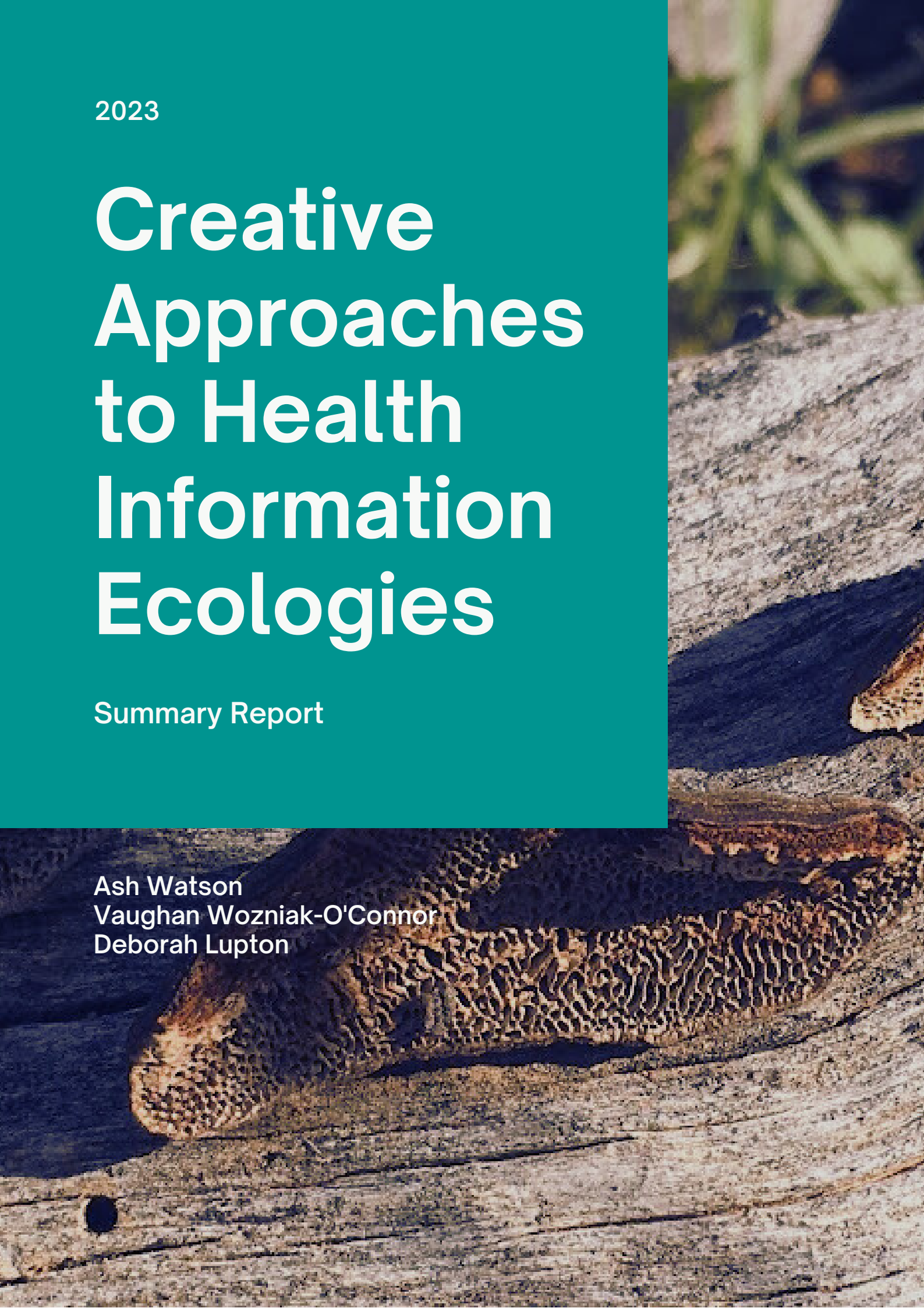


2023

Creative Approaches to Health Information Ecologies

Summary Report

Ash Watson
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Creative Approaches to Health Information Ecologies is a study into how people make sense of health information and how they understand the connections between their health, wellbeing, community and world.

Suggested citation:

Watson A, Wozniak-O'Connor V, Lupton D (2023) *Creative Approaches to Health Information Ecologies: Summary Report*. Sydney: UNSW Sydney and ARC Centre of Excellence for Automated Decision-Making and Society.

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Acknowledgements

Many thanks to the Health Consumers NSW participants who generously shared their time and experiences with us and with each other.

Thanks to the members of the project Advisory Group and our partner organisation, Health Consumers NSW.

Thanks also to the staff at UNSW Library who supported the associated creative exhibition, *More-than-Human Wellbeing*, and to our commissioned filmmaker Edmund Renew for his work in making the short film.

Ethical approval was provided by UNSW Sydney Human Research Ethics Committee (HC220202).

This research was supported by funding from the Australian Research Council Centre of Excellence for Automated Decision-Making and Society under grant CE200100005, and the UNSW Sydney Faculty of Arts, Design and Architecture via a Faculty Research Partnership Scheme.

The investigator team included Professor Deborah Lupton, Dr Ash Watson and Dr Vaughan Wozniak-O'Connor.

We acknowledge Dr Megan Rose who contributed artwork to the *More-than-Human Wellbeing* exhibition.

This project was conceptualised and undertaken on the lands of the Bedegal and Gadigal peoples of the Eora Nation, who are the Traditional Owners of the lands on which UNSW Sydney is located. We acknowledge that this land was never ceded and that we have benefited greatly from their custodianship of Country over tens of thousands of years. We have also benefited from the knowledges from other Australian and First Nations peoples in developing this study and our exhibition.

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Executive Summary

This report shares findings from *Creative Approaches to Health Information Ecologies*, a project led by researchers at the University of New South Wales (UNSW Sydney) in collaboration with Health Consumers NSW.

This project used creative and qualitative methods to explore how people learn about their bodies and health. A total of 27 people took part in online workshops via Zoom during mid-2022. In these, participants mapped personal forms of health information and discussed the connections between health, wellbeing and the environment.

Their discussions and maps provided valuable insight into the forms that health information takes and what matters about information, health and wellbeing in people's everyday lives.



Health information is something to collect, something to share, and something to help create

When participants used the term ‘health information,’ they referred to protected kinds of personal information about their own health (symptoms, diagnoses, treatments, appointments) and the more general things they know or seek out about health and wellbeing (others’ experiences, research findings, how they feel).

They see health information as something to collect, something they need in order to be informed, something that helps them ask questions during appointments, and as something to arm themselves with. They also recognised that health information is something that needs to be filtered, in order to find sources that are recognised and can be trusted, and so they can engage with information at times that are beneficial rather than harmful to them.

Participants emphasised the importance of the many forms that information can take: telephone calls, news and documentaries, medical data, annual reports and research articles, diaries they keep, newsletters, infographics and diagrams. Participants also talked about the other things that help people access health information that we might not normally think about — like the cost of the bus ride to a local community centre or exercise group. Local places mattered to how people make sense of health information and sense their own wellbeing: community centres, the coffee shop, and spaces like beaches, rivers, lakes and nature reserves.

Importantly, participants did not only talk about receiving health information. They are important sources of health information for themselves and for other people. Participants emphasised their feelings (in terms of emotions and how their bodies feel), and talked about who impacts how they learn, use and share health information: family, friends, pets, doctors, pharmacists, specialists, and people in their local communities. They see health information as something to pass on, through their networks, their activism and by participating in research projects, in order to improve other people’s lives and experiences.

Avoiding isolation, prioritising connection and balance, and participating in relevant events like consumer roundtables were important activities for participants that shape how, when and why they engage with health information. So were their everyday routines, and doing things they enjoyed like cooking and spending time outside — knowing the significance of not wanting to do these things is an important source of information about their own health.

Being in touch with their bodies and how they feel, being in touch with others in their lives and local communities, and being in touch with nature are all critical elements that shape how people make sense of and use information about their health and wellbeing.

Introduction

Digital technologies such as mobile devices, wearable devices and electronic medical records are becoming increasingly central to how health information is made and shared. In response, much work is being done to improve people's digital health literacy. While this work is important, it tends to focus on the skills an *individual* needs to use digital technologies and to understand and act on health information. How people learn about health and wellbeing, however, is complicated.

It is important that we look beyond the individual and their personal skills. It is also important that we look beyond novel digital technologies, to the other things that shape how health information is created and shared. We must also consider the social, environmental and sensory dimensions of health information — the other people, communities, places and bodily feelings that impact how we come to learn about and understand our health.

This report shares findings from the project 'Creative Approaches to Health Information Ecologies,' a collaboration between researchers at the University of New South Wales (UNSW Sydney) and Health Consumers NSW. This project explored the many different ways that people learn about their bodies and health. This included their use of digital technologies, as well as their encounters with other people and the world around them.

To do this, we recruited a range of participants with the help of Health Consumers NSW to take part in online workshops. In these workshops, participants drew maps showing the flows of health information in their lives and discussed the connections between health, wellbeing and the environment, inspired by nature photographs. The maps our participants made and the discussions they had together gave us great insight into the things that matter about information, health and wellbeing in people's everyday lives.

This report shares our findings from these workshops. It also shares details on a creative exhibition about wellbeing related to this research project.

Study Aims and Methods

The *Creative Approaches to Health Information Ecologies* project was developed to consider and inspire new ways of thinking about how people learn about their bodies and their health. We aimed to identify the kinds of health information people use and why, and the forms that this information can take. We also sought to understand what people observe, sense and document about their health and wellbeing by using digital technologies as well as non-digital things.

To explore health information in this way, we conducted a series of online workshops with health consumers via the videoconferencing platform Zoom in mid-2022. We chose this online medium to ensure COVID-19 safety for those involved and to increase access for people where face-to-face workshops can be challenging or prohibitive. The workshops were advertised by Health Consumers NSW through their email newsletters and social media platforms. Those who were interested contacted a member of the research team directly to discuss the project, confirm their eligibility and availability, and give their consent to participate. We recruited a total of 27 participants, and conducted seven workshops with three or four participants taking part in each. Each workshop lasted for approximately one hour and all were video-recorded.

Of the total of 27 participants, 16 identified their gender as female, 10 as male, and one as non-binary. One participant was aged in the 25-34 years band; 4 were aged in the 35-44 years band; 4 were in the 45-54 years band; 6 were in the 55-64 years band; 9 were in the 65-74 years band; and 3 participants were aged in the 75-84 years band. The majority of participants (22) identified as having an Anglo-Celtic or continental European ethnic/cultural heritage, with the others reporting East Asian, sub-continental or South American heritage. Sixteen participants lived in the Greater Sydney area, with the remaining 11 living in smaller cities, regional towns or in rural areas. Many participants were living with chronic or acute medical conditions or were carers or advocates for family members. Some were currently working as health care professionals in a range of positions, such as translators, administrators and nurses, or had retired after a career in health care.

Each workshop began with a general introduction to the project, including the requirements and expectations of participation. Participants were given the opportunity to ask any questions or clarify aspects of the workshop before the video-recording was enabled. Each person present was then invited to introduce themselves, and the workshop activities were commenced.

For the first activity, ‘health information ecology mapping,’ we showed participants a series of questions:

- How do you learn about your body and your health and wellbeing?
- What kinds of information about your health and wellbeing do you collect and use?
- What senses do you use to do this (touch, sounds, sight, smell, taste, feel)?
- What places do you connect with your health and wellbeing? What places make you feel happy and well? What places make you feel sick or unhappy?
- What objects or actions make you feel connected to other people? What makes you feel connected to your local environment? What makes you feel connected to the world?
- What can we learn about ourselves and our health from the natural world? How can we use this information to improve our health and wellbeing?

We asked participants to reflect on these questions and create a map in response, using either a pen and paper or a digital program (e.g. a word processor or voice-to-text software). Participants had been advised of this activity in advance and had these materials prepared. We explained that participants did not have to answer these questions by, for example, writing down responses to each one; rather, these questions were prompts to help inspire detail in their maps.

We gave suggestions of what their maps could include – for example, themselves in the centre (e.g. as a stick figure) in one or more environments (e.g. places, buildings, nature), with people or other things (e.g. doctor, family, a pet, a phone), labelled with health information (e.g. types of information, where information comes from and goes, senses related to health). We explained that this map would represent the people, places and things that matter to them about health information. With it, we could see how they find, feel, sense, and learn information about health. Importantly, we stressed during recruitment and again when explaining this activity that participants did not need to know anything about drawing to take part; we were not seeking artistic drawings, and participants were free to ‘map’ these elements however they wished.

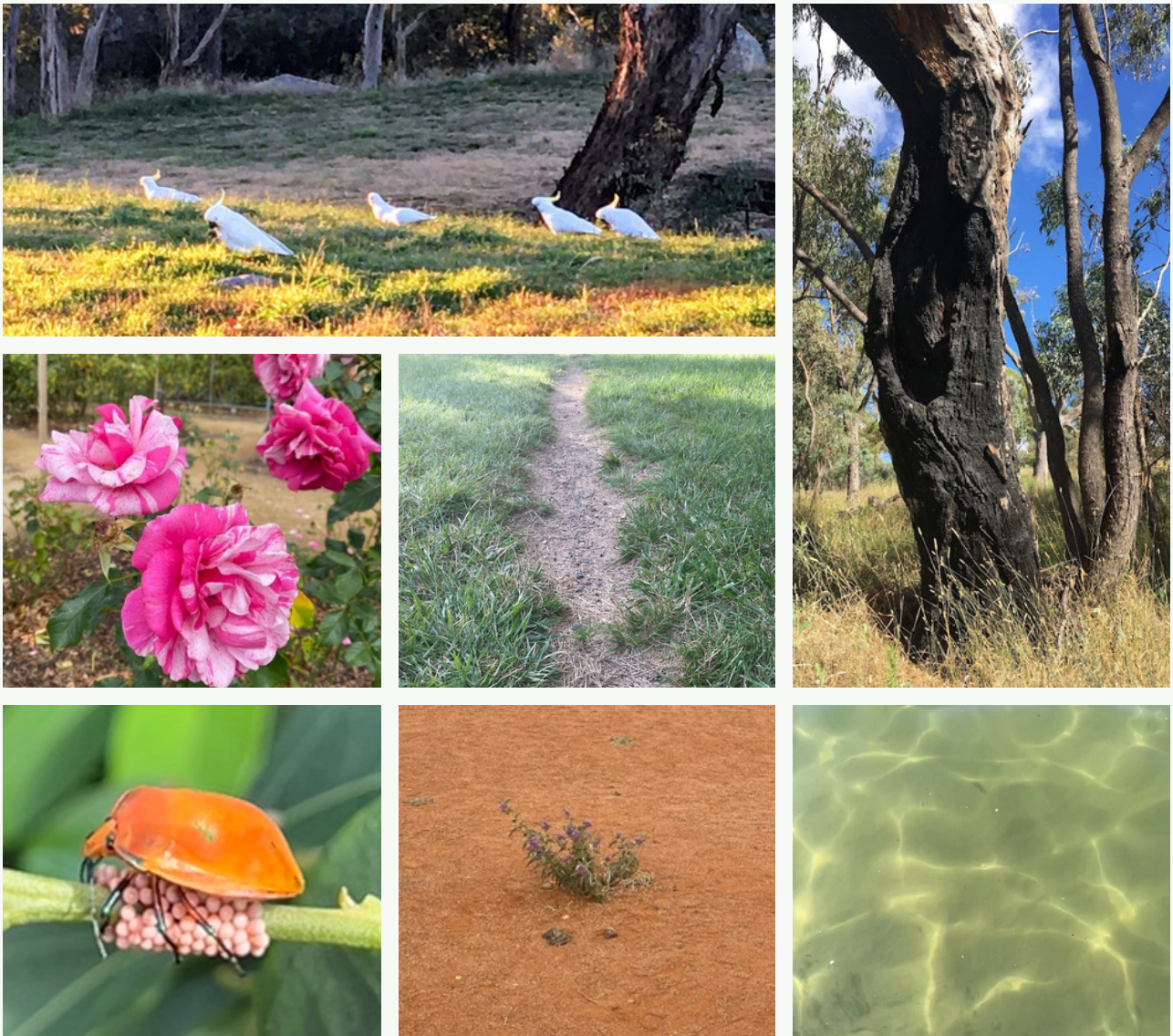
Participants were given approximately ten minutes to each work quietly on the task before joining together for group discussion. We asked volunteers to share their maps, and participants either held up their paper to their web-cameras, screen-shared, or simply explained what they had detailed and why. Participants were encouraged to keep adding to their maps during the group discussion if they wished to. This discussion lasted for around 30 to 45 minutes.



We then moved onto the second activity, 'new health information metaphors.' For this, we showed participants a series of approximately 40 photographs taken by members of the research team. This included images of the sky, trees, waterways, animals, footprints and the moon. Participants were asked to discuss any images that drew their attention, that they could relate to health information.

We stressed that there were no wrong answers, and the researcher who led the session offered some example responses. This was a creative free association task to explore some different ways that we might think about and talk about health. Discussion of these photographs lasted for the remainder of the workshop.

Afterwards, we worked as a team to analyse the workshop recordings and the maps that participants made, to understand how they engage with information about health and wellbeing and how they connect with both digital technologies and nature.



Some of the photographs we used in the 'new health information metaphors' activity

Findings

What is health information?

Health information includes personal information about your physical and mental health or disability, details about treatments or health services that have been or will be provided to you, and genetic information about yourself or those you are related to. This incorporates things in your medical record such as notes about symptoms or a diagnosis, specialist reports, test results, prescriptions, service and treatment details, as well as things like your record of appointments, your billing details, your wishes about future care, and any other information you give to health service providers. This is how health information is officially understood, and this is the information protected by legislation such as the *NSW Health Records and Information Privacy Act 2022* (HRIP Act). In everyday life, people also use the term to refer to the diverse range of details they know or might learn about particular conditions or experiences, and about wellbeing in general.

The people who participated in our workshops used health information in both of these ways – to refer to protected kinds of personal information about their own health, and the more general things they know or seek out about health and wellbeing. When discussing and making maps of health information in their own lives, our participants showed that they understand health information to be many different things. In their words, health information is:



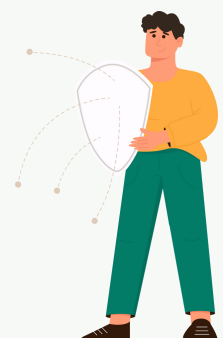
something to collect

something you need,
to be informed



something that helps you to ask
questions — the right kinds of
questions, or questions that will
get you useful answers

a defence — something
to be armed with



Health information also:



needs filtering

so you do not overburden yourself

so you can find official and recognised sources you can trust

so you can connect at times that are right for you and helpful rather than too heavy



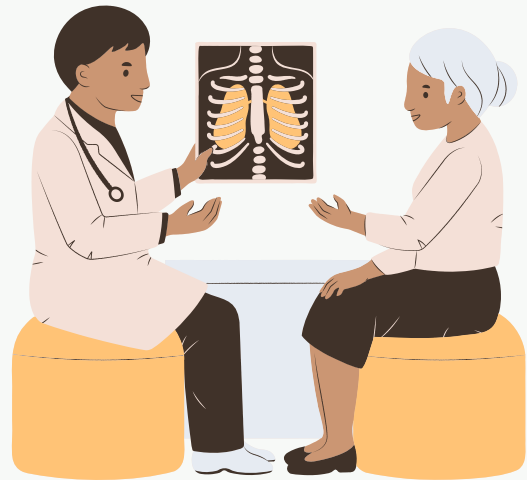
Participants talked about being a filter of health information for people in their lives who ask questions or want to give advice, who are well-meaning but often not helpful. They also talked about being an important filter for themselves, so they can work through and make sense of the growing masses of information that can be overbearing, irrelevant, or only partial.

In one of the workshops, participants had a detailed discussion about the differences between information and stories, in terms of what you take away and what you feel. A number of people felt that better storytelling would make health information easier to understand and easier to use. As part of this discussion, they reflected on what they want from conversations with different sorts of people — from health professionals, from the media, from loved ones, from support organisations, and from friends or others in their local communities.

They focused on the example scenario of receiving a diagnosis from a General Practitioner. Across the workshops, participants talked about GPs as being *the* channel for accessing formal health information. In their experience, however, many felt that GPs provide little to no information and simply funnel patients towards specialists. This process causes people to experience an information double bind, where people feel they have both no choice (in terms of who treats them) and the burden of too many options (in terms of what treatment might involve). Participants recognise a critical information gap or lack of information capacity building in such scenarios.

As one person articulated, in a moment like this they would want to know who the relevant experts are, what the research is currently saying, and what other people's experiences have been like in the area where they live. Others agreed that people want this kind of direction from a GP, and see these details as critical forms of health information.

Moments like receiving a diagnosis are significant times. People want to receive tailored information from someone they know and have placed their trust in. They want to be directed to resources that are relevant to their life and where they live, to help them make informed choices.



What matters?

When talking about health information, participants highlighted a number of specific things that matter to them and make a difference in their lives. These were the main elements of the maps they each made in response to the first workshop activity. We share their words below, categorised into four main groups: who matters, where matters, what things matter, and what activities matter.

Who matters?



family and friends are vital
pets too

your doctor
your pharmacist
your specialists

other people matter too
people you meet through clubs
people in your local community

Where matters?

community centres
local hubs
the coffee shop

places to meet up with others
and have conversations



the water
beaches, rivers, lakes, all kinds of
natural waterways and blue spaces
swimming pools
rain



places like the GPs office also matter

but health buildings are a mixed bag — you go there when something
is wrong, but you can go there because something can be fixed

hospitals and doctors surgeries make people feel nervous, but
happier if they are solving a problem

What things matter?



digital technologies
computers, smartphones
fitbit and apple watch

the telephone and phone calls

the media — TV, radio, websites,
newspapers — these connect you
to information, they are a vehicle for
stories, and also they connect you
to loved ones and the wider world

medical objects
medications

texts — annual reports, research
articles, reference books, brochures,
flyers, newsletters, keeping a diary

visual representations of information,
diagrams

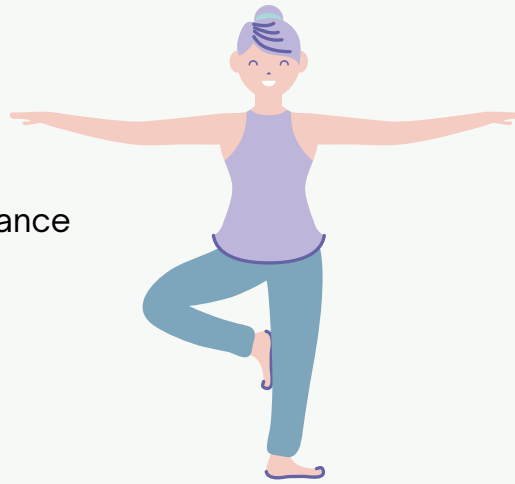
what is local and accessible to you,
like the cost of the bus

trust



What activities matter?

connection, balance
and self-care



avoiding isolation

roundtables — these are
opportunities to learn, be heard,
and connect

doing the things that you do
when you feel well, like cooking
and seeing friends, listening to
music, playing tennis, spending
time outside



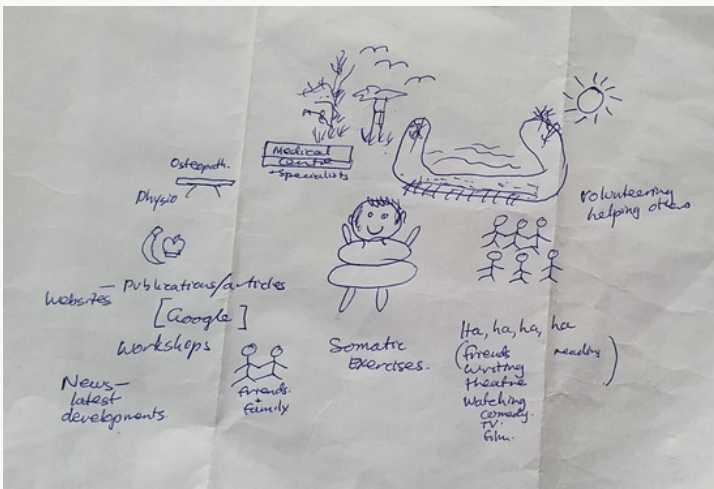
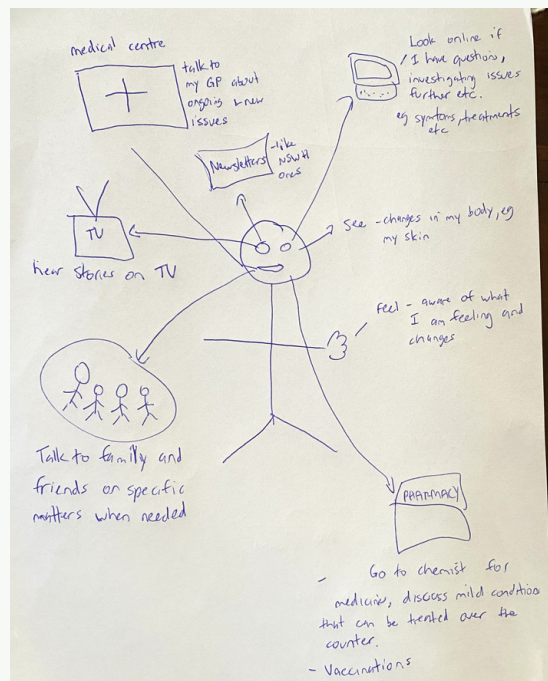
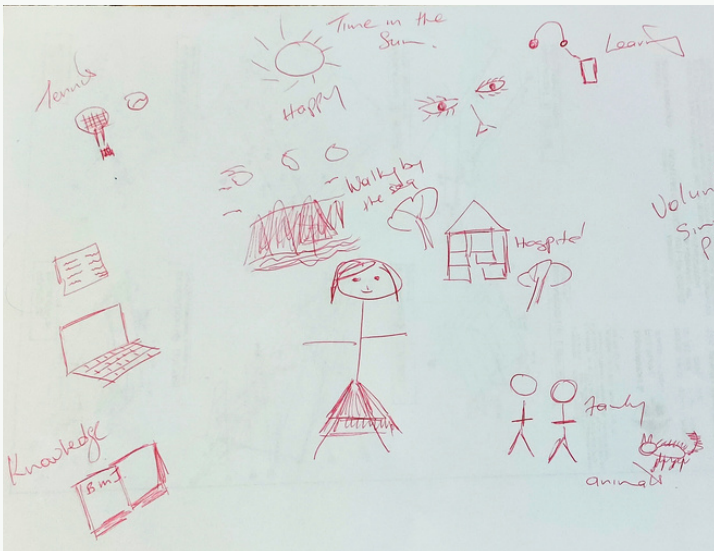
knowing the significance of
when you stop doing those
things



being in touch with nature

our health is not separate
from the environment

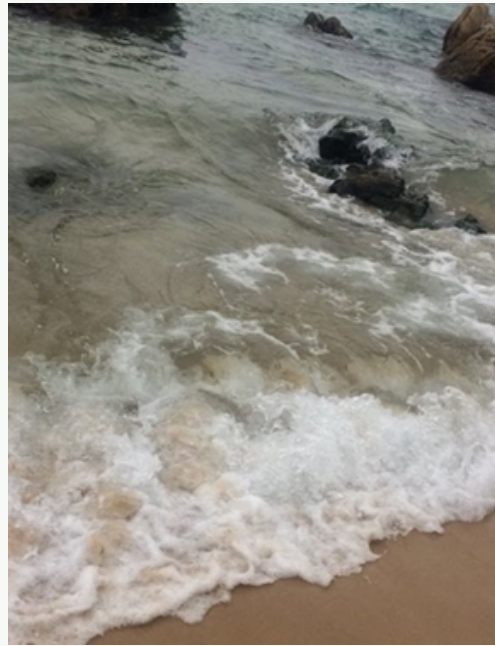
The maps that participants made show these important elements of health and wellbeing:



Their responses to the nature photographs we shared articulate the strong connections between personal health, wellbeing, community and world.



the flower represents fragility to me — that life is precious



the water reminds me of my health: sometimes it's ebbing, flowing, sometimes it's rough



...having experienced bushfire season, it was really depressing, but nature can renew itself. Yeah, maybe our health is a bit like that



we're all separate things, but up towards the canopy, we all intermingle

Health consumers create and generate

When talking about how they find information about their own health and wellbeing, participants did not only talk about sources like doctors, websites and research articles. They also talked about being a source of information themselves. They emphasised the importance of *feeling* and their *feelings* — with their fingers under their skin, within their bodies, and emotionally. This included how they feel in the spaces they usually inhabit, such as their home or local shopping centre, and whether they find these relaxing or stressful. This also included how they feel around other people, through conversations and the ways they connect.

Wanting to spend time by the beach, or go for a walk, or catch up with friends (or *not* wanting to do these things) is an important health indicator for many people. These feelings and senses are important forms of health information.

Importantly, our participants see health information as something to pass on, through their own activism or by participating in research projects, in order to improve other people's experiences and lives.

In their eyes, health information is a lively body of knowledge.

Health information is something to participate in.



A number of people we spoke to told us that they value organisations like Health Consumers NSW because of the information and support they receive themselves, to stay up-to-date and continue learning new things from others. They also connect with these kinds of organisation to volunteer, advocate and share information with their local communities, because they recognise that many people have less than they do — less health, less wellbeing, less literacy, less access, and less voice.

Health consumers connect to contribute information about their own lives and things they have learned, in order to help others facing the same challenges or who may have similar experiences, now and into the future. They feel a sense of responsibility and want to give back, to make a positive difference to other people's healthcare experiences and overall wellbeing.

Creative Exhibition

More-than-Human Wellbeing is a creative exhibition that explores how human health and wellbeing is entangled with the health and wellbeing of the planet. The exhibition uses art to communicate key concepts and findings of multiple projects including *Creative Approaches to Health Information Ecologies*.

The exhibition seeks to attune visitors to these entanglements. It shows that digital data and devices are only part of the many ways that people learn about their bodies and health. It acknowledges that human health is always more-than-human health, and natural and human-made objects and spaces intertwine.

Some questions we'd like exhibition visitors to explore include:

- What traces does the world leave on you, and what traces do you leave on the world?
- How do you learn about your body and your health and wellbeing through your interactions with other people and the world?
- How can we conduct our lives so as to promote mutual health and wellbeing with the other people and living things that are part of our ecosystems?

One work featured in the exhibition is a short film. This depicts insights from the workshop we conducted in the *Creative Approaches to Health Information Ecologies* study. Participants' own words about their health and wellbeing were revoiced and layered over images and sounds captured from nature, poetically bringing their insights to life with emotional force and depth.



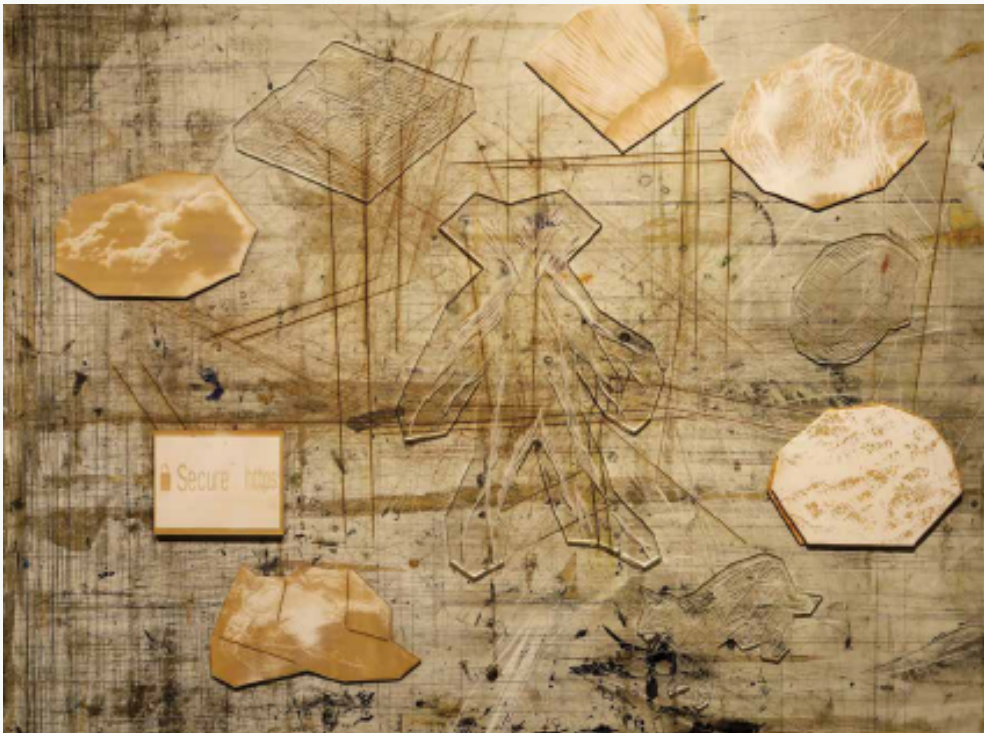
A still-shot from the Creative Approaches to Health Information Ecologies film



Still-shots from the Creative Approaches to Health Information Ecologies film

This film is free to view online, and can be accessed on YouTube at this link:
https://www.youtube.com/watch?v=aaPf_WevkwI

Some of the other pieces featured in the *More-than-Human Wellbeing* exhibition are shown on the following pages. This exhibition is on show from 22 May to 18 August, 2023, at the UNSW Sydney Main Library Gallery. We plan to tour the show in community spaces around Sydney in the future. You can access the exhibition reader and more at: <https://dlupton.com/publications/>



Vaughan Wozniak-
O'Connor and
Deborah Lupton

*Homo Signorum for
the Digital Age,*
2022

Laser-etched found
MDF, acrylic,
walnut, plywood

This work extends and update the Zodiac Man concept by incorporating contemporary forms of information that flow into and outwards from human bodies. Our reimagined Homo Signorum includes digital information created when humans move in public spaces embedded with sensors, use mobile devices, or go online.

Vaughan Wozniak-
O'Connor and
Deborah Lupton

*More-than-Digital
Data Cloud,* 2022

Laser-etched found
MDF, walnut,
plywood



This work plays on the metaphor of cloud computing, a term used to describe external archives of digitised information. It shows digital data in the form of a cloud but also incorporates other forms of information that people collect and interpret when they seek to improve their health and wellbeing.



Vaughan Wozniak-
O'Connor and
Deborah Lupton

Lively Smartphones,
2022

Recycled European
oak, 3D printed
resin

These 'Lively Smartphones' were inspired by considering how the apparently 'cold', 'non-living' technologies that are smartphones can be reimagined as living organic entities that extend into and engage with the natural world.

Vaughan Wozniak-
O'Connor and
Deborah Lupton

Hand of Signs 2022

Laser-etched walnut
and plywood



This work reinterprets the practice of palmistry and refers to the newer tradition of digitising human bodies through scanning and data visualising technologies. In palmistry and more contemporary monitoring technologies, one's health can be deduced through the map, the lines of the palm and the errant traces of satellites and sensors.

Conclusion

What matters to how people make sense of information about their health and wellbeing?



Being in touch with themselves

- Feelings and emotions matter
- How their bodies feel matters
- Knowing how and when works for you to engage with information matters



Being in touch with others

- Support from loved ones matters
- Trusted professional matter
- Local community networks matter



Being in touch with nature

- Access to blue spaces (beaches, rivers, lakes, swimming pools, rain) matters
- Feeling part of a bigger world matters
- Learning from nature helps

Health information takes many forms in people's everyday lives. It includes official kinds of personal or private health information, such as their symptoms, diagnoses, treatments, records of appointments and other information they share with healthcare providers. It also includes the other things people seek out and learn during the course of their everyday life, like other people's experiences, research findings from articles or the news, and how they feel in themselves. Digital technologies play a growing role within health information ecologies, but things like smartphones apps and digital medical records are part of a bigger and more complex landscape. It is important that we understand what matters to people about health information, and what shapes how they make sense of this information, as we study and engage with new digital health technologies and information forms.



Scan for more information

We thank you for your interest in our study. If you would like more information, please reach out.

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