Making Unexpected Connections to Create Real Change.

Installation Art: The HIVE Maridulu Budyari Gumal Sydney Partnership for Health, Education Research and Enterprise (SPHERE) Symposium Partnerships for Better Healthcare Welcome to the inaugural exhibition of the HIVE, an immersive art installation co-created by: the SPHERE Knowledge Translation (KT) Strategic Platform team; artists-in-residence; members of Clinical Academic Groups (CAGs); consumers of health services; and carers.

Simone Chua – an installation artist and industrial designer – has spent the last year working with the KT team to transform the vision of SPHERE into an immersive art installation. The HIVE represents the spirit of collaborating to improve healthcare and enhance health – the focus of this symposium.

Simone Chua, Barbara Doran, and Caitlin Gibson took the reigns as 'uber' curators when the HIVE was in its infancy, inviting other outstanding artists to join forces as SPHERE artists-in-residence. Together, we have created a body of work that aims to provide information about the work of SPHERE in a way that engages the public imagination, highlighting qualities of accessibility, inclusion, audience engagement, and socio-political commitment.

SPHERE KT STRATEGIC PLATFORM

KT is both a multidimensional concept and an emerging discipline that examines methods and mechanisms to close the oft-cited chasm between what we know and what we do. It is a dynamic and an iterative process that involves the creation, synthesis, dissemination, exchange, and ethicallysound use of knowledge to improve healthcare and, relatedly, health. The SPHERE KT Strategic Platform is committed to enhancing capacity in KT and raising the profile of the brilliant efforts of each SPHERE CAG. Towards this aim (and as per the Knowledge Translation Strategic Platform Strategic Plan), it develops the INFRASTRUCTURE required to ENABLE individuals and collectives to EXCHANGE knowledge to give rise to EVIDENCE INFORMING KNOWLEDGE and PRACTICE. This involves (but is not limited to) the use of innovative arts-based KT strategies to communicate knowledge within and beyond SPHERE.

SPHERE KT Strategic Platform Team:

- Katherine Boydell, Director, Professor of Mental Health, Black Dog Institute
- Ann Dadich, Deputy Director, Associate Professor, Western Sydney University
- Zoi Triandafilidis, Project Officer, Black Dog Institute
- Chloe Watfern, Research Assistant, Black Dog Institute

ARTISTS-IN-RESIDENCE

SPHERE artists-in-residence collaborated with academics, health professionals, consumers of health services, and carers who were associated with seven exemplary SPHERE initiatives. Together, they explored how art can be used to communicate complex community and social issues, such as the wellbeing of children from refugee backgrounds, palliative care, and mental health and addiction. Each project featured in the HIVE draws on different art forms – from textiles and sculpture, to poetry and video – highlighting the many ways that the arts can enrich conversations on health(care) and how research can be communicated using visual, performative and literary means.

- Simone Chua, curator, installation artist, Amigo & Amigo
- NIDA collaborative, with creative direction by Barbara Doran, visual artist, filmmaker, and creative cognition lecturer
- Caitlin Gibson, curated conversations producer
- Michele Elliot, ephemeral textile pieces
- Kate Disher-Quill, photography, film, multi-media
- Lucy Klippan, visual artist, strategic design
- Peter Maple, actor, writer, director
- Anton Pulvirenti, 3D chalk artist, graphic scribe, observational artist

Contributing Artists:

Simone Chua is an internationally exhibiting contemporary installation artist. At the core of her work is the simple idea of capturing audience imagination and bringing people together in public spaces. Simone is principal of the design studio Amigo & Amigo, cofounder of the environmental group PlasticWise InnerWest and on the organisational board of independent art space Join The Dots.

For the past 5 years Simone has led Amigo & Amigo to exhibit internationally across, Asia, Europe, South America and the Middle East. Her expertise in lighting design and sculptural form has created connections for collaboration with some of Australia's leading creatives. These interactions have further informed her development and desire to explore beyond lighting and deeper into areas of sensory experience. The stories of Simone's works continue to grow in complexity and sophistication as she further enriches her palette with the inclusion of local musicians, researchers and sensory artists.

Overview of the HIVE: artist perspective

At the initial research workshop in September last year a map of all the different CAGS was drawn on the wall showing interconnections. It was a complex and intersecting network of ideas and communication that itself was at the heart of SPHERE. So being asked by Katherine and the team to represent SPHERE as a whole became a task of expressing this complex structure of CAGS, people, and ideas, and then the movement of information between all of these elements. The HIVE as a modular structure, 'pollinated' with different artworks was born.

Artist were invited to contribute to the HIVE, with works to be absorbed in their own right, but also coexisting in the context of the disperate works and concepts of the other contributing artists. The HIVE's bold lines and interconnecting nodes are used to help encourage movement around these works and assist in connecting them. The HIVE encourages you to explore, meld and experiment with these different ideas, and potentially bring them together in unique and novel ways.

The HIVE in its rawest form is the infrastructure (in the form of a roving exhibition) that supports the evolving conversation. My journey with the HIVE and all the artists has been a very rewarding pleasure, and I'm interested to see where the HIVE takes me.

You Feel Where You Live

In conversations with Evelyne from the HUE CAG, it was clear that there were obvious similarities between SPHERE and the success of cities. The main one being that cities impact on good and bad health. And that through design of these spaces there was an opportunity to positively affect health, "you feel where you live'.

It was interesting to find that, "Mobility and transport are one of the determinants of health, for instance every dollar invested in public transport reduces the health care cost by half a cent...". An odd outcome, but explained by public transport not just being about moving people around, "... it's also social capital, it is how you connect to your community, you feel where you live. You're on the bus you see people, you're surprised, you're bored, you smell them you hate them ... It is a whole body experience to use public transport." So looking into how people engage with a city and it's infrastructure, "... creates opportunities for health."

The insights gained through the CAG, Evelyne and HUE, ultimately informed and transformed the creation of THE HIVE.



Knowledge **Translation** Strategic Platform



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They inspired me to take these ideas and embed them into the HIVE, asking the question, "Who Creates Your Health?" The structure then becomes like a micro-city and the transport map shows some of the ways you can engage with it and its community. To reward and encourage movement throughout the HIVE I created pockets of surprise dappled throughout the installation. As you find them and connect with them you will be connecting with our little city in a positive way. Novel opportunities for; engagement, reflection, conversation, and a sense of being & community that all lead to opportunities for positive health outcomes.

Our HIVE map allows you to journey in no set order to each artwork where you are encouraged to disembark at a 'stop' and invited to answer a question.

CAG Partners: Healthy Urban Environments (HUE) Collaboratory; Evelynee de Leeuw, UNSW, Julie Dixon, South Eastern Sydney LHD, Donald McNeill, WSU, Stephen Conaty, South Western Sydney LHD, Jason Prior, UTS, Leila Niemela, SPHERE **CAG Project:** Improving the health of Australians living in urban environments.

Thank you to P. S. Wallace for additional design consultancy

What 3 statements or words have captured the experience for the CAG? "Engaged, disruptive, inquisitive"



NIDA collaborative: NIDA (National Institute of Performing Arts) MFA (Masters of Fine Arts) students, NIDA staff and SPHERE CAG partners worked collaboratively on two distinct projects for The HIVE. The NIDA MFA program brings together students from the Writing, Design, Voice, Directing and Cultural Leadership courses. This program fosters the collaborative and creative offer embedded in performing arts. This project brings together rich material for narrative, scenographic design, health research and important issues of collective well-being.

Student work has been supported by NIDA staff expertise including the leadership of art director and senior lecturer Barbara Doran. Barbara Doran straddles the world of the arts and academia. She is a transdisciplinary researcher /educator with a specific interest in wellbeing and the value of the arts in helping to work with complex systems. For over 20 years, Barbara has worked as an artist, creative director and educated in public health. This project is unlike any other in that it brings together all these strands. Barbara works at NIDA and UTS, Faculty of Transdisciplinary Innovation.

NIDA senior lecturer Suzanne Osmond, Head of Properties and Objects Marcelo Zavala-Baeza and sculptural producer Lewis Dean were all invaluable contributors to these projects. Special thanks to Imelda Gilmore, Peter Stanbury and Collen Fong for their contributions and insights into palliative care. In the spirit of Maridulu Budyari Gumal, this work has been a genuinely cross disciplinary collaboration.

MOODY TUNES: HEAR YOURSELF NOW!

Music is medicine but not all medicine is good for us – being alert to our responses is an important part of the feedback! The 'Moody Tunes' research team tapped into lingering concerns that listening to music is not always constructive and sometimes our choices can lead us further into a state rather than providing release. We each respond to music in deeply personal ways and are usually aware that music has emotional impact. We tend to be less aware of how our choices are guided by mood and how these choices can impact our internal responses. Becoming mindful of how our musical choices affect our ongoing mood can be supportive and at times critical in finding balance. This work creates a cocoon like world where you can choose a piece of music and spend time feeling for the way the music is resonating throughout your whole body. We invite you to consider your mood and where it might rest in your body as you enter the cocoon. Inside the cocoon spend time with yourself and a piece of music while sensing for how the music interacts with your whole being and then, when you step out, check in again with your mood. We'd be interested in hearing if this experience has expanded the way you think about and choose music.

CAG Partners: Neuroscience & Mental Health; Katherine Boydell, Black Dog Institute, Sandra Garrido, WSU, Tanya Meade, WSU, Quang Vinh Nguyen, WSU, Emery Schubert, UNSW, Tania Waitokia, NSW Ministry of Health. CAG Project: 'Moody Tunes': A mobile app to target youth

depression and music listening

What 3 statements or words have captured the experience for the CAG? **"'Sound'sational, hybridity, working in concert"**

IN OUR HANDS: THE ROLE OF INFORMAL CARERS IN PALLIATIVE CARE

Often when we think of health care our imaginations jump to the professionals, institutions and technologies that signify institutional support. Underlying these interactions there is usually a carer who supports, adjusts and attends to the quality of this journey. The palliative care journey is one that tends to occupy little of our collective imagination. It is a cultural elephant in the room. We have slowly given credence to the significance of parenting in early life but what about the end of life? In palliative care, the terrain is always shifting and informal carers play a critical role in navigating these unchartered waters. They hold the record of the journey and preside over the nuanced and often immeasurable details that nurture dignity and warmth. It's the invisible qualities of being touched that can make all the difference - the time to feed, to make eye contact, the tone of voice, the responsive hand and attendance to tiny personalised details be it grooming, food seasoning or scent. It's a kind of care that comes from deep interpersonal connection and is founded in the intangible value of time – time together, time to give, time to be present - to care.

This kind of care isn't the kind that fits an audit but it is one that we need to honour as invaluable in the life course of our community well being. It can be a lonely and isolating journey where friends, work and social life fall away and it can be one that enters at any stage of life. This work seeks to bring attention to the journey of informal carers and stimulate wider recognition, value and support for their profound role.

CAG Partners: Age and Ageing (AAA); Genevieve Steiner, WSU **CAG Project:** Healthy ageing to improve quality of life.

What 3 statements or words have captured the experience for the CAG? "Creative, innovative, fun"

Caitlin Gibson is a creative producer working in audio, community arts & events. She is a curator of talks and ideas at TEDxSydney, co-director of independent art space Join the Dots, and regularly produces community development arts projects with diverse communities across Sydney. She has produced podcasts for Kinderling Radio, Sydney University, FBi Radio, and The Guardian Australia and her feature documentaries have been broadcast by the ABC.

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Knowledge **Translation** Strategic Platform

THE ART OF COMMUNICATION

Knowledge Translation is about moving information generated in academic, scientific or clinical research into the hands of those in the 'outside' who could benefit from it or put it to practical use. But one of the biggest challenges in bridging that divide is clear communication. Research is more often than not presented in language and spaces inaccessible to those of us who exist outside of the academic community.

How can we create spaces and possibilities for our worlds to come together?

This curated conversation program was envisaged as a space for researchers, clinicians, patients, artists and policy makers to come together, to share their diversity of knowledge, in an accessible format that we can all participate in: a conversation.

CAG Partners: All CAGs CAG Project: Sharing the SPHERE story

Kate Disher-Quill is a Melbourne based artist working across photography, film and multimedia. As a visual communicator she is drawn to weaving stories into art to explore themes reflected in her community and the wider Australian society. Central to her artistic practice is the desire to create new and empowering works that inspire connections and understanding between the subject and audience. She has exhibited in numerous group and solo shows around the country. Most recently, Kate published a book titled Earshot, of an ongoing project centred around deafness. It combines photography and illustration with poignant storytelling to provide a unique and powerful insight into the experiences of deafness and hearing loss. As well as running a full-time photography business, Kate has facilitated workshops, given keynote addresses and talks, participated in numerous panel discussions and produced events for venues including Melbourne Recital Centre.

FACT VS HUMAN

For a multitude of reasons, whether short term or long term, there are babies, children and adults whose bodies need to access their food and nutrients via a tube. Sometimes via the nose or directly inserted into the stomach or bowel. The simple fact is that these tubes allow people to access food and nutrients which keep them alive. But while that may be simple, this daily reality can often be fraught with isolation, shame and fear.

In working with SuCCEED (the Supporting Children with Complex Feeding Difficulties (SuCCEED) Study Group, I was invited into the homes of seven families with 'tubie kids'. I spoke at length with the mothers and was struck by the common threads which embodied their stories. The isolation they felt in the initial weeks and months of tube feeding their kids, with no social support, they were often too afraid to leave the home. The shame and fear they felt when taking their child out into the world - how would people react when they saw their beautiful baby with a tube attached to their face? Would people stare in disgust if they fed their child in public?

The lack of support given to these families and lack of conversation around these experiences is the very reason why SuCCEED exists. From a young age society conditions us to hide our weaknesses or our differences. It is often done as a form of selfprotection. We fear rejection. We fear the unknown. But it is through sharing these experiences and these differences that we find strength, community and a sense of wellbeing. This series of portraits aims to share the challenges and vulnerabilities of these mothers while celebrating the courage and resilience that I witnessed. It also gives a voice to these children, who just like any other child, need to be nurtured, loved and accepted.

CAG Partners: Early Life Determinants of Health (ELDoH); Christopher Elliot, South Eastern Sydney LHD, Ann Dadich, WSU, Nick Hopwood, UTS, Khadeejah Moraby, Sydney Children's Network, Anna Ierardo, Carer, Irene Bernard, Carer, Sonia Cvetanoska, Carer

CAG Project: Improving palliative care to enhance quality of life for people with advanced illness and their families

What 3 statements or words have captured the experience for the CAG?

"Exciting. Inspiring. Innovative. This is the most obvious and important thing to do with research that isn't being done anywhere"

Michele Elliot is a visual artist, educator and occasional writer whose practice spans sculpture, installation, textiles and drawing. Her artworks encompass material explorations in relation to human connectivity, mapping and memory. Michele's survey exhibition some kind of longing: textile works 1995–2018 was shown at Tamworth Regional Gallery in 2018. Her artworks have been included in Horizon: Exploring the West Coast with The Clipperton Project, 2014; Tamworth Textile Triennial, 2010–12; Kindness: Udartha, New Delhi and Melbourne, 2012.

TODAY IS A GIFT

This artwork has been assembled with the generosity of people who work in or come to palliative care. Nurses, care-givers, educators, advocates, clinicians, ward staff, volunteers and those bereaved are my collaborators. The words you see are theirs and have been collected through a series of informal conversations. The materials and processes respond to the research of the Palliative Care CAG and to the experiences of those with whom I have spoken. The cloth is muslin, for transparency and softness. The letters are hand-cut, signifying a lightness of touch. They are hand-stitched, in order to imbue the cloth with the elements of time and labour. The words come and go. Knowledge, phrases, thoughts, wishes. Some are unfinished, it is not always possible to say everything.

At the heart of the work lie these and other conversations. Every person stressed the importance of communication and the dynamics at work between nurses and patient, families and doctors, ward staff and volunteers, with the need for open discussions around the process of dying. At the heart of the work is the preciousness of time. Every person I spoke with mentioned the significance of time, as a constraint, a hurdle, a luxury, a marker. Finally, the enduring thread woven throughout the work is the person, living well, right up until the moment of death. Thank you to Imelda, whose words provide the title of the artwork.

CAG Partners: Palliative Care; Meera Agar, UTS, Misbah Faiz, SPHERE; Kerrie Noonan

CAG Project: Improving palliative care to enhance quality of life for people with advanced illness and their families

What 3 statements or words have captured the experience for the CAG? "I have a greater understanding of the importance of supporting vulnerable people in difficult journeys."

"Respect and compassion should be at the centre of providing health."

"I never thought I would be contributing to an art installation in this role and it has been interesting and a rewarding experience."

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Knowledge **Translation**

Anton Pulvirenti is a visual artist who works mainly in the mediums of drawing and painting. Anton is a 3D pavement artist, comics and zine maker, and educator. Anton completed a PhD at Sydney University in 2014, where his thesis was concerned with family and memory in the context of Australia's World War 2 internment camps, when his grandfather was interned as an enemy alien in 1942. Anton's work is frequently concerned with the idea of the migrant 'other' and the role of the camp in the manufacture of national sovereignty and identity. Anton has produced many exhibitions and comics to this end, most notably the 'Goomiland' series which includes graphic novels and large-scale drawings. Anton's work has been exhibited in Australia. Korea. Italy, Singapore and Germany. Anton is a volunteer teacher with the Refugee Art Project, an initiative that works with refugees though workshops, exhibitions and various publications that challenge negative stereotypes towards refugees.

CHRONOSYSTEM

This work combines children's drawings with a 3D representation of the Bronfenbrenner ecological research model. Its aim is to translate migrant children's drawings and academic research into an artistic response that invites consideration and contemplation about the issues that migrant children and families face. These drawings were produced in two workshops held at Liverpool and Fairfield libraries in collaboration with Dr Jess Baker, research fellow in psychiatry at UNSW, Afaf Al Shammari, community connector at Lost in Books, and Damon Amb, an Iranian painter and photographer. There were also 4 other assistants- Shanti Raman, Valsa Espen, her daughter and Nora Samir. The workshops brought together children who had recently arrived in Australia who were given guestions in relation to their arrival experience. The questions were designed to

create drawings based upon the children's perceived ideas about their strengths, hopes, needs and wants and experiences with child health services in Australia.

CAG Partners: Early Life Determinants of Health (ELDoH); Jess Baker, UNSW, Valsamma Eapen, UNSW, South Western Sydney LDH, Ingham Institute, Afaf Al-Shammari, Think+DO Tank Foundation, Shanti Raman, South Western Sydney LHD, Karen Zwi, Sydney Children's Network, Holya Hasan, UNSW, Damon Agha Mohammad Bagher, independent artist; Deepthi Mathew, independent, Nora Samir, UNSW

CAG Project: The wellbeing of children from refugee backgrounds as they prepare for school.

What 3 statements or words have captured the experience for the CAG?

"Expressive, synergistic, and warm"

Peter Maple is a writer, actor, producer, director working extensively across all mediums of film, TV, radio, stage, online, and the written word. He holds a Bachelor of Performance from Theatre Nepean (Western Sydney University) and a Master of Fine Arts (Writing for Performance) from the National Institute of Dramatic Art. A dedicated and versatile collaborator, Peter inhabits all things story. Peter has particular interest and expertise in exploring questions of mental health and society. www.petermaple.com

LISTEN. SHARE. is an attempt to dramatise and experientialise (mis)communication that can occur between different parties working towards the same goal; and to highlight the need for patience and listening, in collaboration, in order to accurately understand.

CAG Partners: All CAGs **CAG Project:** Sharing the SPHERE story Lucy Klippan is a designer and illustrator. Much of her work is focussed on issues concerning social justice, environmental design, community connections and health. To these issues she brings a background in visual design and an interest in exploring how we communicate with each other. In her freelance work and in her role with Designing Out Crime and the Design Innovation Research Centre at the University of Technology Sydney, Lucy applies her creative skills to complex health and social problems in a range of areas, including detention environments and systems, mental health and community safety. The common thread throughout Lucy's work is an innate interest in finding the human within the system, always aiming to highlight and emphasise meaningful connection between people and with their environment. She is interested in exploring ways to visualise different perspectives and stories within a given context, where they would otherwise be invisible. Lucy is also interested in exploring how complex systems can be adapted or rebuilt to work for people, rather than forcing people to work around the systems, as so often seems to be the case.

HOLDING THE FAMILY

This installation is an abstract representation of projects that explored a new outreach model of care in early childhood developmental surveillance for children from Culturally and Linguistically Diverse (CALD) backgrounds in South Eastern Sydney. These projects brought health professionals into local family and community centres to connect families with support to identify and treat developmental issues in young children. Training was also provided to staff working in these centres so that they could support parents with concerns about their child's development.

The team behind this work described the model as a "safety net". This net aims to catch the families who

are otherwise more likely to "fall through the gaps" and not access available guidance for a range of reasons, including language and cultural barriers.

Family and community centres are safe environments for families in a way that clinical environments are not. They are typically more accessible for the local community, encourage children to play and parents to socialise, and enable specialists to offer guidance in a non-threatening way. This approach naturally lends itself to taking a broader, whole-of-life view of a child, beyond a clinical diagnosis. These features are critical in overcoming the failings of the large systems constructed over time around health and education.

In this installation, the dark canopy symbolises the health and education systems, which are difficult to navigate and peppered with complex language that has little meaning to many parents, let alone children. Below this is a bright, colourful entanglement that this represents the play, mess and connection of the new model of care. Arms and hands symbolise the importance of human connection and the literal "reaching out" of the system. Staff, parents and children from the centres involved are also represented to reinforce the critical role that individuals play in making this community thrive.

CAG Partners: Early Life Determinants of Health (ELDoH); Valsamma Eapen, UNSW, South Western Sydney LHD, Ingham Institute, Sue Woolfenden, UNSW, Sydney Children's Network, Tania Rimes, South Western Sydney LHD, Jane Kohlhoff, UNSW, Amanda Webster, South Western Sydney LHD

CAG Project: Children from culturally and linguistically diverse communities with limited access to timely and appropriate support for developmental disorders.

What 3 statements or words have captured the experience for the CAG?

"creative, inspiring, a moving new narrative"





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Caitlin Gibson: Conversation Program

Supporting Children with Complex Feeding Difficulties (SuCCEED) Project

The HIVE, Thursday 29th August, 11 am - 12pm

The Supporting Children with Complex Feeding Difficulties (SuCCEED) Project aims to improve the lives of children with complex feeding difficulties, and their families. Towards this aim, SuCEED is working to find innovative and fun approaches to highlight what works; understand what is not working; and learn from the expertise of children, their families, and the clinicians who support them.

As part of the SPHERE Artist-in-Residence program, Kate Disher-Quill was invited to work with the SuCEED project, exploring the potential of the arts to generate new knowledge, deepen understanding and respond to this unique health research initiative.

Presented as part of the 'Curated Conversation' program at The HIVE, this panel will bring together people with a diverse experience of children's complex feeding issues, to interrogate the benefits and challenges of inter-disciplinary research practices, and what we can learn when we step outside of our own realm of expertise.

Speakers:

Ms Kate Disher-Quill, artist in residence Ms Kady Moraby, speech pathologist Ms Anna, mother of child with experience of complex feeding issues A/Prof. Ann Dadich, researcher Moderated by: Ms Caitlin Gibson Knowledge Translation, the Arts, and Healthcare Research: What we learned developing the SPHERE Artist-in-Residence program.

The HIVE, Thursday 29th August, 3pm to 4pm

Research and scientific data is notoriously difficult to understand. Scholarly articles and science presentations don't always reach the people who need to know about them. Even when they do, they can be written in a language few understand.

Could art be harnessed to overcome these barriers?

This conversation will reflect the amazing discussions and work done by the SPHERE artists-in-residence and Knowledge Translation team, to devise an innovative program that facilitates meaningful collaboration and deepens understanding in healthcare research.

Speakers:

Ms. Simone Chua, artist and designer, The HIVE Ms. Barbara Doran, curator and NIDA project facilitator, The HIVE Ms. Lucy Klippan, artist, The HIVE Prof. Katherine Boydell, Director, Maridulu Budyari Gumal (SPHERE), Knowledge Translation Strategic Platform Moderated by: Ms. Caitlin Gibson The Palliative Care Clinical Academic Group

The HIVE, Friday, 30th August, 1pm — 2.15pm

The Palliative Care Clinical Academic Group aims to improve end of life care, outcomes and quality of life for adults and children living with progressive and/or advanced illness(es), and their caregivers.

In this conversation we are reflecting on the dominant role that families and communities play in delivering end of life care, and how clinical practice and palliative healthcare policy can be better informed by listening to the intimate experiences of those closest to death and the dying.

Speakers:

Ms Michele Elliot, artist in residence Ms Jesse Williams, CEO of The Groundswell Project Ms April Creed, healthcare worker & Co-Founder of ExSitu A/Prof. Ann Dadich, researcher Moderated by: Ms Caitlin Gibson

Notes:

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