as adaptive musical instrument design. Anthea is currently the coordinator of Melbourne Youth Orchestras' Adaptive Music Bridging Program providing instrumental music education to children with disability.

Beau Windon – Panellist

Writer | Author | Poet

Beau is a neurodivergent writer of Wiradjuri descent based in Naarm (Melbourne, Australia). He writes quirky stories about quirky people and all of the dark goo living inside him. He is more confident on a stage in front of an audience than in social gatherings. Currently, he is looking for a home for his debut memoir (which is best described as the genre-hopping Taylor Swift of memoirs) and his comedic YA novel.

Sarah Stivens – Panellist

Poet | Editor

Sarah is a poet and editor living on Boon Wurrung/Bunurong land. She is the founding editor of Sunder Journal, and her work appears in Cordite, Australian Poetry Journal, Baby Teeth Journal, Catalyst, and other outlets. She was the 2022 Ray Koppe/ASA Varuna fellow, and a 2022 Writeability Fellow. She writes about mental illness, disability, and rural identities. When not writing, you'll find her swearing at her sewing machine.

Dr. Tamara Borovica

Chancellor's Postdoctoral Fellow | Creative Artist

Dr. Tamara Borovica is Vice Chancellor's Postdoctoral Fellow and creative artist at RMIT University's Social Equity Research Centre. Her work focuses on the sociology of emotion and health, particularly in the context of trauma and resilience. Using participatory and arts-based methods, she explores how emotions and lived experiences, including the collective ones, shape mental health. Tamara is an emerging leader in critical mental health research, continuously pushing the boundaries of how creative practice and arts can be utilised for social change. She is a co-director of HealthTalk Australia, co-convenor of HASH Arts and Creative Practice for Wellbeing thematic group and member of Social Equity Research Centre and Digital Ethnography Research Centre at RMIT.

Key Insights from the Panel

HOW CREATIVE PRACTICE COULD IMPROVE HEALTH CARE

1 STORYTELLING AND CREATIVE EXPRESSION AS A TOOL FOR CONNECTION

*"There's something about **creative mediums that enable us to connect with each other as humans**, with ourselves, with communities and beyond community." - Panellist*

Creativity fosters connection, self-reflection, and shared understanding. Storytelling - through writing, art, movement, or music - allows individuals, patients and practitioners to communicate health experiences beyond clinical language. Panellists pointed to existing and effective interventions already practiced in care settings. Examples like **storytelling workshops, creative journaling, and embedding performance arts into healthcare**, allow individuals, whether patient or clinical side, to better process emotions and advocate for their needs more effectively.

"Tick tock murmurs. The only way to know peace is with a pen."

- Extract from Raging Grace

2 EMBEDDING CREATIVITY IN TRAUMA-INFORMED AND ACCESSIBLE CARE

*"**Creativity is trauma-informed care.** Creativity is accessible care and it's essential. And I think we need to embed it in all of our systems, whatever that looks like." - Panellist*

Creative practice aligns with trauma-informed care principles, offering non-threatening, patient-led ways to engage with health experiences. Arts-based interventions can be particularly effective for individuals with complex trauma, mental health challenges, and neurodivergence, providing safe spaces for self-expression and connection to community.

Embedding creative or holistic care approaches into hospitals, clinics, and community health settings can improve patient engagement and emotional well-being.

3 LEARNING FROM FIRST NATIONS WAYS OF KNOWING

*"There is so much we can learn from First Nations and Indigenous culture and ways of knowing, being and doing – where **culture and creativity are not separate from health, they are health**."*

- Panellist

First Nations' knowledge systems offer a deeply interconnected view of health, where creative practice, storytelling, land, culture, and community are integral to well-being. Rather than separating healthcare from cultural expression, these traditions embed healing within creative and communal practices.

Healthcare systems can learn from holistic approaches by integrating art, ceremony, storytelling, and connection into care models. Embracing Indigenous perspectives invites a more inclusive, relational, and culturally safe vision of health, that values belonging, shared responsibility, and deep listening.

It is essential that these ways of knowing, being and doing are not viewed as 'alternative' approaches, but longstanding and sophisticated systems of care that can be learned from, in improving incumbent health norms and outcomes in Western Health approaches.

In the Australian context, panellists pointed out the need for and **commitment to sovereignty - ensuring that creative practices, drawn from indigenous cultures, are not extracted or co-opted into institutions that have historically caused harm.**

4 HOLISTIC HEALTH AND THE ROLE OF THE ARTS

*"We need art groups and inclusive design as much as **we need doctors who listen**." - Panellist*

Panellists emphasised the importance for healthcare to support overall well-being. Spaces that feel creative, inclusive design, and arts-based programs can contribute to a patient's sense of agency, dignity, and mental resilience.

Health institutions should partner with artists, designers, and creative practitioners to develop healing environments, interactive creative programs, and arts-based interventions in hospitals, aged care, and rehabilitation centres.

5 TIME AND RELATIONSHIP-BASED CARE

*"I suppose my one thing would be around time with healthcare professionals... Really **being able to have time with your medical practitioner** can change so much."*

- Panellist

One of the biggest barriers, cited by panellists, was time constraints around medical consultations. Short appointments often left patients feeling unheard and frustrated that they had insufficient time to provide information they felt was critical for their diagnosis.

Borrowing from the ideas of listening and collaborative approaches embedded in creative practice, a relationship-based care model, where practitioners allocate more time for dialogue, active listening, and collaborative decision-making, would significantly improve patient trust and health outcomes.

"To write ourselves a better future. To write ourselves into history. To rest and watch time. Lift from edge to center. To practice the art of laughing into darkness, of laughing out of it, to practice again."

- Extract from "Coalescent", Raging Grace

6 ART THERAPY AND CREATIVE GROUP THERAPY INFLUENCING IMPROVED OUTCOMES

*"The absolute **top-tier outcomes I've seen are when we move away from the diagnostic approach** of 'why are you using substances? Stop using substances.' We do a lot of different modalities, including art therapy and creative group therapy." - Panellist*

Traditional diagnostic frameworks may not necessarily address the deeper emotional and social needs of patients. The panellists highlighted art therapy, music therapy, and creative group workshops as powerful tools in areas such as mental health, addiction recovery, and chronic illness management.

Expanding access to arts-based therapy programs, within mainstream healthcare services, could enhance treatment effectiveness and long-term recovery rates.

BROADER CHANGES TO THE HEALTH SYSTEM AND LIVED EXPERIENCE INCLUSION

7 GREATER INCLUSION OF LIVED EXPERIENCE AND CULTURAL PERSPECTIVES

*"The writings also show that much **more work needs to be done** to really understand these critical relationships between creative practice, lived experience, and what it means to truly bring about an inclusive healthcare system." - Panellist*

Health system reform requires co-design with those who use the system. The panel emphasised the need to incorporate lived experience and diverse cultural perspectives into policy-making, healthcare training, and service design.

This could be achieved by:

- Establishing patient advisory boards that influence healthcare policies
- Integrating First Nations and culturally diverse healing practices
- Creating health education programs that amplify patient narratives through art, film, and storytelling

8 SOCIAL REFERRAL AND PEER CONNECTION

*"I would love for people to **be referred to other people with that condition** so that you have a kind of social referral... I can meet other people who are also complex and also have diverse experiences." - Panellist*

The panellists spoke about **social referral models, where patients or individuals are connected with others** who share similar experiences. This indicates an opportunity to complement medical specialist referrals with social and peer support services.

Examples of potential implementation include:

- Peer-led support groups for chronic illnesses, disability, or mental health conditions
- Creative mentorship programs, where experienced patients guide newly diagnosed individuals
- Community health initiatives that integrate art, storytelling, and peer advocacy

2. INTERACTIVE EVENT
2.2 PARTICIPANT INSIGHTS

This section showcases the ideas and **expressions of the event's interactive element.** As they are guided through a creative writing experience, participants experience in real time the potency of creative practice as a means of expression, empathy and creating human connection.

IN THIS SECTION

- CREATIVE ACTIVITY: COLLABORATIVE WRITING EXPERIENCE
- REFLECTION ACTIVITY: IF YOU HELD THE PEN, HOW WOULD YOU WRITE THE FUTURE OF HEALTH?

CREATIVE ACTIVITY: Collaborative Writing Experience

A key part of the event design was to take the audience through a similar process used by Andy Jackson and the fellowship writers in the creation of *Collab/Oration*, with the intention to offer participants the chance to experience the event themes in real time. Using extracts from *Raging Grace* as sentence starters, participants were guided through a creative, and collaborative writing activity.

The excerpts below are unedited creative responses produced by participants during a facilitated writing exercise. They reflect individual lived experience, emotion and perspective, and are included to honour the integrity of participant voice. They should be read as individual and creative expression, not as policy or institutional positions of HTL or RMIT University.

Extracts (unedited) from collaborative writing exercise

I am dealing with...

The impact and adjustment of having an invisible disability made visible at work.

Blank faces and glazed eyes when I say, "I am in pain,"

or specialists exclaiming how difficult it must be to be a woman.

Doctors saying "well it shouldn't be doing that," instead of helping.

All I want is...

Understanding.

Rest without life nibbling at my heals, telling me to run until I break.

A hand to hold when the pain is overwhelming.

All I want is that we no longer need to give art a label - that we recognise it as part of who we are, not just something we might choose to create.

We need...

To acknowledge that the idea that we should all 'return to the office' is an undoing of great shifts in accessibility for all.

Seeing the value of art not as dollar signs but something we all have a right to. Something that gives meaning.

To stop controlling disabled folk.

Extracts (unedited) from collaborative writing experience (cont.)

No-one is denied their humanity…

Art is for everybody. Barriers must be acknowledged and removed,
and there is beauty in sharing our lived experience.
There is beauty in seeing ourselves as both the artist and the artwork.
There is enough to go around. My life has value. Burn capitalism.
No one is denied their humanity, means compassion is central.
It isn't a burden to be in your soft body, and that the pleasures of our bodies – food, sex, play, etc. – are not regarded as peripheral but at the centre of what it means to live a full life.
That the power to advocate exists for everyone, and we can embed centuries old wisdom about how to do this by examining non 'traditional' (mainstream) systems.

No one is denied their humanity means…
Expanding and exploding the definition of 'human.'
Which means rethinking the human as an 'individual' and the dominant health & economic system, as 'consumers' in which our health, our time, our pathologies and their cures are commodified.
Don't we have more in common, that transcends diagnosis? But also have diversity and uniqueness in needs?

REFLECTION ACTIVITY: Participant Self-reflection

"IF YOU HELD THE PEN, HOW WOULD YOU WRITE THE FUTURE OF HEALTH?"

At the close of the event, participants were invited to reflect on the question, "If you held the pen, how would you write the future of health?" This final activity invited participants to respond to three reflective prompts, guiding consideration about the ideas surfaced throughout the event, from systems-level opportunities to personal insights, takeaways, and motivations beyond the life of the event.

The excerpts below are unedited creative responses produced by participants during a facilitated writing exercise. They reflect individual lived experience, emotion and perspective, and are included to honour the integrity of participant voice. They should be read as individual and creative expression, not as policy or institutional positions of HTL or RMIT University.

Where do you see the greatest potential for creative practice to influence systems change towards a more inclusive future for healthcare?

Its multi-dimensional aspect allows real possibilities for creative expression, and interactions in the formation of more current and relevant policy

Undergraduate training of healthcare practitioners

Gaining courage to tap into my fragmented thoughts and be unafraid to be messy, and reflect actively in the presence of other people

Moments to engage creatively are essential for everyone

Systems change need stories to shift dominant narratives

REFLECTION ACTIVITY: Participant Self-reflection

Cont.

What was your biggest take away or learning from today?

The need for authentic community and conversation

The role of creative practice in health

Creative collaboration does so much for empathy

I was really inspired by the process and methodologies of the broader project – but also the questions it posed

My health and the health of my community sits in our soft bodies and the spaces between us. I've learnt to respect pleasure, desire and need as part of that.

How does it motivate, provoke or inspire you to do things differently tomorrow?

With all the specialists I am referred to currently, I am motivated to ask them questions too. Often they ask all the questions, but I am inspired to ask them about their experience with the allegedly 'rare' condition I am told I've got

Well, I'm ADHD so I'm thinking about a PhD about something around peri-menopause, ADHD and AI

To learn in this field of using the arts as a transformational community tool

Start creative writing in my teaching of Chinese medicine students

Consider ways to systematise this type of engagement more

How to structure my research project, and to integrate more creative practice into my intellectual approach (without being a creative practitioner myself)

3. SHAPED THROUGH LIVED EXPERIENCE

LEARNINGS FROM THE LIVED-EXPERIENCE CONSULTATION

This section summarises **6 key learnings** from the Collab/oration *In Conversation* lived experience consultation, highlighting key considerations for the creation of safe, accessible, inclusive spaces.

IN THIS SECTION:

- KEY LEARNINGS FROM LIVED EXPERIENCE CONSULTATION: CRITICAL CONVERSATIONS AND SAFETY FOR LIVED EXPERIENCE INCLUSION
- DETAILED INSIGHTS: GUIDANCE ON CREATING INCLUSIVE AND SAFE SPACES

Key Learnings from Lived-Experience Consultation

CRITICAL CONVERSATIONS AND SAFETY FOR LIVED EXPERIENCE CONTRIBUTIONS

A lived experience consultation process was a critical starting point for designing Collab/Oration *In Conversation.* The consultation process, co-designed with Andy Jackson, included several sessions with participating writers and panellists, both online and in the event space.

In addition to shaping the event, the insights gathered through this process offer practical guidance for those seeking to develop models that more collaboratively engage lived-experience expertise safely, effectively and more consistently.

These considerations *(see Detailed Insights, page 13)* spanned *language and topic* sensitivity, the *creation of safe spaces*, the *design of events* and *panels* for engagements involving lived-experience expertise, particularly in the context of disability and neurodivergence. Together, they point to approaches that foster inclusivity, emotional safety, and accessibility for diverse audiences.

"We need to create a space for active listening that is reciprocal on both sides; this is the power of change" - Participant

KEY LEARNINGS SUMMARY

1. **Acknowledgement and Accessibility**
   Creating a safe environment begins with acknowledging the vulnerability involved in sharing lived experience, particularly in health-related contexts. Acts of recognition, as simple as thanking participants for their contributions, are important to establish trust and respect. Accessibility should be viewed as a spectrum in which individuals may have diverse, and sometimes conflicting, access needs that must be thoughtfully anticipated and addressed.
   See Detailed Insights: Creating Safe Spaces

2. **Inclusive Facilitation and Event Design**
   Organisers and facilitators should consider a broad range of ways to build inclusivity into an event. From provision of hybrid delivery formats, and low- sensory spaces to captioning of event content and considerations for visual accessibility, there are many examples of nuanced ways to provide an inclusive, equitable and safe experience for participants with disability. Critically, it is important to

avoid assumptions about individual engagement preferences, and to ensure both online and in-person environments are accessible, and inclusive.
See Detailed Insights: Creating Safe Spaces, and Event Format

3. **Language and Framing**
The language used in lived experience spaces matters. Participants noted terms like "disabled" were preferred over euphemisms, which can imply shame or discomfort with difference. Avoiding language that positions disability as something to be “fixed” was also crucial. Participants warned against simulation exercises and highlighted the trauma that many people associate with medical environments, which can function as sites of harm as well as care.
See Detailed Insights: Language and Topics

4. **Representation and Power Dynamics**
Participants in this project strongly advocated for representation of disabled people in leadership and facilitation roles as a step towards equalising power imbalances in the event space. Participants saw this as particularly important for conversations about health systems, which have historically marginalised them. Facilitators must be conscious of power imbalances between disabled people, health professionals, and academics, and take care not to place the burden of education solely on those with lived experience.
See Detailed Insights: Creating Safe Spaces and Panel Considerations

5. **Honouring Intersectionality**
Intersectionality was highlighted as essential to inclusive practice. Participants highlight that many people with disability experience compounded forms of marginalisation based on gender identity, race, culture, language, and sexual orientation. Inclusive spaces must be designed to recognise and honour this complexity.
See Detailed Insights: Language and Topics

> *“[An] important take away is to create space, don’t rush, allow voices in equal measure, create space around being heard”*
>
> *- Participant*

6. **Importantly, Lived Experience *is* Expertise**
   Lived experience is its own form of expertise and should be compensated in accordance with this contribution. Best practice includes remuneration models that consider travel and accessibility challenges for onsite engagements, and wellbeing loading in recognition of the emotional labour and psychosocial toll involved in sharing personal experiences.
   HTL sought guidance from Australian lived experience compensation frameworks prior to undertaking consultation, which were tested with key participants before engagement commenced.

> *I'm an organic database of all kinds of information on the workings of my body, a research, a stream, an archive ripe for exploration. Any doctor worth their salt would eagerly tap into my vast knowledge. But doctors don't.*
>
> *- Extract from "Mind the Gap", Raging Grace*

Creating inclusive environments is ultimately about "creating space" for people to feel heard, valued, and safe. This includes slowing down, equalising participation, and treating disabled people not as problems to be solved, but as whole humans with insight, creativity, and expertise. The goal is not just better events, but more human-centred and responsive systems.

Detailed Insights: Creating Inclusive and Safe Spaces

Below is the full summary of insights from the Collab/Oration *In Conversation* Lived Experience Consultation process, offering guidance for safe and accessible engagement in health contexts, supported by direct quotes from participants.

LANGUAGE AND TOPICS

- **Using the actual term '*disabled*' is better** than '*differing abilities/all abilities*' or euphemising the term, as this suggests there is something shameful about disability, rather than just part of the diversity of human experience.
- **Ensure discussions do not imply people with a disability need to be 'fixed'**, which can make people feel like a problem to be solved, rather than a human being.
- **Make sure invisible disabilities aren't trivialised**. *"There is no hierarchy of disability."*
- **Never design activities which involve simulating disability** (e.g. by imagining you are disabled in the health system) - this reinforces negative assumptions and stereotypes.
- **Be conscious that a lot of people have trauma about interactions in medical settings.** Health spaces may not be experienced as neutral or safe spaces for people who have experienced trauma in these environments.
- **Intersectionality is critical** – experiences of marginalisation can be compounded for women and women identifying people, the LGBTQI+ community, First Nations people, people of colour and those for whom English is not their first language. *"The best thing about the Collab/Oration collective was that we were all intersectional, and the space that was made to honour this diversity and intersectionality."*
- **"Abled bodied people have the privilege to keep their perspective secret/personal".** One writer emphasises *"my body is MY body, but also someone else's workplace."* Participants express this can lead to an exposing and vulnerable experience. Acknowledging this difference in perspective and experience between people with disability and people without disability is important to keep in mind.

CREATING SAFE SPACES

- **Importance of acknowledgment**
  An upfront acknowledgment of the vulnerability of the work, and a recognition of the challenges that people with a disability - or other intersectional lived experience - can experience when engaging with the health system, can go a long way in creating a safe environment. Simple efforts like saying "thank you for sharing your experience" should be common practice.
- **Accessibility is never a yes/no question**
  Accessibility can be likened to a constellation of considerations, as individuals have differing (and sometimes conflicting) ability and accessibility needs. For example, providing bright lighting may assist some people with low vision while overwhelming others who live with sensory processing differences. Similarly, individuals may experience conflicting needs, for example, a person might require seating for pain management but also need to stand or move frequently to prevent stiffness or flare-ups. Both sitting too long and standing too long become barriers. Accessibility is an ongoing practice of balancing diverse needs – and importantly, no one adjustment may suit everyone.
- **Creating an inclusive environment is the responsibility of the event facilitators.** For Collab/Oration *In Conversation* this included considerations like:
  - Inviting participants to share accessibility requirements in advance
  - Hybrid delivery for individuals with mobility and immune challenges that prevent comfortable or safe in-person attendance, including sub-titles and presentation design for diverse audio and visual requirements
  - Wheelchair accessibility
  - A 'chill-out space' / a low-sensory room for persons needing time away from the event environment
  - Scheduled short breaks in the event plan, for participants to move / stretch
  - Encouraging participants to 'do what they need to feel comfortable' including moving around or exiting the space as needed

"There is a desire to transform these spaces, but we need to keep in mind this isn't neutral; it needs to be rebuilt from the ground up" - Participant

- **Let people with disability speak for themselves**
  It is important to listen and not to make assumptions. Notably participants expressed that it is rare to find forums where *"disabled people have the chance to speak without being interpreted, so these kinds of engagements are very useful."*
- **Sometimes disabilities are invisible**
  It is important not to assume an individual's lived experience.
- **The intention to 'create space'**
  Don't rush, and allow voices in equal measure, create space around being heard in ways that equalise power imbalances.

EVENT FORMAT

- **Hybrid considerations**
  It's important for the in-person space to be made inclusive and accessible as well as offering an online option, to enable people with a disability to attend, e.g. quiet breakout spaces, inclusive language, visible representation of people with a disability, portable air filters, making face masks mandatory.
- **Online shouldn't be the solution**
  Online delivery for people with a disability can be a good option but shouldn't be considered as the only/best option as it can be isolating, as described by a participant
  "the sequestering/siloing effect can be physiologically damaging."
- **Online components are still critical for those who cannot attend in person**
  Events should enable participation from people with a disability who can not attend in person.

PANEL CONSIDERATIONS

- **Facilitation**
  To create a safe(r) space for discussion, the panel facilitator should be a person with a disability, particularly if the topic is about experiences of people with disability.
- **Power dynamics**
  Facilitators should be conscious of, and actively take measures to address, power imbalances in groups that include people with a disability and people without a disability.
- **Consider ways to curate the discussion** to create a safe space for lived-experience participants so there isn't an *"undue weight of burden on the disabled to explain and educate the abled."*

*"the best thing about the Collab/Oration collective was that we were all intersectional, and the **space that was made to honour this diversity**."*

- Participant

DISCUSSION

This section explores the themes and **relationships between creative practice and lived experience** in the context of **systems change**, emerging from the inaugural *Writing the Future of Health Fellowship* project and Collab/Oration *In Conversation*, including lived-experience consultation and event insights.

IN THIS SECTION

DISCUSSION

EXPLORING HEALTH SYSTEM INNOVATION AT THE INTERSECTION OF CREATIVE PRACTICE AND LIVED EXPERIENCE

***Writing the Future of Health* set out to explore the role of creative practice in visioning future healthcare systems. Collab/Oration *In Conversation* asked what happens when lived experience and creativity are treated not as add-ons to care, but as lenses through which to redesign it? These efforts revealed that creative practice doesn't just have potential to support wellbeing, it may also model the values, relationships, and systems-thinking required to build healthcare futures that are more inclusive, humane, and responsive to the full spectrum of human experience.**

Across Collab/Oration *In Conversation*, participants with lived experience of disability, chronic illness, neurodivergence, and mental health challenges, described the system as one that struggles to listen, one that does not credit individuals with the "experience of living in their own bodies" and one that needs to look beyond the composition of symptoms to see the "whole human".

Specific examples mentioned by participants included:

- Individuals who reported their expression of symptoms, pain, or experiences as being dismissed, and/or not meaningfully addressed
- Individuals who felt they had limited or no input in developing suitable care plans
- Individuals who reported they received fragmented care and misdiagnosis, especially where comorbidities were present
- Individuals reporting overwhelming and isolating experiences navigating the system
- Individuals who felt clinical interactions failed to meet their health concerns with empathy, particularly in relation to additional physical and emotional toll, chronic pain, neurodivergence, disability, or intersecting forms of marginalisation

In contrast, panellists spoke about the transformative outcomes they had experienced or witnessed when care approaches moved beyond a purely diagnostic lens, to one that saw individuals in their full complexity. This included experiences where the integration of creative practices, or their underlying principles, had achieved greater health outcomes than that of clinical interventions.

Experiences shared across the project suggest creative modalities like art therapies, when embedded in care, can help to encourage mutual understanding and may improve wellbeing by creating space for people to be seen beyond labels or symptoms.

Creative practice as a gateway to understanding

Creative practice was described as a 'gateway to empathy and understanding' between patients, practitioners and the broader system functions.

Perspectives from across the project suggest this manifests primarily in three ways. Firstly, where creative practice is used as a *therapeutic approach,* that encourages self-expression and self-understanding, helping to navigate complexity of illness, or the burden of stress illness places on the self. Secondly, as a *medium to connect* people and create a sense of belonging - combatting feelings of isolation that may be experienced through different expressions of ill health, or helping to build trusting relationships between user and system. Thirdly, when used as *a tool* to reimagine and convey new possibilities for a better health future. Examples include:

- Artistic practice that enhances sensitivity, empathy and understanding in patient care
- Creative writing that promotes emotional resilience and overall wellbeing of patients and healthcare workers
- Creative games that improve critical thinking, problem-solving abilities, and adaptability in clinical settings, with the goal of improving patient outcomes

"Listening is an intensely creative act" – How empathy underscores creative practice

Creative practice can also be likened to *a participatory conversation* between the creator and audience. For the creator, personal experience is inseparable from the creative process - as it comes from the self, 'the self' cannot be extracted from the art. In much the same way, experiencing art - whether by listening to music, reading literature, or observing visual artwork - requires active engagement. At a theoretical level, it is the audience who channelled through their own world view, emotions, experiences. At a neurological level, the process of interpreting or engaging with art activates regions of the brain associated with imagination, memory, and emotional processing. It can also stimulate the same neural pathways as

performing the act itself. In this way, Andy Jackson suggests that *"listening is an intensely creative act."*

Participants and panellists reflected that harm experienced through the system often exists where this process of listening is absent, and that it is this reciprocity of engagement, offered by creative practice, that bridges understanding between people. It fosters collaboration, shared vulnerability, and shared narratives. Beyond offering tools to reimagine systems or redefine health, this suggests the power of creative practice lies in its ability to cultivate empathy and deepen connections between healthcare systems and the people they serve.

At the heart of these conversations is a powerful call to centre lived experience.

"Lived experience is the care"

This statement from one panellist, drawing from their experiences as care provider and receiver, offers a profound reminder of the value of lived experience.

The importance of lived experience voice in system design is not a new idea, although consistent and effective models of inclusion are relatively nascent and not consistently adopted.

To engage with lived experience meaningfully is not just to consult or include. It requires that institutions allow themselves to be changed by what they hear. It requires crediting people with lived experience as knowledge holders, carers, strategists and theorists, in their own right.

A vital consideration that was consistently mentioned by participants, is that the sharing of lived experience is a deeply vulnerable experience. There is an emotional and energetic toll of sharing stories, irrespective of contexts. Some participants from Collab/Oration *In Conversation* further highlighted the fatigue of being asked to revisit trauma by institutions who did not provide sufficient support, acknowledgment, or compensation.

Participants of Collab/Oration *in conversation* strongly advocated for the transformative potential of creativity and lived experience in healthcare. From storytelling and art therapy to social referrals, integrating creative practice into healthcare has the potential to enhance patient well-being, strengthen communication, empathy and transparency between the system and individuals, and lead to more compassionate, holistic models of care.

Acknowledgements

RMIT Enabling Impact Platform Strategic Impact, Thought Leadership Fund 'Collab/Oration *In Conversation*' Collaborators and Acknowledgements:

Andy Jackson, Nithya Solomon, Maxime Hexter, Dr Tamara Borovica, Dr Juan Sanin, Professor Vishaal Kishore, Diane Brown, Dr Brad Crammond, Mondo.K, Sai Gitte, Callie Clifford, Professor Jessica Wilkinson, Kiri Delly, John Reeves, Professor Naomi Stead.

Inaugural Fellowship Writers, of *Collab/Oration* project and *Raging Grace*:

Alex Creece, Andy Jackson, Angela Costi, Anna Jacobson, Beau Windon, Bron Bateman, CB Mako, Esther Ottaway, Gaele Sobott, Gemma Mahadeo, Heather Taylor-Johnson, Jasper Peach, Jess Kapuscinski-Evans, Katerina Bryant, Kerri Shying, Kit Kavanagh-Ryan, Leah Robertson, Michéle Saint-Yves, Rachael Wenona Guy, Robin M Eames, Ruby Hillsmith, Sam Drummond, Sarah Stivens.

The HTL team would like to again especially acknowledge our writers and those with lived experience who were involved in this project. We would like to take this opportunity to thank you for all you do and have already done in moving us forward - through your deep insight into the way our system works, and where it fails to.

Without you, this project and the impact it generates would not be possible.

RMIT UNIVERSITY

Health <Transformation> Lab