

Creating **Space** Project



Young People's Voice in Healthcare

Michael Neufeld

Supervised by Dr Cath Conn, Dr Tineke Water, and Dr Jennifer Nikolai

An exegesis submitted to

Auckland University of Technology

in partial fulfilment of the requirements for the degree

Doctor of Health Science (DHSc)

Faculty of Health and Environmental Sciences

School of Public Health and Psychosocial Studies

2022

Abstract

Introduction: The legal mandate set out in the United Nations Convention on the Rights of the Child (UNCRC) (1989) states that every child has the right to express their views freely in matters that affect them and to have those views considered. In Aotearoa New Zealand, representation of the perspectives of young people in healthcare policy remains limited and generally tokenistic. The invisibility of young people's voices suggests that any inclusion that does occur does so within distinct and contested spaces. This project, titled *Creating Space—Young People's Voice in Healthcare*, invited young people to explore and share their perspectives on what is important to them regarding their health and well-being. It aimed to answer the question, "How can participatory video and drama facilitate collaboration with young people to empower their voices in healthcare policy and provision?" The project identified barriers to and protective factors for young people's health and presents them in short video artefacts. These videos can inform policymakers, health professionals, and anyone involved in young people's lives of some of the challenges that young people face in achieving and maintaining good health.

Methods: The project set out to determine if participatory video and drama can facilitate collaboration with young people to enable them to identify the health issues that most affect them and empower their voices in healthcare policy and provision. The participatory action research methodology and associated critical theory epistemology enabled the participatory video methods to create the literal and metaphorical space for young people to "have their say." A five-day participatory video and drama workshop included 29 young people aged 11 to 17 years who worked alongside facilitators to develop a social and creative space to promote reflection, discussion, collaboration, and filmmaking skills. Using creative and analytical exercises, the participants produced stories captured in video about some of the health issues that young people face today. The participants wrote, storyboarded, performed, filmed, and co-edited these videos themselves. The videos present the project's findings, contextualised by the researcher's reflexive critical commentary.

Results and analysis: The creative, narrative processes expressed in video are literal artefacts of the participants' "voice" and form a summary of the perspectives, ideas, and potential solutions

expressed during the iterative, exploratory process. These creative, narrative video artefacts, along with examples of the analytical processes (captured in video), are hosted on a dedicated YouTube channel as a repository to share participants' ideas and perspectives with other young people and anyone involved in caring for young people. Using a reflexive critical commentary to add current and contextual knowledge, the findings indicate that the participants are most concerned with issues relating to their mental health and emotional well-being and believe they are commonly defined by visible but immutable characteristics such as age, race, and sex that can leave many feeling “invisible” and unable to “fit in.” The participants shared experiences of physical and online bullying, anxiety, depression, and health and sexual health education that doesn't fit their needs. They suggest solutions that include calls for easy access to counselling services, “kindness” and courage from each other to confront all bullying, and changes in how health and sexual health education is taught at school.

Discussion: Situated within a critical rights-based paradigm, the project aligns with an established human rights discourse. It answers the research question through collaborative and creative reflective processes that deliver young people's perspectives using video. Providing a nuanced understanding of young people's stories and perceptions on health, the video artefacts enable a wider dissemination of their ideas to other young people, families, and adults who provide care, education, and health governance. The project also demonstrates that youth-centric methods (such as participatory video and drama) can enable young people to participate as co-researchers in exploring the health problems that they see as most salient to them, gaining the benefits of participation (as promised under the UNCRC) and the opportunity to advocate for change in how schools, communities, and the government manage issues that impact on their health and well-being.

Conclusion: The participants identified that mental health issues are the key barrier to young people living healthy lives. They suggest a need for government, health professionals, teachers, and young people themselves to address the prevalence of in-school and online bullying and the distinct lack of appropriate sexual health education. This project demonstrates that the use of artistic and collaborative participatory video and drama methods can provide positive and empowering

experiences for young people and insights into their experiences and stories of health. It represents the first use of participatory video and drama with young people in the Aotearoa New Zealand health context and contributes to a wider repository of knowledge in participatory research with young people. The unique video artefacts present young people's perspectives in perpetuity, in their own images and literal voices, enabling them to be seen, heard, and considered by adults and other young people alike. This is an important example of research with young people, for young people, that can be disseminated to audiences not traditionally served by academic platforms. The interactions between the facilitators and participants, and between the participants themselves, constitute an original contribution to child and youth health research. The embedded stories do not simply mirror the world or experiences within it but aspire to express and make attainable much deeper truths and understandings. They present a call for wider use of creative and youth-centric participatory methods to enable young people to contribute directly to solving the problems that affect them.

Keywords: participatory video, drama, child health, youth health, participatory research, participatory action research, youth voice

Table of Contents

Abstract.....	2
Table of Contents.....	5
List of Figures.....	10
List of Project Videos and Links.....	13
Attestation of Authorship.....	14
Acknowledgements.....	15
Overview of the Exegesis	18
Chapter 1: Introduction.....	20
Researcher Positioning	22
All the World’s a Stage	23
We Are Who We Meet.....	25
On Moral Values and Ethical Obligations.....	25
Thoughts on Knowing	26
On the Value of Stories	27
Chapter 2: Background and Context.....	31
Patient-Centred Healthcare.....	31
The UNCRC and the Rights of the Child in Aotearoa New Zealand.....	33
Non-discrimination (Article 2).....	33
The Best Interests of the Child (Article 3)	35
Ensuring the Child’s Survival and Development (Article 6)	35
Participation (Article 12).....	36
History, Paternalism, and Participation	37
Politics and Patchy Progress.....	38
Measuring the Effects of Discrimination: Comparisons and Layering	41
Children’s Place in Aotearoa New Zealand Society.....	45
Shifting Paradigm and Priorities.....	46

Children’s Voice in Aotearoa New Zealand Healthcare	47
Participation Matters for Adults... What About Young People?	48
Building Relationships “For” But Not Necessarily “With”	50
Acceptance of Co-design With Adults, But Not Yet Young People?	52
Legislative Influence and Constitutional Confluence.....	53
Rights Without a Constitution?	54
Recent Political Movements.....	55
Roadblocks and the New Unknown: The Impact of COVID-19.....	56
Chapter 3: Research Design.....	58
The Research Questions	58
Primary Question.....	58
Sub-questions	58
Methodology: Participatory Action Research	58
A Rights-Based Approach.....	59
Nothing About Us Without Us	60
Tensions in the Making	62
Self-Realisation and Capacity Building	64
Construction of Childhood: Beings or Becomings?	64
Participatory Congruence: Consulting With Young People About Research Methods	66
Developing Video Facilitation Skills	68
Conceptualising the Unfolding Process of Knowing, Doing, and Becoming	69
Research and Creation “With” Not “On”	71
Importance of Process Over Product.....	72
Why Use Video: Tools for Change	74
History of Participatory Video: The Fogo Experiment Raises Voices of “The Silent”	78
Being Participatory	80
Research Ethics	81

Recruitment of Participants/Co-researchers	81
Creating Safe Spaces—Balancing Protection Against Potential.....	83
Chapter 4: Putting Theory into Practice—The Participatory Video Workshop.....	86
Entering “Their” World.....	86
Researching in the Time of COVID-19.....	87
Ongoing Delays and Shifting Timelines	89
Portrait and Landscape Views	90
Day 1 – Developing Portraits and a First Go With the Camera	93
Who Are They and What Moves Them?.....	93
Fitting In.....	95
Disability Is Bad Luck.....	95
Wanting to Be Seen and Make a Difference	96
Helping Other “Invisibles”?	100
Thinking About the “In-betweens”	102
Incorporating Their Shadow.....	104
Is This All About Self-Realisation?	107
“Not Gonna Miss My Shot”	108
The Technical Skills: See One, Do One, Teach One	110
Group Reflections and Closing the Day.....	115
Day 2 – “Story and Tell” and the Margolis Wheel.....	116
What Is Health to Me? Revisiting the Interview Technique	117
Telling Their First Story: Diverse Representations of Health.....	118
Group Reflection	126
Determining the Specific Health Issues Young People Identify as Most Important.....	126
Spinning the Margolis Wheel: Ideas to Action	128
The Political Side to Health: A Call for Revolution.....	133
The Problem With Human Nature.....	137

Moving Beyond the Political.....	140
Every Voice Counts: Using Democratic Process to Choose a Final Topic.....	141
Exhaustion and Changing Direction.....	143
Day 3 – Pre-production Analysis: Considering Cause, Effect, and Solutions.....	145
Planting the Seeds and Growing Problem Trees	146
River of Life and Audience Pathway	151
Storyboarding	153
Day 4 – Lights, Camera, Action.....	158
Day 5 – Paper Editing and First Cut.....	162
A Surprise Worthy of Note	166
Moving From Paper to Digital	167
Adding the Final Touches	170
The Show Must Go On: Sharing the Participants’ Videos.....	172
Rolling Out the Red Carpet, Virtually.....	172
Sam’s Story – Sassy 7 Productions	173
Quest for Courage – Just a Label Productions	175
The Change We Need – 8-Ball Productions.....	176
Walking in These Shoes – K4D & Company.....	178
Chapter 5: Reflective Provocations.....	179
Stories as Praxis: Leading the Way	179
Not With Anger but With Hope	180
The School Landscape and Confronting Dragons.....	182
Frustration With Complacency of Power.....	184
More Than Pointing Fingers: Finding Strength Within	185
Significance of This Research	188
On Pursuing a “Good Life”	189
New Tools for Change	190

An Online “Playground”: Voices Amongst the Chatter.....	191
New Ways of Learning and Collaborating.....	193
Importance of Reciprocal Relationships With Young People.....	193
Chapter 6: Future Possibilities: Where to From Here?	196
Recommendations	196
Policy.....	196
Education.....	198
Health System	200
Research	203
Limitations and Considerations.....	205
Young People Are Not a Homogenous Group	205
Recruitment May Have Left Some Still “Invisible”.....	206
Collective Versus Individual Perspectives	206
(As Yet) Unknown Ability to Inform.....	207
Final Comments.....	207
References.....	210
Appendix A: Ethics Approval.....	234
Appendix B: Participant Information Sheet.....	235
Appendix C: Parent Information Sheet.....	237
Appendix D: Participant and Parental Consent and Waiver Form	240

List of Figures

Figure 1	Interrelation Between Biology, Ecology, and Health & Development	42
Figure 2	Photo of InsightShare Participatory Video Course Participants	69
Figure 3	The Māori Ponga, or Silver Fern	70
Figure 4	Conceptual "Unfolding" of a Verse From "Desiderata"	71
Figure 5	Participatory Action Research Cycle	72
Figure 6	Example Images From the First Public Movies	75
Figure 7	Portrait Versus Landscape View	92
Figure 8	Creating Body Map Portraits	94
Figure 9	"Squeezing" Into Each Other's Portraits	96
Figure 10	Field Notes From the Portraiture Exercise	98
Figure 11	Depiction of a Veela	105
Figure 12	Impromptu Performance From Hamilton	109
Figure 13	The Disappearing Game: Group 1, Terminal Illness	111
Figure 14	The Disappearing Game: Group 2, Virus	112
Figure 15	Citizen Journalism and "News With Katie"	113
Figure 16	Maslow's Hierarchy of Needs	114
Figure 17	A Reflective Screening Session	116
Figure 18	Story and Tell, Part 1	118
Figure 19	Six Types of Shots	119
Figure 20	Behind the Scenes of "Story and Tell"	121
Figure 21	Story and Tell: AirPods	122
Figure 22	Story and Tell: The Plant	123
Figure 23	Story and Tell: A Journal	125
Figure 24	Hart's Ladder of Participation	127
Figure 25	A Conceptual View of the Margolis Wheel Exercise	130
Figure 26	The Margolis Wheel in Action	132

Figure 27 Group Process of Thematic Analysis	141
Figure 28 We Chose Our Topic!	143
Figure 29 Shaking Out the Heaviness (Video)	144
Figure 30 Shaking Out the Heaviness (Images).....	145
Figure 31 Problem Tree Analysis	147
Figure 32 Just a Label Productions Problem Tree	148
Figure 33 K4D & Company Problem Tree	149
Figure 34 8-Ball Productions Problem Tree	150
Figure 35 Sassy 7 Productions Problem Tree	151
Figure 36 Example of the River of Life Storytelling Method.....	152
Figure 37 Example of the Audience Pathway Storytelling Method.....	153
Figure 38 8-Ball Productions Storyboard	154
Figure 39 Sassy 7 Productions Storyboard	155
Figure 40 Just a Label Productions Storyboard	156
Figure 41 K4D & Company Storyboard	157
Figure 42 8-Ball Productions Filming	159
Figure 43 Just a Label Productions Filming	160
Figure 44 K4D & Company Filming	160
Figure 45 Sassy 7 Productions Filming	161
Figure 46 Lead Researcher Reflections After the Day of Filming	162
Figure 47 Just a Label Productions Editing	163
Figure 48 8-Ball Productions Editing	164
Figure 49 K4D & Company Editing	164
Figure 50 Sassy 7 Productions Editing	165
Figure 51 Lead Researcher Reflections During Editing	166
Figure 52 Participant Thank You Videos.....	167
Figure 53 "Hello" to InsightShare.....	169

Figure 54 Last Words From the Participants	169
Figure 55 Facilitator Wrap-Up Comments	170
Figure 56 Creating Space Project YouTube Channel	173
Figure 57 Sam's Story (Sassy 7 Productions)	174
Figure 58 Quest for Courage (Just a Label Productions)	176
Figure 59 The Change We Need (8-Ball Productions)	177
Figure 60 Walking in These Shoes (K4D & Company)	178

List of Project Videos and Links

Creating Space Project – Supporting Youth Voice YouTube channel:

<https://www.youtube.com/channel/UCekEZOZnSadZXRLVQgk6Lbg>

Exercises and workshop activities:

Impromptu performance from *Hamilton*: <https://youtu.be/PgFZ495i8sE>

Citizen journalism and “News with Katie”: <https://youtu.be/fb7yc1bjKeo>

Behind the scenes of “Story and Tell”: <https://youtu.be/SQOr5OOSTeQ>

“Story and Tell: AirPods”: <https://youtu.be/1G1UN-gFPho>

“Story and Tell: Hamish and His Plant”: <https://youtu.be/-Q1-5ofE2jc>

“Story and Tell: A Journal”: <https://youtu.be/fGDV6gV1LU8>

The Margolis Wheel in action: <https://youtu.be/803OpfOrTig>

Shaking out the heaviness: <https://youtu.be/CvFybwv4IsQ>

Reflections and messages from facilitators and participants:

Lead researcher reflections after the day of filming: https://youtu.be/r83D_oZvLCU

Lead researcher reflections during editing: <https://youtu.be/JoUQumZFpHM>

Participant thank you: <https://youtu.be/Uama8x2-WDM>

“Hello” to InsightShare: https://youtu.be/C7E2F-_Ti3c

Last words from the participants: https://youtu.be/XbGhd_b_-nQ

Facilitator wrap-up comments: https://youtu.be/_7Ipqv3hNbo

Final video artefacts:

Sam’s Story: <https://youtu.be/N8-uLttMbBk>

Quest for Courage: <https://youtu.be/wixW0SpjHdA>

The Change We Need: <https://youtu.be/atg2qDDyuN8>

Walking in These Shoes: <https://youtu.be/mAhhKTNtCFE>

Attestation of Authorship

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.

Michael Neufeld

August 1, 2022

Acknowledgements

To my “babies,” Naia and Mateo,
you have grown up alongside this project
and have been utterly forgiving every time I’ve said
“I’m sorry, sweetheart, but I just can’t play right now.”

I hope that you will come to understand
why this project was so important to me.
I want the world to listen to your voices,
recognise and accept your unique sparks,
and reward you with lives that are full of
love, purpose, and meaning.

Thank you for filling mine with all three.

Love always,

Daddy

July 2022

Completing this exegesis would not have been possible without the generosity and kindness of many. I would like to first thank all of the young people who participated in the project—from those in the advisory groups who aided in the design through to those who participated in the workshops as co-researchers. You have all shown a desire to make the world a better place, and I believe that you can and will “fix” whatever problems you inherit. I am still raving about your incredible dedication and talents to anyone who will listen. You have given me hope for the future. You are amazing!

I'd like to thank Tim Bray and the Tim Bray Theatre Company and Stephen Dallow and the Kids4Drama Youth Theatre Company for welcoming me into your troupes and sharing your dramaturgy. You showed me how you make space for young people to explore ideas and build their confidence. You truly embody what it means to put young people first.

Stephen, your way of being alongside young people is remarkable. You are an incredible role model for them, and the participants in the project said it themselves: you are always listening.

To my supervisors, Dr Cath Conn, Dr Tineke Water, and Dr Jennifer Nikolai, you have been there for me through all the trials and tribulations. From lockdowns and cancellations to new iterations and possibilities, I've been lucky to have such a breadth of experience to draw on.

Cath, you have been unflappable and kept me moving without fanfare. I have found your supervisory approach inspiring—in particular, how you brought many of us together through your thesis lab.

Jennifer, your intense creativity and positivity allowed me to believe in the importance of beauty and aesthetics. You're always willing to pick up a call or look at things from a new angle or even just talk about home in the land of the Great White North, and I confess to purposefully hording your positive comments in my drafts long after I should have deleted them and moved on.

And Tineke, my friend, colleague, and mentor, you have been supporting and pushing my thinking for almost 20 years. I'm not sure what you did to deserve such penance, but for this, I owe you a particular depth of gratitude. You've listened to my angst often and challenged my assumptions frequently in order to direct my energy. You have introduced me to people worthy of emulation, explored ideas beyond all expectation, and helped me remember that life is indeed a dance. I miss our philosophical catch ups over a Trappiste and hope we are in the same country again sometime soon.

To Paul Ripley, my friend and co-facilitator, thank you for being the extra hands needed to be in three places at once during the workshops. Travelling to Oxford together to train at InsightShare and sip pints at The Eagle and Child in the shadows of Tolkien and Lewis was incredible. I am looking forward to future participatory video projects together.

To Nick and Chris Lunch and our facilitation gurus Sabine and Maddy at InsightShare, thank you for imparting your knowledge and methods and showing us that cultures are indeed living and in need of compassion and care. I hope that we have done justice to your teaching. Looking forward to our New Zealand reunion in 2029.

To Jason Harvey, thank you for so generously sharing your time and technical resources to support this project during the critical final editing phase of the workshop.

And above all, I want to thank my Sarah. Stories have played a large part in this project, and whenever I think of our story, I can't help but think of the lyrics from Pearl Jam's "Future Days": "everything I have found dear, I've not found by myself." We have sailed across oceans and climbed mountains, overcome injuries and illness. You have supported me selflessly, always creating space for the pursuit of dreams. Thank you for the hours, days, months, and years that I've been buried in thought and writing. Thank you for all the times you've listened when I just couldn't stop talking about perceived injustices or hopes for the future. You remind me that not everything is as complicated as it seems and that love is far more important than things.

Beyond all else, thank you for bringing our children into the world. Everything changed colour when they arrived, and there is no doubt that every child deserves to be loved in the way that you love them.

Without you, none of this would have been possible.

Overview of the Exegesis

Chapter 1: Introduction

This chapter defines the context of youth health in Aotearoa New Zealand and introduces the disparity between how adults and young people are involved in the development of health policy and provision of health services. It introduces the inception point for this research, offering a reflexive exploration of the researcher's positioning on the value of stories and creativity in the development of knowledge.

Chapter 2: Background and Context

Though the lens of a critical literature review, this chapter outlines current trends in patient-centred and child and youth healthcare and considers the status of children and young people's health in Aotearoa New Zealand and globally. It highlights the legal and ethical obligations that Aotearoa New Zealand holds in relation to the United Nations Convention on the Rights of the Child (UNCRC) (1989) and includes commentary on current political trends that hold the potential to both hinder and improve the general health and well-being of children and young people in Aotearoa New Zealand.

Chapter 3: Research Design

Chapter 3 outlines the research question and sub-questions and the methodological and epistemological approaches central to the project. Participatory action research (PAR) informed by critical theory and a rights-based approach to participatory video and drama methods are explored and linked to a Freirean concept of liberation through the development of individuals' personal capacity (the capacity in this instance being an individual's ability to be critically conscious and capable of reflecting on and articulating their perspectives in their own voice).

Chapter 4: Putting Theory Into Practice—The Participatory Video Workshop

Chapter 4 describes the preparation, processes, and practices of the five-day participatory video and drama workshop, including the rationale for the exercises chosen. It critically examines the stories and perspectives that the participants shared during the workshop, outlining the collaborative analysis approach used and providing context for the creative choices they made. This chapter also presents the video artefacts that the participants created and decided to share with an audience of their

peers, the research facilitators, the theatre director, and the wider community using social media (a YouTube channel). These final videos provide insights into the health issues that the participants believe are most salient to young people.

Chapter 5: Reflective Provocations

Using the key themes from the participants' work as a foundation, this chapter provides reflective provocations on key aspects of the project. Focusing on the health issues and potential solutions identified by the participants, it acknowledges and situates new understandings through a critical commentary that explores the landscapes and personal geographies that the participants have exposed in their videos. The chapter revisits the research question and sub-questions in this context, reflects on the value of building reciprocal relationships with young people, and establishes the significance of the research.

Chapter 6: Future Possibilities: Where to From Here?

This final chapter provides the researcher's recommendations for policy, education, health systems, and research within the context of the methodological and epistemological limitations of this project. It also presents final thoughts for future action and implementation.

Chapter 1: Introduction

This chapter defines the context of youth health in Aotearoa New Zealand and introduces the disparity between how adults and young people are involved in the development of health policy and provision of health services. It introduces the inception point for this research, offering a reflexive exploration of the researcher's positioning on the value of stories and creativity in the development of knowledge.

As of June 2020, 943,200 young people under the age of 15 years were living in Aotearoa New Zealand, comprising 19.5 per cent, or approximately one-fifth, of the country's population (Ministry of Health, 2021). Between 2014 and 2018, there were 345,492 hospitalisations for people under the age of 15 years, with approximately 49 per cent of emergency presentations deemed to be the result of injury or illness that was immediately life threatening (Ministry of Health, 2019). The Health and Disability System Review (2020) also identifies that "eleven percent of children [in New Zealand] are living with disabilities" (p. 15). There is no doubt that young people are significant users of and critically reliant upon the Aotearoa New Zealand healthcare system (Child Poverty Action Group, 2021).

Yet, despite their reliance on these services, young people's perspectives on health and healthcare are often overlooked or at least not given primacy in the design and delivery of their care (Dickinson, Wrapson, & Water, 2014). Annual planning documents created by Aotearoa New Zealand district health boards (DHBs) directly reference the rights of children to have a say in the things that affect them and stipulate that "children, family and whānau will be at the centre of service design" (Aickin & Jellyman, 2012, p. 29). However, despite the stated commitment to children's rights to "participate in decision-making and, as appropriate to their capabilities, make decisions about their care" (p. 11), there is a paucity of evidence showing how such ideals have been actioned or implemented. There are also examples in practice in which clinicians and services continue "working in the dark" in regards to their understanding of children's experiences of care (Neufeld, Spence, & Water, 2017) and a growing international call from young people and child health clinicians for rights-based standards, developed in collaboration with young people, to be

applied to all clinical procedures (Bray et al., 2021). Decisions are frequently made by adult proxy—adults assuming they know what children are thinking and experiencing and making decisions on children’s behalf without consultation (Coyne & Carter, 2018).

Children exist in complex and, at times, disparate emotional geographies (Blazek, 2018). Landscapes and conceptions such as family, school, and physical and emotional health are both physical and emotional spaces (Blazek & Hraňová, 2012). More specifically, these conceptualisations underpin policy and professional practice with children and the wider politics of children and childhood (Blazek, 2018). Lawton (2013) and Lloyd (2013) also point out that for adults to understand young people, we must ourselves be mature enough to listen and relive with them (and through them) the thoughts and feelings of childhood. For us to do this reliably in the realm of healthcare, more needs to be done to ensure that children and young people are consulted on their experiences of it.

Eliciting information from young people can be a complex and daunting endeavour, with concerns about risk and capability often raised as barriers to actively seeking young people’s views (Dickinson et al., 2014; Ministry of Social Development, 2003). Effectively, this impacts on children’s fundamental right to participate and be heard on things that affect them, as outlined in Article 12 of the United Nations Convention on the Rights of the Child (UNCRC) (1989). The convention states that all children should have a say “on every aspect of their life – at home, in school, in healthcare, in play and leisure, in the media, in the courts, in local communities, and in local and national policy-making, as well as at the international level” (Lansdown, 2011, p. vi).

Co-constructing knowledge with young people has become more common in recent years, and using methods that involve creative methods even more so (Coyne & Carter, 2018). Blazek (2012) points to the benefits that participatory video with young people can bring, highlighting the differences between participatory action research (PAR) undertaken with children and PAR undertaken with adults. Blazek suggests that the creative process of developing videos is as important as the video artefacts themselves, as it elicits the participants’ voices and addresses the additional layers of disempowerment that young people face. Coad & Evans (2007) also explain that including

young people in data analysis substantially increases their voice, lessens the risk of tokenism, and improves outcomes for young people, organisations, and communities.

Participatory video processes can diminish the distinct power differences that exist between researchers and young people and can meet the diverse needs and motivations of each individual participant (Blazek & Hraňová, 2012). This project seeks to emulate this commitment to child rights and role model the use of participatory video and drama as a means to amplify and promote the perspectives and voices of young people. Participatory video is the practice of using “a set of techniques to involve a group or community in shaping and creating their own film” (Lunch & Lunch, 2006, p. 10). By using collaborative and participatory methods to create a literal space for young people to tell their stories about health and healthcare, this project can inform policymakers, healthcare providers, and indeed anyone involved in the care of young people of the health issues most salient to them.

Researcher Positioning

My specific interest in young people’s rights in relation to their health and well-being began in my 30s when, as a new clinician, I witnessed children’s suffering and fear in a children’s emergency department. Specifically, I was shaken by seeing the negative psychotropic reactions that some young people had when emerging from ketamine sedation, as well as the speed at which treatments could be forced upon them. I was concerned with our team’s inability (and my own) to explain to the young people and their families what exactly was happening to them and what, if any, harm might come from it. In one instance, a 12-year-old young girl emerged from ketamine sedation, screaming in terror and begging to know if she were dead. She told us that her grandmother had come to her and told her she had died. We learned later that her grandmother had passed away a year prior. This young girl told us she had watched us set her broken arm and could hear our conversations while floating above her own body. Even with all our team’s knowledge and experience (we represented the largest and most advanced paediatric emergency healthcare facility in Aotearoa New Zealand), we had no answers and no strategies whatsoever to assess what exactly she had experienced, what she thought about it, or how it might affect her going into the future. More importantly, not knowing

meant until we could figure it out, we could not stop it from happening to other young people. I wanted to talk to more young people about their experiences.

That sense of wanting to understand what was happening for the young people during ketamine sedation led to my exploration of the moral and ethical tensions within paediatric practice (Neufeld, Water, & Godbold, 2012) and subsequently my master's research into health professionals' stories of paediatric ketamine sedation (Neufeld, 2016). I found that despite wanting to "know," in many instances clinicians are "working in the dark" when it comes to children's experiences of care (Neufeld et al., 2017). The realisations showed me that to achieve positive change in paediatric practice, both young people's experiences and clinicians' perspectives must be considered. It also taught me that by looking at potential risk and harm and potential solutions through critical and at times opposing lenses, we can put aside the presupposition that our current understandings are infallible.

I thus come to this research project with a distinct appreciation for how much our clinical actions and wider "adult" behaviour and actions are predicated on what we *think* or *suspect* is happening for young people as opposed to what we *know* to be happening. I also come with an awareness of the disparate views that healthcare practitioners hold on what contributions young people are capable of and should be entrusted with.

All the World's a Stage

As an adult, I lived and worked as a professional musician and in the world of boat building and yachting until an unfortunate illness-fuelled epiphany drew me into the nursing profession. However, long before any of that, at 19 years of age, my first undergraduate pursuit was a Bachelor of Fine Arts. It was an acting major with an art history/psychology minor. I went on to specialise in Shakespearean and musical theatre and studied psychology in the hopes of convincing those responsible for casting that, at 20 years old, I understood human nature sufficiently to deliver a plausible Richard the III monologue ("Now is the winter of our discontent made glorious summer...") (Shakespeare, 1987, p. 627). I can't say for certain that my performance was worthy but, nonetheless, I was accepted into the troupe.

I practised stagecraft at the Phoenix Theatre in Victoria, British Columbia, Canada, for the better part of four years. A highlight was delivering Jaques' "[All the world's a stage](#)" speech from Shakespeare's *As You Like It*.

All the world's a stage,
 And all the men and women merely players;
 They have their exits and their entrances;
 And one man in his time plays many parts,
 His acts being seven ages. At first the infant,
 Mewling and puking in the nurse's arms;
 And then the whining school-boy, with his satchel
 And shining morning face, creeping like snail
 Unwillingly to school. And then the lover,
 Sighing like furnace, with a woeful ballad
 Made to his mistress' eyebrow. Then a soldier,
 Full of strange oaths, and bearded like the pard... (Shakespeare, 1987, p. 239)

At the time, I thought it such an accurate reflection of the human condition that I secretly marked out my own life's path against its transitions and wondered who will I love, what battles will I fight, how many children will I have, and of course what will become of me in old age? Jaques' apparent cynicism and disdain for the frail human condition seemed appropriate to the invincible younger me. Now, reflecting on his seven stages of a life, I can't help but wish I could meet Shakespeare and at least debate his representation of childhood: "the whining school boy, with satchel and shining morning face, creeping like snail unwillingly to school" (Shakespeare, 1987, p. 239).

Such a depiction of children in a Western paradigm is relatively commonplace and perhaps might accurately reflect how young people (or anyone) undertake activities that are not of their own volition. They are, however, the antithesis of my experience as a father of two school-aged children and as a collaborator with the young people in this research project. None of these young people seem to shy away from the rigours of hard work *if* it serves their interests, nor do they whine or whinge about challenges faced while learning new skills that they themselves want to master. On the contrary, in their hopes of negotiating their own learning, they show courage, creativity, and brilliance. Regardless of their age, size, or level of experience, they display incredible ability, strength, and aptitude. So, perhaps it is we adults who constrain the young, painting them with pictures of laziness and incompetence to free ourselves from the necessary work required to inspire them.

We Are Who We Meet

I am a stalwart of the idea that we are both who we meet and more than the sum total of our experiences. In other words, we are influenced by all we come in contact with, and our individual experiences and interpretations foster leaps of understanding that transcend mere addition. I would argue that this is particularly true for children, who develop their first sense of self and identity through both intrinsic and extrinsic forces. Their “way of being” is thus determined by cognitions created from their embodied position—multidimensional acquisitions of sensory experiences and developing language (Goswami, 2020; Kohler, 2008).

As for me, my pursuits as an actor, musician, boat builder, nurse, clinical educator, father, and now academic researcher are all themselves embodied forms of practice, each with its own unique language and praxis. This means that I have been a practitioner in some form or other for my entire adult life. The importance of signposting these disparate practices is that they now literally frame how I perceive the world around me and all its various threats and potential. It is the unique assimilation of these different ways of being that provides the lenses through which I examine the perspectives that the participants brought forward in this project and enable me to function effectively and credibly as a research facilitator and participatory video and drama practitioner.

On Moral Values and Ethical Obligations

I believe that the ethical and moral tensions inherent in working with children and young people are immutable without a fundamental change in what we, as healthcare practitioners, choose to value. Aotearoa New Zealand has signed the UNCRC (1989), so it is important that we foster our curiosity about young people’s experiences and perceptions to provide a measure from which to gauge our success against the UNCRC outcomes that we claim to value.

Establishing exactly how we structure our values is no easy task but, having borne witness to (and been a perpetrator of) many occasions of young people’s suffering within clinical spaces, I am convinced of the need to incorporate their stories and perspectives into our understandings with the same determination and effort that has been shown with adults. This seems to me the only way to recognise that children and young people are themselves intrinsically valuable.

The young people that will be introduced through this work have given so much time and insight into their perspectives on health and well-being—indeed, on life—that I found it difficult to start this writing. I suspect that all emerging researchers are confronted with a sense of such paralysis. I know that the best way forward is to take a tentative step, so will move now to reflect and think on thought itself.

Thoughts on Knowing

Wilczek (2015) suggests that problems that continue despite repeated efforts to address them will not be solved by doing again what has already been done. Youth health outcomes in Aotearoa New Zealand have remained suboptimal since the signing of the UNCRC more than a quarter of a century ago, and yet, despite this, approaches to resolving the inequities in child health outcomes have been relatively conservative and ineffective, particularly for the highest risk groups of Māori and Pasifika children and any children living in poverty or with disability (Child Poverty Action Group, 2021; UNICEF, 2007a; UNICEF Office of Research, 2013, 2014, 2016, 2017).

The real challenge in coming to “know” in relation to health and healthcare is that “knowledge” is propositional, which means it is reliant on having justified beliefs—justified beliefs being an alignment of evidence that supports the beliefs being expressed. However, although we can believe that something may be true (for example, a need for change), Williams (2007) suggests that “knowing” what was and currently is, is easier than knowing what will be. The nature of knowing the future (upon which healthcare bases much of its utilitarian decisions) is therefore far more complex. Understanding this complexity is particularly important to decision making in clinical practice. We don’t know or fully comprehend children’s experiences of health and healthcare, not because it is impossible, but because it is not yet common practice to work collaboratively with young people to expand our knowledge of their perspectives (Coyne & Carter, 2018). Even though all adults were once young, we simply do not have the innate ability to understand young people’s perceptions and rationales without inquiry. We cannot imagine our way into seeing things through children’s lenses to contextualise their experiences any more than we can remove our own filters of experience and return to being a child. As the philosopher Heidegger suggests in *Being and Time* (1962), we adults have

already been torn from childhood by experiences of shock and awe—forced into our adult shapes and ways of being, from which we cannot return. Thus, without young people’s participation in knowledge creation, decisions about the healthcare they receive are devoid of the explicit benefits that their knowledge can provide (Wilkinson & Wilkinson, 2018).

On the Value of Stories

After reading Arthur Frank’s *The Wounded Storyteller* (1995) in 2008 and more recently the clinical psychologist Jordan Peterson’s *Maps of Meaning: The Architecture of Belief* (2002), I’ve come to agree that stories are how we view and understand the world. Arguably, even research findings are in themselves a story, and I am now, more than ever, an avid collector of them.

Story is a central tenet of creativity and an integral aspect of our being, both genetically and psychologically embedded within us (Fletcher, 2021; Peterson, 2002, 2018). Stories are what create a counterbalance to the complex chaos of the world and the antithetical strict and repressive order we find in societal structures such as laws and customs. More specifically, stories situate us and advance us as individuals, as communities and, more broadly, as a species because they evolve our structure of values. This enables us to more easily see the world through abstractions that reduce the infinite number of complexities to more manageable representations (Lwin, 2019). As I will explore further in this work, by gathering and considering young people’s stories and creating artistic representations of them in video, we have the potential to foster change through the establishment of new and agreed-upon patterns. These patterns exist across many stories and are pulled together to form a more singular story, making life’s potential risks and possibilities more easily identifiable and relatable (Fletcher, 2021).

The value of heuristic patterns in story and their contributions towards making sense of the world cannot be underestimated (Peterson, 2018). The stories embedded in a participatory video don’t just mirror the world or experiences within it: they aspire to express and make attainable much deeper truths and understandings. In this way, all stories (in particular archetypal stories) allow us as the audience or reader to see or experience them as enduring representations of living cultures, as

examples of wisdom and beauty, and as maps to follow (Babich & Ginev, 2014; Hickel & Haynes, 2018).

Stories allow us to position ourselves so that we clarify to ourselves and project to others what we believe. Placing our own experiences within and alongside the frameworks of particular stories is a means of collectively guiding ourselves towards how we should be and act. As Hogenboom (2015) points out, the use of story has enabled a collective “hive” mentality that has accelerated human progress in ways no other animal could achieve. Stories therefore serve as judges of our actions and inactions just as any literal existential judge might, with language laying out our values in a hierarchy that forms the landscape we live within and providing the maps to be followed as purveyors of purpose.

The success of humanity’s evolution has been in part because our language identifies not only objects but also, and more importantly, concepts (Farrar, 2022). We can communicate plans, reflections, and emotions and situate ourselves into larger societal constructs by sharing stories. Take, for example, the stories that children create to navigate play and establish their place in the world. Peterson (1999, 2018) explains that children’s use of stories is far more complex than simply acting out or mimicking what they have seen done by others. On the contrary, children take all their observations over time and amalgamate them into a conceptual understanding of how to behave in order to act out a story in accordance with that collective representation. It is incredibly sophisticated. Children and young people’s stories are therefore complex representations and adoptions of the “essence” of the people, characters, and situations they are portraying. This is how they make sense of and communicate their positions and understandings, and it is this adoption, adaptation, and sharing of stories that enables the pursuit of self-actualisation (Rogers, 1961; Thorne & Sanders, 2012).

Provided we listen, through the sharing of stories we can learn from others’ experiences, their losses and gains, without actually risking our own literal skin. We do not need to experience young people’s struggles to attend to them, as listening and considering their perspectives can illicit shared understandings (Frank, 2002, 2005, 2010).

Anecdotally, stories from young people, their families, and my colleagues have immediately affected my actions as a clinician and in some cases forever changed how I respond to patients. Stories can therefore inspire and influence practice (Zak, 2013). It is a short leap to view the process of undertaking and disseminating any research as an example of sharing “stories” so that others learn, adopt, and adapt without having to re-do the same experiments. In this way, stories can provide us with compounding gains.

Over the last two centuries, information and stories have been created and shared faster than ever. With the advent of the printing press and media such as radio, film, and TV, ideas spread very quickly, enabling incredible sharing of ideas and rapid progress. The more people gained access to collective knowledge, the more chance it could be built upon. Yet all of these early tools for sharing information pale in comparison with the power of the internet. In 2013, David Shilling (2013) claimed human knowledge was doubling every 12 months but pointed out that “the internet of things” would soon lead to a doubling every 12 hours. Since then, social media has become ubiquitous to billions of people, and platforms such as Facebook, YouTube, Instagram, Google, and TikTok (among others) are the new distribution networks for stories and ideas. The realm of social media has upped the ante with its ability to spread ideas as efficiently as a virus and without the costs and control of previous technologies. With access to the internet and a computer (or even a smartphone), almost anyone can publish ideas and stories that have the potential to reach millions of people.

We now have ever increasing access to ideas—good, bad, and indifferent. Virtually every idea now holds the potential to go “viral” and promote local and systemic actions and reactions. Of course, reactions can be planned but they can also be potentially unforeseen. Social media is now ubiquitous to most young people’s lives (Tseng and Wang, 2021). If we don’t want to miss out on the unknown potential that each and every young person has to offer, it is vital that we find ways of working with them using social media to access and share their unique knowledge and perspectives.

Lunch and Lunch (2006) describe participatory video as “particularly useful in giving marginalised groups a means to ‘show and tell’ their situation, their challenges and their achievements in their own words and images” (p. 14). This *Creating Space* project acknowledges this and sets out

to answer the question, “How can participatory video and drama facilitate collaboration with young people to empower their voices in healthcare policy and provision?”

Chapter 2: Background and Context

This chapter places my research within the wider context of children's health and the standards set out in the United Nations Convention on the Rights of the Child (UNCRC) (1989). It explores the existing literature around (1) patient-centred healthcare and a growing focus on the design and delivery of healthcare with the patient at the core; (2) the United Nations Convention on the Rights of the Child (UNCRC) and its recognition in Aotearoa New Zealand; (3) paternalism and politics of youth participation; and (4) legislative and constitutional influences on youth voice.

I undertook a literature review at the beginning of this research to determine current understandings of children's health and well-being in Aotearoa New Zealand. This literature review further explored if and how children participate in the creation of health policies and service delivery in accordance with the rights afforded to them by the UNCRC (1989). I conducted the literature search using the databases CINAHL, ProQuest, EBSCO, and Web of Science, using combinations of the following search terms: "child", "children", "health", "child centric", "outcome", "participation", "collaboration", "human rights", "children's rights", "voice", "best interest", "legislation", "patient", "consumer", "service user", "practitioner", "health professional", "nurse", "doctor", "clinician", and "policy". As I gained greater understanding, I sought additional information from Aotearoa New Zealand district health boards (DHBs) via email requests, personal contacts, and website searches. Lastly, I completed additional searches of "grey" material, seeking to explore wider media perspectives and reporting, using Google and Yahoo search engines.

Patient-Centred Healthcare

Whether adults or children, patients have traditionally been the recipients of healthcare rather than active designers of or participants in it (Farrington, 2016; Sanders & Stappers, 2008; Stalberg, Sandberg, Soderback, & Larsson, 2016). More recently, borne from a consumer culture, there has been a trend towards inclusion of adult patient perspectives in their care and an adoption of an experience-based co-design (EBCD) philosophy (Boyd, McKernon, Mullin, & Old, 2012). One important benefit of EBCD is that it allows patients and practitioners to engage in difficult and challenging conversations to improve understandings and effect positive change (Donnetto,

Tsianakas, & Robert, 2014). EBCD helps designers and practitioners in “seeing the person behind the patient” (p. 16). Patients report this as an empowering experience and, in Aotearoa New Zealand, some DHBs have now fully committed to the tenet of patient participation and co-design in their adult service delivery, creating and implementing co-design toolkits to guide development (Boyd, McKernon, & Old, 2010). However, despite these reported successes, there is less evidence of similar commitments to consult children and young people in healthcare situations, design, or policy. While there is a growing body of literature regarding the value of child and youth participation, in healthcare there remains a paucity of research on or from children’s perspectives (Gilljam, Arvidsson, Nygren, & Svedberg, 2016). The importance of including children in EBCD is twofold. First, the health service itself benefits from the mitigation of unintended negative consequences (and therefore future costs). For example, co-design has been successfully used to create apps that allow young people with severe depression to self-monitor their mental state, thereby assisting with timely response from the health service and mitigating the frequency of hospitalisations and severity of exacerbations (Thabrew et al., 2018). Second, children gain self-confidence and an increased sense of belonging, promoting good citizenship, agency, and self-advocacy skills that carry on into their adult lives (Children’s Commissioner, 2017a, 2017b; Office of the Children’s Commissioner, the Paediatric Society New Zealand, & Ko Awatea – Centre for Health System Innovation and Improvement 2013).

Coyne (2008) noted that in the United Kingdom (UK), there has been ongoing concern regarding the lack of information available on children’s involvement in healthcare and treatment services and specifically identified that children’s views were given insufficient priority by policymakers, health services, and health professionals alike. Since 2008, however, the UK government has begun to address this issue through the implementation of legislative acts such as the Children and Young Persons Act (2008), which amended the 1989 act (Children Act 1989) and, though not mandatory, recommends that all new policy and legislation be considered in relation to its potential impact on the young before it is passed.

The extent to which children’s voices are considered in Aotearoa New Zealand health policy remains a pertinent question. It is important not only because of the ethical and moral duty of care that

health professionals hold for children, but also for the definitive legal mandate to consider children and young people's perspectives as set out in Article 12 and 13 of the UNCRC (1989).

The UNCRC and the Rights of the Child in Aotearoa New Zealand

Aotearoa New Zealand is a signatory to the UNCRC (1989), having ratified the treaty in 1993 and joining 194 countries in a formal commitment to advancing and promoting the well-being of children. The 54 articles contained within the UNCRC have been conceptualised into four fundamental principles that form the crux of children's rights and governments' responsibility to act on them:

1. Non-discrimination (Article 2)
2. The best interests of the child (Article 3)
3. Ensuring the child's survival and development (Article 6)
4. Participation (Article 12)

These principles are directly applicable to children's rights within healthcare and, more importantly, form the basis for any argument suggesting that children's opinions and views on healthcare should be considered and acted on.

Non-discrimination (Article 2)

The principle of non-discrimination is intended to ensure that factors such as race, religion, language, parents' background, culture, gender, socioeconomic status, disability, and age itself do not stop children from being able to participate in society or achieve positive health outcomes to their individual capacity. The principle demands that no child be treated unfairly for any reason; importantly, this is inclusive of their age. This is vital because children are particularly vulnerable to acts of discrimination, as they experience an exacerbation and layering of discriminatory effects (Johnson, Agbényiga, & Hitchcock, 2013). They are subject not only to all factors that marginalise their parents or family unit, but also to the additional discrimination and marginalisation that occurs when their age may preclude them from making their positions known or having their positions recognised.

While the very young may be incapable of articulating their position, an equally common factor in the marginalisation of children is adult perceptions and beliefs about children's age, ability, and value, which can lead adults to make decisions on children's behalf by proxy, without consultation (Coyne & Carter, 2018; Qvortrup, Corsaro, & Honig, 2009).

In contemporary Aotearoa New Zealand healthcare, age rather than maturity (individual capacity) is the primary factor used to determine whether children will or will not be consulted about their thoughts on care (van Rooyen, Water, Rasmussen, & Diesfield, 2015). As opposed to a maturity-based approach to children's inclusion, age-based policy frequently precludes children and young people from having a voice in their care, even in instances where they possess the life experience and ability to do so and would be perfectly able to exercise their autonomy (van Rooyen et al., 2015).

The notion of autonomy itself brings additional complexity. Healthcare professionals remain uncertain as to how to establish the degree to which children and young people should exercise autonomy given that the ability and desire to express their autonomy is variable. Even when fully competent, children and young people will sometimes want to make decisions for themselves and sometimes want others to make these decisions on their behalf (Carter, Bray, Dickinson, Edwards, & Ford, 2014). This suggests that age alone may be a poor indicator of competence and should not be a point of discrimination that withholds the fundamental human rights that have been afforded to every other human being (van Rooyen et al., 2015).

Despite governmental commitment to the aforementioned UNCRC principles (see the start of the "[The UNCRC and the Rights of the Child in Aotearoa New Zealand](#)" section [page 33]), a quarter of a century on, child health outcomes in Aotearoa New Zealand remain subpar in comparison with many other Organisation for Economic Co-operation and Development (OECD) nations and, according to the Health and Disability Commissioner, are "requiring urgent attention" (UN Convention on the Rights of the Child Monitoring Group [UNCRCMG], 2017, p. 6). This is particularly so in relation to areas of child violence, abuse, neglect, and health outcomes for Māori children, Pasifika children, and children with disabilities. All children, but particularly these additionally marginalised groups, are dependent on access to relevant healthcare services, making

them especially vulnerable if they cannot engage with those services or if the services do not know or consider their specific needs.

The Best Interests of the Child (Article 3)

In all decisions affecting children, their best interests should be a primary consideration, and the manner in which the determination is made must be “applied in a systematic manner” (United Nations High Commissioner for Refugees [UNHCR], 2008, p. 20). This second principle is arguably the very reason the UNCRC principles were proposed and instituted, and yet establishing “best interests” is far from easy. There are no clearcut guidelines on how to weigh a child’s own beliefs on what is best for them against potentially countering paternalistic positions.

Parents have traditionally determined a child’s best interests. However, following the introduction of children’s rights in the UNCRC, such power is no longer unlimited. Health professionals can find themselves caught in what has been described as the “zone of parental discretion” (Gillam, 2016, p. 4), a space that is rife with moral and ethical tensions if those health professionals find themselves at odds with the parents’ values, understandings of health, and expectations of life and death. The challenge in establishing a child’s best interests lies in the impossibility of projecting every possible outcome from any given action. All procedures, invasive or otherwise, carry with them an inherent risk, but so too does overriding a child’s or family’s decision should they wish not to receive the care (Gillam, 2016). Gillam goes further to describe the difficulty in maintaining children’s rights to autonomy and self-determination, pointing out that any breakdown of the family unit, caused by the removal of either parental or child rights, has the potential to negatively affect a child’s well-being and future development.

Ensuring the Child’s Survival and Development (Article 6)

Article 6 of the UNCRC states that “Children have an inherent right to life, and governments should ensure to the maximum extent possible that children can survive and thrive” (UNCRCMG, 2017, p. 5). Acknowledging that childhood is rife with exposure to risk, this tenet suggests that governments have a responsibility to minimise those risks to help children safely navigate their developmental years. In the Aotearoa New Zealand context, there is an expectation that all efforts be

made to ensure that children have adequate access to healthcare. From immunisations, to other primary healthcare initiatives, to more acute and tertiary services, any approach to improving child survival rates should not be limited to reactionary physical treatments but should include “wraparound services” (Ministry of Social Development, 2015, p. 7). The UNCRC stipulates that these services should be child centric and meet children’s individual needs relating to adequate education, housing, and food security while also establishing a high degree of health literacy and diminishing the inequities caused by discrimination.

Participation (Article 12)

If we accept that access to an environment that maximises the potential for positive health outcomes is an inalienable right for children and young people in Aotearoa New Zealand, we need to then consider how such environments come to exist and what such a context might look like. Fundamentally, for individuals to meet their potential, they must have some degree of autonomy and agency—both of which require the freedom and ability to change either the environment or themselves to make gains.

Article 12 in the UNCRC stipulates that “Children have a right to an opinion, and for that opinion to be heard, on matters that affect them” (UNCRCMG, 2017, p. 5). Views on children’s rights to inclusion, expression, and self-determination are complex and divergent. On one hand, children are often seen as incapable of making decisions beyond their immediate needs or concerns; on the other, it can be argued that children are the only ones to know what is in their best interests (Carter & Ford, 2012; Coad & Shaw, 2008). The former positions children in a state of immaturity, which effectively precludes them from understanding the adult world or at least of being able to articulate their experiences of it or to predict outcomes accurately (Kirk, 2006). This perspective also aligns with a common paternalistic discourse in which children are seen as too vulnerable to make decisions and therefore need protecting from the ills of an adult world. Paternalistic perspectives are somewhat at odds with the intentions of Article 12, which seeks to acknowledge that children and young people can in fact possess expertise in the things that affect them.

History, Paternalism, and Participation

The paternalistic intent of not seeking children's input into and opinions on decisions about their care is, ostensibly, to keep them safe. However, it may also be as much about protecting adult power and resources as it is about the children's best interests (Alderson, 2007; Carter, 2009). It is not difficult to imagine (and perhaps be fearful) that children might want a radically different healthcare system. However, there is also the distinct possibility that children might not want revolutionary change at all, but rather merely opportunities to be involved in decisions surrounding their care. Santos, Silva, Depianti, Cursino, and Ribeiro (2016) explain that children's views on hospitalisation include a general acceptance of both the need for treatment and systemic limitations. However, they also identify a strong resentment in young people about not being treated with respect: that is, not being consulted or informed about decisions regarding their care and the rationale for health professionals' actions (Santos et al., 2016).

A UK scoping review of children's choice in healthcare by Coad and Shaw (2008) identified that children want more consultation and input into the care they receive. Skyrme and Woods (2018) go further to explain that a desire to contribute to and participate in healthcare decisions is inherent in virtually all children, whether able bodied or disabled. Furthermore, Lloyd and Emerson (2017) have found a strong correlation between children's subjective sense of "positive well-being" and their participation in decision making at home and school; they identify that, in their pursuit of self-actualisation and ultimate attainment of positive well-being, children have a fundamental need to feel valued and "heard" when contributing to decisions being made on things that affect them.

These perspectives sit in opposition to a more traditional and paternalistic approach that excludes young people from being active contributors to decisions about their own care, which potentially marginalises and disempowers them. Such a paternalistic approach can marginalise the young even in situations where they are fully capable of making determinations or contributions that would benefit them. Coyne (2008) points out that children's attempts to participate are often thwarted by adults' actions, and thus children tend to assume a passive role within a traditionally paternalistic healthcare system, thereby leaving the status quo unchanged. Decisions on a person's competence and

whether to assume paternalistic power that are based solely on a status granted by age as opposed to maturity and capacity are effectively discriminatory.

In the legal precedent established in *Gillick v West Norfolk and Wisbech Health Authority* (Healthcare Ethics and Law, n.d.), paternal authority was determined to apply only until the moment a child or young person attains competence. In other words, it concludes that a maturity-based approach to rights of inclusion rather than one of status based on age should be followed. Thus, with the increasing maturity and development of a child or young person, there follows a diminishing paternal responsibility and power (van Rooyen et al., 2015).

While it is easy to imagine or portray adult motives as altruistic, it must be considered within context. Children are not a homogenous group any more than adults are. On the contrary, every child is unique and develops within a cultural context that will, depending upon the specific situation, be served best by either a paternalistic paradigm or a more autonomous one. van Rooyen et al. (2015) explain that children sit on a dynamic continuum when it comes to their competence to make decisions relating to their health. However, in practical terms, determining this competence and accounting for it in individual practice decisions is complex given “the inconsistent alignment of New Zealand health legislation and policies” (van Rooyen et al., 2015). Regardless of what legislation or policies are in place, if they are not embedded in the day-to-day actions of health professionals and policymakers, by default they are simply relegated to periodic consideration and arbitrary application.

The United Nations High Commissioner for Refugees (UNHCR) guidelines stipulate that the views of the child should be given “due weight in accordance with the age and maturity of the child” (2008, p. 68). The guidelines specifically refer to the importance of ensuring a “flexible attitude to age, taking account of relevant cultural and developmental factors” (p. 68). The principle of participation in this context is a call to empower children, not simply as an emancipatory action but rather to acknowledge them as human and afford them safe passage and place within society.

Politics and Patchy Progress

Historically, children’s issues have not been given primacy in many governmental policies or healthcare settings (Dickinson et al., 2014; Hopwood & Tallet, 2011). Despite a strong narrative and

evidence that many children in Aotearoa New Zealand experience poverty and poor health outcomes (Auckland District Health Board & Waitemata District Health Board, 2012; Cotterell, John, Dale, & So, 2017; Child Poverty Action Group, 2017), there is also a counternarrative within Aotearoa New Zealand such as that put forward by Immigration New Zealand (INZ) (n.d.). INZ suggests that children in Aotearoa New Zealand exist within and are living in a state of perfection. This crafted image portrays Aotearoa New Zealand as the perfect place for children and families, enticing people from around the world to come and build a life on a “¼ acre of paradise” (p. 1).

For the majority of Aotearoa New Zealand children, this paradisiacal state may be somewhat representative of their experience. However, UNICEF’s *Innocenti 2017 Report Card* on child health does not paint as kind a picture, instead ranking child health outcomes in Aotearoa New Zealand at 36 of 41 industrialised nations (UNICEF Office of Research, 2017). That child health outcomes in Aotearoa New Zealand can be placed alongside those of children in nations such as Turkey, which has been engaged in armed conflict and subject to political unrest and terrorist attacks, is confronting (International Crisis Group, 2022; Mandıracı, 2019). As the UNICEF report highlights, it is evidence that the financial performance and success of a nation does not protect all children within it.

Although the Innocenti Report Card series provides a snapshot of the life of children in Aotearoa New Zealand in direct contrast to the counternarrative described by INZ (n.d.), public perceptions (which tend to reflect this counternarrative) have been slow to change. Children’s marginalisation in Western society has been manufactured and reinforced by prevalent attitudes that commonly exclude children from adult domains. If we consider how public and private spaces are owned and controlled, the spaces in which children live (whether physical or conceptual) are not typically theirs to create and, in most cases, have been constructed from a discourse that suggests children should be “seen and not heard” (Horton & Kraftl, 2006, p. 2).

Children are not welcome in many public spaces and are commonly seen as a nuisance or risk, particularly when they are in groups not directed or controlled by adults (Lansdown, 2001). In this way, children’s geographies are a result of longstanding views on children’s subservient place in

our society. It could be argued that children exist in the shadow of adults, encouraged to stay separate, until they let go of “childish” beliefs or ways of being.

Interestingly, there are dichotomous arguments in the discourse. One perspective suggests that coddling young people and not expecting them to assume responsibilities could be a contributing factor to an overall lengthening of childhood—even instantiating a belief within themselves that they are vulnerable and helpless as a result of unjust “powers.” This infantilises them and pushes adulthood away altogether (Peterson, 2018). The other perspective implies that children have insights, knowledge, and demands that should be honoured at all costs, irrespective of wider contextual issues. This latter way of thinking fits most cleanly within a rights-based approach, but it is perhaps also less capable of differentiating between positive and negative outcomes for the young. This is particularly true if the young people making health decisions have yet to establish their ability to understand long-term health or life consequences. Ironically, both perspectives could be perceived as wanting the best for young people and might be better considered along a continuum.

This is relevant to the context of my research because society’s stance on young people’s potential ultimately influences how we deliver and assess healthcare. Most understandings of children’s experiences of healthcare come from observations made by proxy—observations made from a vantage point far from the centre of a child’s lived experiences and filtered through an adult contextual lens. There are, of course, many researchers and organisations committed to making children’s voices heard in healthcare. However, in many cases, the current approach to care falls decidedly short of meeting the child-centric goals of the UNCRC and the call of the Aotearoa New Zealand Children’s Commissioner for children’s inclusion in all matters that affect them. The most recent Innocenti Report Cards focus on children and young people’s well-being in relation to the environments within which they live and has been critical of Aotearoa New Zealand and other countries’ failure to keep children and young people safe and include their voices in policy development (UNICEF Office of Research, 2020, 2022; United Nations Children’s Fund, 2021). Tokenism rather than true inclusion and participation appears to be the predominant state of young people’s voice in Aotearoa New Zealand.

Measuring the Effects of Discrimination: Comparisons and Layering

In analyses of the Aotearoa New Zealand health system, the UK National Health Service (NHS) is often used as a point of comparison. Like Aotearoa New Zealand, the UK has also experienced less than adequate improvements in child health since the adoption of the UNCRC, despite significant commitments to the principles (UNICEF, 2000, 2007a). Although there have been overall improvements in both Aotearoa New Zealand and the UK in relation to child well-being, it is important to note that these improvements are not experienced universally by all children (D'Souza, Signal, & Edwards, 2017). In the UK, this is attributed to a large degree to the austerity programme implemented by the Conservative governments following the global economic crisis of 2009 (British Medical Association [BMA], 2016). The UK government's inclination to deprioritise the NHS and foster private healthcare has continued, and these increasing trends (improvements in child well-being yet inequitable distribution of those improvements) are shared globally (UNICEF, 2020).

The global mortality rate for those under five years of age has fallen from 12 million per year in 1990 to below 6 million in 2015 (World Health Organization, 2016). This may be attributed to more children in developing countries receiving immunisations and improved pre- and post-natal nutrition. It should not be overlooked that a significant drive behind the implementation of such programmes is governmental uptake and application of the guiding principles of the UNCRC (United Nations Inter-agency Group for Child Mortality Estimation [UN IGME], 2017). However, in many nations, as in Aotearoa New Zealand and the UK, there is a deepening disparity between the health of rich and poor, with marginalised groups such as Māori and Pasifika children in Aotearoa New Zealand continuing to have poorer health outcomes overall (UNICEF, 2007a, 2007b; UNICEF Office of Research, 2013, 2014, 2017). The effects of poverty negatively affect life course outcomes for children, and the disparities between rich and poor imply that discrimination is, at least in part, structurally founded (BMA, 2016 & Schmidt et al., 2021).

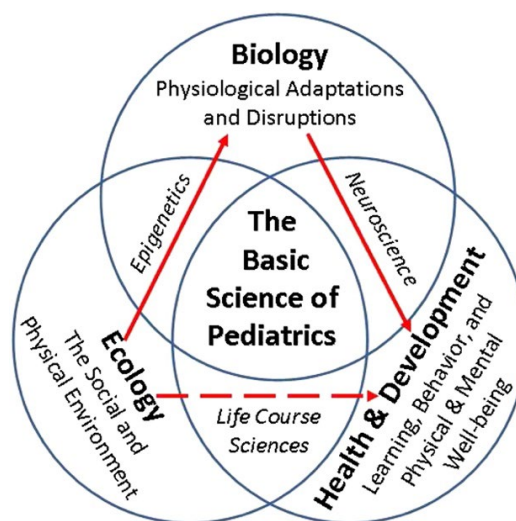
The data on poor health outcomes for impoverished and marginalised children in Aotearoa New Zealand are largely indisputable. With upwards of 328,200 children, or 29 per cent of all children in Aotearoa New Zealand, living in low-income households as of 2019, the increased

mortality and morbidity faced by this segment of children and young people remains a blight on the nation's reputation (Duncanson et al., 2020).

For a percentage of people, poor health outcomes either occur in childhood itself or can be linked directly to discrimination, marginalisation, and adverse events within childhood that go on to manifest in poor health in adulthood (Shonkoff & Garner, 2012). The triad (see Figure 1) of significant associations between the ecology of childhood and a wide range of developmental outcomes and life course trajectories is important to note because children and young people are exposed to multivariate developmental pressures. With young people experiencing discrimination based on ethnic and socioeconomic judgement in addition to age itself, they are tremendously vulnerable to intended and unintended consequences of social policy and political action and therefore the convergence and accumulation of negative health outcomes.

Figure 1

Interrelation Between Biology, Ecology, and Health & Development



Note: Figure from Shonkoff and Garner (2012, p. 234).

Take, for example, some children's exacerbated experience of poverty in Aotearoa New Zealand. When parents who are beneficiaries have their funding cut because they have not met the government's criteria for seeking work, their children are further disadvantaged through no fault of their own (Krassoi & Cording, 2018). Similarly, parents who are unemployed but in a committed

relationship are eligible for less financial support from the government than those in single-parent households, a policy that compounds already multivariant disadvantage by encouraging single-parent living (thereby forcing a couple to have two residences or avoid detection) simply to access financial support (Chapple, 2009; Krassoi & Cording, 2018). Funding rules that discriminate against a child's immutable characteristics are by definition discriminatory and simultaneously diminish young people's security by fostering environments that do not support well-being or positive health or educational outcomes (Krassoi & Cording, 2018).

In Aotearoa New Zealand, the beneficiary reforms introduced in 2010 affected children's ability to mitigate the negative impacts of these socioeconomic changes because funding meant to support children is not attached to an individual child, but rather the child's parents. Policies that discriminate, such as these reforms, are in open conflict with inalienable human rights set out in the New Zealand Bill of Rights Act (1990) and, arguably, breach the principles of the UNCRC (1989). The then Minister of Social Development, Paula Bennett, enacted these policies with the knowledge that human rights against discrimination would be broken, stating "I think that [this] is a discrimination that most New Zealanders will see as being fair and reasonable" (Young, 2010).

Whether socially acceptable or not, discrimination marginalises and can harm those being discriminated against. Children experience discrimination based on the family they are born into, becoming disadvantaged by immutable characteristics over which they have no control. Such outcomes are evidence that many policies fail to take into account their knock-on effects on children and young people. For example, the fact that children from families living in poverty are three times more likely than those from affluent families to experience hospitalisation (Child Poverty Action Group, 2017).

Despite the publication of league tables in UNICEF's Innocenti Report Cards, it is difficult to accurately assess or measure the specific areas of progression, or regression, of inequalities of child well-being in Aotearoa New Zealand. This is primarily because Aotearoa New Zealand has consistently not reported enough disaggregated data for the precise measures and comparisons to be made (UNICEF, 2000, 2007a, 2010; UNICEF Office of Research, 2013, 2014, 2016, 2017, 2020,

2022). So, while Aotearoa New Zealand has demonstrated strong economic growth and many improvements for the bulk of society, its overall ranking remains 38 of 41 nations for children's "good health and well-being" and 26 of 41 for inequalities (UNICEF Office of Research, 2020, 2022). It is therefore challenging to determine the exact extent to which children's rights to health are being met or, more specifically, the extent to which some children are being left behind.

This uncertainty has drawn criticism from the United Nations in its Fifth Periodic Report on Aotearoa New Zealand's commitment to the UNCRC (UN Committee on the Rights of the Child, 2016; UNCRCMG, 2017). The UNCRC Monitoring Group (UNCRCMG) points out that it has been 25 years since Aotearoa New Zealand made the commitment to improve the state of children's rights and well-being, yet successive governments have done little to produce a comprehensive and verifiable plan of action. The report makes the following recommendation:

Develop a comprehensive mechanism for data collection and an information system on all areas of the Convention. The data should be disaggregated by age, sex, disability, geographic location, ethnic origin, nationality and socioeconomic background, to facilitate analysis on the situation of all children, and particularly Māori and Pasifika children, children in care, children with disabilities, children living in poverty, refugee, asylum-seeking and migrant children, and children in other situations of vulnerability. (UN Committee on the Rights of the Child, 2016, p. 3)

The concluding observations of the Fifth Periodic Report (UN Committee on the Rights of the Child, 2016) also reminds the Aotearoa New Zealand government that it has failed to act on previous recommendations relating to domestic legislation. It goes further and "urges the State Party to bring domestic legislation relating to children into compliance with the Convention," imploring legislators to "implement the child impact assessment: best practice guideline, and make its use obligatory, including during the allocation of public resources" (p. 2). Doing so would most certainly increase the expectations of consultation at all levels of decision making within healthcare policy. Despite this, the government has tabled the *Oversight of Oranga Tamariki System and Children and Young People's Commission Bill* (2021), which proposes the removal of certain investigatory powers of the Office of the Children's Commissioner in favour of a new Children and Young People's Commission tasked with independent monitoring of children and young people's issues. As of June 2022, the bill was entering into its second reading, but uncertainty remains as to whether the loss of the strong advocacy

position of the Children's Commissioner would lead to future regressions or, alternatively, improve outcomes through a broader independent commission.

Children's Place in Aotearoa New Zealand Society

The uncertain and arguably slow progress towards developing a robust action plan to improve child health outcomes may in part be rooted in the very way children are perceived in Aotearoa New Zealand. There is a philosophical tension between a predominant (and traditionalist) developmental view and a social constructionist view of children and childhood (Debski, Buckley, & Russell, 2009).

In the developmental view, children are seen as incomplete human beings or, as Qvortrup (1994) describes them, "human becomings." Children's path to adulthood is thus "in progress," with the view that they require constant guidance and shaping to become adults capable of contributing to and, perhaps most importantly, continuing the views of their adult predecessors to maintain the status quo. In other words, this view suggests that children follow an adult-led plan to their future selves, relinquishing their less valued childish selves to be socialised and shaped into humans whom adults deem competent and useful. Only then are children permitted to assume their place in society (Debski et al., 2009; Qvortrup, Corsaro, & Honig, 2009; Waksler, 1991). In this model, the child's world is only seen as relevant in relation to achieving adult outcomes.

The social constructionist view is on the other end of the spectrum and assumes that children are inherently complete human beings and are as important in their role as children as they will be once adult. While children may be naïve or lack life experience, a constructionist view holds children as social beings deserving the same rights and respect afforded to adults. Such a view acknowledges that childhood is a partially or wholly constructed notion, and children will navigate it through negotiation with adults and other children to ultimately become adult (Debski et al., 2009). The conceptualisation of childhood as a transitional and developmental space within a wider life course acknowledges their "otherness" yet gives greater credence to the value of raising youth voices in the context of health to bridge the gap between adult and youth understandings (Blazek, 2017).¹

¹ Whether or not adults are "complete" human beings or also on a continuum of actualisation due to the limitations of their own understandings is an important distinction within participatory video projects, because participants are fundamentally assumed to be expert in their lives, regardless of age or stage (Lunch & Lunch, 2006).

The introduction of the rights of the child in the UNCRC (1989) relies heavily on acceptance of a constructionist view of children, and the continuing proclivity towards the developmental view in Aotearoa New Zealand society may be a stumbling block. Take, for example, the perpetration of violence against children in Aotearoa New Zealand: it is substantial, with on average nine children killed per year as a result of family violence (New Zealand Family Violence Clearinghouse, 2017). It may be that until children are considered complete human beings with the same rights to health, life, and well-being as any other, the principles of the UNCRC cannot be met nor can child health in general flourish.

Shifting Paradigm and Priorities

Recent changes in Aotearoa New Zealand's political landscape may indicate a potential shift towards a stronger commitment to child-centric policy and legislation. The newest rendition of the Aotearoa New Zealand Health Strategy, initiated in 2016, represents the first significant change in health strategy since 2000 (Minister of Health, 2016). For the first time, the strategy acknowledges that the ability of an individual to live well is fundamentally rooted in the acquisition of skills and knowledge that aid in the avoidance of risks to their health. These are skills that begin in childhood, and the strategy links people's health to their wider environmental context. The strategy specifically brings to light the interrelation between individual and family health and wider systems such as education, housing, workplace, transport, recreation, and healthcare. Most significantly, the adoption of this "life-course approach" (Minister of Health, 2016, p. 4) is an acknowledgement that every individual's health trajectory begins in childhood, and allocating energy and resources in these early years provides the best platform for positive health into the future. This represents a model of investment rather than response. The adopted construct of learning "life skills" is important to acknowledge because it broadens the definition of well-being to include children's world views and the values of all the relationships within them, promoting the inclusion of participatory frameworks that align with the UNCRC principles of participation. This essentially promotes a strengths-based and capacity-building approach as opposed to viewing young people as having "deficits." Successful implementation of the strategy in its true spirit will consider any barriers that children perceive as

affecting their ability to achieve positive well-being and ultimately influence the funding of services that directly affect children's health.

There is an accompanying "Roadmap of Action" for the Aotearoa New Zealand Health Strategy that goes further to define eight "refreshed guiding principles for the system" behind the strategic approach (Minister of Health, 2016, p. 6):

1. Acknowledge the special relationship between Māori and the Crown under the Treaty of Waitangi[Te Tiriti o Waitangi]
2. The best health and wellbeing possible for all Aotearoa New Zealanders throughout their lives
3. An improvement in health status of those currently disadvantaged
4. Collaborative health promotion, rehabilitation and disease and injury prevention by all sectors
5. Timely and equitable access for all Aotearoa New Zealanders to a comprehensive range of health and disability services, regardless of ability to pay
6. A high-performing system in which people have confidence
7. Active partnership with people and communities at all levels
8. Thinking beyond narrow definitions of health and collaborating with others to achieve wellbeing (Minister of Health, 2016, p. 6)

The roadmap openly acknowledges that there are disadvantaged individuals in society whose health status should be considered at every level and from every sector. This is the responsibility of the nation as agreed in the UNCRC.

Unfortunately, while it reflects the intent of the Aotearoa New Zealand Health Strategy, the roadmap leaves out specific and intentional mention of child health and child participation in the design of healthcare delivery. Furthermore, neither the strategy nor the roadmap itself refers to the specific principles that were agreed to in 1993 at the signing of the UNCRC. These UNCRC principles may be inferred within the strategy and roadmap, but the absence of any specific mention of children does not send a message that the proposed changes will be child centric.

Children's Voice in Aotearoa New Zealand Healthcare

The principles of the UNCRC are particularly important because they point to the significant issues that children face in the healthcare arena within Aotearoa New Zealand: most significantly, that children's voices are at times unheard. The Office for the Children's Commissioner piloted an online toolkit in 2013 in the hopes of encouraging healthcare providers to measure their performance in relation to working with children and young people (Office of the Children's Commissioner, the

Paediatric Society New Zealand, & Ko Awatea – Centre for Health System Innovation and Improvement, 2013). Although I could not find a record of uptake for the toolkit, its release itself may be evidence of concerns by the Children’s Commissioner regarding children’s participation in their healthcare at the time.

During the lead up to the Aotearoa New Zealand Health Strategy rollout in 2016, the Office of the Children’s Commissioner made a strong case for re-focusing efforts to make the UNCRC principles more concrete (Children's Commissioner, 2015), stating “the health strategy would benefit from a greater recognition of the centrality of children” (p. 1). The report goes on to suggest that children remain distinctly disempowered in relation to their healthcare needs and that greater efforts should be made to make information and opportunities for participation available to children. However, despite the inclusion in the report of a clearly proposed roadmap to children’s inclusion, there are limited examples of children’s voices being considered at practice levels. And although the UNCRC (1989) acknowledges that children and young people have rights and can positively contribute to the construction of the society that they will live in as adults, its principles are still not central to healthcare legislation or policy development. On the contrary, in many if not most cases, children remain invisible when it comes to healthcare design and delivery (Dickinson et al., 2014).

Participation Matters for Adults...What About Young People?

The consumer movement of the 1960s led the way for healthcare to be seen as a consumer service, and in adult health services this viewpoint has strengthened substantially over the last four decades (Boyd et al., 2012). Patients expect more from their service providers, and the use of focus groups, co-design, and collaborative principles have been proven to lead to better patient health outcomes. This has become the gold standard for stakeholder participation and can lead to improved services and decision-making processes around resource allocation and care delivery (Farrington, 2016; Longtin et al., 2010).

DHBs in Aotearoa New Zealand have broadly accepted this standard, and examples of their desire to apply human-centred and experience-based co-design concepts to service provision are myriad. One such example comes from the Auckland DHB (ADHB) *2015/16 Annual Plan*: “We are

committed to delivering a patient centred, clinically driven high quality health care approach” (Auckland District Health Board, 2015, p. 97). Other annual plans also include commentary about the centrality of patients and the importance of person-centred care, with one particularly strong example of this philosophy put forward by the Waitemata DHB (WDHB). The largest DHB in Aotearoa New Zealand by population, the WDHB, has shown leadership through the creation of the design forum, which was part of the “Patient Co-design of Breast Service Project” outlined in their *Health service co-design toolkit*, which is capable of guiding and supporting adult-centric co-design processes (Auckland District Health Board, 2022, p. 23).

While the rhetoric may indicate a shift towards patient empowerment and inclusion, there is still a paucity of discussion relating to expectations of children and young people’s participation in service design and delivery. Ten years ago, the ADHB and WDHB collaborated to create a Child Health Improvement Plan (CHIP) (Auckland District Health Board & Waitemata District Health Board, 2012). The plan contains nine underpinning principles:

1. Children are our highest priority.
2. Children’s best interests are paramount.
3. Children’s rights must be upheld.
4. Children and family and whānau² are at the centre of everything we do.
5. Inequity in health outcomes must be addressed.
6. The first years of life are the most important for future health.
7. Excellence in health care service delivery.
8. Our obligations under the Treaty of Waitangi of partnership, protection and participation.
9. Families actively engage with health services. (p. 2)

In support of these principles, the plan commits to taking a child-centric approach that specifically includes listening to children’s voices:

We will lead child health in New Zealand, and, over time, help return New Zealand to a place of health status excellence relative to other OECD countries. To do this we must work with the many and various child health stakeholders. Most importantly, we must listen to the voices of our children and their families and whānau. (p. 2)

² “Whānau” in Te Reo Māori (the indigenous language of Aotearoa New Zealand) refers to an extended family or family group, which may include friends without specific kinship ties to other members (Te Aka, n.d.-b).

Despite the many ways that these principles intersect or mirror those within the UNCRC, this publication does not appear to have demonstrably changed how health providers engage with children in the healthcare system. Ten years on from the publication of the CHIP, there are limited examples of any inclusion of children's or family/whānau's voices in the day-to-day business of the DHBs: the business of improving health outcomes.

In the "[Measuring the Effects of Discrimination: Comparisons and Layering](#)" section earlier (page 41), I discuss the Aotearoa New Zealand government's ineffective reporting on child health outcomes. This lack of reporting may be a direct result of the DHBs' own approach to reporting on child health. Despite the Aotearoa New Zealand government making a commitment to establish an annual dedicated child health report, the DHBs have instead incorporated information on child health outcomes into the overall DHB reporting structures. While there may be arguments for this approach, such as efficiency and information aggregation, the DHBs have not articulated a specific reason for it. Certainly, this approach does not address calls from the UNCRCMG for the government to provide disaggregated data reporting at this level, and without specific measures in place to establish how the DHBs are upholding children's rights and making children their highest priority (as promised in the CHIP) (Aickin & Jellyman, 2012), there is no way to substantiate any such claims.

Building Relationships "For" But Not Necessarily "With"

The stated intentions of Aotearoa New Zealand DHBs' commitments to improve child health outcomes and engage in participatory practice with children and young people certainly align with the expectations of the UNCRC. However, as Dickinson et al. (2014) point out, intentions are not always enacted. The 2012 CHIP called for the establishment of the Child Health Stakeholders Advisory Group. This appeared to be a move towards better consultation and engagement with children and young people. However, according to the ADHB/WDHB Funding Manager for Child, Youth and Women, the stakeholder advisory group did not include any children or young people. It was instead a group of service providers hoping to effect better collaboration to improve their care delivery. The group included but was not limited to the New Zealand Police, the Ministry of Social Development, and the Ministries of Health and Education, along with a number of non-governmental organisations

that work closely with these groups. The clear intention of the Child Health Stakeholders Advisory Group was to formalise and strengthen interagency relationships, in particular the “formalization of the relationship with Child, Youth and Family (CYF) [subsequently renamed Oranga Tamariki – Ministry for Children] to help combat child abuse and neglect through a memorandum of understanding between healthcare providers, New Zealand Police and Child, Youth and Family” (p. 14).

A review of the Bay of Plenty District Health Board (BOPDHB) *Annual Plan 2017* (BOPDHB, 2016) similarly acknowledges the principles of the UNCRC and a commitment to improving child health outcomes. However, its plan to achieve the improvements also makes no mention of consultation or strengthening of relationships with children and families/whānau but instead outlines a distinct goal to strengthen relationships with police and social services.

A focus on building relationships with these governmental agencies to protect the most vulnerable is understandable and perhaps to be encouraged. However, the absence of any mention of what is important to children and young people themselves or of any building of relationships with them and their families/whānau is potentially indicative of an unconscious paternalistic approach and an inherent focus on resources rather than relationships. The Children’s Commissioner supports this perspective by specifically mentioning the general failure of governance bodies and policymakers to include children in the development of legislation and policies. In 2017, Andrew Becroft wrote:

Children’s voices need to be heard in our country. We are very bad at seeking out their voices, listening to them, factoring them into our decision-making and then reporting to children, the decisions made. If the practice was ingrained in government departments and community groups, there would be a significant change in the way policy is created here – for example in areas of education, health and housing, and in the way we respond to child poverty. (Office of the Children’s Commissioner, 2017, p. 1)

With this perspective in mind, it is unfortunate that the aforementioned Child Health Stakeholders Advisory Group did not actually include any children or young people. Equally disappointing is that no reports or minutes of meetings from the group are readily available. When I sought these from the Strategy and Planning Manager, Women, Youth and Children, I learned that the

advisory group had lasted little more than a year before it was devolved and morphed into a smaller “alliance” to become a more health-centric service (personal communication, January 29, 2018).

Now, more than eight years on from the group’s dissolution and awaiting the next iteration of the CHIP, there is still no information or terms of reference on DHB or Ministry of Health websites relating to this formed alliance. When I requested an explanation as to why the ADHB chooses not to include children as stakeholders in the development of policies, the Strategy and Planning Manager, Women, Youth and Children responded that “we are aware that we should include children’s views and include them in decisions that affect them, but including children is difficult” (personal communication, January 29, 2018). It is clear that consultation with children and young people is not yet a mandatory part of healthcare policy development processes in Aotearoa New Zealand.

Furthermore, it is clear that children and young people are not kept updated on the outcomes of acts of health advocacy reportedly done on their behalf. This counters the government’s public commitment to the UNCRC and may be indicative of continuing marginalisation and discrimination of children and young people.

Acceptance of Co-design With Adults, But Not Yet Young People?

In keeping with DHB commitments to an experience-based co-design philosophy in healthcare service development, adult users of health services in Aotearoa New Zealand are routinely contacted and asked to participate in the Health Quality & Safety Commission (HQSC)’s annual patient satisfaction survey (PSS). The survey gathers patient opinions and perspectives on the four domains of communication, coordination, partnership, and physical and emotional needs, which are then directly quoted within annual reports and recommendations for improvements (Health Quality & Safety Commission New Zealand [HQSCNZ], n.d.). Aotearoa New Zealand DHBs adopted the PSS in 2014 as a way to measure their success in providing quality care. The PSS seeks feedback from all adult care contexts including inpatient, primary, and aged care (HQSCNZ, n.d.). As of November 2021, it was in its 19th cycle.

In the final report on the development of the domains and associated questions for the PSS, Cook and Bazett (2013) posited that meeting patient expectations relating to the domains is

paramount to ensuring good health outcomes for the users of care services. Interestingly, despite this, there is no reference to any consideration of children and young people's experiences of care within the HQSC's survey (HQSCNZ, n.d.)—in spite of the UK's NHS 2013 operating framework (2011) informing the creation of the PSS and specifically identifying the importance of including children's voices. The NHS includes indicators for measuring children's experiences of healthcare in experience surveys specifically directed at young people.

Despite a growing acknowledgment that many children and young people are fully capable of considering and articulating their experiences in relation to concepts such as those of the aforementioned domains (communication, coordination, partnership, and physical and emotional needs) (Coyne, 2008; Coyne & Carter, 2018; Soderback, Coyne, & Harder, 2011), I could find no evidence that the HQSC nor any DHBs in Aotearoa New Zealand have yet extended such surveys to young people. This inability, or unwillingness, to actively seek children's perspectives on health and their experiences of it falls short of the New Zealand Health Strategy's intentions and thus does not meet the rights afforded to children and young people under the UNCRC.

Legislative Influence and Constitutional Confluence

The further my research progressed into children and young people's perspectives on and contributions to the health practices and policies that affect them, the clearer it became that Aotearoa New Zealand is not yet wholly committed to the ideals within the UNCRC. The Aotearoa New Zealand government has continued to pass legislation without apparent consideration of (or despite the potential impacts on) young people. The inequities forged by race, poverty, and other forms of discrimination continue to thrive, resulting in poor health outcomes for many children and young people. These negative health outcomes belie the wealth and economic success of Aotearoa New Zealand. A country once proclaimed to be "nearly classless" or at least "...more so than any other developed country in the world" (Sinclair, 1969, p. 285), Aotearoa New Zealand has experienced a continuing growth and acceptance of disparity. If Aotearoa New Zealanders wish to be seen as a nation that holds "fair play" as an inalienable right, they must choose and pressure successive

governments to create bipartisan agreements that formally keep children and young people at the centre of all decisions on policy and law development.

Rights Without a Constitution?

However, effecting change is not as simple as it may seem. Unlike two-thirds of the UNCRC signatories, Aotearoa New Zealand (like most other common law nations) has not incorporated the UNCRC directly into domestic law (UNICEF, 2007b). One-third of countries have embedded the UNCRC directly into their constitutions, including Spain, Belgium, and Norway, thereby affording children's rights significant stature above regional and domestic law (Lundy, Kilkelly, Byrne, & King, 2012). Lundy et al. (2012) claim this has resulted in the development of a "culture of respect for children's rights" (p. 101) in these nations. It has provided a backdrop for the advancement of children's rights and ultimately their well-being, as evidenced by measurably improved health outcomes (Lundy et al., 2012).

In contrast, Aotearoa New Zealand has no such written constitution in which to embed the principles of UNCRC, which can be seen as a potential liability when it comes to promoting children's rights (Lundy et al., 2012; Lundy & McEvoy, 2012). One of only three countries in the world without a written constitution, Aotearoa New Zealand is governed by not one document but rather a collection of laws found in various pieces of legislation (Constitutional Advisory Panel, 2013). Unfortunately, this potentially leaves children's rights in Aotearoa New Zealand at risk because government funding, policies, and legislation are not mandated to be reviewed for their impact on children. Children are therefore at the whim of political change and travelling policies.

An important step for Aotearoa New Zealand may be to formally embed the UNCRC directly into Aotearoa New Zealand domestic law so that there can be no movement of policy without it meeting the needs of children. This would provide children and young people with the power of the legal system to enforce their rights, heeding the call of the Children's Commissioner to "recognize the centrality of children" (Children's Commissioner, 2015, p. 1).

The alternative to a domestic law solution would include revisiting the notion of adopting a written constitution and determining whether such a binding document would be beneficial to child

health outcomes (Constitutional Advisory Panel, 2013). However, it should not be assumed that a written constitution alone would resolve the inequities in question, because constitutions can also work to maintain or reinforce a status quo. In fact, an “unwritten” constitution (such as those in the UK, Israel, and Aotearoa New Zealand) has the potential for relatively rapid change for the better because legislation can be enacted that then subsequently informs the government’s constitutional behaviour (Constitutional Advisory Panel, 2013; Lundy et al., 2012).

Recent Political Movements

In an address to the nation in 2018, Prime Minister Jacinda Ardern pledged to tackle the inequities that children in Aotearoa New Zealand face and to put children and communities at the heart of every decision that her Labour government or any subsequent government makes. In the January 30, 2018, press release, Ardern states:

My government's plan will roughly halve child poverty within 10 years and establish New Zealand as one of the best performing countries for children... We want to put an end to a political era that tolerated hardship and poverty among thousands of children and refocus governments on what's required to ensure all kinds have the opportunity to thrive. (Young, 2018, p. 1)

These sentiments and projected actions align with the UNCRC goals to ensure that children’s rights are met and maintained. If health professionals and policymakers keep the rights of the child in the foreground of all decision making and invite children and young people to contribute their insights into all matters that affect them, then arguably children and the young can become co-constructors of the very society in which they will ultimately live as adults. In doing so, better health outcomes and life courses for the young can result. Although the failure, to date, of political parties to instigate bipartisan legislation to cement the rights of the child is disheartening, Ardern’s “stake in the ground” is one of many positive signs across the Aotearoa New Zealand political landscape that have shown an awareness of and commitment to the principles of the UNCRC. In combination with the supporting acknowledgements within DHB annual plans and the New Zealand Health Strategy, as well as the exemplifying directive from the Children’s Commissioner (Office of the Children’s Commissioner, 2017) that “children's voices need to be heard in our country” (p. 1), the road to follow has certainly been lit.

Roadblocks and the New Unknown: The Impact of COVID-19

The path towards more inclusive child health practice may not be as clear as it seemed back in 2018. Since I began this literature review and project, multiple extrinsic and intrinsic forces have affected healthcare policy and provision in Aotearoa New Zealand. Most notably, in early 2020 the world was besieged by the COVID-19 pandemic and many aspects of “normal” life were turned upside down. Political unrest and a multitude of public health mandates displaced many previous plans and are having a disproportionate and compounding effect on young people. This is particularly so for young people from Māori, Pasifika, and lower socioeconomic backgrounds (Maxon, Bacalso, & Serban, 2021). In September 2020, while the world was still in its early response to COVID-19, Menzies, Gluckman, and Poulton (2020) reported that young people were already in the midst of a mental health pandemic that hadn’t yet begun to show the impacts of the global COVID-19 pandemic. While their observations were focused on young people’s mental health, it would be easy to argue that all aspects of young people’s health and well-being are likely impacted by the isolation of lockdowns, with redeployment of health workers, the closing of clinics, and restrictions on free movement directly affecting young people’s access to services and vital social connections.

In all aspects of their lives, children and young people are at the will and mercy of law and policy changes, but the myriad and dramatic shifts in policies associated with the COVID-19 pandemic and lockdowns have negatively affected many young people’s access to education, health services, and even their family, social communities, and other support networks. At the time of this writing, mandates that represent clear impediments to previously normal childhood activities, education, growth, and development remain in place. The impact of these mandates on young people’s current and future well-being is uncertain, but there are indications of unwelcome trends. In 2020, the percentage of young people who considered themselves as having mental health issues had doubled since 2012. Only 69 per cent of the 7,721 respondents to a Youth19 survey (school years 9–13) reported “good emotional well-being” (Menzies et al., 2020, p. 3). Reports of self-harm, depression, and suicidality were all on the increase, disproportionately affecting girls and those of Māori and Pasifika cultures (Menzies et al., 2020).

While the gender differences are consistent with overseas findings, Aotearoa New Zealand has a history of an insidiously high rate of suicide among young people. In 2019, there were approximately 23 suicides per 100,000 in the 15- to 19-year-old age group, compared with the UK rate of 7 per 100,000. The reasons for the threefold rate are not entirely clear, but the history of inequality of health outcomes within Aotearoa New Zealand identified by UNICEF (UNICEF, 2000, 2007a, 2010; UNICEF Office of Research, 2013, 2014, 2016, 2017) could be indicative. Access to services is not equal for all, and the widening disparity could be reflective of the increasing efforts that the UK is making (though not yet instantiated in domestic law) to ensure that before social policies are enacted, consideration is first given to their potential impact on children and young people.

The reality for Aotearoa New Zealand is that we have been chasing the tail of a tremendous problem for decades, and while there have been some successes, we now face stark new barriers to achieving the goals set out by the UNCRC. The statistics just discussed are based on young people's lives before the depth of the COVID-19 pandemic had been felt. There have since been two additional years of subsequent restrictions on young people's access to health services, education, socialisation, and many of the "normal" aspects of life that serve as developmental and protective measures. Young people's "spaces," such as school, sports, clubs, and community, have all been disrupted by actions and mandates implemented in the name of protection but undoubtedly at a cost to many young people (United Nations Children's Fund, 2021; Webb, Kingstone, Richardson, & Flett, 2020).

In addition to clear evidence of the global impact of the COVID-19 pandemic on young people, Aotearoa New Zealand youth have identified their own significant concerns regarding their well-being in the wake of COVID-19 lockdowns, and in at least one survey they have expressed an interest in being directly involved in and contributing to potential solutions (Webb et al., 2020). Aotearoa New Zealand government and policymakers will hopefully see this desire of young people to be active participants in the recovery from the pandemic for what it is: an opportunity to move towards more substantial collaboration for a healthier future, not just for young people, but for all in Aotearoa New Zealand.

Chapter 3: Research Design

This chapter outlines the research question and sub-questions and the methodological and epistemological approaches central to participatory action research (PAR) informed by critical theory and a rights-based approach. It then reflects on how the methodology influenced this study's design (considering factors such as the need for people to have a say in anything that affects them, the inherent tensions that arise between people given their differences in language, context, experience, and culture, and perceptions of young people and childhood in society). It introduces the use of video in PAR, including the importance of process over product as well as the essential collaboration between researchers and participants ("co-researchers"). It concludes with a discussion of the study ethics and consideration of creating "safe spaces" for the young participants.

The Research Questions

Primary Question

- How can participatory video and drama facilitate collaboration with young people to empower their voices in healthcare policy and provision?

Sub-questions

- What do young people see as the most important issues and challenges they face in relation to their health and well-being?
- What ideas do young people have that might help resolve the issues they face in relation to health and well-being?

Methodology: Participatory Action Research

To answer the research questions, this study employs a PAR methodology informed by a rights-based approach, critical theory (CT) framework, and Rogerian humanistic philosophy (RHP). I acknowledge outright that there is a tension in applying the term "Rogerian" as it is not a term Carl Rogers himself was entirely comfortable with (Rogers, 2012). I am, however, constrained by a need to articulate the specific philosophical forces that have been amalgamated to create my epistemological approach.

A Rights-Based Approach

Situated within a critical rights-based paradigm, the *Creating Space* project aligns with an established human rights discourse (Lundy & McEvoy, 2012). As outlined in the “[The UNCRC and the Rights of the Child in Aotearoa New Zealand](#)” section (page 33), the United Nations Convention on the Rights of the Child (UNCRC) (1989) establishes children’s right to participate in all things that affect them, and one legacy of its signing is that it encourages child health researchers to shift perspectives and paradigms from research “on or about” children to research “with” children (Coyne & Carter, 2018). While this may challenge some who prefer a positivist approach, at its heart, PAR fundamentally recognises the need for participants to be involved in all stages of the research, including design, execution, and dissemination (MacDonald, 2012).

Defining PAR precisely is challenging because it is an overarching descriptor that can include many collaborative approaches and methods (Kim, 2016). Kidd and Kral (2005) suggest that participation involving social action is central to the methodology and, therefore, that the primary goal of PAR is to promote social justice by creating democratic partnerships that can liberate an oppressed population.

The CT framework in this study has been predominantly informed by the works of Freire, Kant, Foucault, Peterson, Nietzsche, and Rogers, all philosophers who, within their works, have identified the implications of power hierarchies and values on individuals’ perceptions, development, and life outcomes. As such, this work specifically identifies and questions (and at times defends) traditional hierarchies of power within society and the associated assumptions about children and young people’s capacity for involvement in social, political, and economic worlds.

CT acknowledges that human power struggles result in different realities for different groups and, perhaps most importantly, that with any marginalised group in society, there is always a struggle for control of the versions of a story. This struggle involves education, healthcare, channels of communication, and legal and political structures (Tyson, 2011). For the children and young people in this project, it is no different, and I will share how participants’ struggles and variable desires for

control were evident across the hierarchies that emerged in the groups and within the methods themselves.

As raised in the “[On the Value of Stories](#)” section (page 27), the importance of story and language in our individual and collective development is indisputable. Freire also suggests that mastery and control of language (and anything that is imbued with language, such as art, music, and cinematography) are key to marginalised groups advancing their own interests (Dearfield, Bamum, & Pugh-Yi, 2017). This may well be the most important aspect of PAR, because it enables the articulation of participants’ emotions and thoughts to derive a shared understanding of their experiences, hopes, and dreams for their future. In this project, the participants used creative methods that include language, as well as images, video, sound, and music that are imbued with their language, to facilitate their storytelling. As their fellow collaborator, I can’t help but think of the process as akin to the collaborative creation of poetry (the poet Robert Frost once claimed that poetry comes into existence in the moment “an emotion has found its thought and the thought has found words” [Gear, 2021, p. 80]).

Nothing About Us Without Us

CT highlights and explores beliefs and practices to identify and acknowledge the constructs that have given them status and acceptance within a wider social context (Crotty, 1998). I incorporated RHP because it suggests that every person, whether a child, adult, participant, or member of society, is capable of obtaining a deeper understanding of self and thus can achieve dreams and desires through self-actualisation (Rogers, 2012). This is vital for working with young people, as Rogers argues that people actually have but one motive: to self-actualise and fulfil their potential to achieve the highest level possible of “human-beingness” (Rogers, 1959; Thorne & Sanders, 2012). Rogers acknowledges young people’s individual capacity to carry responsibility for their own independence and outcomes. He makes the following specific point in relation to knowledge: “As no one else can know how we perceive we are the best experts on ourselves” (Rogers, 1959, p. 122).

Rogers' suggestion that there is no one better to determine best outcomes than those affected is far from the first attestation of the concept, but his was possibly one of the earliest mentions of it in relation to young people and their health. The idea can be found in a number of political movements and conflicts of the 18th, 19th, and 20th centuries, perhaps nowhere more dramatically than the American revolutionary war, which was itself predicated on a demand by settlers to be involved in central decision making with "no taxation without representation." In Poland and other European nations, such as Turkey, the late 19th and early 20th centuries saw their monarchies devolve much of their power to parliaments, and the idea of public representation was generally incorporated into law as egalitarianism gained support (Everdell, 2000). This, in turn, guided dramatic political change and global conflicts that would lead to two world wars. Following the atrocities of World War II, in 1945, the United Nations (UN) was formed and by 1948 had created and adopted the Universal Declaration of Human Rights. This reflected an increasing desire in democratic nations to build on previous ideas established in the Magna Carta (1215), the English Bill of Rights (1689), the French Declaration on the Rights of Man and Citizen (1789), and the US Constitution and Bill of Rights (1791) (Amnesty International, 2016). Although designed to incorporate all people, inclusive of children, the UN Universal Declaration of Human Rights (1948) was not explicitly aligned with children and young people's specific vulnerabilities and needs.

Rogers (1959) considered disabled youth as particularly marginalised by society and sought to incorporate the recently declared human rights into his work, thereby seeking to ensure that all people, regardless of age or ability, can have a say in things that affect them. Rogers' work brought some positive returns for how the disabled and young were perceived and funded, but it wasn't until the 1980s that substantive shifts in societal perceptions were achieved. It was then that James Charlton, a disability activist and social constructionist, coined the phrase "nothing about us without us," the moniker making a clear distinction that those on the margins of society do have a right to participate and be heard regardless of characteristics that differentiate them (Charlton, 1998). The phrase has since become synonymous with the rights of the marginalised to autonomy and inclusion.

As I have highlighted in [Chapter 2: “Background and Context”](#) (page 31) children and young people are frequently marginalised within society and, as such, the tenet of “nothing about us without us” fits clearly within the purview of the UNCRC (1989), which is the guiding source of the rights-based approach that this work strives to achieve. The need to incorporate a critical approach is supported by the nature of group and social dynamics, which can displace the voices of marginalised people and stop them from being able to share their insights or contribute to effective problem identification and solving. Any development of new understandings begins with a recognition of the “give and take of social existence” (Crotty, 1998, p. 59) and an awareness that power structures serve first to avoid change and protect certain interests.

This is an integral aspect of all PAR, as it acknowledges the power differentials and inequities within society, identifies them, and seeks to empower and amplify the voices of marginalised or oppressed groups (Aldridge, 2015; Harris, 2009). Depoy and Gitlin (2019) go on to describe CT as a unique way of thinking that employs multiple strategies united in the pursuit of a common socio-political purpose. In other words, it is a way of thinking that critiques the status quo in the hopes of changing perspectives and achieving social change—the action.

Tensions in the Making

There are inherent tensions in this, or any, participatory project. The participants and I (all people for that matter) have a variable and uncertain grasp on shared language. Our ages, contexts, experiences, and cultures all work to create uncertain nuances that conflate the language and stories in play. This is true for all PAR, but perhaps especially so in PAR with children versus adults, given the additional complexity of how children are perceived (see the “[Construction of Childhood: Beings or Becomings](#)” section [page 64] for more discussion on this) and how children “are used to having to please adults” and “may fear adult reactions,” which could influence how they participate in the research (Punch, 2022, p. 326).

To counter this, the Rogerian concept of unconditional regard was purposefully employed at the outset. Thus, the participants and facilitators³ tried to collaborate purposefully and with unlimited patience for each other's questions and analysis. Our aim was to understand the broader collective stories as well as the specific meanings of the language, images, and creative expressions being put forward.

In this way, PAR not only values the participants' voices but also positions the participants as the experts in the very things that affect them (Percy-Smith & Thomas, 2010). In keeping with this notion, this study acknowledges that children and young people are not only experts in their own lives but also, as Coyne and Carter (2018) assert, fully capable of problem solving and making decisions to achieve outcomes that they deem to be in their best interests. This philosophy holds that people have the right to "participate meaningfully in the process of analysing their own solutions" (Gibbon, 2002, p. 552).

This project focuses on social change outcomes for the participants by enabling the collection of data through the development and building of each participant's capacity—capacity to identify topics, analyse issues, and disseminate understandings using participatory video and drama. This project is rooted in an educational process based on both reciprocity and the devolvement and disembrace of power during creative collaborations (Aldridge, 2015; Percy-Smith & Thomas, 2010; Tyson, 2011). In this project, the participants have been my co-researchers. We have completed the activities together, passing knowledge and understandings back and forth between us (both between each participant and me as the researcher and equally between the participants themselves). This reciprocity not only strengthened the participants' own community and understanding of the issues that affect them but also provided the literal and metaphorical spaces to consider and develop ways to overcome those issues.

³ The facilitators are the lead researcher, Michael Neufeld, second facilitator Paul Ripley, and third facilitator Stephen Dallow. Each was chosen to participate for their unique skills. Paul is a nursing lecturer in Aotearoa New Zealand; he was chosen to facilitate given his experience working with young refugee people as a nurse and child health researcher, his knowledge of educational pedagogy, and his participation in participatory video facilitation training at InsightShare Oxford, UK, with the lead researcher. Stephen is a director at one of the theatres from which the participants were recruited; he contributed by helping with theatrical games and liaising with the young people and families before and after the five-day workshop.

Self-Realisation and Capacity Building

Child and youth participation is often only considered in terms of individual self-realisation or agency, rather than a systemic and continual social engagement that accepts children and young people as a cultural group in their own right (Lansdown, 2010). This is an important distinction to note in relation to this project because the participation occurred within a wider context of society's relatively restrictive cultural traditions. However, the critical pedagogy that informs this study mitigates this to some extent by demanding researcher reflexivity, identifying these cultural contexts and subsequently purposefully seeking to diminish the existing barriers (Freire, 2000).

Considering that children and young people are, to a greater or lesser extent, indoctrinated and “educated” into adult ways of being, Freire (2000) suggests that to assume those who are marginalised from power are incapable of possessing or contributing to knowledge is akin to seeing them as being non-human. With a tendency for adults to see young people as needing to be controlled and socialised to assimilate into a safer society, it is relatively commonplace to dehumanise them, which of course adds potential for even further marginalisation. Freire goes further to suggest that unchecked biases of any “oppressor” rapidly establish and cement the oppressive force as the expected norm, thereby forming a positive feedback loop, reinforcing the very systems of power that created and fostered the original imbalance (Freire, 1982, 2000).

Construction of Childhood: Beings or Becomings?

Any assumption that children and young people are not capable of contributing to resolving outcomes that affect them might also stem from the traditions of a developmental view of childhood. As discussed in the “[Children's Place in Aotearoa New Zealand Society](#)” section (page 45), a developmental lens views children as incomplete beings or “human becomings” rather than social participants in their own right who have the same value and worth to society when they are children that they will have as adults (a social constructionist view) (Debski et al., 2009; Qvortrup et al., 2009).

The traditional propensity within Aotearoa New Zealand to view children and young people through a developmental lens has contributed to their lack of voice. The nature of this specific type of marginalisation makes the PAR methodology particularly well suited to provide potentially

emancipatory outcomes. In this context, emancipation relates specifically to actions that deliver on children and young people's right to be heard and maximise their self-determination and broader inclusion in society. As Langhout and Thomas (2010) point out, PAR is unique because emancipation can occur not only for the actual participants themselves, but also for others in the wider community.

However, an important consideration when using participatory methods with young people is the challenge of balancing the rights of a child against the rights of adults—in particular, the rights, needs, and wants of their parents (Nuffield Council on Bioethics (UK), 2015). Such potential conflicts cannot always be rectified and thus present a continual risk of defaulting to governance based on previously established power or privilege. Interestingly, Bradbury-Jones, Isham, and Taylor (2018) also point to this tension and suggest that this juxtaposition can serve to create and maintain marginalised subgroups within an already marginalised group, effectively making those voices even harder to hear. In other words, children and young people are vulnerable when it comes to being heard, but they also have the potential to be oppressive or marginalising, not only to adults, but also to other young people. Such are the inherent complexities and contradictions of attempting to balance different degrees of power and oppression within a context that invariably constructs ethics from multifaceted hierarchies of value.

Despite children and young people's experiences of disempowerment, their lived experiences of oppression and discrimination can in fact be used to help them deal critically and creatively with their own reality (Freire, 2000). Through active participation, young people can gain understandings and insights that empower them to contribute to the shaping of their participation in the wider world rather than continuing to be manipulated or oppressed by it. Through this critical lens, the very goal of this PAR project was to both consider the effects of discrimination and marginalisation on the participants and find a means or action capable of diminishing that discrimination and marginalisation. That is, I hoped that the experience would assist the participants to develop not only their voices, but also the knowledge and skills to make their perspectives visible to all.

Participatory Congruence: Consulting With Young People About Research Methods

With the distinct goal of amplifying young people's voices on health, I established and sought advice from three separate child and young person advisory groups before determining the ages of participants to be included and the methods to be used in this project. In consultation with their parents, I recruited 20 young people between the ages of 6 and 18 years for advisory groups from locations commonly frequented by families, including a family campground (ages 5–9 years), a community centre (ages 10–14 years), and two separate youth theatre companies (ages 13–16 years).

Recruitment was done by approaching parents to explain the project and then, with their permission, speaking to the young people to see if they would like to participate in a small group discussion. It was remarkably easy to have the initial conversations. In the youngest of groups (5–9 years) I knew two of the five families, but the others were simply families at the campground. The discussions took place in public spaces but without the parents present. Although the recruitment locations were somewhat geographically diverse within the city of Auckland, Aotearoa New Zealand, I made no purposeful attempt to ensure that the advisory groups represented specific cultural, ethnic, or racial diversity nor those with disabilities. I made this choice because I felt that a sampling of young people in spaces designed for young people would yield results that were indicative and transferable and because my experience of working with young people is that they generally do not see themselves through their particular disability or as different from other young people (particularly as pre-teens). My experience seeking feedback from these ad hoc advisory groups was overwhelmingly positive, and in the future, a more purposeful sampling to ensure inclusivity beyond markers of age could yield even more beneficial results.

The groups were generally representative of the Aotearoa New Zealand population and included ten Pakeha (50 per cent), two “Other European” (10 per cent), three Māori and Cook Island Māori (15 per cent), two Pasifika (Samoan and Tongan) (10 per cent), and three Asian (two Chinese and one Filipina) (15 per cent) young people. In the three groups, I asked the young people what they thought about their ability to participate in decisions that affect them, whether they saw value in the

proposed PAR project that would explore youth perspectives on health, and what methods they thought young people would want to use to explore health issues.

All but one individual in the advisory groups thought that young people's views should be considered by government and healthcare professionals. When presented with a variety of research method options, such as interviews, surveys, questionnaires, and creative methods such as art, drama, photography, and video, all suggested that they found arts-based methods most appealing. The groups identified video, music, and drama as their first preferences and overwhelmingly called for the use of methods capable of changing people's thinking by "going viral" on social media. This was essentially a green light to employ methods capable of rapid and widespread dissemination through platforms such as Instagram, TikTok, Facebook, and YouTube—platforms that are now clearly endemic in the lives of young people in Aotearoa New Zealand and that arguably contribute to their exploration and "framing" of the world (Kemp, 2022). Interestingly, all of the 6- to 9-year-olds identified YouTube as their platform of choice. This was the same for the majority of boys across all the groups; however, the girls in the older two groups pointed to Instagram and Snapchat as their preferred medium. Despite TikTok's popularity since 2018, at the time of the group meetings, it was only mentioned as the "new thing" and had only been in existence for a year.

According to all but the youngest in the groups (those under 7 years), these social media platforms are the spaces they claim to have virtually unlimited access to and where they often go to look for information. This is frequently at the behest of their schoolteachers, as several in the group explained that their schools require them to have YouTube accounts or other accounts to research subjects. For those under 7 years old, they too used these platforms but pointed out that they "usually" need to ask their teachers or parents for permission. It thus seemed fitting that these platforms would be where they would want to see any expressions of their own views.

Ultimately, the selection of participatory video for this study reflects its strength in storytelling and supporting a narrative approach—giving a voice to participants' perspectives in a way that may be more natural to young people than other forms of creative PAR. Furthermore, video can

represent the complexity of the underlying emotional context with a nuance that a less dynamic medium could achieve (Emmison et al, 2013).

Developing Video Facilitation Skills

Video methods can serve as an umbrella for presenting virtually any creative technique or genre, as they can simultaneously facilitate the creation, telling, and sharing of stories. The use of participatory video to create effective links between diverse segments of a community or group is relatively well documented. Even more importantly, as Harris (2008) suggests, it can have a bridging effect between established societal groups and those more marginalised. This bridging can make it possible for dialogue to flourish where previously there had been only alienation and division, giving rise to new ways of looking at societal challenges and solutions (Harris, 2008).

With video specifically identified by the young people in the advisory groups as a desired method for the participatory project, I sought external advice and guidance as to how best to use it to elicit stories and ideas from marginalised groups. This led me to Chris and Nick Lunch and the InsightShare organisation (<https://insightshare.org>). Since 1990, InsightShare has undertaken more than 200 participatory video projects in more than 60 countries, making the organisation one of the most prolific and influential purveyors of participatory video practice. In September 2019, I took the opportunity (together with Paul Ripley, a fellow child health researcher who ultimately supported this project during the participatory video workshop phase) to travel to Oxford, United Kingdom (UK) to train as a participatory video facilitator under InsightShare's tutelage (see Figure 2). The exercises that I developed for this project are premised on and adapted predominantly from those teachings.

Figure 2

Photo of InsightShare Participatory Video Course Participants



Note: I am wearing black and seated. Fellow facilitator Paul Ripley is the second from the right and standing. An InsightShare promotional video also captured the essence of our six-day course:

https://www.youtube.com/watch?v=1BxI5SjF_tM.

Conceptualising the Unfolding Process of Knowing, Doing, and Becoming

Participatory video and drama methods and the wider umbrella of participatory action research (PAR) facilitate an unfolding process of thinking, doing, and becoming (Aasgaard, Borg, & Karlsson, 2014; Benjamin-Thomas et al., 2019; Canosa, Wilson, & Graham, 2016; Harris, 2008; Lunch & Lunch, 2006; Milne et al., 2012; White, 2003; Willis & Edwards, 2014). This process of “becoming” uncovers the emancipatory potential of participatory video, which is not simply a method of collecting information but rather a method for building relationships, developing networks, and continual sharing of perspectives independent of the initial facilitation processes. Participants become part of solutions in this project by giving feedback on the proposed exercises, proposing new timelines, and recruiting other young people to participate. This is important because the participatory process involves facilitating opportunities to think about problems and solutions, reflecting on them to

develop new knowledge or “knowing,” and then doing something with that knowledge by sharing the stories with audiences to effect change. Participants thus “become” capable of independently attaining future goals and self-actualisation.

Conceptually, this process is representative of a framework that Craig (2018) suggests is often applied in educational praxis and frequently represented by metaphors such as gardening or the sowing of seeds in order to “grow” and cultivate people’s potential. This “unfolding” is culturally significant for many people in Aotearoa New Zealand, where there have been calls to adopt the Māori ponga, or silver fern, as a symbol of unity since the 1880s (Fitzgerald & Perrie, n.d.). The fern notoriously unfurls in a koru, or spiral, to expose its strong fronds and underlying silver colours as it matures (see Figure 3). It is considered by many Māori people a symbol of strength and enduring power.

Figure 3

The Māori Ponga, or Silver Fern



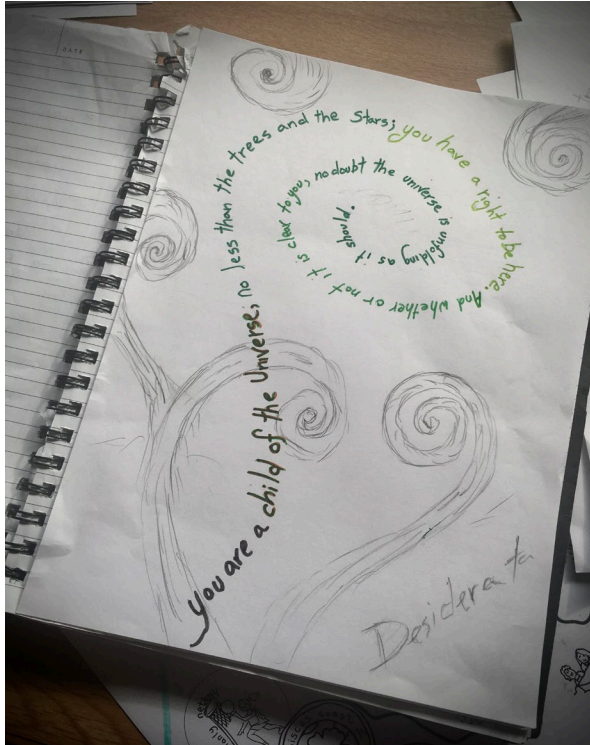
Note: Photo from iStock.com/Craig Buckland.

As I began to conceptualise the participatory video processes and align the philosophical position of unconditional regard required, I too adopted this metaphor and sketched an unfolding koru made from a verse from Max Erhmann’s poem “[Desiderata](#)” (Sharp, 2007) in my research journal (see Figure 4). “Desiderata” is Latin for what is needed or wanted, and for me, aligned with the

unfolding nature of the participatory research cycles and the importance of capacity building for participants that are at the crux of every exercise.

Figure 4

Conceptual "Unfolding" of a Verse From "Desiderata"



Note: Photo taken from my research notebook.

Research and Creation “With” Not “On”

Fundamental to PAR is an awareness that research and creation are not separate steps. On the contrary, together, they are the method. The PAR process aims to create opportunities and conditions that facilitate both individual and group empowerment, the outcome of which is intended to be cultural actions that achieve social change (Aasgaard et al., 2014). In this project, the specific cultural action and social change being sought is a wider acceptance of children and young people’s rights to be heard and to contribute to healthcare decisions affecting them.

The use of participatory video methods places the researcher alongside and “with” the participants (in this case, children and young people), rather than objectively distanced from them.

This project uses video production as a hands-on method that serves as a constructivist tool (Lunch &

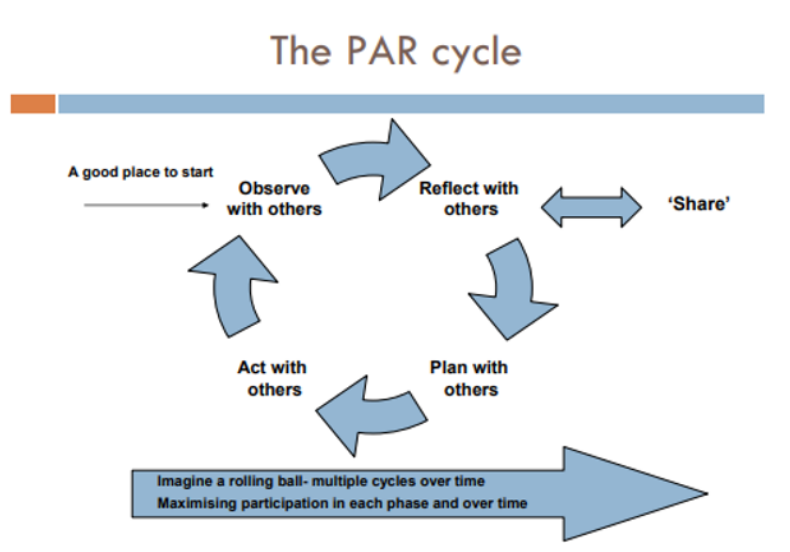
Lunch, 2006; Veale, 2005). Undertaken in cycles—or more specifically cycles of observing, reflecting, planning, and acting—participatory research allows participants to generate information and share their knowledge using their own terms, language, and creativity (Loewneson, Laurell, Hogstedt, D'Ambruoso, & Shroff, 2014). The participatory exercises used in this study demanded that as the researcher, I take a less objective stance than might be required in many other methodologies, instead assuming a far more facilitative advocacy role (Jennings, Parra-medina, Messias, & McLoughlin, 2006; Percy-Smith & Thomas, 2010).

Importance of Process Over Product

Participatory video methods place the process of building trusting relationships above any need to create polished video content (Gruber, 2016; Lunch & Lunch, 2006; Snowden, 1984). The process is fundamental to empowerment. This is because, regardless of the final “product,” any content created facilitates discussion. The resulting relationships fully establish participants as co-researchers and promote the commencement of distinct action research cycles. While there are a number of different examples of PAR cycles, all include a process of observation (identification), reflection, planning, and implementation of action that then leads to the next observation and subsequent cycles of analysis (Crane, 2010) (see **Error! Reference source not found.**).

Figure 5

Participatory Action Research Cycle



Note: Sourced from Crane (2010).

The participants in my study had significant ownership over the planning, design, and execution of the workshops themselves and ultimately wholesale freedom in their selection of the topics and stories that they developed and shared, which helped ensure that the processes were as participatory as possible (MacDonald, 2012). To enhance participant “ownership,” we met prior to the workshops to discuss how they would like to approach the days, covering start and finish times, types of exercises, and expectations regarding behaviour from each other and the facilitators. For the types of exercises, I shared with them the workshop plan that I had created, and we worked through it so that they could envision the week. When they challenged items on the itinerary, we made amendments. For example, we removed a planned name game and two “icebreaker” exercises because the participants thought those would be uninteresting and they had done something similar before in school. The behavioural expectations that the participants requested be documented included that everyone act with kindness, respect, and resilience. We also added that “mistakes are great” and wrote these points on a poster for day 1. At the morning debrief on the first day, the participants added an additional point: “help each other as best you can.” Everyone (participants and facilitators) then agreed to these points, and we all signed the poster as a “contract” between us.

Children and young people are far more capable of complex thinking than is often presumed and, in many cases, can contribute to and even lead aspects of data analysis (Kellett et al, 2004). The participatory video process integrates data collection with analysis by using exercises and discussions that probe participants’ thoughts and ideas about the videos they are creating. There is a distinct gap in the lexicon relating to data analysis in participatory video literature. In this project, Crane’s (2010) PAR cycle (**Error! Reference source not found.** [page 72]) guided the analysis, and the participants undertook the data creation and analysis concomitantly during individual and group work discussions as well as in the months that followed the sessions, as I edited and modified the video artefacts under their guidance.

The participants’ creative performances and stories formed catalysts for discussion, helping identify key concepts that in turn informed the planning and creation of their next undertaking. These

ongoing and iterative discussions—a key component of the data analysis—enabled a collective reflexivity that garnered shared understandings between the participants and me. The discussions and analysis also informed the interpretations presented in my critical commentary throughout [Chapter 4: “Putting Theory into Practice—The Participatory Video Workshop”](#) (page 86) and [Chapter 5: “Reflective Provocations”](#) (page 179) and support the recommendations I make in [Chapter 6: “Future Possibilities: Where to From Here?”](#) (page 195).

The final versions of their videos represent the culmination of multiple iterative and analytical feedback and consultation cycles. These video artefacts—created by the groups—embrace and incorporate the participants’ reflections and stories, serving the iterative thematic analysis (Given, 2008) that identifies the overriding themes and issues and provides suggestions for attaining positive change.

Why Use Video: Tools for Change

To fully understand and appreciate the power and potential of participatory video and drama, it may help to first explore the rise and influence of film and cinema itself. The first semblance of what would become cinema was created by Thomas Edison in 1891 when the Edison Company created the Kinetoscope, a machine that allowed people to observe relatively short moving pictures through a small viewing hole in a box. Within only a few short years, the public was able and very willing to pay to see these scenes. Kinetoscope parlours, the first and most well-known of which was the Holland Brother’s Parlour in New York, became lucrative businesses, limited only by the number of machines they could procure and house (Nowell-Smith, 2017). The initial movies were simple recreations of everyday events, small moments in time such as blacksmiths at work, a “strongman” flexing muscles, and (reportedly one of the most popular) scenes from a boxing match performed by cats (see Figure 6).

Figure 6

Example Images From the First Public Movies



Note: These images are captured from the corresponding videos hosted on YouTube:

<https://www.youtube.com/watch?v=86X85MMcdzk>. When I showed this video to the young people participating in this project, one of the participants exclaimed that it was “*hilarious!...because people still love videos of people who are naked and cats...that’s YouTube! It’s like nothing’s changed*” (SV, 15 years old).

The effect on the public was immediate, and their hunger to see representations of their world clear. Soon, sound was being synchronised to the images and the experience of watching these new moving pictures became even more immersive and captivating. Although initially reluctant to risk what was a lucrative business model, the inventor Thomas Edison and others began exploring how they could lengthen the films and maximise their audiences, by projecting the moving images onto walls or screens to allow for more than single viewers at any one time (Nowell-Smith, 2017).

By 1895, the first projector was created, and in the ensuing five years many other projection systems emerged around the world. The films became more purposeful in their use of story to share

ideological positions, and the cinema soon replaced live theatre as the locale for the hearts and minds of society. People flocked to focus their attention on the screen (One Hundred Years of Cinema, 2016a).

This universal focus allowed for the use of an ever-increasing complexity of both technical and narrative storytelling to influence societal behaviour. Throughout the 20th century and into the 21st, both private organisations and governments adopted film for the purposes of propaganda and the dissemination of ideas to maintain power. Some examples of how cinema became an ideological platform and battleground (Nowell-Smith, 2017; One Hundred Years of Cinema, 2016a; Shipman, 1993) include:

- “Battleship Potemkin” (https://www.youtube.com/watch?v=g5WbeoP_B8E), directed by Sergei Eisenstein of the Soviet Moscow Film School (One Hundred Years of Cinema, 2016b).
- “Triumph of the Will” of the Nazi Party of Germany (<https://www.youtube.com/watch?v=p7hJVatW45M>), directed by Leni Riefensthal (One Hundred Years of Cinema, 2018).
- Multiple Hollywood films promoting American exceptionalism, a notion that America is the greatest country to have ever existed (<https://www.youtube.com/watch?v=em3T5KnLAX0>) (Aperio, 2015).

Film and video are tools capable of maintaining cohesion and establishing dissent and division, and so they must necessarily be regarded with some degree of cynicism and certainly respect (Auerbach & Castronovo, 2013). By the 1940s, cinematographic depiction had become a remarkably efficient means of sharing political messages and establishing a society’s value hierarchy. More people can watch and listen than can read, and during World War II, film fuelled war efforts on all sides, with the public going to the cinema in throngs to view the propaganda or escape in a story. The cinema was a place to come together to experience shared stories, like a new kind of communal campfire. In Europe and North America, the commercial power of the film industry grew exponentially, securing its influence on politics. The establishment of a dominant opinion by the

major players in national film industries (and subsequently TV) all contributed to a reinforcement of societal norms, capable of silencing opponents or other views by establishing what was later coined by Elisabeth Noelle-Neuman as the “spiral of silence”—a positive feedback loop that plays on individual’s tendency to avoid risk of ostracization and isolation by not speaking out against popular opinion (Noelle-Neumann, 1993, 2013).

Between YouTube, Instagram, Facebook, and other social media sites, today billions of people consume video and graphic content that is ultimately informing values and world views. As Facebook founder Mark Zuckerberg claimed in 2016, his powerful medium was created to “give people the power to share and make the world more open and connected” (Lepore, 2021). In contrast to the historical role of film to reinforce social norms, social media has created the potential for video to disrupt existing “spirals” and establish new dominant opinions, not constrained by geographical boundaries and available on demand.

However, such power is also a catch-22.⁴ It can induce its own spirals of silence that may dismantle aspects of societal cohesion that serve to protect rights and responsibilities. The algorithms behind these social media platforms that determine who sees which stories, when, and how often can be used to reinforce specific beliefs that are controlled by certain entities for particular gains. This, in turn, keeps people returning for more similarly messaged content and affirmation of their beliefs, while also serving the financial or ideological interests of the creators and platforms, which pursue advertising revenue as much as any altruistic desire for emancipation or growth of mindset (Farrell, 2018). This concentrated messaging provides viewers with confirmation bias and thus justification for a hardening of their positions. The effects of this form of propaganda in social media spaces can be terrible when weaponised to derive dissent and polarisation around key issues. A prime example of this is the proliferation of antivaccination messages or conspiracy theories that, at least on the surface, are not always grounded in measurable evidence. When we take into account the potential for “deep

⁴ A “catch-22” is a “problematic situation for which the only solution is denied by a circumstance inherent in the problem or by a rule” (Merriam-Webster, n.d.).

fakes” or other lies that can be used to further specific agendas, all media platforms should be considered with a lens of potential for both benefit and harm (Chandler & Munday, 2020).

History of Participatory Video: The Fogo Experiment Raises Voices of “The Silent”

In 1967, poverty in many rural communities of Canada was expanding, and government resettlement programmes that seemed not to understand the people or their needs left those in these regions feeling abandoned and marginalised (Wright, 2003). For Don Snowden, an academic at the University of Newfoundland, the resulting internal migration from impoverished regions to newly designated “economic opportunity zones” (urban centres) was distressing (Newhook, 2009). His distrust of the new urban focus of government led him to the realisation that people in rural areas did not have a voice and were thus unable to influence government decisions on the issues they faced locally. His solution was to use media to help the marginalised people of Newfoundland express their thoughts and feelings about their poverty and government policy (Fogo Island Inn, n.d.).

Ultimately funded by the National Film Board of Canada (NFB), Snowden formed the “Challenge for Change/Société Nouvelle” (CFC/SN) programme (Waugh, Baker, & Winton, 2010). He and his colleagues entered the Fogo Island community in Newfoundland and created a process for helping the islanders explore local and national issues. This was the beginning of a new form of ethical documentary making that focused on relinquishing control of the filmmaking process to those most affected. The participants were then able to share their experiences and potential solutions widely using film. This “Fogo Process” represents the inception of participatory video and a point at which empowerment rather than observation became the focus of the film work. The participatory process was a distinct move away from the ethnographic roots of more traditional documentary film (Milne, Mitchell, & De Lange, 2012).

The resulting films raised awareness and pulled many rural communities together, as they could now see similarities between the Fogo Islanders’ plight and their own. Soon after, similar CFC/SN projects were funded in many rural and impoverished communities across Canada. The CFC/SN programme produced over 200 films, and the resulting dialogue with central government managed to establish some shared understandings of rural issues despite the immense geographical

and cultural distances between them (Waugh et al., 2010). Film had found a way to amplify and reveal previously silent voices and hidden stories.

The process of rummaging through Canadian film archives and YouTube renderings to see how the issues of the time were presented by Snowden and the NFB filled me with nostalgia. I was a child in Canada in the 1970s and first saw many of the films when they were played in my school gymnasium. We looked forward to these “movie days” when the NFB promoted the sharing of films in the school curriculum, sending a projectionist to schools even in the most rural and remote locations. Our parents were invited to attend these showings as well, and it felt almost like a reverent experience—both a solemn and a celebratory exploration of fellow Canadians’ hardships and experiences. It was certainly novel, since digital video didn’t exist. Watching a film was not only an exciting way to learn about aspects of our country, but it also arguably connected us into a wider sense of togetherness, solidarity, and nationality. That the films were Canadian (as opposed to the more widely available American television and Hollywood films) undoubtedly contributed to their power to effect local change. Although as children we simply experienced the power of Snowden’s works through gymnasium viewings, oblivious to the political forces that led to their inception, we were still effectively transported thousands of kilometres across the country while visual and audio messages literally changed our perspectives and understandings of our own context and selves.

This is particularly relevant to this research project because of the potential for change that the participatory video process creates. Within two years of the first Fogo Process production, the Fogo Islanders were seeing radical and positive changes in their community. The Fogo Process created previously unavailable opportunities for co-operatives, networking, and growth. It was clear that the use of visual media through participatory video can effect positive change. The collaborations had created new ways of opening dialogues and understandings of others’ positions, and the proposed solutions that the participants had offered were now rightfully being acted on.

The Fogo Process has since been used all around the world, with Snowden widely recognised as a participatory video pioneer (Asadullah & Muniz, 2015; Lunch & Lunch, 2006; Milne et al., 2012; White, 2003). Snowden, despite being an academic, was not prolific in his writing, instead focusing

on fieldwork in what he considered a practice of participatory revelation. He did not think that the films were responsible for creating an understanding of the problems people faced, but rather the people and the inquisitive, collaborative processes required to make the films. The process is what reveals people's perspectives and the reality of their lives (Snowden, 1984).

Many other practitioners have followed in Snowden's footsteps, including the brothers Nick and Chris Lunch who founded the non-profit organisation InsightShare in the 1990s. Chris's background as an anthropological researcher led him to view observational research as inadequate to meet the needs and desires of the people themselves. He came to believe that the uniqueness of participants' voices was lost by the time the works had been written, interpreted, and published by researcher proxy. As early adopters of video, these brothers describe participatory video as "a tool for positive change" (Lunch & Lunch, 2006, p. 4), capable of telling the real story by sharing first-hand the perspectives of those most affected by an issue.

As described in the "[Developing Video Facilitation Skills](#)" section (page 68), it was in 2019, at InsightShare in Oxford, UK, that I had the good fortune to meet the Lunch brothers. Their ethos and approach to participatory video heavily inform the methodological design and practice in this project. Most notably, this project reflects their focus on the collaborative process and on developing trusting and sustained reciprocal relationships as opposed to product outcome. This focus was fundamental in enhancing my collaboration with the study participants and fostering their capacity to contribute freely. Creating a space that allows for the greatest degree of free expression possible and ensures reciprocal learning relies on developing trusting and enduring relationships. This attention to fostering unconditional regard and the opportunity to be heard is paramount if young people's ultimate well-being is to be improved (Lloyd & Emerson, 2017).

Being Participatory

The importance of inclusion and participation to ensure positive intergroup relationships and achieve positive social outcomes has been a long and instantiated position in ethnographic, anthropologic, and action research methodologies (Lewin, 1946; Lunch & Lunch, 2006; Pink, 2007; Willis & Edwards, 2014). Gruber (2016) identifies participatory video and filmmaking as an

ethnographic exercise in supporting participants to create new knowledge and shape their own image. However, according to Lewin (1946) the reliance on interconnectivity and the inherently complex nature of group dynamics can also lead to instances of “unclearness, [due to the] lack of standards by which to measure progress” (p. 35).

Arguably, any lack of clarity could be due to the nature of ethnographic and anthropologic inquiry itself, which according to Gunn, Otto, and Smith (2013) is always attempting to orientate the “presence of the past, in the present” (p. 63). To counter this, the intention is to reveal what is currently emergent within the intersocial dynamics of participants, recognising that these exist within a “living culture” (Benest, 2010; InsightShare, n.d.). While the need to consider what has come before may be vital to creating shared understandings, I am also conscious that anything that constitutes more than a backwards glance to provide context could aptly serve to reinforce what has been and potentially displace or lessen the ability to foster meaningful change.

This participatory video and drama project seeks to enhance youth voices, not by focusing solely on young people’s individual experiences, but by gathering their stories and considering them in the context of their present challenges as they see them. The use of collaborative design processes is an intentional epistemological shift away from more observational ethnographic and anthropologic approaches towards an inclusive participatory action-oriented approach. In this way, participatory video is an emergent and iterative process perhaps best considered as an attempt to diminish, as much as possible, the gap between the researcher and the researched (Gruber, 2016).

Research Ethics

Ethics approval for this project was received from the Auckland University of Technology Ethics Committee (AUTEK) on March 19, 2020, reference number 20/42. ([Appendix A](#), page 233).

Recruitment of Participants/Co-researchers

The study’s inclusion criteria initially welcomed any young person aged 13 to 18 years capable of communicating in English or with translation assistance. Although I originally planned to include 5- to 18-year-olds to represent all school-aged young people, I made the pragmatic decision to

focus on the slightly older group in order to enable the recruitment from local youth theatre companies whose programmes are also split into groups of 5- to 12-year-olds and 13- to 17-year-olds.

The power differentials between adults and young people (and researchers and young people) did have me considering at the time who might miss out on the opportunity to “have a say.” Shortly after publishing the invitation to participate, the answer became clear when a number of young people and their parents contacted me asking if there were any plans for a project with younger children. A number of 11- and 12-year-olds asked to participate, and so I applied to the AUT Ethics Committee and requested an amendment to recruitment to also include those 11 and 12 years of age. In the PAR methodology, a reflexive and responsive process is integral (Lunch & Lunch, 2006). My reflection on the arbitrary choice of age inclusion is important to consider as it highlights the nature of power differentials. Inclusivity is a fundamental aspect of any PAR project (Lwin, 1946). Including the 11- and 12-year-olds (the oldest of the younger theatre groups) reaffirmed the participants’ role in shaping the project and strengthened the project outcomes because it amplified both younger and older youth voices.

The study recruitment process lasted nearly a year and was convoluted given a series of disruptions and starts/stops resulting from the impacts of COVID-19 (see the “[Researching in the Time of COVID-19](#)” section in the next chapter [page 87] for a detailed description). Ultimately, I had a recruitment invitation published in a youth theatre company’s quarterly online newsletter in December 2020, providing both written and video options to learn about the project. The invitation was for young people to participate in the project through a five-day school summer holiday programme in January 2021. Information regarding the nature of creating videos and disseminating findings through the sharing of videos with viewers was discussed in information sessions, via emails and phone inquiries, and on day one of the workshops. All participants and parents were asked to sign a participant and parental consent and waiver form (see [Appendix D](#), page 239) to ensure that they agreed with the public showing of their approved final works. Part of the final day of the workshops was used to discuss with participants how they would like to disseminate their work and what they felt were the benefits and risks of different methods.

The initial plan accommodated up to 20 young people as participants/co-researchers and included provisions for anyone with physical or learning difficulties to have a caregiver or support person present as required. Although there were plans for a much wider recruitment strategy, within days, the theatre company had received expressions of interest from or on behalf of 35 young people. As the programme was advertised as a first-come, first-served opportunity, I made no additional advertisements. To avoid any need for exclusion due to numbers, I arranged for additional funds and provisions so that up to 35 young people could participate. This meant purchasing additional video equipment and supplies and increasing the budget for refreshments and USB drives.

At the start of the summer programme, the final number of participants/co-researchers who attended was 29. One young person came and participated on some of the days but could not attend the study in its entirety, and another came on opposite days. The ages of the co-researchers ranged from 11 to 17 years. The group comprised 14 girls, 14 boys, and one other who asked that they not be specifically identified with either gender.

Creating Safe Spaces—Balancing Protection Against Potential

Children and young people are often considered vulnerable both inside and outside of research contexts (Stalberg et al., 2016). Creating spaces that are considered safe can, however, be a catch-22 dilemma or, worse, illusory. It is not easy to establish what is or is not actually safe or decide who is or is not competent enough to be self-determinant. The longstanding tensions inherent in establishing children and young people's competency frequently results in erring on the cautious side, often precluding young people's participation with a paternalistic, protectionist rationale rather than allowing any exposure to risk that might foster potential contributions (Carter & Ford, 2012; Carter, Jackson, Hayter, & Nyamathi, 2012).

There are broader issues at play when we default to stopping discourse unless it is risk free. The approach taken in this research has been to focus on creating opportunities for supported and collaborative development and expression—an expression of co-design (Stalberg et al., 2016). Unfortunately, according to ARTICLE 19 (2021b), we are currently seeing a reduction in the defence of free expression globally. This activist organisation, named after the article in the UN Universal

Declaration of Human Rights that protects freedom of opinion and expression, suggests that there has been a general move away from open questioning and communication relating to governmental and institutional responses during the COVID-19 pandemic (ARTICLE 19, 2021a). While the extent of this shift may be debatable, the issue of censorship and control of language is fundamentally a threat to any groups already marginalised. The ability to deliver on the rights of “freedom of speech” is always at risk when considering whether young people can participate.

The fundamental question is, do we encourage young people to have open discussions regardless of what they themselves may wish to say or do in these conversations or do we shut down dialogue to protect and avoid discomfort and the potential for risk and harm? Creating truly safe spaces for young people demands that we juggle competing interests to both protect and serve at the same time. This is difficult when the ideas that young people share and are exposed to may be seen by some as controversial or potentially “triggering.”

According to Peterson (2002, 2018) and Bamberg (1997, 2011), to encourage true thought and the development of understanding, all ideas must be able to be spoken, particularly the ones we find most difficult to hear or discuss. They posit that most people are not capable of processing their thoughts independently of verbalisation or writing, so the speaking or discussion of ideas is particularly important in the creation of new understandings and any subsequent application of them. The open expression of ideas should, therefore, be protected and fostered at every possible opportunity and arguably default towards participation rather than exclusion. To do otherwise would more likely produce more marginalisation, not less.

In defence of this approach, consider the American Psychological Association (APA) (2017a, 2017b) best practice guidelines for treating people’s fears and anxieties. The APA suggests that people are not best served by simply removing threats or sheltering them from offense. On the contrary, the guidelines indicate that the best way to strengthen people’s self-belief and empower them is through supported exposure to the very things that are seen as threatening or anxiety inducing (APA, 2021).

When young people are empowered to make decisions and drive the processes of analysis and dissemination, they are no longer passive recipients or objects of research, but rather valued contributors. Therefore, while there are aspects of young people's vulnerability that must be considered and addressed, these are less troublesome than any wholesale paternal refusal to allow them to participate or for interpretations of their thoughts to be made simply by adult proxy.

I applied these principles to the design of this study to create the safest possible space while allowing for the greatest possible freedom of expression. Participants had full control over which aspects they participated in, what they created, and what they shared. Equally, they had the option of remaining anonymous in the dissemination of their findings or of being openly recognised and acknowledged for the work they produced. I undertook feedback processes each day of the study and in the weeks and months that followed to guide the creation of the final video artefacts. There were many examples throughout the workshop of images and scenes being removed or altered at their request, and participants always had the ability to withdraw from the project at any time or have all of their creative works removed from the final artefacts to be shared. All 29 participants remained engaged throughout the entire process. We have used pseudonyms in some cases where individuals wished not to be identified in relation to some statements.

At its core, this study holds a desire to enhance participants' own understanding of their world while also building their capacity for critical and creative thinking and acquiring skills necessary to express their ideas through storytelling and video production. This promoted the potential for a broad sense of emancipatory empowerment against a backdrop of potentially uncomfortable discoveries. By ensuring that the environment was continually reflexive and predicated on unconditional regard, a balance was struck between potential risk and gain to create an inclusive and participatory experience. Furthermore, I believe that this provided the closest possible approximation of a "safe space" and ensured that their contributions and ideas could be made available not only to their peers in the workshop, but also to wider, more disparate audiences.

Chapter 4: Putting Theory into Practice—The Participatory Video Workshop

This chapter describes the conceptual considerations of, preparation for, processes used in, and practices of the five-day participatory video and drama workshop, to establish the context in which the participants shared their perspectives and stories and reflected upon them to form new understandings. It begins by describing (1) how I identified the theatre groups that I ultimately ended up recruiting from and working with, (2) the challenges of conducting research during the COVID-19 pandemic, and (3) my take on portraiture and landscape views and how I used these to frame the exercises in this project. It then recounts the structure and exercises of each day of the five-day workshop, culminating in the presentation of the final video artefact from each participant group. Capturing the essence of these exercises and analytical processes helps demonstrate how the theoretical and methodological underpinnings translate into the overarching themes and stories expressed in the participants' video artefacts and project outcomes.

Entering “Their” World

At the inception of this project, in 2018 I searched for organisations or groups in Aotearoa New Zealand that publicly stated that their focus was on enhancing young people's voices. I searched grey literature, academic literature, and web pages for “children's voice loc:NZ” and “promoting young people's voices loc:NZ”. I found very few references that were outside of the Aotearoa New Zealand Office of the Children's Commissioner. There were a number of international examples, but within the Aotearoa New Zealand context, there were only two main search results, both for websites for youth theatre companies located in Auckland. I reached out to them and asked them for feedback on the premise of this project. I also sought advice on how they use creativity to foster young people's expressions to meet their stated goal of helping “children and teenagers to find their own voice and place” (Tim Bray Theatre Company, n.d.).

Tim Bray from the Tim Bray Theatre Company and Stephen Dallow from Kids 4 Drama were both incredibly generous with their time and welcomed me into their theatres as an observer for the better part of a year. I observed and assisted the Tim Bray Theatre Company in a week-long summer acting programme (July 2019) for young people aged 6 to 16 years and spent most of 2019 and early

2020 attending weekly evening theatre classes with 12- to 17-year-olds at Kids 4 Drama. Embedding myself into their world in this way was instrumental to my realising just how capable and passionate these young people are about creating and telling their stories. It was also during this time (September 2019) that I travelled to InsightShare in Oxford, United Kingdom (UK), to undertake my participatory video facilitator training course.

By January 2020, I had begun drafting a written facilitators guide to using participatory video and drama with young people, to support the facilitators (my colleague Paul Ripley, Kids 4 Drama director Stephen Dallow, and me) in the *Creating Space* project. This guide outlined plans for how we would document the project, including the use of notebooks by the facilitators to capture ad hoc observations, an anonymous feedback box for participants to provide ongoing feedback on their experience, audio and video recorders for group discussions, Go Pro cameras to be worn by facilitators and participants to capture first-person perspectives of the discussions and exercises, and set timepoints for facilitators to document progress through reflexive notes and video logs. The guide also outlined the format and exercises to be used in the project. The more I observed the weekly youth theatre classes, the more I found myself revising exercises to include more complex technical and conceptual narrative filmmaking skills and thematic analytical techniques. These young people demonstrated significant focus and potential week in, week out, as they created works of theatre. I was reminded of van Rooyen et al.'s (2015) position that young people's age can belie their true competence and ability to contribute.

Researching in the Time of COVID-19

During my observation of the Kids 4 Drama classes, I explored the possibility of undertaking a participatory video and drama workshop with the students. The idea was for the workshop to run over multiple weeks through their weekly classes. After receiving ethics approval (in March 2020), I was ready to initiate the first session with these participants. However, the arrival of the COVID-19 pandemic had unexpected, albeit ultimately positive, consequences on this project timeline.

From March 2020 until November 2021, Aotearoa New Zealand maintained an elimination strategy for the COVID-19 virus. The first cases of COVID-19 in Aotearoa New Zealand sparked a

nationwide lockdown the night before our first scheduled workshop session. This resulted in a postponement of the project until we were again permitted to meet, over two months later. There was considerable frustration and uncertainty relating to what may or may not be done under various “alert levels,” and at the end of the formal lockdown, new mandates relating to visitor access at theatre spaces and schools made starting the workshops impossible. Furthermore, the participants now had limited availability given their need to catch up on schooling and prepare for upcoming theatre performances. As a result, the participants and the youth theatre company director proposed a new start date in August 2020.

Throughout this time, I stayed in contact with the director of the youth theatre company, sending out regular email updates to the 14 young people who had thus far expressed an interest in participating. Unfortunately, only a day before the new August 2020 start date, the Aotearoa New Zealand government reported that the COVID-19 virus was again in the community, and we entered another mandatory lockdown.

It was devastating to again be forced to delay, and as I’m sure many people have come to appreciate during the global COVID-19 pandemic, the financial impact of lockdowns on businesses and groups that rely on performances, public attendance, or face-to-face social interactions has been significant. Kids 4 Drama was no different. At the time of this writing, COVID-19 still continues to threaten the viability of many organisations and is very clearly impacting on children and young people’s well-being (Duncanson et al., 2020; Maxon et al., 2021; Menzies et al., 2020; United Nations Children’s Fund, 2021; Webb et al., 2020).

The most significant impact of the pandemic for young people is the negative mental health consequences that fear and isolation bring (Maxon et al., 2021; Menzies et al., 2020). The young people in this project experienced an incredible amount of disruption leading up to the workshops and had family members lose jobs, schools closed, clubs and sports cancelled, and their acting curtailed for many months. As we will see in the stories they present on health, their mental health is a key concern and fits with the increasing number of young people in Aotearoa New Zealand and

internationally who are self-identifying as experiencing poor mental health (Maxon et al., 2021; Menzies et al., 2020; Yang, 2021).

Ongoing Delays and Shifting Timelines

While it was difficult to watch the theatre company being buffeted by extrinsic economic pressures that threatened its existence, the challenges they were facing became even more clear when a number of the young people and their parents called me and expressed a desire to put off this participatory video project until the beginning of the following year. They explained that they wanted to avoid anything new, so that the kids could just focus on school and their “normal.” Although this was disappointing to hear, I gained a better understanding of the pressures that some of the young people and their families were experiencing. It was also very positive that they were not asking to cancel the project but only delay it for five months. At the time, it struck me as interesting that what they perceived as getting back to normal didn’t include an overt mechanism for the kids to talk about their health and well-being.

Given the delays and new timing (within the school summer holidays), I worked closely with the theatre director and five of the original potential participants to revise the structure for the workshop, condensing it from weekly two-hour sessions over several months to five full-day sessions over one week. We met in person several times for 30 minutes following their weekly theatre group and spoke via phone to discuss how they wanted to help with recruiting other young people to participate. The theatre director and I also met independently to discuss health and safety issues and to verify that both the other facilitator and I had valid police clearance to work with young people.

We booked the facilities to accommodate the workshop for the middle of January 2021 and formally advertised the study to recruit additional participants, with a target of 12 to 20 in total. After we ran an initial advertisement in the Kids 4 Drama newsletter in December 2020, I received an overwhelming response that immediately exceeded the planned recruitment capacity. I therefore did not pursue any further recruitment.

Interestingly, Auckland City arts regional trust Te Taumata Toi-a-Iwi (2021) published an arts review shortly after our workshop. It highlights the significant strain that artists and those in the

arts sector are experiencing in the face of societal lockdowns, suggesting that flexibility and repeated negotiations are now the new normal for artistic endeavours. I am grateful for the reciprocity and iterative decision making that the participants and facilitators offered me while navigating the planning for the five-day workshop and the execution of the day-to-day exercises within it around the unprecedented impacts of COVID-19.

Portrait and Landscape Views

The exercises in the five-day workshop aimed to foster a culture of unconditional regard within the group, providing opportunities for participants to contribute towards individual and group goals. More specifically, the exercises worked to guide participants in considering their own experiences and perspectives, while building their capacity to listen to others' stories and encourage them to tell them. Lunch and Lunch (2006) identify that the process of facilitating storytelling through participatory video creates distinct focal points for undertaking content and thematic analysis—all while promoting the acquisition of the hands-on technical skills required to capture collective concerns, ideas, and solutions on video.

Health professionals often fail to look at people or problems holistically, instead seeking to find individual things or pathologies that we can “fix.” This is particularly true in emergent care contexts, which often follow a “patch and dispatch” mantra and do not give primacy to the complex multifactorial psychosocial contributors to illness or injury. This is not out of purposeful neglect or malice, but rather ignorance or the necessity to control the immediate chaos of illness and injury, particularly within an environment of relative resource paucity (Neufeld et al., 2012).

Having explored the idea of portraiture as a way to consider clinical problems for almost 15 years, I was drawn to Lightfoot's description of portraiture as a bridge between art and science (Lawrence-Lightfoot, 2005, 2016; Lawrence-Lightfoot & Davis, 1997). I considered her autobiographical methods as a tool for understanding my own experiences of nursing practice, but in doing so, needed to adapt it to a clinical context. Lightfoot establishes people's place and importance within a wider societal construct, making visible the importance of their humanness and the multifactorial forces that shape them (Lawrence-Lightfoot, 2005, 2016). In this way, she brings value

to what is often unseen or buried under the surface. She equates the exploration of people's existence to a storytelling process akin to sketching and carving people into recognisable and attributable shapes. Her descriptions are, in my opinion, as beautiful as any literal painting, and her reflections on children's ability to teach adults lessons that may be long since forgotten are absolutely relevant to the aims of this project (Lawrence-Lightfoot, 2016). Hill (2005) also describes the ability of portraiture to develop and communicate research findings in "multidimensional ways," blurring boundaries between aesthetics and empiricism and providing the "essence of events that many of us may have lived at one time or another" (p. 96).

Lightfoot's examination of people and organisations from multiple perspectives led to my consideration and adaptation of portraiture in a more literal photographic sense. In photography and cinematography, we can both literally and metaphorically open and close the apertures of our lenses. We do this to add or remove light in order to illuminate different fields of focus—bringing viewers' eyes upon exactly what it is we wish them to see. The wider the aperture, the narrower the focus: we see great detail through the portrayal of isolated subjects (i.e. less context). The more we close the aperture, the less light there is to blind us and the greater the depth and clarity we then have across the entire scene. This is an integral part of the art of portraiture and allows for specific aspects of a topic to be placed in or out of focus. Adjusting aperture is a means of controlling where we "shine our light," literally highlighting people and their perspectives.

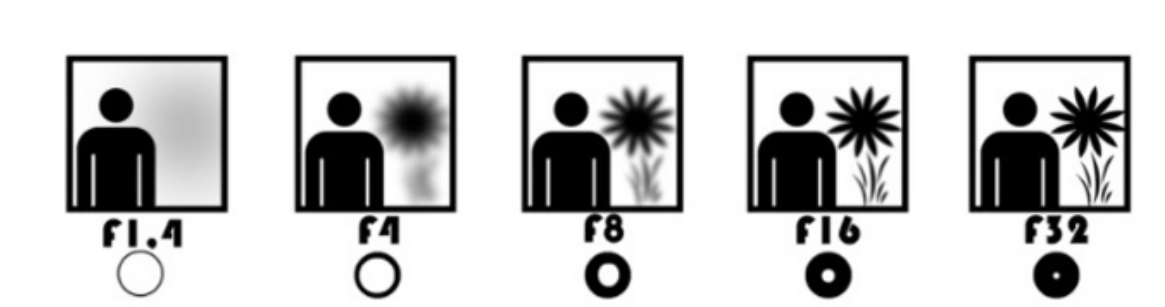
In my opinion, by widening the aperture to "blow out" the background for a purposeful and close focus on an individual, the portrait directs our awareness to that individual's specific existence in isolation. Simultaneously, this focus can displace our ability to see the bigger picture or influencing factors that are the "why" behind the individual's experience—and, where a problem exists, what to do about it.

One of the greatest values of a portrait is, therefore, that it can identify or isolate the specific challenges facing a person or people. It specifically locates what is of value to them. Then, we can change our lens to look from other vantage points—close down the aperture and pursue a greater depth of field, thereby allowing for the consideration of historical influences, societal constructs, and

the myriad of intrinsic and extrinsic factors that contribute to and surround the individual. This contextualisation is akin to shifting from a portrait to a landscape view (see Figure 7), enabling issues to be identified, in a metaphorical sense, geographically so that they can then be mapped and approached appropriately.

Figure 7

Portrait Versus Landscape View



Note: The wider a photographic aperture, the lower the “f-stop” (as shown by the f1.4 and f4 representations). A singular focus on a problem’s existence is akin to taking a photographic portrait that focuses only on the person themselves, blurring the background to eliminate distractions rather than illuminating the landscape they exist within. The narrower the aperture, the higher the f-stop (as shown by the f16 and f32 representations). As we change our lens, the depth of field (area of focus) changes, and so too does our ability to understand the context of what we can see, interpret, know, and do. Focusing on an individual (portrait) may be important, but to do so without also looking at wider contextual pressures and background (landscape) may preclude broader understandings that could bring positive outcomes.

This conceptualisation supports all of the exploratory exercises in the *Creating Space* participatory video and drama workshop, but none more so than the first exercise, “portraiture.” In this group exercise, it helped the participants develop trusting relationships and a sense of belonging in the project—centring the participants as unique individual “portraits” worthy of focus, while also acknowledging the contextual and contributory landscape that lay behind, within, and all around them.

Day 1 – Developing Portraits and a First Go With the Camera

Day 1 was all about setting the foundation for the workshop, through exercises designed to help the participants reflect on themselves, learn more about their similarities and differences, and begin developing the technical skills that they would need for the participatory video approach of the project.

For the first activity, I applied my aforementioned portraiture concept to InsightShare's body maps exercise (Lunch & Lunch, 2006, p. 42) (see section "[Who Are They and What Moves Them?](#)" [page 93] that follows). It provided an opportunity for the participants to create a self-portrait, reflecting on what makes them who they are and introducing themselves to each other and the facilitators. The focus on the individual then allowed for reflection on how they "fit in" to the wider group. At the end of the exercise, we hung the portraits on walls and placed them on seats in the theatre to watch over the space and act as members of an imaginary audience. This placement of their portraits helped to further reinforce each participant's position as a unique individual and belonging within the larger group—situating them simultaneously as both observers and on centre stage, in control of the unfolding reflections, discussions, and analysis.

Who Are They and What Moves Them?

To create their portrait, participants began by outlining their bodies on large sections of paper using markers (see Figure 8). I then asked them to write or draw:

- By their feet, words or images of where they came from—their "roots."
- On their legs, whatever motivates them—what "moves them."
- On their hearts, who or what they love.
- Around their head, their dreams and aspirations for the future.

Figure 8*Creating Body Map Portraits*

Note: Creating portraits through body mapping on day 1. The participants drew their outlines and then placed their origins/roots at their feet, what motivates them to move in their legs, who and what they love in their hearts, and their dreams and visions for the future in and about their heads.

This exercise was full of giggles and laughter and immediately started a number of conversations as the complexity and diversity of the group emerged. They identified themselves in terms of their origins and their “roots” predominantly along geographical, cultural, and ethnic lines. In most cases, they considered these roots as points of pride, and it was clear from the outset that these young people respected each other’s origins and whakapapa highly. Whakapapa is the Māori expression of genealogy, translated more literally as “the process of layering of one thing upon

another” (Mahuika, 2019). In Aotearoa New Zealand, whakapapa plays an important role in how many people view their belonging within a wider collective. It also has a strong connection with the geographical region where someone was born. I was humbled by the young people’s openness and even more so by their intense curiosity and acceptance of each other’s uniqueness. I took this as evidence that we had developed a community of trust and the participants were trusting the process so far.

Fitting In

Once the participants had finished their body maps, I asked the group to walk around and explore each other’s silhouettes and to consider each one as a rough map of the artist’s being. I asked that they consider the similarities and differences in the things they value and encouraged them to discuss these with each other to see if there were any consistent hierarchies of value across the group. I also asked them to try to find drawings that showed values or dreams that were similar to their own and literally lie down and try to “fit” themselves into that drawing.

Some found this exercise challenging, not so much in terms of finding similar value structures, but rather in finding shared future dreams, as these were often very career specific. Another challenge for the older or larger young people was fitting in to a smaller frame, which they reported as “difficult.” In some ways, this reminded me of the challenges that adults often face with children’s games, as it can be difficult when we become too big—both physically (when we’ve outgrown certain things) and mentally (when we have replaced younger concepts with bigger, more unwieldy concepts).

Disability Is Bad Luck

Interestingly, the only “portrait” that no one else tried to “squeeze” into was of a participant in a wheelchair. When asked why no one wanted to try on the values and dreams situated in the wheelchair, there was first laughter and then a distinct silence. Naomi, the young person in the wheelchair, told the others in the group that she had now been in the chair for weeks and was getting used to feeling like she was different. It had heightened her awareness of what it means to be disabled and how hard it was to take part in the theatre group. She described feeling more like an observer than

a member now. After some time, a few kids spoke up and pointed out that while the values were the same as theirs and “fit” them, the physical shape was awkward and wasn’t something they could fit into. Tammy (12) said *“It’s like tempting fate...I think it might be bad luck.”*

A few kids did eventually try to squeeze in, but not without loudly expressing their discomfort at doing so. This led to no small amount of laughter but also reflections on what disability means and how it is hard to understand what people with disability actually go through if they need to fit into others’ particular (“normal”) shapes. After lying in the portrait for 60 seconds, one boy, Luca (14), got up and commented, *“I didn’t want to hurt anyone’s feelings or whatever, but I just knew I wouldn’t fit. It’s totally horrible...like being forced back into being a helpless baby.”* As the photo in Figure 9 shows, he was, in fact, literally forced into a foetal position, curled up and restricted.

Figure 9

“Squeezing” Into Each Other’s Portraits



Note: The portraiture exercise highlighted the limitations of disability, and the group seemed very aware of how a disability can stop others from interacting with them.

Wanting to Be Seen and Make a Difference

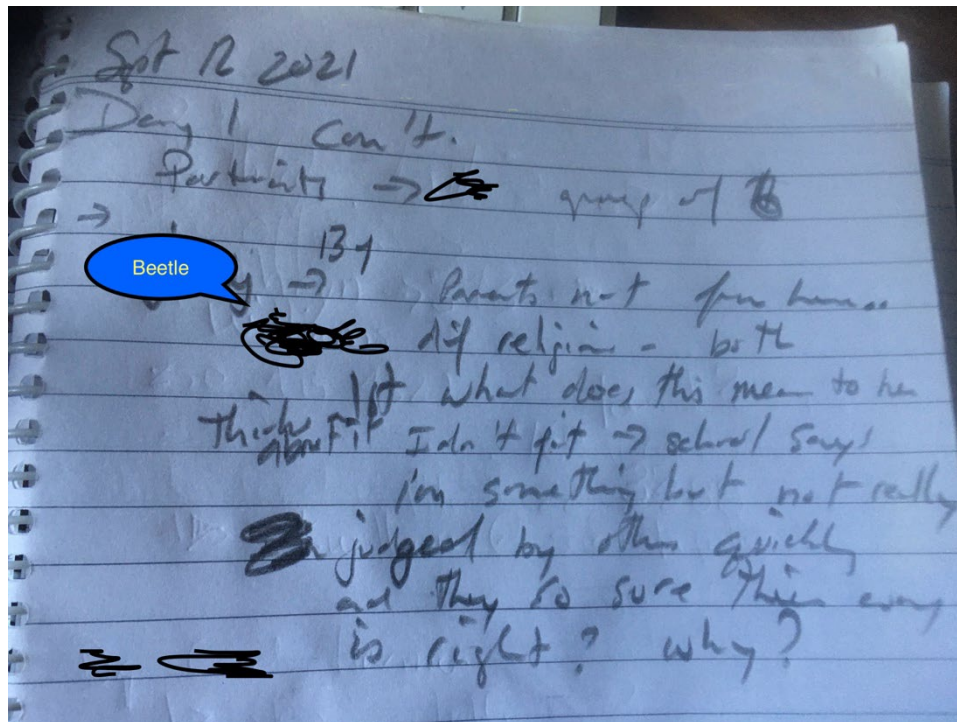
The participants formed clusters and discussed the main themes that they identified within the portraits and the contortions they had to make to fit into the portraits of those smaller than themselves. Together, we identified the most commonly represented and overarching themes within their self-portraits:

1. Love of family and friends
2. Being the same but different
3. Wanting a future that contributes positively to society

These themes are perhaps not particularly surprising in themselves, but they were a starting point to encourage further reflection. It was interesting to hear their discussions about “self” and, in particular, how many thought their parents were somehow unique or different than other young people’s. I couldn’t speak to every participant individually during this phase of the exercise, but several of the clusters raised the point of feeling “alone,” feeling “different,” or being an “outsider” wanting to find ways to “fit in” to future jobs or “make a difference.” The participants raised these as points to be proud of but also with a distinct sense of uncertainty for their future.

One 13-year-old participant, who asked to be referred to as “Beetle” in the reporting of her discussions on her portrait, summed up this uncertainty of identity well (see also Figure 10):

My parents are totally not from New Zealand...not even from the same place. They don't have the same religion and so I don't have either of them. What does that make me? I mean, like, I think about this a lot, because, you know...we are taught...we are, you know...this or that in school, or whatever...but it's not always what I feel I am—so it's like sometimes I don't fit, like I.... And I don't get why people are so quick to judge or to think their way is the way to be healthy or live right. Like why? – Beetle (13)

Figure 10*Field Notes From the Portraiture Exercise*

Note: Photo shows a page of my field notes taken during the discussion following the “portraits” exercise on day 1, reflecting comments made by Beetle (13).

The vast majority of the portraits point to desires to adopt jobs or roles in adulthood in which they can help others. Some participants wanted wealth but this was, by and large, not a primary focus, instead being more subtly evidenced in the small dollar signs scattered around written words like “fame” or “success.” The most common jobs and careers listed as aspirations for the future included politicians, police, doctors, nurses, and teachers. Given that the participants were all recruited from a youth theatre environment, naturally many also included dreams of fame as actors, musicians, and performers. Some participants also listed very specific jobs, such as one who wants to follow his cousin’s example and become a biochemist to make better biodegradable plastics, one who wants to become a zoologist and learn about every animal in the world to protect them, and one who aspires to be a soldier so she can serve as a peacekeeper and stop wars.

Almost every vision expressed for their futures was focused on achieving positions or becoming someone capable of building a better world. Only one person in the group had an aspiration for their future that wasn't as easily labelled as an occupation. Nathan (13) decided his aspirations were to *"feed the poor, build houses for the homeless, and secure world peace."* Perhaps "humanitarian" best describes his vision. When he was expressing this, I initially felt viscerally uncomfortable by his dream, feeling like I needed to protect him from it in some way—reduce the expectation, perhaps. However, the feeling was fleeting, and I displaced my adult-centric cynicism to celebrate with him what were undoubtedly lofty but very real desires that I truly hope he can achieve.

When 14-year-old Etty reflected on Nathan's pursuit of world peace, she said *"That's cool Nathan"* and then addressed me specifically with a degree of angst but free of malice (and laughing): *"Your generation pretty much fucked shit up, and we're gonna 'fix it'."* Although somewhat disturbing, it was hard not to laugh with Etty. Her light-hearted certainty that their generation is "gonna fix it" was as comforting as it was confronting. When I asked what "it" was she hoped to fix, she went on to explain that there is too much fighting. She said everyone is always trying to "destroy" or humiliate everyone else.

Just look at the way people talk online. They find little things and twist them into something they aren't. Like...I've got a friend who cut her hair short and all the sudden she's getting picked on and memes made about her? Like her hair makes her [not a girl]? – Etty (14)

Etty's ideas capture the essence of "cancel culture"⁵ and seem so important in considering the well-being of young people in a digital world. It brought me back to the reason the youth advisory group had suggested we use video methods. That reason had been to "go viral," but now here was the rub. In pursuit of viral affirmation, people had used social media to harm Etty's friend, pushing the real person out of view and hiding them behind memes reportedly not based on anything more than a single transient characteristic.

⁵ According to Wikipedia, cancel culture refers to "a form of ostracism in which someone is thrust out of social or professional circles – whether it be online, on social media, or in person. Those subject to this ostracism are said to have been 'cancelled'." (Cancel culture, 2022)

Helping Other “Invisibles”?

Several in the group spoke of being “invisible” in school, and some tied this to the dreams and aspirations they listed in their body maps. I pulled together five participants who had expressed an interest in one day becoming teachers and asked why teaching interested them. Dana (15) pointed out that, sometimes, she felt invisible to her teachers, her counsellors, and other adults involved in her education. Tessa (14) and McKenzie (15) also said that they too want to teach so they could “*be there for the invisibles...the kids who need someone.*” They contrasted their experiences at school with their involvement with the youth theatre group, where they said they felt respected and almost always welcome and listened to. They identified how in theatre, they were given time to speak and time to be creative.

When I asked if they thought their schoolteachers intended them to feel this way, no one responded directly, and some just shrugged. There was an undercurrent that they seemed resigned to this situation, and I got the sense that they just didn’t know why. But several spoke about the teachers’ awkward conversations and unreal expectations. When I asked them if this also related to adults in general, several nodded, saying that adults “*mostly just see you as stupid.*” However, Thoma (17), one of the oldest in the group, countered that thought:

Thoma: *Nope, that’s not true with Stephen [the youth theatre director]! We’re not ignored here...here we get to say lots of things and people listen...they are the audience, they have to! [lol] But it’s ok when we screw up too...you know, here we can say and do whatever we want or at least try. That’s the point of it, to try and work it out. But that’s not really the case outside.*

Facilitator: *Thoma, what do you mean by outside?*

Thoma: *...you know...like at home or school or just anywhere that isn’t in the theatre. It’s gotta be perfect.*

I was intrigued by the idea that everywhere “outside” the theatre was seen as wanting perfection, as I had presumed that performances would also bring with them high expectations of the kids. I was left understanding that perhaps in the creative space of this theatre group, it was okay to try things and risk failure—as though risking failure brought the chance of something better, something “good.” The participants seemed to relish having the freedom to “work it out.”

With this, the group was going quiet, so I brought the conversation back to health and asked whether they felt they had any say about the care or information they receive from health professionals. Some suggested that although they know they should be able to ask questions, it depended on the individual. As Jenna (12) put it:

Sure, it's my body my health or whatever, but whenever I'm treated as "just a kid" I like, mostly keep quiet and don't ask more questions.... Doctors or nurses are just like teachers...you can tell whether you can talk to them or ask questions, you know...if they want to help or just get out of there. – Jenna (12)

This thread of invisibility would ultimately carry through many aspects of this project and certainly surface in the group's final creative, narrative processes captured in video artefacts. A picture of how young people perceive themselves and the adults around them was emerging.

PJ, a 14-year-old boy, directed another comment to me, suggesting that the experience of looking for differences between themselves wasn't helpful because it causes anxiety. He thought that schools should take a better approach that focuses on what people have in common as opposed to what makes them different:

School can be weird, ya know? We're all connected in some way. I mean, we live in the same city, learning the same stuff at school and are here now because we love drama. Maybe we're not normal...[lol]? I don't know. But we are...well...maybe.... It's like to be well and healthy, we should actually...maybe should actually focus on that [the similarities], rather than where others are from, or what they prefer to eat or wear or look like...you know? – PJ (14)

Those closest to him nodded in agreement, but Jess (13), standing next to her own portrait, which identified her Asian, Irish, and Pasifika roots, had more to add. She thought what PJ was saying should be obvious, but that school and “old people” teach kids otherwise: “*We know that we should just say things as they are...that truth is best...and we shouldn't judge a book by the cover you know? But old people just....*” At this point, I instinctively (and foolishly) interrupted with an unconstrained cough and laugh. I literally looked down my old nose and judgementally sought clarification, saying “*what do you mean by 'old people'?*” —stepping in when I should have just listened. Jess responded, “*uhmm, okay, adults...lol.... Adults and teachers basically teach you that you shouldn't or can't actually be happy and the world's ending or whatever. That you shouldn't say or do what you think, only to say certain things 'cause...well...just because.*”

Thinking About the “In-betweens”

This rippled through the group, and they shuffled away from me back into smaller conversation clusters or joined others that had been out of earshot. Some were left hovering around the portraits as I slinked away, asking myself why I had jumped so quickly on the “old people” comment. Later, upon considering the makeup of these new conversation clusters, it was as though Jess’s statement and my response had shaken the room and, as a result, the kids had aggregated into clusters generally delineated by age. The older participants (14–17 years) made up three groups along the front of the stage, while the younger participants (11–13 years) situated themselves more towards the back. This left the “in-betweens” literally jumping back and forth between different groups. I couldn’t precisely determine the reason for the timing of their moves, but maybe my sudden interjection had shifted power back to an adult—startling them or breaking the trust that they could say anything? It seemed to me that they were now looking for new conversations.

Clinical psychology tells us that when we criticise someone when they do something right, it inevitably throws them off guard and forces them to re-establish their reality by either internalising it as their own error (the plight of the powerless) or externalising it and placing blame on the one that harmed them (a sign of confidence and self-worth) (Peterson, 2018). Here, Jess had been expressing herself openly, but I knocked that back with my interjection. I think we often do this unconsciously with young people. I have certainly done it unwittingly with my own children: they do 10 things as expected, but I still ask about the one thing left undone—socks on the floor, a bed unmade, eating with their mouths open (even if they are happily eating their vegetables!).

This is, of course, a father speaking, but when I watched one of the “in-betweens” approach a group tentatively, arm outstretched, and then touch the arm of another, it felt as though she were trying to “look” into that group, as though through a door left ajar, a door that might lead her farther into or away from the thread that had just separated them from me—from “adults.” This touch, look, and enter could be seen in many of the in-betweens’ entrances and exits. I think it represents a normal process of negotiating where they belong, or where they could be heard or feel most welcomed and

therefore safe. I also think the space they were accessing was unique to them and unavailable to the adult facilitators without a young person's purposeful facilitation.

This facilitation came as some of the older participants and a couple of the more confident youngsters stepped out of their clusters to engage with me and the other facilitators to share summaries of what their group was now discussing. These impromptu interactions with group "liaisons" were generally accompanied by an invitation for us to join in the group's conversation. When I later reviewed video footage of some of these discussions, I realised that when we responded to these invitations, we facilitators were also "in-betweens": approaching the group, arm outstretched, hands open, head tilted trying to "peer" into the group's ideas, only to eventually be pulled away towards another opportunity when it arose. It was awkward to feel at once both connected and separate from the participants.

One group of four older participants (14–16 years) was reflecting on how they believed some teachers wanted them to feel bad about who they were. Their main issue was that those educators criticise but never actually provide any idea how NOT to be who they are. As Emily (15) pointed out:

I can't change who my parents are can I? I can't change what I look like...can't change it. So why do they (teachers) focus on it? The whole thing is just about them feeling superior, like they never struggled! It is so dumb! – Emily (15)

The mood in this group of four was generally sobering, but also intriguing because despite some cynicism, they also took the time and effort to explore a counter position. Thoma (17) explained that in his home schooling he had been taught to take another's position before forming conclusions. He raised the idea that teachers themselves probably don't know how to "be" and might just be trying to help, even if it seems like self-protection or judgement. Emily (15) and Tessa (14) responded with a fair amount of eye rolling and scepticism but did not contest this viewpoint to any great degree. They all spoke with such certainty about things so uncertain that I trusted the positions were all accurate reflections of their experiences. Thoma's points, in particular, seemed an honest albeit potentially generous deduction.

As we continued exploring the portraits, it didn't seem to matter what combination of factors we discussed (i.e. where they were born, ethnicity, age, passions, family structures, goals and dreams,

etc.), many of them seemed both proud of their drawings and also slightly hesitant to share some of the more intimate details. In some cases, it was as though they weren't sure whether it was right to value certain things over others or whether their traits were in some way inadequate in comparison with others. They were worried about being judged unfairly or inappropriately. As George (14) put it, *"How can I know what I will become? How can the teachers? If we don't, we're a problem but...can I actually know who I am or what I should be yet?"*

When George and Emily expressed doubt about whether they can actually know who they are or change it, the group responded with lots of giggles, and many began to poke fun at themselves for being "outsiders" and "mutts," laughing at each other's blends of traits, immutable characteristics, and aspirations. It was difficult to track the multiple conversations that were occurring, as well as what was serious or in jest. Some participants put on accents and performed affected theatrical introductions to each other, as though in a play, such as *"Hello, madame, I am Monsieur Kiwi McKiwiface."* Another broke out into a Tongan dance, while yet another responded to the dance with a haka (a Māori dance that celebrates life's triumph over death) complete with pūkana, facial expressions that accentuate the words and meanings of a dance (Te Aka, n.d.-a).

As the facilitator, although I found these interactions rich and interesting, it also felt on the verge of chaos. Paul, another facilitator, was at the other side of the stage, surrounded by similar chaos. We were certainly not in control of the flow of information, and the irony of my discomfort is that the whole point of this process was to relinquish control and facilitate their expression of ideas. This was a watershed moment, as the group's burst of energy was both informative and (I believe) a signal of their restlessness and desire to move on to new discussions and activities. I responded by calling everyone into a circle to ask if they wanted a break. They did, and so we took 15 minutes to have a drink and then engaged in some playful theatre games before starting the next exercises.

Incorporating Their Shadow

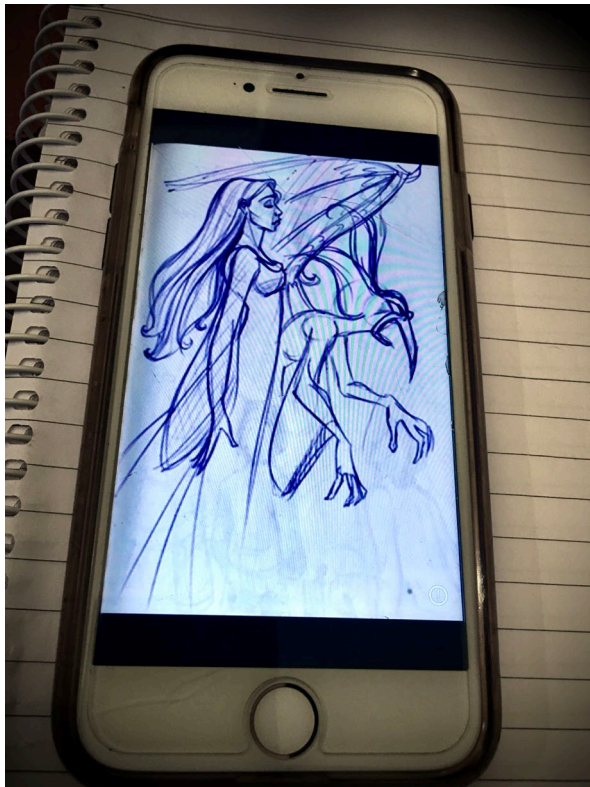
After my suggestion that we take a break, Beetle (13) approached me and explained that her Irish, Māori, and German ancestry was "bloody complicated" and something akin to making her "like a Veela half-breed." I didn't understand the reference, so she explained that Veela are from the

wizarding world of Harry Potter, and just the mention of Harry Potter had a few of the kids close by pretending to cast spells, acting out what I later learned to be a scene from *The Goblet of Fire* (Newell, 2005).

I wasn't very familiar with the stories of Harry Potter at that time, and so I'm certain I was perilously close to losing their respect (their rolling eyes were a dead giveaway), but Beetle grabbed a phone and shared a photo of a drawing she believed captured how she felt about being "a kid" and not knowing who to be (see Figure 11). She said, *"It's like we've got so many different things inside us, all competing to get out. Sometimes the wrong things get out."*

Figure 11

Depiction of a Veela



Note: Photo of the image of a "Veela" shown to me by Beetle (13), who explained that it represents how she and many young people feel about themselves—a veneer with a powerful and ferocious creature inside. Image source unknown.

Veela are considered to be magical, beautiful, and graceful creatures but can transform into terrible monsters when angered or betrayed. Popular youth fiction contains many references to Veela or other similarly dangerous creatures with transformational powers, such as werewolves and vampires, and they are an integral part of author J.K. Rowling's blending of magical worlds with the real (Rowling, 2000, 2017).

The dichotomy of a Veela's beauty and capacity for ferocity and power seemed to appeal to Beetle and a number of the other participants who had joined our conversation. They identified themselves as being uncertain about their own complex origins and dreams. I can't help but wonder if the choice to use the pseudonym "Beetle" was also connected to her own self-image, or perhaps an unconscious choice based on familial history? Beetle had identified her strong Irish roots, and although she did not mention it, the beetle holds a particularly powerful place within Irish folklore. While many cultures have stories about beetles, in the case of the Irish, Celtic symbolism places the *Ocypus olens* beetle as a symbol of betrayal and the devil himself (Notes on Irish folklore, 1916). It was feared for its ability to kill anyone that hurt it.

Essentially, Beetle and the others were saying that they didn't feel they were only one thing. They claimed that parts of themselves were hidden, unknown, and possibly unknowable because they didn't know how they could know everything about themselves or others. Perhaps Beetle's view of herself as a half-breed "creature" shouldn't be too surprising given the societal demands made of young people to fit in, grow up, and be something. If we add to this the collective push from social media for young people to have a wonderful and perfect "highlight reel" that shows perfection, like the beautiful veneer that covers a Veela's hidden and potentially vicious power, Beetle's choice of analogy makes sense. In essence, the participants were expressing the idea that their visible and distinctly identifiable characteristics (i.e. their sex, age, ethnicity, youth, and beauty) are only part of them, yet they are often the first things used to define them—literally hiding aspects that are capable of so much more and that they themselves value more than appearance.

Is This All About Self-Realisation?

Every person unconsciously pursues the highest level of self-actualisation possible within their wider social context (Rogers, 1959). Peterson, in his books *Maps of Meaning: The Architecture of Belief* and *12 Rules for Life: An Antidote to Chaos* (Peterson, 2002, 2018), describes the challenge and necessity of becoming a formidable character as integral to self-realisation, asserting that anyone who wishes to achieve their potential and not fall victim to malevolence or another's control must first be able to incorporate their "shadow" into their personality. In this case, the shadow represents one's ability to be ferocious and potentially harmful, and it must be incorporated in such a way that is accessible when needed but not a primary drive or trait. This idea is an extrapolation of Nietzsche's work in *The Gay Science (The Joyful Wisdom)* in which he encourages people to "live dangerously" in order to reach their human potential (Nietzsche, 1974, p. 228). This is not a literal suggestion to take on physical risk for risk's sake but an encouragement to pursue what is meaningful rather than expedient: a way of being that encourages an adoption of living "truthfully" in pursuit of self-attainment for a greater good. By "live dangerously," Nietzsche meant to live in a way that makes room for speaking truth regardless of the risk of doing so (Martens, 2021). Many of the participants' visions for their future seemed to fit into this category, expressing a certainty of possibility and no fear of hardship. On the contrary, several spoke about knowing how hard it was going to be to pursue a future as an artist and performer, teacher, or humanitarian, adding that it really doesn't matter because they don't have a choice. Sasha (15) made this abundantly clear when she smiled and laughingly said of her future: "*I know I might not make it, or look the part. And I know it will be hard, but whatever...it doesn't really matter does it? The heart wants what the heart wants.*"

In Sasha's comments, she makes her value hierarchy clear and demonstrates her willingness to pursue meaning at a cost rather than pursuing more expedient or diminutive outcomes. Speaking on the enduring nature of the human spirit, Victor Frankl, a renowned psychotherapist of the 20th century, also speaks of the need for meaning in order to survive or truly live. Specifically, he points to Nietzsche's concept that "he who has a why, can endure any how" (Pytell, 2015, p. 101). We often

think of young people as vulnerable, and undoubtedly in some ways they are, but Sasha's perspective shows a resilience and fearlessness that is inspiring.

“Not Gonna Miss My Shot”

Many in the group, and most significantly those who were 13 years and older, identified with the idea of a shadow within themselves, or at least in a piece of themselves that can “transform” into something else. As became evident in the video artefacts that they created, the young people identify with struggles against adversity and the courage it takes to effect changes to overcome them. Sasha's sentiment about the heart wanting what it wants surfaced in various forms throughout the week, none more poignantly than an impromptu performance at the end of this exercise. Some members of the group spontaneously put on a song from the musical *Hamilton*, expressing their excitement about taking their “shot.” Hamish (14) stepped out of the singing to explain to me that *Hamilton* is a musical all teenagers can relate to “*because it is about class and trying to join something...take power and change the world [for the better]...it's like outsmarting the other side, right? We've all got important shits to say! Ain't gonna miss my shot!*”

I found the impromptu performance electrifying and perhaps even a little bit scary. The intensity of it led me to start recording, and I handed the camera to one of the kids hoping he would capture the group's energy from his own perspective (see Figure 12).

Figure 12*Impromptu Performance From Hamilton*

Note: Image is a screenshot from the recording made of the group’s impromptu performance of a song from *Hamilton* after Hamish said “we’ve all got important shits to say! Ain’t gonna miss my shot” and then laughed and jumped back into the performance. Video here: <https://youtu.be/PgFZ495i8sE>.

What was unclear to me amidst the excitement of their performance was exactly what revolution they wanted, who Hamish’s “other side” was, and what “shot” or opportunity he didn’t want to miss. Hamish seemed to be insinuating that this week’s programme was an opportunity to speak out, to “take a shot,” but it is difficult to displace my own bias that might lead me to this conclusion. What became evident as they created increasingly complex video artefacts in the exercises that followed were their calls for young people’s struggles to be noticed and for changes to be made in how some adults engage with them to lessen their struggles. It could be that those singing in this impromptu performance identified with the principled main character of the musical, Alexander Hamilton: an abandoned child of the West Indies, Alexander bonds with American revolutionaries seeking independence from England and an end to “taxation without representation” (Miranda, 2016). This harkens back to the discussion in the “[Nothing About Us Without Us](#)” section earlier (page 60) and arguably sits as evidence of the group’s need and desire to be heard.

I don't suspect that Hamish was insinuating a need for a bloody revolution such as the musical portrays, but rather I believe the performance was a symbolic representation of these young people's desire for respect and to contribute to a greater good. Certainly, the personal accounts of alienation at school, bullying, loneliness, and mental health challenges that the participants were sharing in conversations would become embedded in the fictional videos they produced. Examples of each participant's real-life stories that they shared are literally woven and folded into the stylised fictional accounts they created. Without the perspectives revealed through the portraiture exercise (and other exercises on subsequent days, such as discussed in the "[What Is Health to Me? Revisiting the Interview Technique](#)" [page 117] and "[Telling Their First Story: Diverse Representations of Health](#)" [page 118] sections), the stories might be seen as only acting or entertainment, rather than expressions of real experiences, perceptions, problems, and possible solutions. We as the audience should make accommodations for this and, rather than consider the works fictional because they are enacted or staged, consider them as potentially "hyper-real" examples, because they are an amalgamation of so many stories. They are shared experiences of bullying, anxiety, sexual education, and struggles with mental health. I suggest that it is from the tensions inherent in these experiences that the participants' revolutionary energy arises and possibly that they "lived dangerously" during the week by sharing them. In so doing, they willingly allowed themselves to be vulnerable in order to incorporate some of their shadows.

The portraits they drew and then explored are clear examples of how portraiture can help us understand the complexities of an individual's position and location within their social landscapes. As we moved on to the next exercises, which focused on acquiring technical skills, these portraits formed the foundation for the content to be explored further—this time captured on video.

The Technical Skills: See One, Do One, Teach One

With a series of fun exercises, I introduced the participants to the video equipment using a model of "see one, do one, teach one," giving them an opportunity to explore how to both operate the cameras and microphones and frame their subjects to tell their stories.

The Disappearing Game. The first exercise was the “disappearing game” and involved controlling the camera to start and stop a scene and using the “cuts” to manipulate time to tell a story. The participants had to create a static freeze-frame story about anything to do with health without using movement or words. Each person in turn had to leave the scene and control the camera to record the next 2 seconds of a frozen scene. The “story” proceeds in a frame-by-frame manner and ends when the last person is gone. The purpose of the exercise was twofold: first, to facilitate the learning of the camera recording function and shot timing, and second, to get the group working together towards telling a collective story. It also gave the participants the experience of playing with the illusion of time, as the playback shows a frame-by-frame story.

Each group developed their own scene, with the only instruction being to “tell a story about health in a ‘time lapse’.” They had 10 minutes to plan. Interestingly, despite being created in isolation, each of the group’s scenes depicted stories of illness and loss. They depicted how cancer (group 1) (see Figure 13), a virus (group 2) (see Figure 14), or depression (group 3, not depicted) can ultimately leave people ill, dying, or all alone. The imagined locations for the scenes were eclectic and included a hospice, a hospital waiting room, and a school yard.

Figure 13

The Disappearing Game: Group 1, Terminal Illness



Note: In the disappearing game exercise, group 1 depicted a story following a diagnosis of a terminal illness. Initially the afflicted person (with crutches) is surrounded by friends and family. Slowly people stop coming around because they don’t want to see their loved one suffer, and soon there is

only the husband and patient left. When she dies, the husband is then also alone, and when he is gone, the empty chairs represent the group's collective grief.

Figure 14

The Disappearing Game: Group 2, Virus



Note: In the disappearing game exercise, group 2 created a scene in a hospital waiting room in which the patient in the middle coughs into his arm and then disappears. One by one, each person becomes unwell and disappears. The group explained that they were expressing the fears they have in relation to COVID-19 and that crowds of people are now risky. They are trying to show the randomness of transmission and the inevitability that everyone will get sick.

At the end of this exercise, every participant had now used the video camera and could set up a framed shot and record and review footage. This was the beginning of learning how to plan scenes for a cinematic storyboard.

Citizen Journalism. Citizen journalism is “the reporting and dissemination of news and information independently of conventional news institutions by individuals who are not professional journalists” (Chandler & Munday, 2020, p. 18). The main aim of this exercise was to empower the

participants with the skills to gather information by asking questions and reporting on it: the group learned how to set up the cameras and microphones, frame questions, and explore ideas through interviews. The groups practised how to plan interview questions to explore each other's perspectives and meanings within their portraits. We discussed how different types of questions (such as open, closed, or leading) make them feel and affect the responses they receive. Following this instruction and practice, they took turns filming each other as journalists conducting interviews (see Figure 15).

Figure 15

Citizen Journalism and “News With Katie”



Note: The photo montage shows examples of the participants interviewing each other as citizen journalists. Video example of “News with Katie” here: <https://youtu.be/fb7yc1bjKeo>.

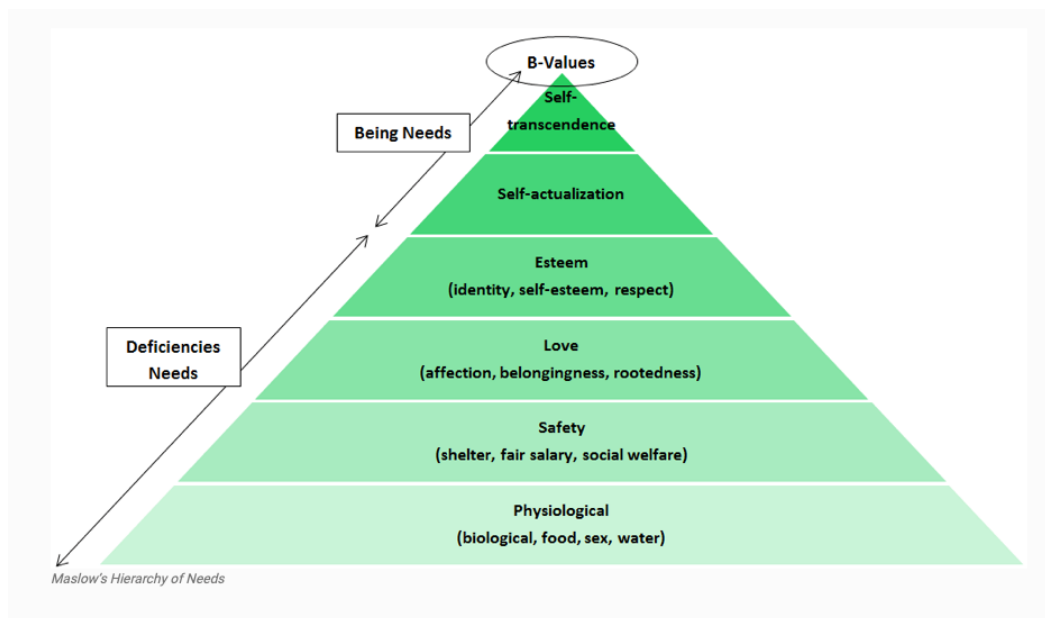
The short clips were then screened to the group and became the starting point for the group to ask more questions about the perspectives expressed in the interviews and the filming and

interviewing techniques used. While delivering on promises of skill acquisition, these interviews also proved priceless in supporting their critical reflections on their portraits (see video link in Figure 15).

This process of reflection and discussion produced layers of analysis of their portraits, identifying additional perspectives on their motivations and their hierarchies of needs and values. In his contribution to humanistic psychology, Maslow identifies the importance of these hierarchies of value through a list of B-values or “being values” (Maslow, 2012). These are values that individuals select and apply degrees of importance to as they work towards self-actualisation. The B-values are nestled into the top layers of broader hierarchies of need (see Figure 16) and are seen as necessary to reach one’s full potential. More specifically, the relationship between the person and the B-values is what allows for people to move beyond physical needs and self-actualisation to achieve transcendence, a state of balance with the concepts of truth, goodness, beauty, justice, and completeness.

Figure 16

Maslow’s Hierarchy of Needs



Note: Sourced from Maslow (2012).

Within Maslow’s model, we see that higher functions of values are necessary to establish moral and ethical behaviour and can only be achieved when the lower primary needs have been met.

Hickel and Haynes (2018) point out that all people will first seek to fulfil their basic needs and only then develop the aspects that allow them to achieve their purpose of realising self-actualisation.

It was useful to explore these hierarchies within the group, because the way we view the world and act within it relates directly to what we value. What we value is also dependent upon what we need, so ultimately our values are served by our actions. This is not an objective measure, but rather a subjective, comparative one, placing things we value into an order so that we might then be able to determine what to act on first, second, third, and so on. Our values flex and shift to the context we are in, in direct response to our needs. In simple terms, if we do not eat, the value of food increases; if we are alone, the value of company increases. As they explored their portraits, they found that the things that moved them and that they had drawn on the legs of their portraits were frequently the exact same things that they loved and had drawn on their hearts. While it is impossible to find complete stasis in any individual or group's needs and values, when trying to achieve self-attainment, the fragile scaffold of needs required to underpin it is difficult to maintain (Peterson, 2002). This is because the act of living, in the face of a death we know cannot be avoided, is precisely what allows our human values to exist (Hogenboom, 2015). We use our values to direct our actions, because they become our goals to attain and thus we embody them and perpetuate the values' very existence through our actions.

This journalistic exercise provided a rich and interactive way for us to discuss the participants' hopes and dreams of the future and what they value. Although occasionally stilted by the "performance" of interviewers trying to be reporters, the videos were the group's first opportunity to explore being in front of the camera and taking a formal lead in exploring another person's ideas.

Group Reflections and Closing the Day

The most important aspect of each participatory video and drama exercise is the reflective screening of the videos created (Shaw & Robertson, 1997). Within this workshop, these reflective screening sessions (see Figure 17) became a vital debriefing exercise that allowed the participants to share their perspectives across the whole group while also creating distinct learning moments about the effects that different filming techniques have on the audience.

Figure 17*A Reflective Screening Session*

Note: This photo captures the context within which the reflective screening discussions took place.

The study participants are viewing one of the citizen journalist clips and discussing the content and techniques used.

Our first day ended with everyone decidedly exhausted but in agreement that it had been productive. During a purposeful feedback time that we had allocated to discuss how we could do things better the next day, many in the group were now asking for a slightly faster pace and as much hands-on filming time as possible. We closed with a theatre game, and I then introduced the exercise we would begin with the following day, called “Story and Tell.” In preparation for it, I asked them to undertake a single piece of homework for the next morning: to bring with them any item that represents “health” to them.

Day 2 – “Story and Tell” and the Margolis Wheel

Lunch and Lunch (2006) explain that creating successful participatory video projects relies on exercises that engage participants in technical but fun and playful experiences that promote the sharing of their stories. The first exercise of day 2, Story and Tell, is based on Lunch and Lunch’s

(2006) examples of Show and Tell (p. 42), in which control of the exercise is given to the community to “show” things that are important to them by filming and contextualising them.

What Is Health to Me? Revisiting the Interview Technique

As the group were asking for additional hands-on time with the equipment, I modified the first stage of this exercise to repeat the interviewing techniques from day 1, asking them to explore the importance and meanings behind the items representing “health” that they had brought in with them. This enabled everyone both to be interviewed and to interview someone (see Figure 18). This exercise was very self-directed, and the group took to it quickly. We then screened the interviews on the big screen and discussed how the individual items made people feel. The process exposed how health can be interpreted in many different ways, but the one aspect that almost every item they chose to represent health had in common was that the person who brought it described it as representing a time when it made them feel safe or loved or as having the power to help them feel safe when they have it with them.

Figure 18*Story and Tell, Part 1*

Note: Images from the first part of the Story and Tell exercise, in which participants showed and described “what represents health to me?” The interviewing seemed to go much more smoothly than the previous day, and the participants expressed that they were now feeling much more comfortable in front of the camera.

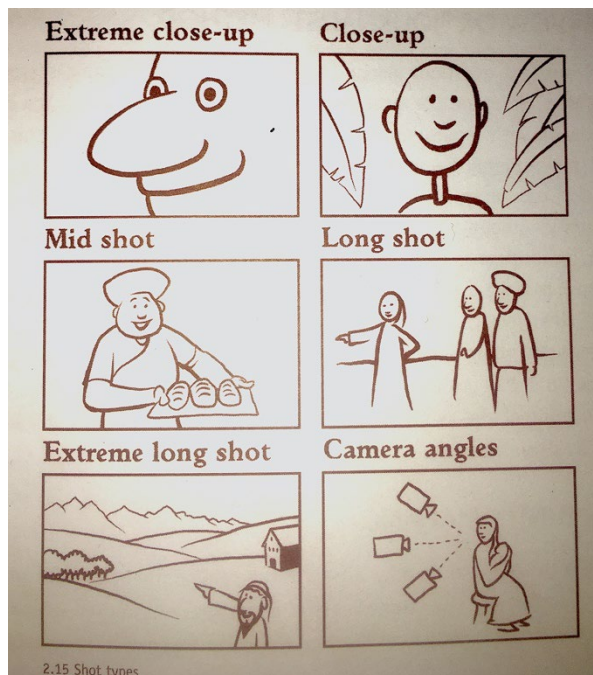
Telling Their First Story: Diverse Representations of Health

In the second half of this exercise, we placed the participants into three random groups, which were then tasked with choosing only one of their items to create and tell a story about. An important aspect of this exercise was to teach digital storytelling techniques to confer specific feelings and emotions via the use of different camera angles and perspectives. It is vital to the participatory process to build participants’ capacity as storytellers, and therefore we showed the participants examples of

six types of shots (see Figure 19) and how they can be used to create a focus on people, places, and things within a story (Lunch & Lunch, 2006; Milne et al., 2012). We introduced basic shot planning techniques and asked the participants to use all six shot types in their “storyboard” for their representations of health.

Figure 19

Six Types of Shots



Note: Important lessons on how to “establish” the scene and present characters for digital storytelling using six different types of shots. Example reproduced with permission from InsightShare (Lunch & Lunch, 2006, p. 33).

When it came to choosing the item to feature in their stories, naturally there were some differences of opinion, but establishing ways for the group to consider each item and discuss how to approach the choice from a democratic perspective was a key aspect of the exercise. There was a remarkably diverse selection of items on display, and the groups were very animated as they looked at the pros and cons of creating a short story about each of the items. They had 29 different items to consider, including teddy bears, skateboards, toothpaste, a plant, books and journals, an iPad, mobile phones, water bottles, and music headphones, to name just a few. Pictures of pets were also

reasonably common, but some of the more curious items were seeds, socks, and even a technicolour coat, straight out of the musical *Jesus Christ Superstar*. Each item identified a unique perspective on how the owner viewed their own relationship with health. In many cases, the participants described their items as being almost magical, which reminded me of Beetle's earlier reference to the magical and transformational power of the Veela (see the "[Incorporating Their Shadow](#)" section [page 104]). The owner of the technicolour coat, for example, described it as a "calming coat," something the boy wore to feel safe when anxiety loomed. Many of the items, whether a teddy bear, a blanket, music, or a plant, were portrayed as "shields" against potential harm.

The groups worked independently to select their health item by way of impromptu voting processes to make their final selections. They ultimately settled on three very different items that represented health to them and set about negotiating their scenes to tell their story. This included drawing a storyboard to establish locations and framing of scenes, creating dialogue, and considering any other necessary inclusions, such as music or sound effects. The items they chose were:

1. AirPods (music)
2. A plant (living thing)
3. A journal (written reflections)

The groups had only an hour and a half from starting their stories through to completion of the filming, so there were significant time constraints. The short timeframe was purposeful, as it was intended to show how planning in the form of a storyboard can serve to keep the story developing and deliverable. The participants had to collaborate, taking each other's ideas and pulling them together to construct a written storyboard that captured the essence of the group's thoughts, and then translate that into the corresponding video footage (see Figure 20 for an example of one group's work behind the scenes).

Figure 20

Behind the Scenes of “Story and Tell”



Note: An image of what participation “behind the camera” looks like. A video that captures this storyboarding process as well as footage of them setting up their shots, filming, and creatively capturing audio here: <https://youtu.be/SQOr5OOSTeQ>.

All three groups completed their filming, and then during the lunch break I quickly compiled their footage into edited shorts as per their storyboards and instructions. We then screened the videos to the group and explored both the content and techniques employed.

The short Story and Tell videos very much explain in the participants’ own voices and projections why and how each item represents health to them. This exercise was instrumental not only in developing their skills in video storytelling, but also supporting their ability to collaborate and contribute towards a shared project goal. As the facilitators, we worked to encourage collaboration and inclusion, with a focus on listening to what they were trying to portray and supporting them when they encountered technical problems or uncertainty about how to achieve the scenes they imagined. Lunch and Lunch (2006, p. 28) explain that the Show and Tell exercise provides opportunities for each participant to consider their own and other’s points of view and to facilitate the working together through complex ideas towards a common goal. What became very clear in the participants’ work is the importance of feeling safe and having protection with regard to their health. Every item was presented as being capable of delivering this to the owner, whether it was a barrier to the outside

world, something to nurture and care for, or a way of reflecting on the things that affect them. The stories presented each of the three items as powerful representations of things that can bring, restore, or maintain good health for young people.

AirPods (Group 1). In this short, the group identifies Apple AirPods (earphones) as a protective filter for some of the negative and overwhelming things that young people witness (see Figure 21). In this case, they are confronted by parental arguments, aggression, and potential violence that arise from the pressures of money and other aspects of life. The group explained that sometimes parents can't provide all that is needed for their kids, and this leads to fighting. The group shared examples from their own lives where they have witnessed adults fighting over things like groceries or schoolbooks. Sometimes, the police are called, and sometimes, young people need to “*hide from it all.*”

Figure 21

Story and Tell: AirPods



Note: A screen capture from the “AirPods” short video created by group 1. Video here:

<https://youtu.be/1G1UN-gFPho>.

The group suggests that AirPods bring music that they can escape into and thus represent health to them. Stella (16), the participant who had brought the AirPods, explained that music shields

young people from “*all the noise, anger, and violence in the world.*” In this way, it is seen as bringing young people peace, comfort, and health.

Hamish and His Plant (Group 2). Having chosen a plant as their item, this group created a scenario that blended several of their personal experiences of pain, hospitalisation, and surgery to create a story that depicts the value of a “living” thing during periods of loneliness and recovery. Specifically, they intended to show how a plant helped reduce their anxiety and suffering when they were alone in hospital. With an included voice over that tells the story of a fictional character named Dean Anderson and his appendicitis, the commentary highlights the challenges faced during diagnosis and treatment, as well as the isolation that occurs in hospitals (see Figure 22).

Figure 22

Story and Tell: The Plant



Note: Images from behind the scenes and during the “Hamish and His Plant” short video created by group 2. Video here: <https://youtu.be/-Q1-5ofE2jc>.

When Dean Anderson is experiencing acute pain, illness, surgery, and recovery, it is the gift of a plant brought by his family that gives purpose and meaning. The plant is described as the key to his health and recovery. When asked what it was about the plant that was so important, Hamish, the person who originally brought the plant in, said he realised that it needs caring for just as people do, and that when he cared for the plant, he felt he was actually caring for himself too.

Interestingly, the description of nurses deciding when to “let family in” was included to show how powerless young people and their families are in hospital. The importance of family and the need for connection and a degree of control (shown in the “throwing away” of the medication and caring for the plant) are at the centre of this story.

A Journal (Group 3). The third group had an interesting take on the healing and grounding nature of writing and reflection, explaining that sometimes sketching and writing things down helps them to “work through” their problems and protect them from overreacting. The story they shared about the journal chosen to represent health is an exploration through the viewpoints of both the owner and a parent. The group chose to employ the specific interviewing techniques we had practised in the previous exercises and incorporated a fictional parent being interviewed. The parent is used as a means of explaining and reinforcing the positive impact of the journal and shows that health is interpersonal, as it affects more than just an individual (see Figure 23). In this case, the journal has the potential to bring healing to more than just the person writing in it as the father, played by one of the boys in the group, explains that he thinks his daughter’s use of the journal has led to more discussion and less isolation in the home. He expresses his surprise and also his happiness that it has been good for her well-being.

Figure 23*Story and Tell: A Journal*

Note: Images from behind the scenes and during the “A Journal” short video created by group 3.

Video here: <https://youtu.be/fGDV6gV1LU8>.

The inclusion of the parental perspective provides some insight into how the young people in the group think many parents feel about their well-being and how they maintain their well-being. It is not entirely captured in the short itself, but after the video was screened to the wider project group for feedback, the wider group articulated that parents sometimes don’t understand that young people don’t always want to talk about things or even ask for help. However, that doesn’t mean they won’t want to talk or ask for help once they have had the time and space to consider things for themselves and make a plan (for example, by writing their thoughts and ideas down in a journal).

Group Reflection

In line with the PAR cycle discussed in the “[Importance of Process Over Product](#)” section earlier (page 72), we screened the Story and Tell videos on the big screen and reflected on the various ways in which each of the stories related to their own personal experiences of health and well-being. In particular, we reflected on the process of creating storyboards and the choices of shooting angles, framing, and language that enabled the telling of the stories so that they are relatable to other young people and could be acted on in future iterations so that their ideas “stick” with the audience.

For the participants’ first attempt, they created remarkably informative and moving short stories captured in video. This, combined with their willingness to discuss their choices and content, gave me a deeper appreciation for the perspectives they have on well-being. In each of these video artefacts and in the discussions, they identified the importance of protecting their mental health.

The creative, narrative process involved in creating even these short one-minute videos had required that they make hundreds of decisions and incorporate eight to nine different people’s feedback and input along the way. The various decisions regarding the messages they wanted to share, dialogue to include, scene locations and framing, and so on all represented pressure points that involved building group cohesion and much give and take between the participants. I perceived the independence with which they negotiated inclusions and concessions as remarkable, but from their perspective, it seemed working together was simply how it should be. As Sasha (15) stated, “*We work in groups in lots of school projects and you just have to make it work.*” It was exciting for all of us to reflect on just how much they had pulled together as a team and already accomplished and conveyed in only a few hours.

Determining the Specific Health Issues Young People Identify as Most Important

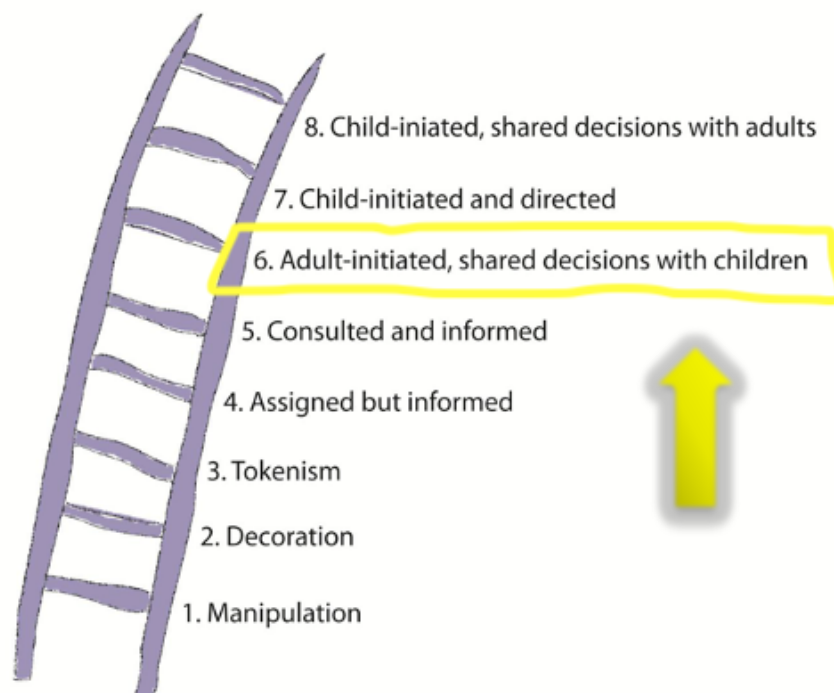
One of the challenges of ensuring youth participatory research moves beyond tokenism is considering the genesis of the research topic and questions (Coyne, 2008; Coyne & Carter, 2018). Are the questions those that the participants themselves actually want to find answers to, or are the participants engaging with the questions only in response to researcher presentation? Given that this research began as a result of my clinical experiences and observations of young people’s

marginalisation, it is safe to say that this is a researcher-initiated participatory project. However, the participants also engaged in the processes wholeheartedly and accepted control of the project as their own, and by all accounts they were very proud of their creations.

This is important to identify now, as the last exercise of day 2 represents a purposeful attempt to further devolve control of the health topics to be explored to the young people themselves. This was predicated on my desire to situate this work as high up on Hart's (1992) Ladder of Participation as possible (see Figure 24).

Figure 24

Hart's Ladder of Participation



Note: The *Creating Space* project was adult initiated but worked to ensure that the young people made the majority of decisions with adults or by themselves, corresponding with the sixth rung of Hart's Ladder of Participation (Hart, 1992, p. 3).

The fact that this project is serving to complete an academic qualification for the lead researcher cannot be forgotten, as it means that some decisions—such as the initiation of the project,

the equipment available, and the development of the specific exercises to be used—have been guided by me towards a particular end. Other aspects, however—such as the overarching methods used (participatory video and drama), the timing of the exercises themselves, and the conversations and analysis of the stories—have been guided and informed by the participants. Most importantly, the stories and opinions that the participants have shared and the details that were or were not included in the telling of those stories have been their decision.

In the last exercise of day 2, we were ready to explore a predetermined but very generalised subject of health. More specifically, the plan was to spend the final hours of the day determining just what aspects of health are most important to the participants and what problems they think adults and other young people should be concerned with. By determining the health issues that they want to explore in more depth, we would establish the foundation for their own independent short stories—to be captured through a creative, narrative process expressed in video.

Spinning the Margolis Wheel: Ideas to Action

Rolling into this final exercise on day 2 did feel somewhat like “spinning the wheel.” The rest of the week’s actions were dependent upon the outcome of this exercise, and I confess that it seemed somewhat akin to gambling, as though we were now putting all the previous work, discussions, planning, and efforts on the line.

Milne et al. (2012) and Lunch and Lunch (2006) point out that, to be effective, participatory video projects should explore participants’ views through structured exercises that give equal weight to individual voices. Ensuring an equal weighting across multiple domains such as age, gender, interests, and personality types can of course present challenges. To support the widest possible inclusion of all participant voices, we employed a technique called the Margolis Wheel (Lunch & Lunch, 2006). Introduced to me by the Lunch brothers during my facilitation training, this exercise encourages in-depth conversations between participants in relation to their perceptions and

perspectives on the topic.⁶ The process would ultimately identify topics of interest and be the catalyst for the stories they would tell using the video methods we had been practising.

The Margolis Wheel is a reflective tool that incorporates timebound conversations with participant movement in order to facilitate wider discussions across a group. The systematic movement of conversation partners ensures that every participant has multiple opportunities to share their thoughts and ideas with others and to listen to many others. It minimises the group dynamic of conversation by focusing participant responses only to another individual, not a wider group (see Figure 25). This has the effect of minimising fear of being different or having ideas that do not fit with other's views. In essence, it seeks to address the negative consequences of the "spiral of silence" discussed in the "[Why Use Video: Tools for Change](#)" section (page 74). The process then aggregates the most salient ideas that develop between participants through a process of individual reflection and subsequent collective discussion and thematic analysis. Once the group has identified the five to six topics that they are most interested in, the exercise culminates using a three-point voting technique that draws out the one topic that most captures a group's collective interest.

⁶ During a Margolis Wheel exercise, participants sit in two concentric circles. Each person in the inner circle faces out and is paired with another participant in the outer circle, who faces in. Each pair then have a timed conversation on a set problem or topic. After the set time period, the outer circle rotates one and repeats the exercise in the new pairing (Lunch & Lunch, 2006).

Figure 25*A Conceptual View of the Margolis Wheel Exercise*

Note: Depiction of the Margolis Wheel by one of the young people from the advisory group held prior to the workshop. I ran a practice session on an unrelated topic with eight 7- to 9-year-olds to test its effectiveness. The advisory group decided a moving conversation was a “good idea for helping us talk about things.”

To facilitate this exercise, the kids arranged themselves into four separate groups: three groups of 8 and one of 6. Although the groups were of their own choosing, we did need to negotiate for two participants to change groups to even out numbers for the exercise. In their groups, they sat in concentric circles facing another participant, and a facilitator then presented a health-related question for them to consider and discuss with their partner. After approximately 5 minutes of discussion, the outer “wheel” rotated and those people changed seats, thereby facing new partners for the next question/discussion point. The participants discussed the following questions in turn:

1. What aspect of health or healthcare do you think gets the most attention in the media and why?
2. What health issue do you think is really important that nobody is talking about?

3. Research tells us that young people aren't often asked about their healthcare experiences or what should be done for them. What are your thoughts on this?
4. In something called the Innocenti Report Card series, put out by UNICEF, New Zealand has been ranked 36 of 41 nations in the world in terms of health equity for young people. In other words, the perception is that some young people don't have the same opportunities as others in New Zealand. What do you think about that?
5. After all of those discussions, we'd like you to be "blue sky thinkers." Imagine that anything is possible and there are no barriers. What do you think the government and/or health professionals should do about the things you have been talking about? How could they make young people's health and lives in New Zealand better?

In this way, each participant ended up discussing five questions in five separate 5-minute conversations (see Figure 26).

Figure 26*The Margolis Wheel in Action*

Note: Images from the Margolis Wheel group discussions within the theatre space. Video here:

<https://youtu.be/803OpfOrTig>.

Once the rotations were complete, we then asked each participant to reflect on their conversations and write down on separate sheets of paper the three things from the discussions that they found most interesting, that they found most important, or that made them want to think, talk, or learn more about.

This resulted in 18 to 24 separate ideas or topics on paper for each group. With these papers then spread out on the floor, the group discussed the ideas written on the pages. Facilitators went around to the groups and asked about the topics they were exploring to clarify them and engage in conversations to ascertain what it was that made them stand out for individuals. This made for some very interesting discussions that ranged from political discourse on the nature of communism through to the impacts of the COVID-19 lockdowns, the pros and cons of social media, poor mental health, bullying, and young people's participation at school.

The Political Side to Health: A Call for Revolution

I had not anticipated the degree to which political discussions would emerge, or some of the young people's fear of raising such topics. In one group, for example, as a possible "blue sky" solution to the problem of health inequality, someone in the group had proposed a communist revolution as a solution. I overheard this because there was a staunch vocal disagreement, and so I approached to listen. Even my turning of attention to the group drew a quick covering up or "hiding" of the suggestion. The person who had written it down did not speak up. By "covering," I mean it was mocked under giggles and laughter with comments made insinuating that communism should not and could not be talked about as a solution in front of the adults. In light of this, I took the opportunity to remind the group of the project rules we had all agreed on, specifically the right for anyone to raise any idea or suggestion, highlighting that the project was designed specifically to "create space" to discuss anything that relates to young people's health. I tried to make clear that there "are no wrong answers." Fortunately, as I explained this, Paul, the other participatory video facilitator, turned on an overhead camera to record our discussion, hoping that it would serve as a representative example of how we promoted participatory processes as a way to clarify ideas (see the Margolis Wheel video clip, minute 3:56, for the footage captured during this discussion: <https://youtu.be/803OpfOrTig>).

As a general note, although the facilitators only had the opportunity to engage with and film one group during this phase of the analysis, similar processes were occurring in all four groups. The depth and weight of the political discussions were consistent across the groups as they explored the various topics. However, given the intensity of this discussion on communism—and our specific

participation in it as facilitators—I feel it warrants a closer look and serves as an exemplar of the process.

Ceili (15), one of the older participants in the group, commented that the person who wrote communist revolution down as a topic “*knows who they are*,” suggesting that they should speak up. Instead, Liam (12), a younger boy who had not raised the topic, spoke out:

Liam said: “*I know what it is...it’s about sharing resources, although...*”

Ceili interjected: “*It’s an area...thing that is like sharing everything, everything is intertwined and everyone knows each other kind of....*”

Liam again spoke out, expressing doubt about the benefit of communism: “*There’s one problem...it doesn’t take account of human nature. Instead of doing the right thing...it benefits leaders who don’t actually do their thing....*”

Ceili countered: “*But I don’t think that’s a good example of how to do it [communism].*”

As we discussed their thoughts on communism and how their ideas might serve healthcare by providing “equal access to all,” a boy named George joined the conversation, indicating that he had written down communism as an idea for the group to explore and identifying that he had been thinking about ensuring equal access. It was an interesting clash of ideas playing out—that equality in health outcomes could be achieved through social redistribution (sharing) and enforcement of mandates.

The collectivist approach to ensuring a utopian vision of equality alluded to by the group is one that at different times of my life I have both believed in and railed against. I found it intriguing to hear their perspectives and agree with Fernando et al. (2018), who describe the important role that utopian thinking plays in both individual and collective development. They posit that regardless of the vision, individuals should always strive towards a higher utopian goal, as it provides opportunities for them to make substantive gains in their sense of purpose and value. The desire for equal outcomes that the group was expressing aligned with their earlier visions in the portraiture exercise. Everyone in this group had outlined visions for future careers that helped other people or the environment, and

their consideration of political solutions here was in keeping with this desire to contribute positively to the well-being of others.

This discussion on political approaches to health was also timely, given that we were all literally living under governmental mandates relating to the COVID-19 pandemic. The Aotearoa New Zealand government policy to “go hard and go early” against the virus was reliant on mandates to redistribute money and change social construction like no other time in our country’s history—with perhaps some exceptions during times of war (Cumming, 2022; Robert, 2020). In this sense, the participants had themselves already given up many freedoms in service of governmental attempts to maintain the health of Aotearoa New Zealanders. Their consideration of other political solutions to large social and health problems is understandable, particularly if the will of the people to do so was sufficient.

Looking once again towards participants’ hierarchies of value, the pandemic has made many Aotearoa New Zealand citizens consider what it is they value most—freedom, health, individual rights, collective rights, etc. The participants spoke of the impact of the governmental mandates on their learning and social connections, sharing stories of being in lockdown and “falling behind” in school as a result of not being able to attend. They spoke of isolation as a “nightmare” that impacted both their own and their friends’ mental health. The group did not come to a consensus on whether the government should have the power to force equality and, as Liam pointed out in his comment on human nature, there is anecdotal evidence that every social action in the name of protection and good also holds the potential for an equal and opposite outcome.

This group’s consideration of pursuing equality through political means, despite their marginalisation from most political processes, is of interest for a number of reasons, not the least of which is their earlier reference to “revolution” (see Figure 12 [page 109]). A political movement’s power to emancipate is ultimately dependent upon the disruption of oppressive potential within a dominant societal class (Freire, 2000). According to Freire, this can only be lessened through the education, empowerment, and democratisation of the oppressed—education serving to liberate people and thereby creating a better, emancipatory world (Freire, 1982). His ideas are clearly informed by

Marxist doctrine, but that is not to suggest he was simply calling out for the same type of violent revolution as Karl Marx.

To my knowledge, the participants had not been studying Marxist doctrine, but the Aotearoa New Zealand educational system has been influenced starkly by Freire's practices (Kotare Trust and AWEA, 2014). In his early works, Freire focuses more on the complex and layered nature of oppression and the structures that create oppressive forces within the classes rather than promoting any sort of violent uprising or usurping of power from the upper classes (Cortez, 2016). In this way, Freire's position was not a call for weapons of violence nor was it entirely a call against revolution. It was primarily a call for critical education—for the minds and attention of the oppressed to be freed from the instantiated societal narratives that imprison them within an underclass or a class that lacks the same rights as a more dominant one (Freire, 2000).

Why is this an important consideration in this analysis? The premise of capacity building that is at the core of this project aligns with Freire's approach to empowering those without voice. The participants critically analyse their ideas relating to health and healthcare and then develop their stories in congruence with Freire's approach. By this, I mean that Freire believed that through dialogue and articulation, every oppressed or marginalised individual holds the capacity to rise above or at least mitigate the oppressive forces that they face (Freire, 1982). They assume their rightful place in human social order and attain freedom through emancipation by amplifying their voice so they might instigate and substantiate change (Freire, 2000). This is what the project hopes to facilitate for the participants and other young people.

While Freire's perspective is valuable and has guided the critical aspect of the project, it is not without my own internal criticism and hesitations. The points that the participants raised about communism were polarising and beg the question as to how a facilitator can support and encourage expression while ensuring that personal biases and fears do not overly influence those expressions? The points they raised, and the stories created as "tools" to serve their needs, should be carefully considered given that stories and ideas can also go on to have a life of their own, outside of the creator's vision and control.

I admire the visions that the participants have for equality and desperately want it for them. However, I also found myself feeling uncomfortable with some aspects of the conversations. I didn't want to counter their ideas with points that might cause emotional upset or shut down conversations, nor did I want to support one ideology over another (I had made that mistake once already with my judgmental response to the topic of "old people"). Yet I couldn't shake my concerns that my silence on ideologies may also cause harm if it didn't provide them with the ability to consider things as deeply as possible and with a degree of fidelity worthy of their energy. Ultimately, I worked to navigate the tensions between Ceili and Liam without overtly steering the conversation in one direction or another. Lunch and Lunch (2006) suggest that this is a fundamental aspect of successful facilitation. However, regardless of my intent to remain objective, it is important to acknowledge that it is impossible to wholly dissociate myself from my own context, experience, and opinions. Canosa et al. (2018) point out that to be effective and internally consistent, PAR demands reflexivity on the part of facilitators so that when opinions diverge from those of the participants, the facilitators are conscious of the disparate positions and make purposeful actions (or inactions) to protect and enhance participants' perspectives, opinions, and ideas.

The Problem With Human Nature

I realise that this discussion has strayed from the immediate topic of "blue sky solutions to health challenges facing young people in Aotearoa New Zealand," so why the exploration on Marxism here? I believe that it is important because the Marxist idealism expressed by some of the participants as a potential solution for forcing equality of outcomes has killed upwards of 100 million people in the 20th century (Rummel, 1995). The idea of absolute equality is certainly beautiful and should be a guiding light, but the implementation of centralised political control through an application of revolutionary force has not yet been resoundingly successful. The general living conditions in countries with communist or totalitarian rule have, in the main, remained less than ideal, with poverty and marginalisation based on group identity occurring at every level of those societies. Alexandr Solzhenitsyn, a war hero imprisoned in the Russian revolution, observed that application of communist doctrine was inherently flawed because it imprisons or "throttles" so many people in order

to redistribute capacity. He advocates that human beings are born with different capacities; if free to make choices, they are not equal, but if forced into being equal, they cannot be free (Solzhenitsyn, 2001). It was precisely this idea that I believe Liam was referring to when he expressed concern regarding the impact of human nature on the potential of communist ideals. The temptation to raise these points was tremendous for me as a facilitator, yet I instead aimed to act as an ally to both perspectives by creating space for dialogue and fostering the conversation further.

Perhaps Liam's insight is precisely what needs to be considered on both sides of the argument? That any and all ideological approaches are subject to the "human" condition? Just as there are criticisms of socialist and authoritarian doctrines, there are opposing views that capitalism and its promises of freedom can lead to equal or greater human suffering (saed, 2021). Listening to the participants' thoughts and visions had me simultaneously agreeing with both sides of their arguments, whether collectivist or individualist. This led me to question any purely utopian visions, regardless of their standing to the left or right of politics, because the forces required to establish and maintain control, by their very nature, oppress: even if their initial goal is to free those previously oppressed, the new paradigm that a revolution presents is just as likely to be problematic.

In a more private conversation that did not include the rest of their group, Ceili later tried to explain to Liam and me that communism only failed because *"Stalin and whoever wasn't real communism. They didn't do enough because they gave up before the people actually controlled everything. They needed to do more and then it would have been better."* Listening to the intensity of her convictions and feelings that I can only describe as a pure desire to achieve utopia was, for me, simultaneously inspiring and worrying. It is difficult to fathom the effort of will that would be required to do "more" than Stalin to establish and maintain Marxist ideals or the terrible forces that were required to undertake China's cultural revolution. During the conversation, I was uncertain as to how to support the participants' ideas relating to revolution and admit that it tested my resolve as a facilitator to keep my opinions to myself. Now having done more reflection as to what politics might serve young people and society best, I have solidified my beliefs that no application of brutal force to attain utopian ends should be pursued as we cannot solve marginalisation or inequality by applying a

different form of marginalisation and inequity. This simply results in our becoming the very thing we were striving to overcome and returns us to exactly what we had set out to change.

Coming back to the concepts of portraiture and landscapes, I wonder if the most valuable aspect of the group's exchange on this topic might be the balance between Liam's and Ceili's positions and their eventual finding of "middle ground" by agreeing to disagree: that is, the striking of a middle ground within the landscape of their views. The participants' consideration of a solution that would involve a wholesale political change with the intent of levelling the hierarchical structures of society is arguably a perfectly logical one, given the degree of disempowerment and "invisibleness" that they have expressed. As they look forwards and try to negotiate a better future, they express empathy for others they see as suffering while placing the needs of these others in front of their own. This is a fundamental aspect of reciprocal altruism, a trait considered to differentiate primates from other species, and is central to ensuring the trust in a community required for stable and productive societies to form (de Waal, 2008).

As we went further into the thematic analysis of their topics, it gave me a sense of foreboding, wondering what topic they would ultimately settle on for their final group video. There is often an expectation that young people be harbingers of change, as is exemplified by the current call for youth revolution set out by the Global Shapers Community at the World Economic Forum (GSCWEF) (Hamza & Pierce, 2019). The GSCWEF suggests that revolution in the face of global warming and mental health emergencies is necessary to "secure the world" so that today's youth will have a future.

The participants were actively considering how they could minimise inequity and poor health outcomes from a political position, and I was amazed at their application of the ideas and their patience with each other's points. While I had expected they might share their parents' or family values, I wasn't expecting the fidelity of their discussions or their ability to articulate their reservations about the utility of other ideas being presented. It may be that the participants are identifying that for them to have a future, their health needs are worthy of revolutionary approaches.

Moving Beyond the Political

This political conversation formed the starting point for the group to look for other threads that related to political ideas. The topic of communism was placed under a broader category or theme of “political change or action.” The group’s analysis brought in several topics under this overarching theme, including “start a revolution to make sure people have what they need,” “changing how governments spend money,” “kids should have the power to decide what they need,” “we need to make healthcare free and make people go,” and lastly “lower the voting age so kids are able to vote to change things.” They deemed all these ideas to fit into the theme of political change, thus forming the first thematic cluster that this group would consider as a potential topic for their final story.

From there, they continued analysing the topics and ideas that lined the papers in front of them, independently going on to identify three other themes: “bullying, depression, and mental health,” “education and family,” and “sexuality and gender differences.” I was almost certain that they would follow the political thread, but it would be the latter, “sexuality and gender differences,” that would ultimately capture this group’s attention and lead the direction of their project. They went on to use stories to explore the different experiences faced by boys and girls including confusion and prejudice around sexuality, bullying, isolation, mental health, and family support (or lack thereof).

Each of the other groups undertook the same process of thematic analysis, collating their papers into “clusters” of topics from the approximately 26 ideas each group had generated (see Figure 27). Facilitators were on hand to help encourage discussion if and when groups stalled or asked for assistance, but the process was almost exclusively driven by the young people themselves. The types of assistance requested mostly related to how to cluster various topics. Facilitators did not tell participants where topics belonged but asked questions to elicit more critical reflexivity on the precise nature of the topic in question. Ultimately, each group ended up with between four and six different clusters of topics. These were broad ranging and, as mentioned previously, included topics such as political change and revolution, mental health and depression, bullying, sexuality and sex education, gender disparities, loneliness, homelessness, feelings of not fitting in, COVID-19, anorexia, and suicide.

Figure 27*Group Process of Thematic Analysis*

Note: Images of the groups analysing the ideas that came out of the Margolis Wheel exercise to come up with four to six topic “clusters” each.

Every Voice Counts: Using Democratic Process to Choose a Final Topic

As each group’s main project would be the creation of a short video about a health topic, they needed to find a means of determining which of the topics they most wanted to tell their stories about. To do this, we adopted a three-point voting system. Each participant had three votes that they could cast on the topics they were most interested in. They could spread their votes across topics or, if there was one that they were strongly drawn to, they could cast all of their votes on the one to increase the odds of it being selected.

While there were some instances of potential recruitment (demonstrated by a few of the older participants in the group asking others to vote their way), most participants cast their votes without incident or hesitation. The few younger members who were unsure or indecisive turned to the older kids for advice and seemed genuinely happy to “buy into” their ideas. The adult facilitators all stood back from the voting process to try to minimise any inference or suggestion.

In hindsight, it may have been useful to have held a blind voting system, but on the whole, all the groups went through the voting without argument. There was, of course, a degree of back and forth by some frantically changing their minds, but at the culmination of the votes, all seemed pleased (or at least content) with the choice their group had made. Most participants seemed genuinely proud of the topic their group had decided on, and there were lots of smiles (see Figure 28). We checked in with each member as we tidied up the papers, and there were three who seemed somewhat disappointed and said they had wanted different topics than were chosen. Despite this, they shared an overwhelmingly positive outlook for the next steps of the process. They acknowledged that they had had their votes and lost but thought their ideas were important. We sat with the whole group for a minute and discussed ways in which the topics that were not chosen had really contributed to the process and could still be woven into their developing stories. Although a few participants expressed frustration about not “winning” the vote, they subsequently went on to participate fully in the group discussions and contributed their ideas. This inclusive process facilitated discussions amongst the group and enabled those with ideas that were not the mainstream to have their ideas heard and woven into the broader narratives of their topics.

Figure 28*We Chose Our Topic!*

Note: One group excitedly showing off their chosen topic. They had asked for their photo to be taken to celebrate. Their overarching theme was mental health, including the topics of courage, bullying, sibling rivalry, anxiety, and depression.

Exhaustion and Changing Direction

Although we still had time left before the end of the day and despite the apparent positive energy and my own desire to press on, when I shouted out asking how they were feeling and if they were ready for the next exercise, several in the group quietly shook their heads or looked away. I had expected a raucous return as they usually gave, so I stopped and undertook a more formal check in. Soon more and more participants acknowledged that they were tired and wanted to do something else, something “fun.” This was reminiscent of my own experience of participatory video as a participant—choosing topics and discussing important and meaningful things left us exhausted too.

In keeping with the participatory methodology, this led to a rapid change of plans. Lunch and Lunch (2006) make it clear that participatory video should always focus on the fun, and Coyne and Carter (2018) argue further that if participatory research with young people isn’t an enjoyable process

for the participants, then participation will be involuntary or tokenistic. It had been a long day of learning skills and holding challenging conversations during the analysis, so we all agreed to cast the planned work aside for the remainder of the day. After a quick overview of what they could expect in the coming days—writing, storyboarding, filming, and editing their video—we finished the afternoon with a number of theatrical games, the sole purpose of which was to shake out the heaviness of the discussions and, as they suggested, simply have fun (see Figure 29 and Figure 30).

Figure 29

Shaking Out the Heaviness (Video)



Note: Topics chosen! Shaking out the heaviness: pushing work aside for some fun! Video here:

<https://youtu.be/CvFybvw4IsQ>.

Figure 30*Shaking Out the Heaviness (Images)*

Note: Images of the theatre games we used to “shake out the heaviness” through teamwork and co-operation.

Day 3 – Pre-production Analysis: Considering Cause, Effect, and Solutions

Wednesdays are called “hump day” for good reason. On arrival in the morning, the kids were ready to go, but energy levels were indisputably low, both for them and for us as facilitators (I personally had been up until 3 a.m. reviewing the video footage and documentation the groups had made the previous day). We had accomplished so much in the first two days, but now we needed to

pull everything together to enable the groups to create their own unique cinematic videos reflective of each group's collective creative, narrative process. And first, before any videos could be created, we needed to facilitate additional exploration of their ideas and ways of storytelling.

The participants gathered into their groups, and we reviewed the topics they had chosen. All were issues or problems that they felt young people face, and we had three exercises planned to help them determine what stories they wanted to share and how they wanted their audiences to experience them. To begin, we asked each of the groups to come up with a production company name. This was done to unite the groups and foster a sense of belonging. Interestingly, despite the groups' cohesion the day before, choosing names was easier said than done. I hadn't considered that this might be the first stumbling block, and it was only after much deliberation, many votes and revotes, and some paper-scissors-rock tiebreakers that the groups found their cohesion and the following "youth production companies" were formed:

1. Sassy 7 Productions

Topic: Bullying, depression, and anxiety. Social media affects young people's mental health.

2. 8 Ball Productions

Topic: Health isn't talked about at school as much as it should be (particularly sex education and mental health).

3. Just a Label Productions

Topic: Mental health—bullying, anxiety, and depression.

4. K4D & Company

Topic: Gender—sexuality, bullying, and fitting in. Girls and boys are treated differently.

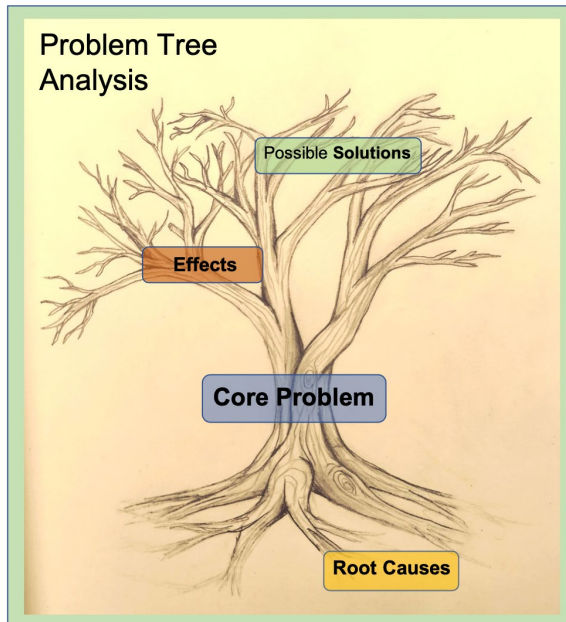
Planting the Seeds and Growing Problem Trees

Chevalier and Buckles (2019) propose the use of a "problem tree" as a tool for creating a structural analysis of the causes and effects of an issue. I adapted their problem tree model to include consideration of potential solutions within the exploration of cause and effects, in essence building on the metaphor of a tree by also "bearing fruit" (see Figure 31). To enable individuals in a group to contribute their ideas and brainstorm to develop those ideas into relatable stories, we plant the "seed

problem” and grow the tree to a point that it bears leaves and fruit, where fruit are potential solutions to the effects and root causes of the problems presented.

Figure 31

Problem Tree Analysis



Note: Problem tree analysis model, adapted from Chevalier and Buckles (2019). This adaptation incorporates “fruit” as possible solutions.

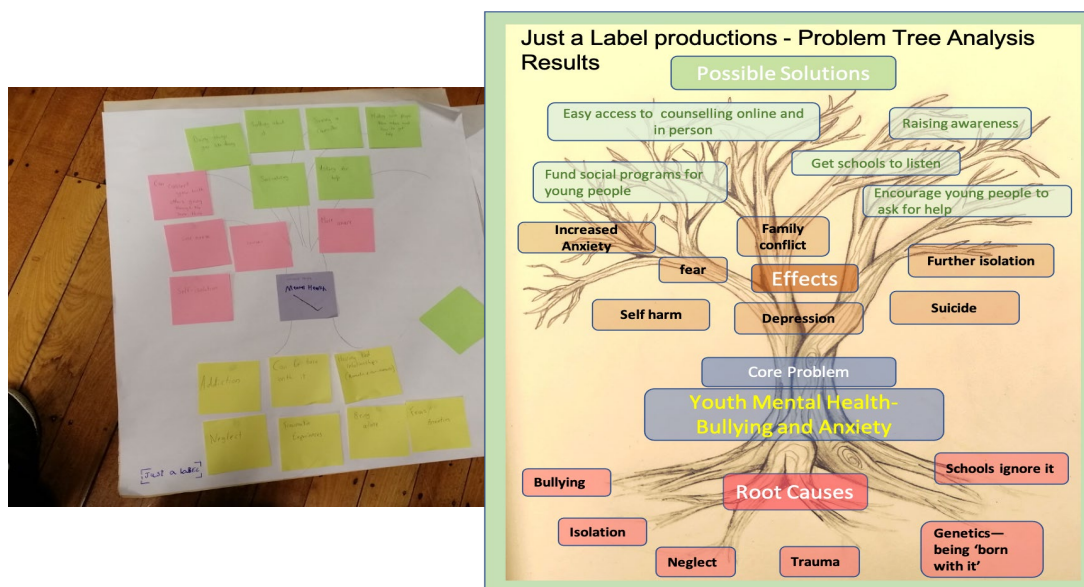
Through this exercise, each group drew a tree on a large piece of paper and placed the core issue they were considering on the trunk. They discussed the root causes of the issue and wrote these down on sticky notes at the roots of the tree. They then considered what the effects of the problem are and placed those in the branches of the tree in a different colour. Finally, they explored potential solutions that cover the causes in the roots and effects in the branches, represented in a third colour as the leaves and “fruit” of the tree. This metaphorical growing provided the groups with opportunities to discuss their perspectives and find common ground in terms of how they see the problem and what might be required to address it.

The example in Figure 32 shows how the group Just a Label Productions considered young people’s mental health in relation to gender inequality as an important problem. They concluded that addiction, neglect, trauma, genetics (“being born with it”), and schools ignoring the problem are the

key underlying causes of youth mental health issues. They went further to suggest that these causes are exacerbated by the bullying and isolation that are common experiences of young people in Aotearoa New Zealand. They thought this was particularly so in light of governmental lockdowns in 2019 and 2020 that kept them home from school for months at a time, forcing them to join and participate on social media platforms. This, they said, brought an increased sense of isolation. Just a Label Productions highlights that the effects of social media are compounding, because while these platforms are meant to connect people, if young people make mistakes, it results in almost unresolvable ostracisation and subsequent self-isolation out of fear of reprisals. The group suggests that this leads to further depression for those involved, increased self-harm and suicidality, and a broader unawareness of the extent of the problem for those who have had positive experiences of social media. The examples that the group pulled together are based on their own experiences or the experiences of friends and loved ones close to them.

Figure 32

Just a Label Productions Problem Tree

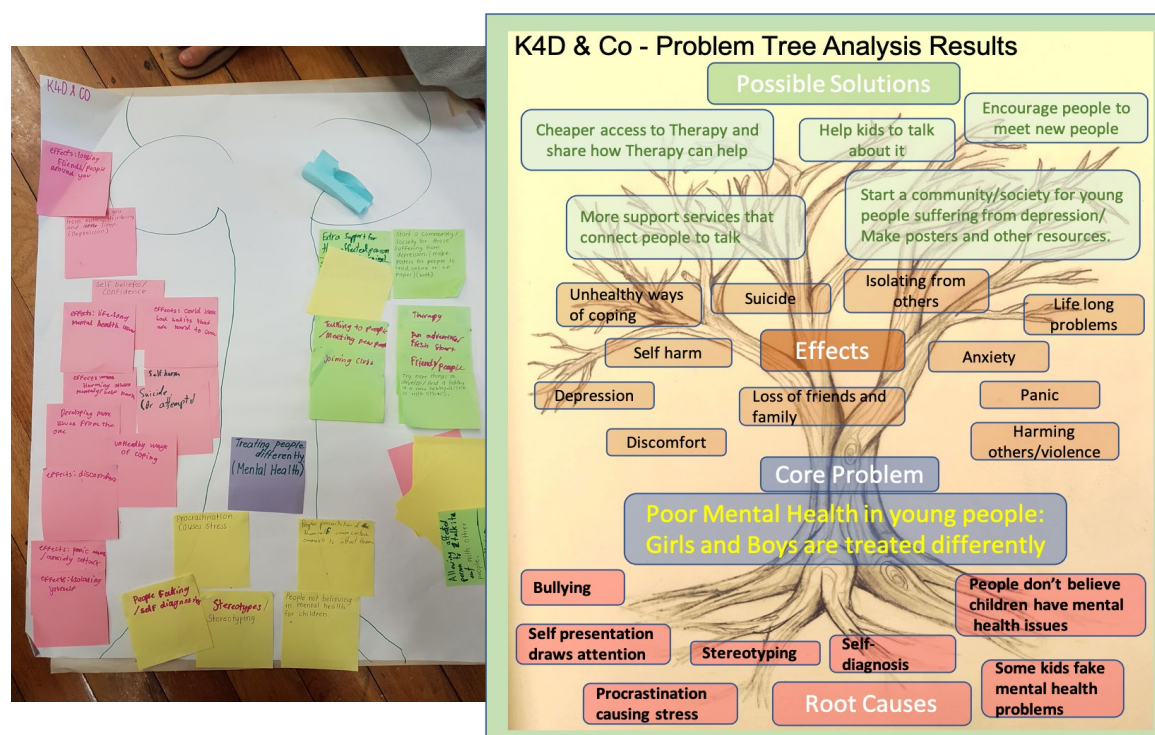


Note: Image of the completed problem tree created by the Just a Label Productions group on their topic of youth mental health.

As Figure 33 shows, K4D & Company produced a problem tree for the issue of poor mental health in young people, focusing on how girls and boys are treated differently. They identify the key causes of poor mental health in young people as bullying, gender stereotyping and inequality, identity issues, and social isolation. Several members of the group reported that they or friends they know have successfully sought help from counselling to support their well-being.

Figure 33

K4D & Company Problem Tree



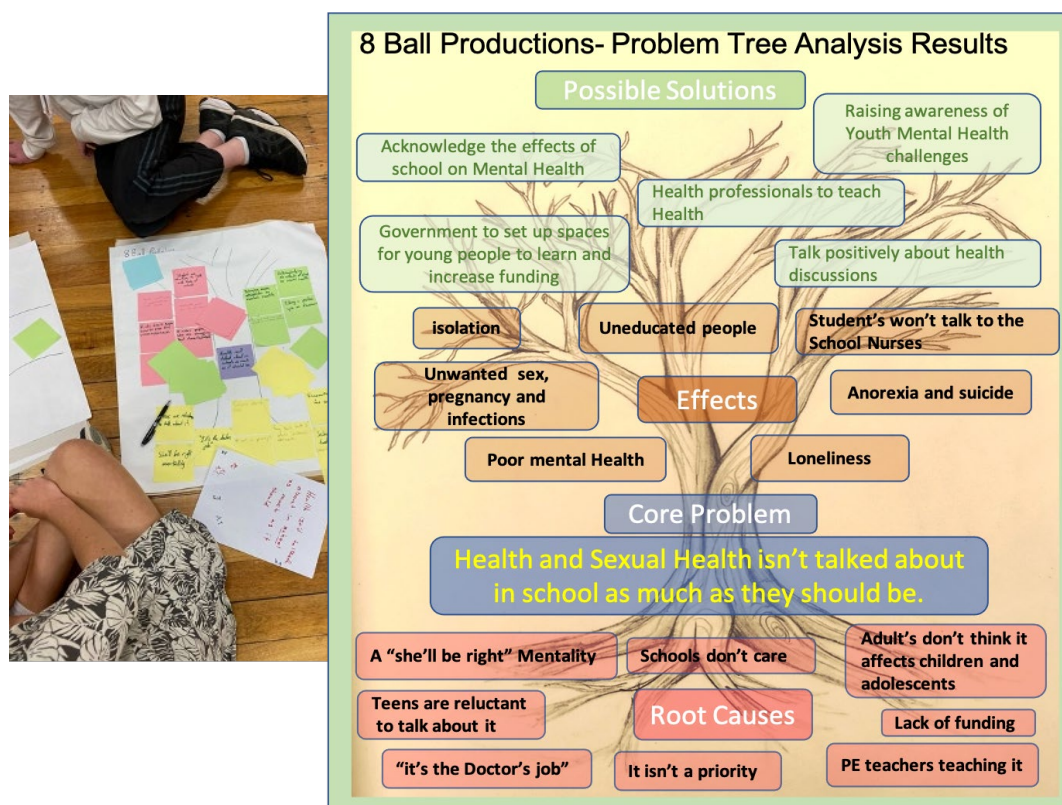
Note: Image of the completed problem tree created by the K4D& Company on their topic of poor mental health in young people and how girls and boys are treated differently.

In the problem tree created by 8-Ball Productions (see Figure 34), on their topic “health isn’t talked about as much as it should be in schools,” the group considers the main cause of poor health and sexual health education to be that teachers address the physical but not emotional aspects of health. They conclude that teachers think “it’s a doctor’s job” to provide health education and that because the government does not consider young people a priority, schools just don’t care about it.

They also acknowledge that teens don't help themselves because they are reluctant to talk about health issues and have nowhere to turn.

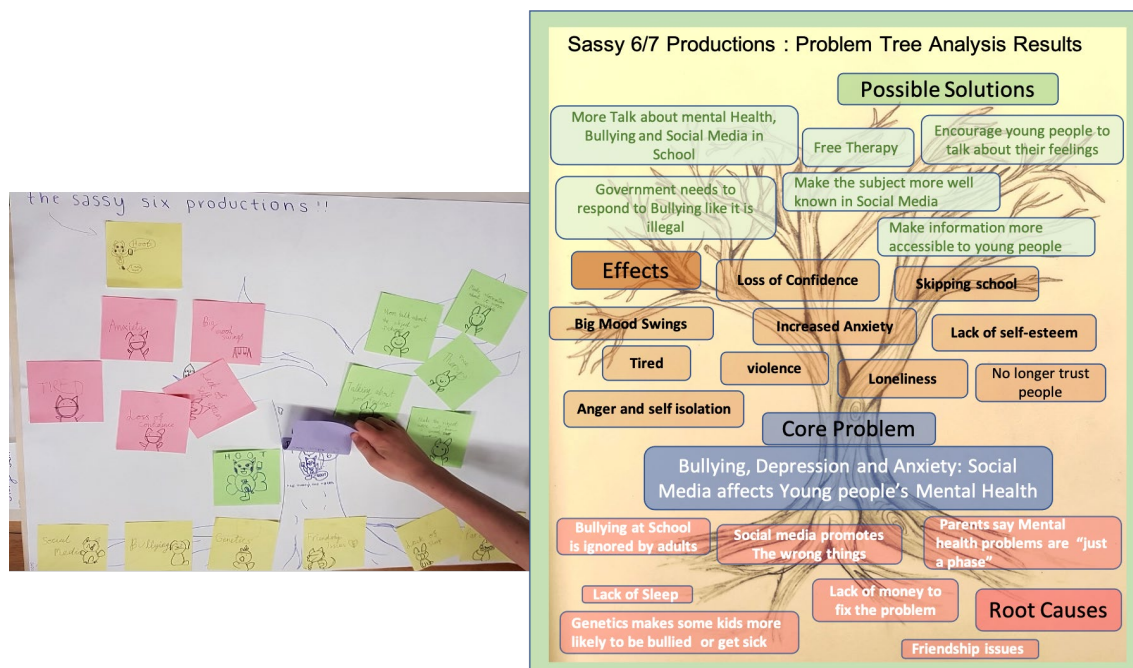
Figure 34

8-Ball Productions Problem Tree



Note: Image of the completed problem tree created by 8-Ball Productions on their topic of “health isn’t talked about as much as it should be in schools.”

And finally, in Sassy 7 Productions’ problem tree (see Figure 35), they consider social media to be a key contributor to poor mental health outcomes for young people. They believe that it increases bullying because it promotes the wrong “sorts of behaviour” and is invisible to adults. They say that in today’s world of instant communications, young people experience friendship issues far more commonly, and the genetic predisposition of many young people to mental illness is made worse by parents and teachers saying they will “get over it” because it is “a phase.” According to the participants, this is further exacerbated by a lack of money for youth-centric mental health services.

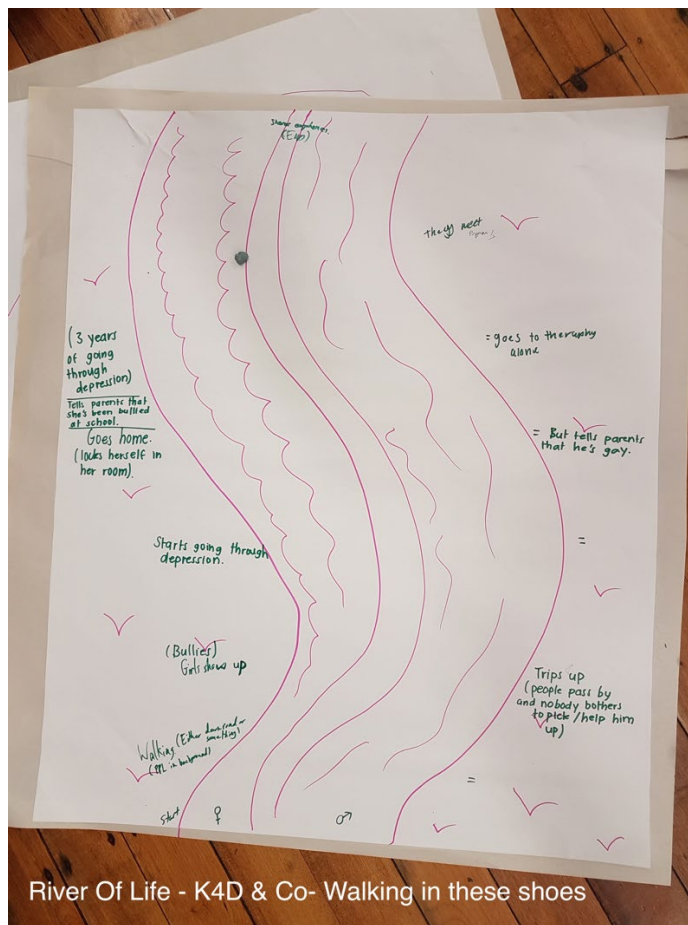
Figure 35*Sassy 7 Productions Problem Tree*

Note: Image of the completed problem tree created by Sassy 7 Productions on their topic of social media and mental health.

River of Life and Audience Pathway

Following the problem tree analysis exercise, the groups were introduced to two different conceptualisation techniques for planning the telling of their stories. One uses the metaphor of a flowing river to carry the main character along (“river of life”), and the other uses a conceptual path or road that the storytellers want the audience to follow (“audience pathway”). Both serve the same purpose, and which one to use depends on how the story will be told.

The river of life technique is best used for stories that have a main protagonist who experiences a series of events across time. It shows their development and tells their life story sequentially, as though the character is being carried along, sharing new information with the audience as the narrative “flows” (see Figure 36).

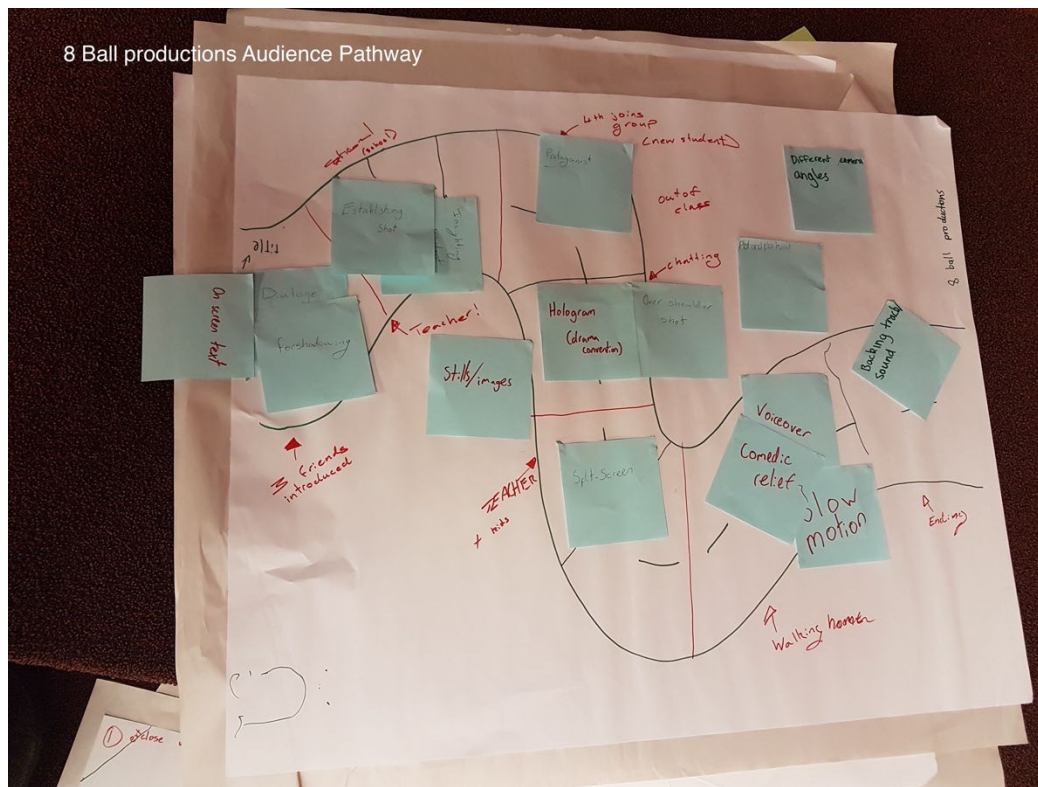
Figure 36*Example of the River of Life Storytelling Method*

Note: Image of how the K4D & Company group used the river of life method to plan their story.

The audience pathway technique helps storytellers consider what they want the audience to experience as they travel along the movie's path. This helps them plan how they want the story to unfold and in what order they want to express their key points (see Figure 37). This method can be used to introduce multiple characters, tensions, and lessons that will then translate into the actual planning of specific shots and content in a production storyboard (the tool they would use to work through the filming process).

Figure 37

Example of the Audience Pathway Storytelling Method

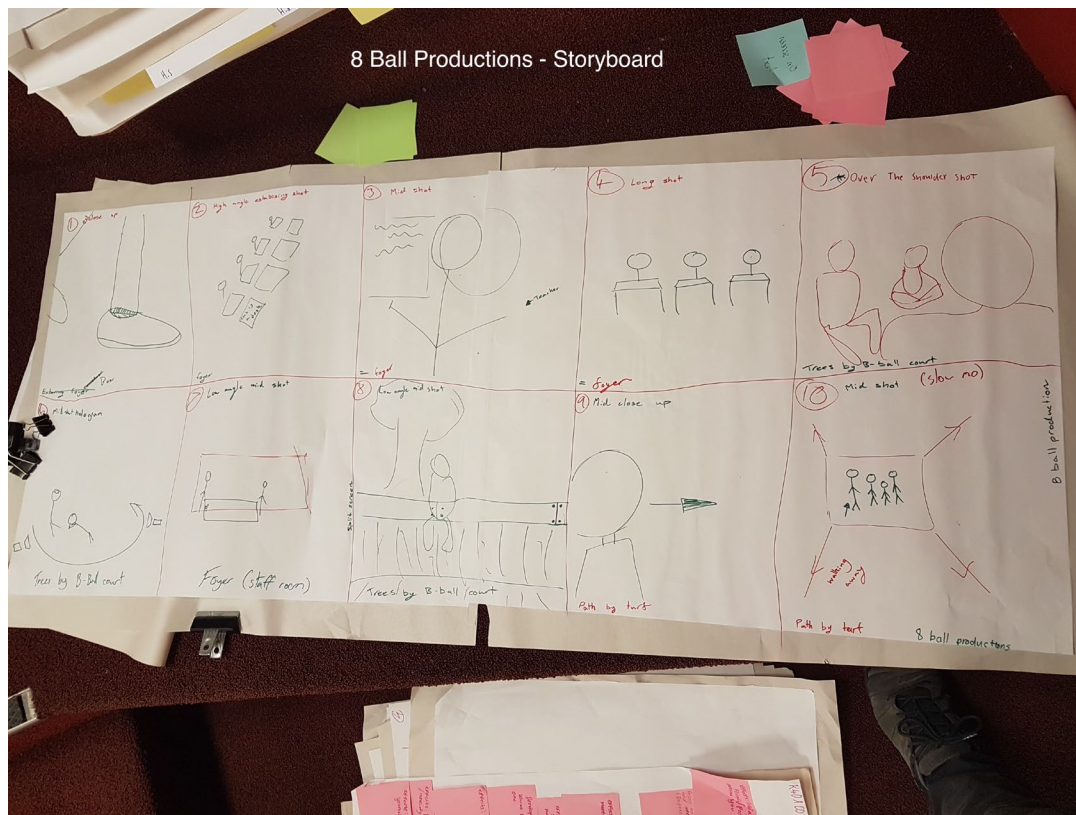


Note: Image of how 8-Ball Productions used the audience pathway technique to plan their story.

Regardless of which method they used, during this exercise each group had to consider what they wanted to show, where in the story they would show it, and why.

Storyboarding

The last exercise for the groups to complete prior to the actual filming of their videos involved creating their storyboards. Building on the lessons they learned in the Story and Tell exercise on day 2, the groups now had to plan scenes to guide their filming. The storyboard is a graphical representation of the narrative and is regarded by most filmmakers as the most important tool to facilitate the filming and telling of a coherent story (Pallant & Price, 2015). In participatory video, the storyboarding process is integral to ensuring that participants have control over the creative process and gain confidence in their ability to translate their ideas into coherent video stories. Figure 38, Figure 39, Figure 40, and Figure 41 present the groups' storyboards.

Figure 38*8-Ball Productions Storyboard*

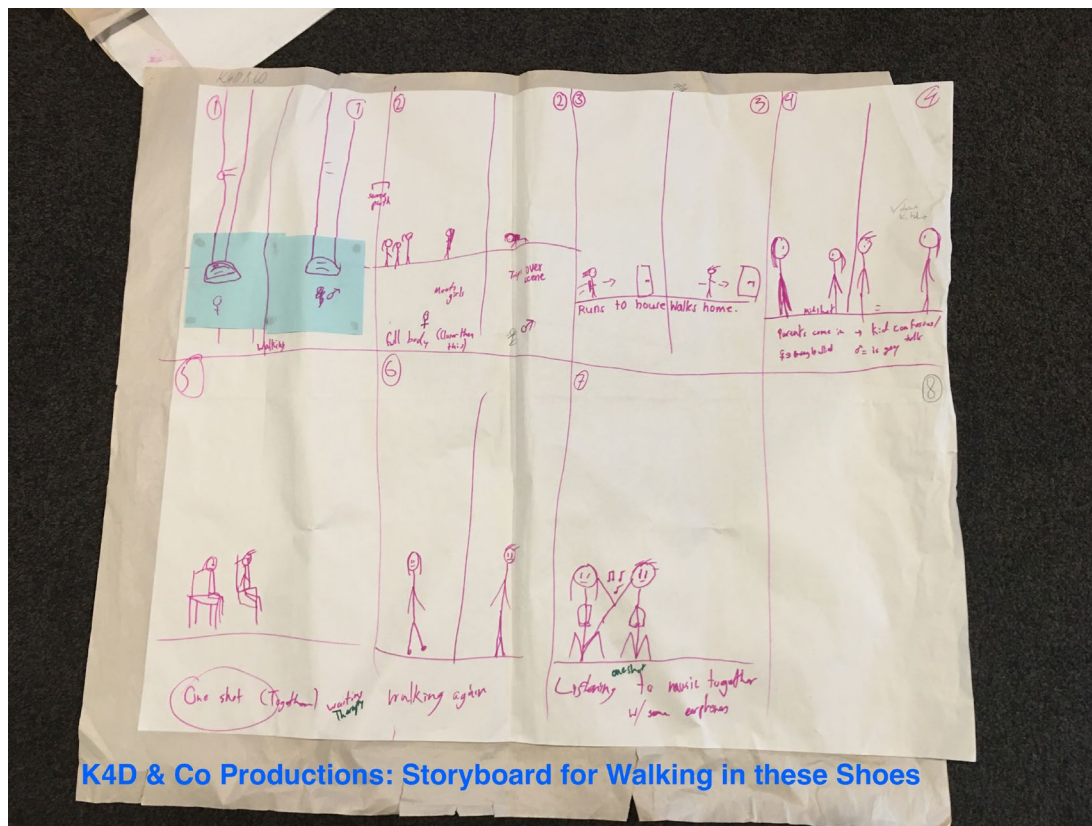
Note: Image showing the storyboard prepared by 8-Ball Productions.

Figure 39*Sassy 7 Productions Storyboard*

Note: Image showing the storyboard prepared by Sassy 7 Productions.

Figure 40*Just a Label Productions Storyboard*

Note: Image showing the storyboard prepared by Just a Label Productions.

Figure 41*K4D & Company Storyboard*

Note: Image showing the storyboard prepared by K4D & Company.

To complete their storyboards, the groups scouted out locations for each scene, wrote down characters' spoken lines, and made lists of any special props or clothing they might need the following day. The groups worked very independently and had clear visions for what they wanted their stories to portray and how they would look. For the most part, they did not request help from the facilitators, with one exception. The group Just a Label Productions had a vision that required some additional consideration. They wanted a dragon that breaths fire and to make their scenes look as though they were in a castle. Given our timeframe and budget, my initial response was to dismiss this as being too difficult, but they were persistent and thought that the theatre company might still have a dragon from their production of *Shrek* the previous year. After discussing this with the theatre director and making a few phone calls, I was able to borrow some green screens (for superimposing backgrounds) and find the large pink dragon. I also had some video footage and photographs I had

taken at a castle in the UK during my participatory video training course. It seemed only fitting that I offer this to them as a backdrop.

I hesitantly promised I would try to learn how to make the dragon breath fire with video effects and to superimpose their scenes on a castle, but I couldn't guarantee success. They were excited about the possibilities, and I too was excited to try and help their ideas come to fruition. Day 3 finished with the group's storyboards complete and the participants looking forward to putting all the week's planning into action. (Of course, it also ended with me worrying that I might not be skilled enough to add castles or fire-breathing dragons to a video.)

Day 4 – Lights, Camera, Action

Day 4 was where the proverbial rubber hit the road. There were no specific exercises to be done, so each team collected their camera gear and set about capturing their scenes on video. As facilitators, we were available to answer technical problems or give advice on lighting and locations, but generally the groups just worked through their shot lists by following their storyboards.

The theatre space we were working in is located within a primary school, and since it was summer break, we were fortunate to have the grounds and theatre building almost to ourselves. This meant that the groups could plan their filming around each other and use a variety of indoor and outdoor spaces—arguably an important factor if you want to have a terrifying dragon in your story! The weather was unpredictable, and the high winds caused havoc for some of the audio recording. Also, I would be lying if I said I wasn't worried about the approximate \$12,000 in equipment distributed between the four groups, with participants at times running from the subtropical deluge outside, dragging cables and bags in their wake. However, the participants treated the equipment with respect, and the accompanying rain, while unwelcome, didn't dampen the teams' spirits. On the contrary, one group (K4D & Company) adapted their storyboard to include footage of a torrential downpour to set the mood and highlight the “stormy” nature of their characters' conflict. We had planned for such events and had umbrellas and plastic bags ready to cover the cameras, so things ran smoothly. Each camera had an external microphone with a “dead cat” cover for wind, so the groups that took the time to swap the microphones fared much better on the audio quality than those that

didn't. The participants' ability to adapt to and accept adversity was inspiring and a reminder that young people are more adaptive and resilient than they are often given credit for. Figure 42, Figure 43, Figure 44, and Figure 45 show the groups busy filming their videos.

Figure 42

8-Ball Productions Filming



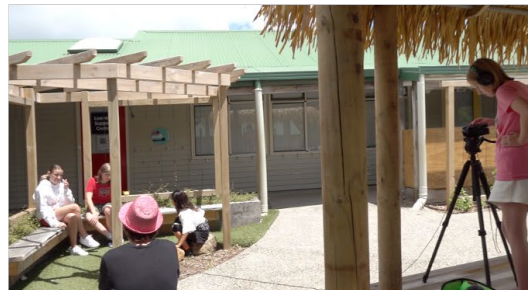
*Note: Images from the 8-Ball Productions group filming *The Change We Need*.*

Figure 43*Just a Label Productions Filming*

*Note: Images from the Just a Label Productions group filming *Quest for Courage*.*

Figure 44*K4D & Company Filming*

*Note: Images from the K4D & Company group filming *Walking in These Shoes*.*

Figure 45*Sassy 7 Productions Filming*

*Note: Images from the Sassy 7 Productions group filming *Sam's Story*.*

Over the course of the day, it became clear that three elements were key to helping the participants achieve their vision in the filming of their videos: (1) careful and clear organisation of the equipment, (2) facilitator knowledge of the equipment and ability to troubleshoot when things don't work properly, and (3) willingness of the facilitators to listen to the participants and help them improvise as required based on the limitations of the setting, equipment, and timeframe.

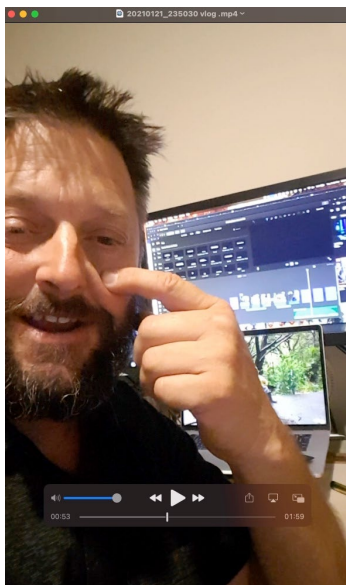
We had periodic group check-ins and played theatre games to provide breaks, and by the end of the day, every group had completed their planned shot lists and had captured the essence of their stories in various video clips based on their storyboards. The next and final day of the workshop would involve their first rough edit to make their videos ready for viewing. There were many smiles and lots of noise as the participants packed up to head home. For the facilitators, we too were smiling,

as the day had been a real pleasure, leaving us feeling privileged to witness the participants creatively using their new skills.

During the day, a close friend of mine, Jason, who had volunteered to supply the project with four complete video editing suites, generously gave his time to set them up in the theatre. After the participants had left for the day and as evening fell, we completed the setup of the editing suites, ready for the last day of the workshop. In the morning, we would be exploring the editing process and get our first chance to see what the videos would look like, but the night still had lots of work ahead as I made backups of the video footage and arranged for it to be ready for each group to work with in the morning (see Figure 46 for a brief facilitator video reflection).

Figure 46

Lead Researcher Reflections After the Day of Filming



Note: My reflection on the day's filming, fatigue, and what lies in store for the final day. Video here:

https://youtu.be/r83D_oZvLCU.

Day 5 – Paper Editing and First Cut

The final day started with an exercise designed to teach the fundamentals of video editing. Each group had a dedicated editing suite, and they set about reviewing their shots and writing down the video clip numbers and timestamps of the shots they wanted to use. As they went, they wrote

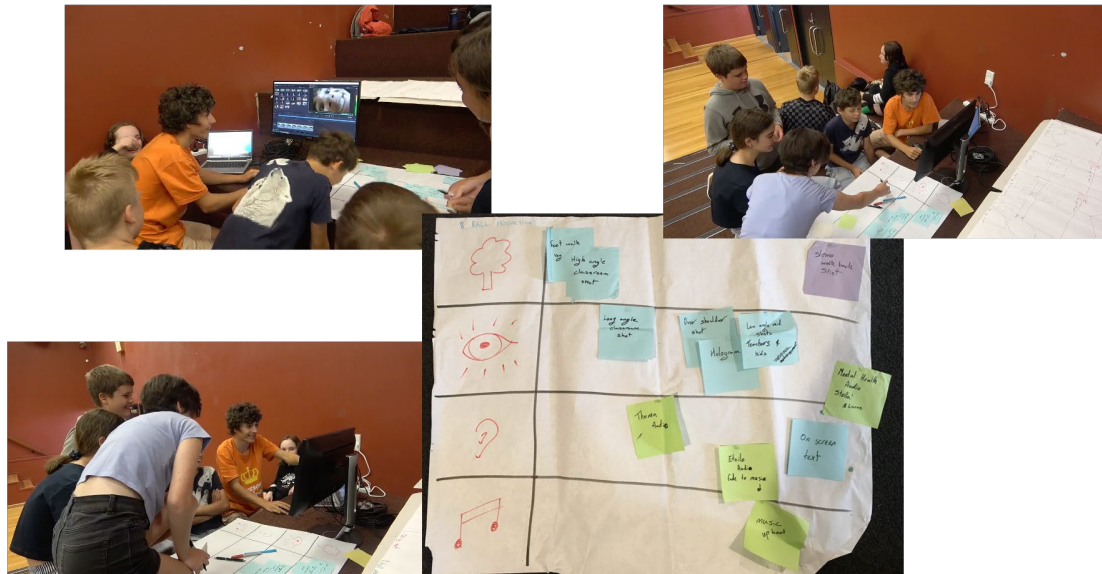
these onto sticky notes and placed the notes in a “paper edit” that sets the story up into a list of primary and establishing shots, along with music and additional audio tracks (see Figure 47, Figure 48, Figure 49, and Figure 50). As they selected the scenes, they imported them into the timeline of the editing software. This is done to familiarise the group with the software, while also facilitating the group’s discussions as to how to “unfold” their story. I also asked the groups to write down their ideas for effects, titles, credits, and music as they came up, because these would later become a reference for me to follow in the final editing processes.

Figure 47

Just a Label Productions Editing



Note: Images of the group Just a Label working on their paper and first digital edit.

Figure 48*8-Ball Productions Editing*

Note: Images of the group 8-Ball Productions working on their paper and first digital edit.

Figure 49*K4D & Company Editing*

Note: Images of the group K4D & Company working on their paper and first digital edit.

Figure 50*Sassy 7 Productions Editing*

Note: Images from the group Sassy 7 Productions working on their paper and first digital edit.

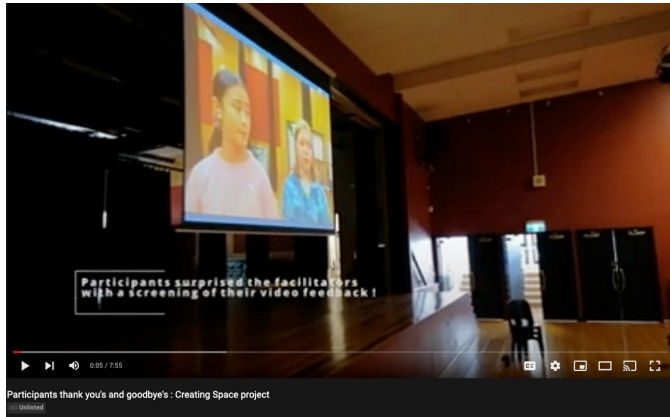
As the groups were moving on from the paper edit and into the digital editing, I checked in with them to learn more about what was going well, where they were experiencing challenges, and how their overall story concepts were coming together (see Figure 51 for a view into one of these interactions and my own reflections on how it was going).

Figure 51*Lead Researcher Reflections During Editing*

Note: Video footage of my interaction with one of the groups during the editing process, plus my reflections on the group's strengths and progress, as well as the challenges of working with technology. Video here: <https://youtu.be/JoUQumZFpHM>.

A Surprise Worthy of Note

During a morning break on this final day, we were treated to a surprise that I believe demonstrates the value of a collaboration that focuses on capacity building. Without being prompted by me, many of the participants had found time to create thank you and feedback videos outside of the project exercises. They had reportedly decided to do this the night before and completed it by the time we arrived in the morning. The videos were not edited works, but the participants told us they believed in our motto “mistakes are great” so did not worry that the videos were not polished (see Figure 52). They recorded with a cell phone and importantly without us knowing, meaning it came as a complete and welcome surprise.

Figure 52*Participant Thank You Videos*

Note: Surprise video clips created by the participants in secret to provide feedback and a “thank you.”

Video here: <https://youtu.be/Uama8x2-WDM>.

The short clips included positive statements about our helping them “have a say” alongside specific comments about feeling supported and listened to as well as what we could improve on in future workshops. Their comments suggest that they really enjoyed the week and appreciated our listening, thought we were kind, were grateful for our sharing of equipment, and valued the opportunity to explore their thoughts on health. They said they would have benefited from more time but that the pressure of time had also been “part of the fun.” An unexpected comment suggested that “one thing [I] could work on is having more authority over [them] so that [they] could listen” (minute 1:40 on the clip). Such is the challenge of balancing participation with expectation.

I was moved immeasurably as they screened their videos for us and can’t imagine a better outcome from collaboration with young people than to see them adopt and adapt the methods that they had learned during the workshop to tell us what they thought of the whole experience.

Moving From Paper to Digital

As the day progressed, despite not having previously used the specific video editing software I provided, many of the participants became very adept with it. I had expected a need to spend more time teaching them how to use the software, but the groups picked this up very quickly and by midday most had completed a first rough edit. This meant that we could spend more time discussing their

videos and the details of their choices while taking away some of the pressures we had all felt during the week.

We finished the day with one last screening of the rough edits so that all the participants could see each other's work. Each group also offered a brief video synopsis of their story, and we discussed what was working well and what could be done to improve the video artefacts before making them available to the public. The groups each elected an editor to be the contact for post-workshop edits and wrote down the names they wanted to have in the credits and any other last-minute additions they might want to make.

We closed the workshop with a group photo and sending a short video "hello" to the people at InsightShare in the UK (see Figure 53) before leaving the camera running for the kids to say any last words (see Figure 54). We (the facilitators) too said a quick "goodbye to the camera" in a reflection (see Figure 55).

Figure 53

"Hello" to InsightShare



Note: A video “hello” for the team at InsightShare at the close of our final day of the workshop.

Video here: <https://youtu.be/C7E2F-Ti3c>.

Figure 54

Last Words From the Participants



Note: A fun “goodbye” from the participants in front of a running camera. Video

here: https://youtu.be/XbGhd_b_nQ.

Figure 55*Facilitator Wrap-Up Comments*

Note: Facilitator comments and reflections at the end of the final day of the workshop. Video here:

https://youtu.be/_7Ipqy3hNbo.

It felt both exciting and somewhat sad to be concluding the week. We had created the space for young people that we had set out to, and even before we had packed up to leave, a number of the participants encircled us asking if and when we could do this again. We had had powerful conversations throughout the week and learned new things about ourselves and each other, and I couldn't help but feel connected and somewhat protective of the participants as they left, wondering if the issues they had identified could be improved. I was looking forward to completing the editing and getting together in a few months to "roll out the red carpet" for a public screening, to share their work and ideas.

Adding the Final Touches

In the months that followed, I worked to complete the final versions of the video artefacts by applying the participants' editing requests. In particular, I worked to translate their paper edits completely into the digital edits they had started. I used their descriptions of how they wanted the videos to look and feel and the detailed planning in their storyboards and paper edits as my guide. The participants had documented the timecodes from the video clips to facilitate an accurate translation from paper edit to video expression, and I used their written "blue sky" ideas in conjunction with field

notes of our conversations and the many hours of video and audio recordings to refine the digital edits and shape them into final versions that portray each group's collective vision.

In trying to deliver on their visions, I found myself needing to learn many new technical skills. Whether I was finetuning their scene transitions, making a dragon breathe fire (*Quest for Courage*), or creating a scene that looks like it is being drawn by pencil (*Sam's Story*), all of my editorial choices were driven by the participants' requests.

After applying their initial suggestions, it had been my intention to have a series of formal, in-person screenings and feedback sessions. Unfortunately, the global COVID-19 pandemic again got in the way, with more lockdowns and restrictions on public gatherings and movements. We were unable to meet face to face and so, instead, I worked more closely with the four participants who had been chosen by their groups to be their editors. I shared the video artefacts using private YouTube channel links and discussed their feedback with them in phone and video calls.

Their initial responses were very positive, and in virtually every instance, the editors were generally happy with the video stories they had produced. There were, however, many requests for subtle changes, in particular with scene transitions, camera panning, titles, and credits. The groups that had made written text for their "messages" to the viewers also sought clarification and editing of these messages, which they now felt were too long. Some of the editors had also changed their minds about the previous choices of music, so we tried several different songs and looked for royalty-free options where possible. Of course, changing music also meant changing the timing of edits, which was very time consuming, but arguably resulted in works that they felt better represented the vision they had for their stories.

Finally, there were some instances where dialogue in the videos suffered from loud wind noise, unclear speaking, and other unwanted distractions. This meant that in some scenes, the voices were not as clear as the editors wanted. Although we explored ways of improving this by applying audio filters and re-recording some audio overdubs, it could not be resolved in every case. While we generally focused on the process rather than the product (as prescribed by most participatory video practitioners), the challenge with audio aesthetics remained one of the editors' largest concerns,

because they felt it detracted from the viewing experience. It also represents an important learning experience for their future creations, as McHugh (2015) points out that audio is a key consideration in the pursuit of successful digital storytelling.

The Show Must Go On: Sharing the Participants' Videos

The nature of PAR is that cycles of analysis and creation are iterative and therefore repeated until the participants themselves are comfortable with the outcomes (MacDonald, 2012). After numerous iterations and refinements of the videos, the editors were now happy with the final versions. We set about making plans for a celebration and public screening should the pandemic allow us to stage one. Most importantly, we explored who they would invite to a “red carpet” screening. Their lists included friends and family, local and national government officials, healthcare professionals and, most especially, their teachers.

Unfortunately, Aotearoa New Zealand remained under pandemic restrictions throughout the year. In consultation with the participants, I decided that we needed to abandon our plans for an in-person final screening. We had postponed the actual workshop for almost a year and now had waited almost 10 months hoping that the restrictions on gatherings would be lifted. This left me at risk in terms of submitting my doctorate in a reasonable timeframe. In light of this, we decided that we would instead pick up where we left off once I had completed my qualification. When one of the participants (Thoma) said “*well, the show must go on! We'll do more after COVID, and once you are a doctor? [lol]*,” I realised just how understanding and compassionate these young people can be. We really had developed a partnership, and while I had their needs in mind, so too did they have mine.

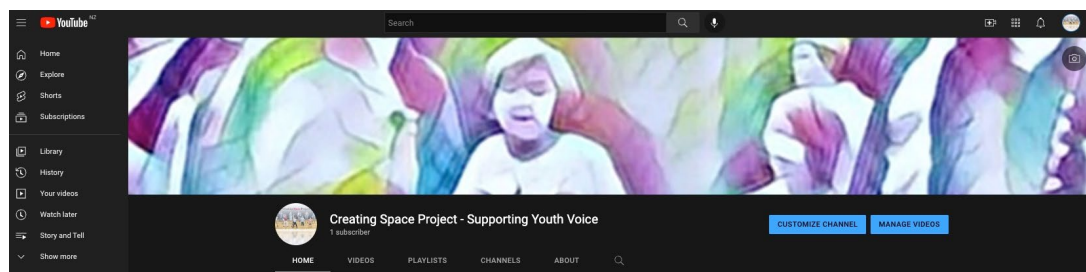
Rolling Out the Red Carpet, Virtually

Embracing their “show must go on” attitude, I have since developed a YouTube channel focused on youth voice called the [Creating Space Project – Supporting Youth Voice](#) (see Figure 56). This channel is intended to serve as a repository for the participants’ creative, narrative processes expressed through video artefacts (including their final video stories), using playlists to share the participants’ ideas and perspectives and the context in which they were fostered. The channel is not yet public, and so currently its content is only visible to the participants and me. Once I have

completed the Doctor of Health Science (DHSc) programme, I will make the channel fully public, and the participants will be moderators and collaborators in it.

Figure 56

Creating Space Project YouTube Channel



Note: YouTube channel dedicated to hosting the videos associated with the Creating Space project.

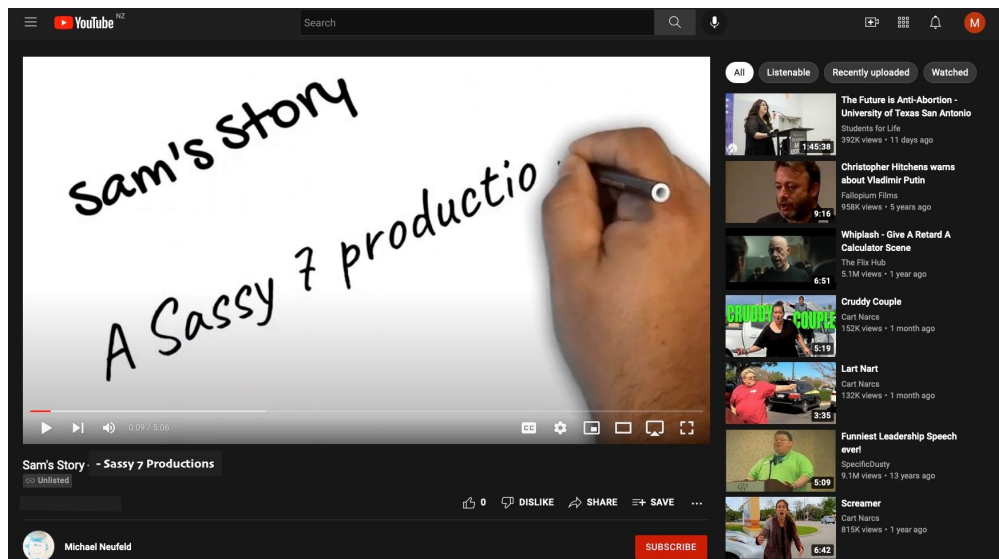
Access here: <https://www.youtube.com/channel/UCekEZOZnSadZXRLVQgk6Lbg> (note that the channel is not yet public and so does not yet display any content; I provide direct access links to the videos throughout this exegesis).

Ultimately, once public, the channel will be a conduit for young people and adults alike to access this project's findings. It has the potential to take on a life of its own and perpetuate the ability of everyone to access young people's research ideas and collaborations.

The sections that follow provide the links to view the video artefacts, effectively "rolling out the red carpet."

Sam's Story – Sassy 7 Productions

Sam's Story (see Figure 57) is about a young person experiencing depression. It is encapsulated in the context of the loss of his close friends as a result of malicious rumours and lies. Although he is trying to maintain his relationships on social media, we see him often sitting alone, uncertain as to why this is happening.

Figure 57*Sam's Story (Sassy 7 Productions)*

Note: View the final video artefact of *Sam's Story* here: <https://youtu.be/N8-uLttMbBk>.

Sam searches the internet and finds information online indicating that the way he feels fits with the signs and symptoms of depression. He seeks help from a mental health professional, who suggests that he “try talking to her.” He tries to reconnect with his friend but is outrightly dismissed and subsequently ostracised by even more of his friends. While struggling to contain his grief and anger, he returns to the health professional, where he is diagnosed as having depression.

The diagnosis is frightening for Sam, and he finds himself hiding from online abuse from his old friends. Another boy notices that Sam is alone and upset and tells Sam that he really likes his artwork and asks to be friends. Despite his frustration and anger, Sam stumbles onto this new friendship when he least expects it.

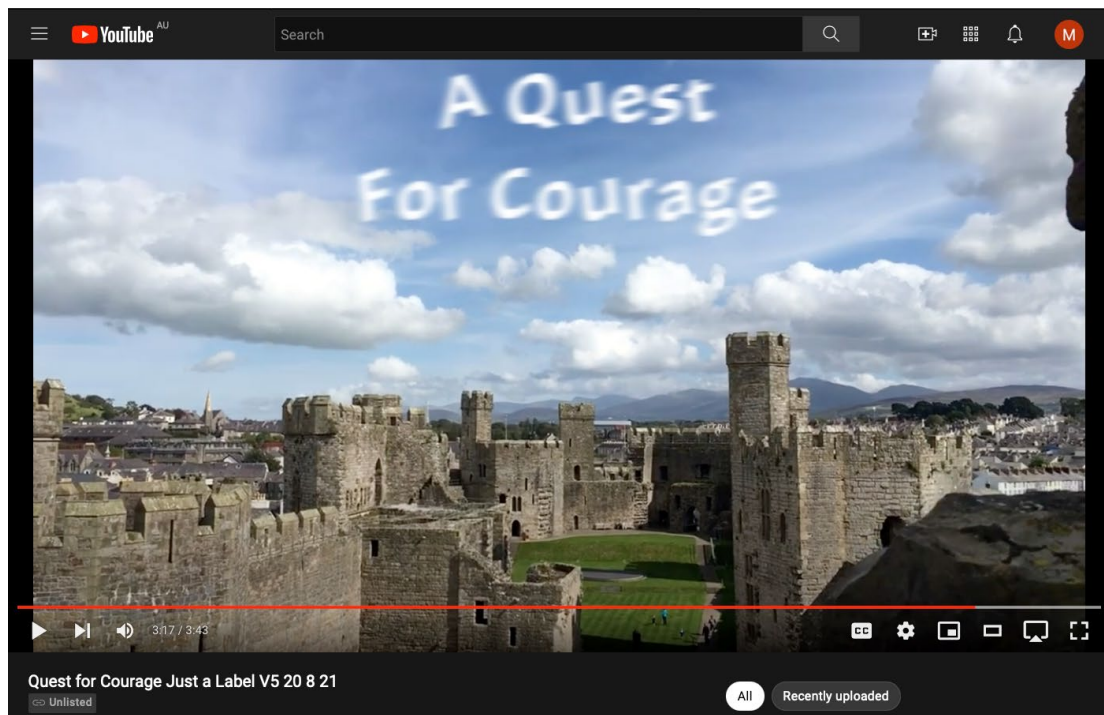
The message that the group wanted to get across is that friendships can be difficult, but despite this, when things seem terrible, there are kind people around who care and new friendships can be born. Sometimes it's as easy as saying “sure” when the opportunity comes. The story closes with a spoken message from the group that outlines the signs and symptoms of depression and the myriad factors that can cause it.

The group spent a lot of time sharing their thoughts on how common bullying is for young people. Everyone in the group reported having felt bullied at some point and how social media adds to the problem because it follows them everywhere. Conversely, they also suggest that social media can be a great place to find information and support. They held a fairly positive view of therapists and counsellors, identifying that the only real problem is finding one who has the space to see young people. *Sam's Story* is meant to show how sometimes there is nowhere to hide from allegations and misinterpretations, and sometimes the people you think are your friends end up being your worst enemies.

The group behind Sassy 7 Productions and *Sam's Story* thinks that mental health is one of the biggest areas young people need support in. They believe adults overlook this and attribute sadness and anger to a “phase” of adolescence. They specifically wanted others to know that when things are going terribly, it is best to ask for help and to remain open to new friendships, because things can and will get better.

Quest for Courage – Just a Label Productions

The inception of *Quest for Courage* (see Figure 58) came from an idea that one of the group members raised: that whether a health professional or young person, when fighting for health and well-being, individuals have to be brave and courageous, just like knights from a fairy tale.

Figure 58*Quest for Courage (Just a Label Productions)*

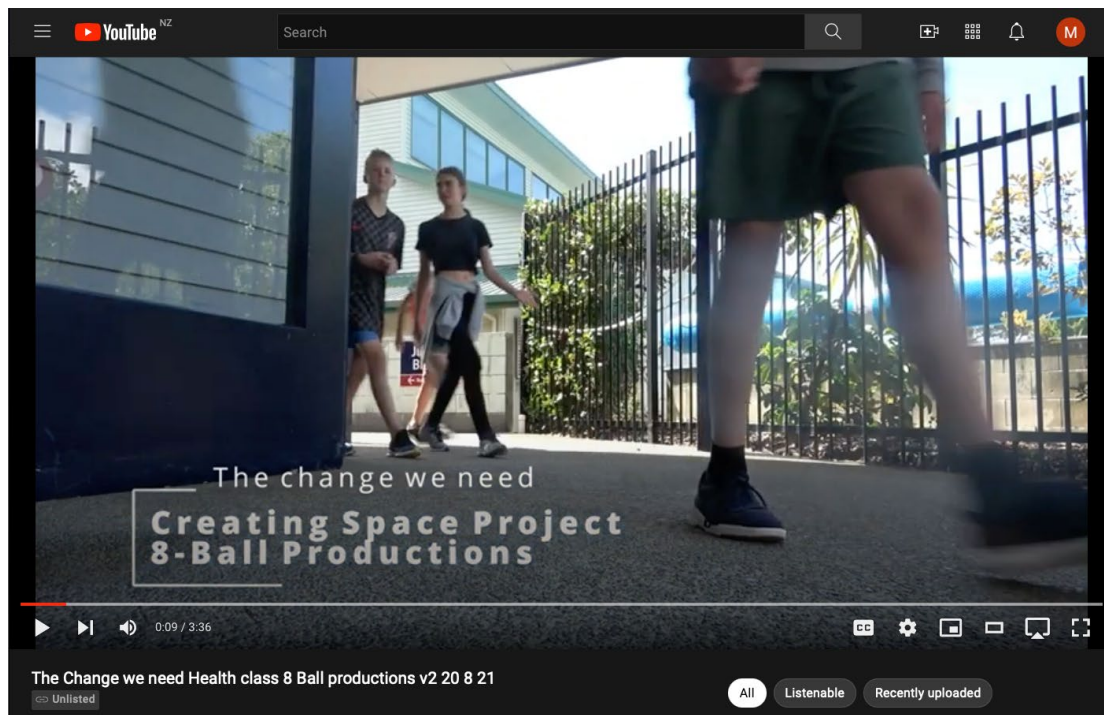
Note: View the final video artefact of *Quest for Courage* here: <https://youtu.be/wixW0SpjHdA>.

This story depicts a young prince setting off on a quest to find the crown of happiness, only to find his inner strength from facing and defeating some difficult foes. A bullying brother, a fire-breathing “sad” dragon, and the “ghost” of anxiety ultimately show him he is stronger and more capable than he ever imagined.

Their message is not a call for adults to “fix things” but rather a call for young people to believe in themselves and confront their ghosts of anxiety and sad dragons in order to find their health and happiness.

The Change We Need – 8-Ball Productions

8-Ball Productions produced *The Change We Need* (see Figure 59) based on their exploration of the challenges young people face in trying to understand the complexity of mental health, puberty, and sexuality. They call for change in the way health and sexual health learning occurs in school and more widely in the way conversations between young people and adults occur.

Figure 59*The Change We Need (8-Ball Productions)*

Note: View the final video artefact of *The Change We Need* here: <https://youtu.be/atg2qDDyuN8>.

The story depicts young people's disdain for the way health and sexual education is taught in schools and how frustrating it is for them that it has to be so "awkward." Interestingly, they present this from both their own perspective and also from the projected perspective of teachers, highlighting that the teachers also feel awkward and all too frequently focus on drugs and alcohol or the biology of sex (the "structure of the lips") as opposed to what young people feel to be far more important—their mental health and well-being in relation to health issues.

The story demonstrates the disconnection between students and teachers by sharing examples of incidents of poor mental health outcomes that they claim happened because "the teachers did nothing about it." They suggest that adults and young people are talking past each other. The video incorporates some distinct points of narration to speak directly to the audience and concludes with direct explanations of their concerns and a call for change. *The Change We Need* offers a clear and actionable idea that participants think can be achieved if there is a will for change. They are

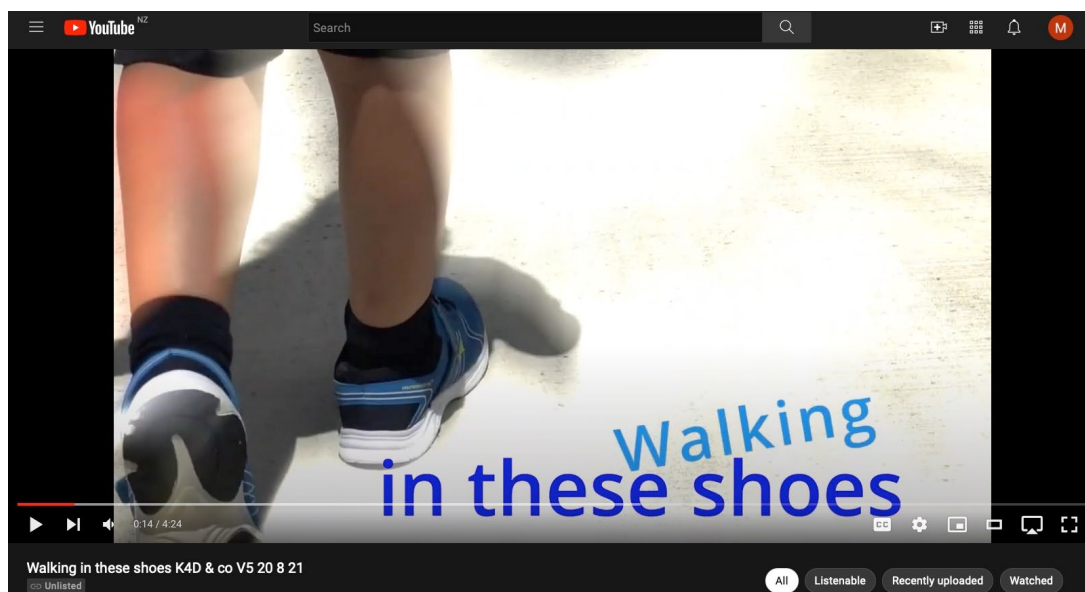
demanding that health and sexual education in schools be taught differently and cover mental health issues so that young people's lives can be better.

Walking in These Shoes – K4D & Company

K4D & Company produced *Walking in These Shoes* (see Figure 60), a story of two young people experiencing similar yet different challenges as they try to find their “way.”

Figure 60

Walking in These Shoes (K4D & Company)



Note: View the final video artefact of *Walking in These Shoes* here: <https://youtu.be/mAhhKTntCFE>.

The opening scene to the story shows a main character being pushed to the ground by bullies, as well as other difficult relationships in his life. It goes on to show another young person's experience of bullying and how those around them act. Considerations of sexuality, counselling, and a call for kindness all resonate from this group's work. After initially calling the story *Wayfinding* to reflect how kids are just trying to find their way, the group changed the title to *Walking in These Shoes* in a nod to one of the story's key messages: asking that everyone try to walk in other people's shoes. They offer a final text statement to the viewer, explaining that for many young people it is hard to “fit in” and advising others to seek help when it is needed, accept kindness when it is offered, and “share music” (i.e. kindness) often.

Chapter 5: Reflective Provocations

My research set out to answer the question, “How can participatory video and drama facilitate collaboration with young people to empower their voices in healthcare policy and provision?”

Answering the question was, and remains, a project of praxis. While it is difficult to offer a precise measure of the degree to which participants may have been empowered through the process or the extent of ongoing advocacy for other young people that could result from the project, the primary question has largely been answered. The participatory video and drama methods in this project have brought these young people’s experiences and ideas into the open, providing them with the opportunity to be heard and for their recommendations to be considered and actioned. This use of creative and narrative processes enables a unique and nuanced understanding of the issues that young people are most concerned about and instantiates participatory video and drama methods as a valuable tool in the pursuit of shared understandings with young people (Blazek, 2017).

Stories as Praxis: Leading the Way

The creative, narrative processes expressed through the final video artefacts expose the significant pressures that young people are experiencing and serve as provocations for further considerations and actions to support their mental health and well-being. Embedded within these fictional stories are the real experiences and stories of young people dedicated to finding their way—their way of being and of navigating relationships, time, knowledge, and numerous other internal and external conflicts. The relationships portrayed in these stories include fractured friendships, worried or confrontational parents, indifferent teachers, and newfound redemptive friendships. The stories lay out for the audience the many complexities of being young and how the confronting nature of fear, threats, and loss can lead to negative health outcomes.

These stories all tip their hat to the courage required to survive and transition through adolescence and into adulthood. After having the privilege of witnessing the high level of analysis and expression that the participants engaged in during the workshops and the creations of their videos, I am now certain that seeing young people as valuable contributors to the world they will inherit is

desirable—both for them and for wider society. I truly believe that people should consider all ideas, regardless of origin, lest they miss out on the potential benefits those ideas have to offer.

However, although I want young people to have their views considered, to have a say, I also do not wish to push them into early transitions away from childhood. Heidegger (1962) implies that childhood is a time akin to the “twilight” of a life and presents childhood as an immeasurable point that hovers somewhere between the magical thinking of naïve youth and the perceived cynicism of adulthood. That childhood is far too short is a common trope of adults and is not lost on me. It is essential that we enable young people to remain in and transition safely and appropriately from their childhood. Childhood is a continuum, and all young people will eventually be pulled from it because of experiences of shock and awe that awake awareness of the potential for malevolence and harm (Hatab, 2014; Heidegger, 1962). This is an important consideration because with the participants’ heartfelt and sincere messages to their audiences, they have opened a window not only into potential experiences of shock and awe, but also its antithesis—their expressions of compassion, love, understanding, and hopes they have for all young people to thrive and live positive lives.

Most notably, each story features issues that relate to the maintenance of young people’s mental health. Of all the explorations into young people’s health that they could have undertaken, the participants have almost universally focused on this topic, which affects every aspect of their well-being and capacity to contribute meaningfully to society. This is significant because each group has, in its own way, articulated the struggles and perceived reasons why so many young people in Aotearoa New Zealand are experiencing poor mental health outcomes. Each group pinpoints that young people are aware of the difficulties of meeting adult and societal expectations: expectations to do well, to fit in, and to not be “awkward.” These findings are particularly important as they align with the global trend of worsening youth mental health highlighted by the United Nations Children’s Fund (2021).

Not With Anger but With Hope

The groups have created stories that are not full of hopelessness or uncontrolled anger at the issues they raise but rather genuine hopefulness. They specifically highlight to viewers that there are

potential solutions and places to turn to for help. They focus on encouraging other young people to muster the strength and courage to pursue friendships and be kind to others. All the stories are asking the viewers to consider the problems and contribute energy towards solving them—portraying an optimism that things can be better and that despite there being bullies in the world, people are generally good.

With concerns of bullying (and associated anxiety) being raised in three of the four stories, physical and social aggression is a significant and ongoing concern for participants. They point to social media as a contributing factor in bullying but assert that it can also be a mitigating factor, by helping people maintain connections with friends and providing a portal for accessing health information. The dichotomy of social media may be difficult to balance, but the participants' perspectives on both its usefulness and its negative impacts on mental health align with what current research shows. Sadagheyani and Tatari (2020) identify that social media is a double-edged sword that is contributing significantly to negative mental health outcomes. Similarly, the Aotearoa New Zealand Children's Commissioner (2017a) points out that the increasing use of social media has direct correlations to the increasing rates of anxiety, loneliness, depression, and suicidality in the young. With social media virtually endemic in young people's lives in Aotearoa New Zealand, there are distinct tensions at play. On one hand, the Aotearoa New Zealand education system is promoting digital communication and social media as a solution to the isolation of COVID-19 lockdowns, while on the other hand it identifies the need to restrict the ability of social media to perpetuate anti-social and bullying behaviours (Sutcliffe & Webber, 2021).

Providing a critical perspective on youth health issues, the stories expose in-person and online bullying as endemic and highlight young people's perception of educators' failure to provide necessary information to maintain young people's health. However, the stories also fit into a broader "hero" narrative in which they show young people as overcoming adversity in order to grow, survive, and even thrive. The hero story is the most common archetypal story told and is generally used to establish blueprints of our values and how to live (Campbell, 1993). The stories that the participants

created paint a picture of the strength and courage they think is required to “survive” and pursue a good life.

The School Landscape and Confronting Dragons

The video artefacts present school as a landscape within which there are many clashes with antagonists. The protagonists, in many cases assuming a “hero” role, must confront and overcome the challenges represented in these schoolground clashes in order to move forward. For example, in *The Change We Need*, the characters must contend with awkward and apathetic teachers and systems. In *Walking in These Shoes*, the storyline focuses on facing and overcoming the forces of bullying at school, questions about sexuality, and parental prejudice and bigotry. In *Sam’s Story*, a school counsellor presents the protagonist Sam with a call to adventure—a prerequisite for any hero story (Saadia, 2021); in this story, a toxic person tells lies that isolate Sam, who is advised by the counsellor to “maybe try talking to her” (which he does, despite the growing momentum of friends turning against him and his increasing isolation).

In *Quest for Courage*, perhaps the most literal hero story, dragons and ghosts metaphorically represent sadness and anxiety that the main character must confront to find the courage to overcome the bullying that he faces at the hands of his brother and his brother’s friends at school. This group’s choice to incorporate a dragon to represent sadness was interesting but perhaps not altogether unusual given the role that dragons play in both Eastern and Western mythology. As far back as ancient Greece and Sumeria, cultures have referred to flying serpentine creatures representative of dragons as creatures to be vanquished (Radford & McKelvie, 2022). More recent depictions of dragons exist in many popular children’s movies such as in the *Harry Potter* and *How to Train Your Dragon* series, which portray them as ferocious yet controllable creatures if the characters are brave enough to try. When I asked the group why they chose a dragon, Michael (13)—who plays the role of the king sending the prince on the quest for the crown of happiness—explained:

Michael: *I don’t know...probably because dragons are huge? Like a dinosaur that flies, and you know, being burned to death is totally freaky, so...like [I] mean...sometimes [I] have dreams about being chased by monsters or the house burning or something...so that makes it double scary. They also have gold and treasure hidden in their lairs, so that’s why you have to kill them, right? You know...get the treasure and live. They’re in lots of fairy tales and that. I mean...you could try to make friends with them if they talk like in some movies, but they*

won't just let you have their gold...you can't just sneak in and take it because...they'll fry you. Like...they have super senses and smell you and come after you. They won't quit or give up, right? Like the crocodile in Peter Pan...so the prince needs to be brave. He needs to win so that he is a hero and has a better life.

Facilitator: *Do you mean he needs to be brave against his bullying brother and also his own emotions?*

Michael: *Yeah, I guess...it's like bullies, right? You aren't supposed to run away, so him beating a sad dragon is like that...it's what he's supposed to do...face it, fight it, or whatever...to figure it out or whatever...get the gold or whatever. That's why we wanted the dragon thing...and the ghost.*

The story thus presents the metaphorical dragon as something that must be overcome for young people to find self-worth and prove they are courageous enough to confront a bully, take their rightful place in society (or a hierarchy), and ultimately find happiness.

Each story holds bravery as fundamental for young people to find happiness, framing courage in the very acts of going to a counsellor, accepting new friendships, or speaking truths about their sexuality or thoughts on education. The characters they have created find themselves confronted with seemingly insurmountable challenges arising from disparities of power. The presentation of their struggles against powerful forces aligns acutely with a broader notion that young people's perspectives are frequently dismissed or not given primacy. Perhaps, in this way, society in general is the bully or (adding this interpretation to Michael's explanation) a "dragon" holding "gold," which represents individual identity and self-worth.

In some respects, I believe these stories exemplify an inherent drive in young people to work towards becoming what they are capable of being. Thorne and Sanders (2012) point to Rogers' (1952) assertion that self-actualisation (i.e. the drive for an individual to reach their potential) is an evolutionary force that is played out in young people's struggles to determine who they will be and how they should act. Rogers further suggests that to self-actualise, the image of the ideal self needs to be congruent with behaviour. If it is not, then the person's hierarchies of value become distorted and corrupt, and the stability of a personality cannot be assured. In keeping with this, these stories present the idea that standing up to oppressive forces in school (and wider geographies), however difficult, is necessary to pursue healthy lives.

These stories serve as an indictment of both the educational landscape and the fragility of human relations. After all, as George (14) points out, “*why should bullying exist? There are so many stories that end bad for bullies. It’s insane that some people find it rewarding or that they are allowed to.*” In his analysis, George is criticising not only the bullies but also the very system that allows such behaviour to continue.

Frustration With Complacency of Power

The insights provided in *The Change We Need* include a sense that there is general frustration and disdain amongst young people for how schools provide health education. This is perhaps indicative of the overarching complacency that they perceive from adults in many of their interactions. For example, in one scene, a teacher says “the kids make it so awkward,” implying that young people are not relating well with some teachers and as a result are missing out on vital information and, worse, vital support. Even more critical is the commentary on the prevalence of mental illness in young people and, in particular, the relaying of a sad story in which a young girl dies from anorexia because “the school and teachers did nothing about it.”

Overall, the participants express that they do not believe enough is being done to protect them from bullying, prejudice, and the “invisibleness” or “awkwardness” in the relationships they have with key adult figures who hold some responsibility for their understanding and maintenance of health. The participants are telling us that they want a health education that fits their needs and, further, a health education system that attends to the prevalence of bullying and the harm associated with it. They have woven their experiences of bullying and fear into their stories, purposefully locating the scenes in isolated places, such as school yards and a forest—places devoid of adults and representative of the isolation they see as common. The change that they are looking for is for young people to be seen and recognised as more than “just a kid,” as individuals needing support, consideration, and (from educators and family) guidance.

Extending across all these video artefacts is the intimation that young people are in almost constant conflict and feel powerless, invisible, and relatively alone in their struggles. However, in *Walking in These Shoes* and *Sam’s Story*, they also point to the positive outcomes that can come from

engaging with counsellors, specifically attempting to normalise counselling by depicting new and positive friendships developing following counselling sessions. This indicates the value that the participants see in such services. In *Walking in These Shoes*, they go so far as to state explicitly in their written messages to the audience that they are “trying to find [their] way,” are “asking for help,” and that “to stay healthy, [they] just need to be accepted for who [they] are.”

Interestingly, the group that created *Sam’s Story* reported that the counsellor they portray is somewhat unique for an adult, in that she truly listens to the young person’s problems and asks their opinion rather than just telling Sam what to do. The counsellor is literally introduced to the audience when she asks Sam, “so what do you think has been happening?” The group told me that this was an intentional choice meant to show that when a young person needs help, they are also capable of contributing to the solution because they actually know what they are experiencing and may just need help to talk through their thoughts to make a plan of action. This fits in very well with the overarching premise of this research project.

The analyses done through the groups’ problem trees clearly identify that they see easy access to mental health support and services such as counselling and therapy as instrumental in maintaining young people’s health. In our discussions about the final video artefacts, the groups further suggested that access to counselling should be easy and free of charge, something that several in the group who personally use counselling services say is not currently the case and causes distinct tensions in their families due to cost and wait times.

More Than Pointing Fingers: Finding Strength Within

I initially anticipated that the videos created by the participants would lay blame or responsibility for young people’s health challenges solely at the feet of adults and institutional or societal entities. However, on the contrary, the groups delivered far more nuanced understandings of the factors impacting their well-being. Most notably, what they explained in the group discussions and reflections and what comes through in the videos is that their stories are as much a call for other young people to reflect on and consider their situations as they are for adults or organisations to do the same.

The participants' suggestions are directed at both adults and other young people, which I had not expected: it would have been far easier to suggest that adults should do something about the problems that young people face. They ask adults to be aware of the bullying that young people experience and to ensure that professional mental health support is accessible for them but, just as importantly, they also ask young people to consider sharing their kindness because it is often young people bullying other young people.

They do not want to be invisible, nor measured by external immutable characteristics or preconceived ideas about who or what they should be. They are asking adults to listen to young people's concerns and acknowledge the prolific bullying and isolation that many young people are experiencing, but equally, they are asking all young people to reflect on their own position on bullying and inclusion and consider whether they are contributing to the problem or helping to reduce it.

The inner strengths depicted in the characters could be considered akin to those of the Veela discussed in the "[Incorporating Their Shadow](#)" section earlier (page 104) in the initial portraiture exercises. The groups discussed their perspectives on this and claimed that they wanted to show the viewers that young people can have the inner strength to stand up for themselves or at least that they have the desire to obtain such strength. They also wanted to let young people know that things can get better as long as you don't give up.

On the last day, Sasha (15) complained that the paper editing was hard, and she was tired. I teasingly reminded her of the comment she made on day 1 when she stated a willingness to engage in difficult things in her future career (see the "[Is This All About Self-Realisation?](#)" section [page 107]): *"I know it will be hard, but whatever...it doesn't really matter does it? The heart wants what the heart wants."* My teasing may not have been entirely welcomed, but she stared dubiously at me for a moment and then reflected *"hmm...okay, well actually, you know, that may be what I want, but mostly right now I just want to be strong enough to get this movie done and show that bullying sucks. I don't know if we can do it."*

Sasha's desire to attain the necessary strength to be capable is exemplified in many of the characters across the videos artefacts. As a result of physical and emotional challenges, the protagonists acquire strengths and capacity that are not initially evident but that unfold as those characters manage to harness them for good. The characters become representations of ideals to be contended with. Having characters call out their teachers and health curriculum (*The Change We Need*), Sam pursuing help from a counsellor and accepting a new friendship (*Sam's Story*), the prince fighting sad dragons and ghosts of anxiety (*Quest for Courage*), and generally asking for people to accept kindness and share their own "music" (*Walking in These Shoes*) are all choices that highlight the participants' awareness of the need to find the strength to confront and overcome oppressive forces. More specifically, the calls to action require us as the audience to reflect on our own vulnerabilities and positions of power and consider how they contribute to or help mitigate the issues being raised.

The videos purposefully and meaningfully show the pursuit of individual "quests" for well-being and happiness in a battle against being punished for "not fitting in," whether as a result of sex, age, or any other arbitrary or imagined difference. In their call for increased awareness, the videos ask that adults, teachers, and health professionals provide guidance on how to overcome bullying and any associated anxiety. They also ask adults to address the ineffectiveness of their health education and the apathy that some teachers seem to hold towards young people's well-being.

As for their fellow young people, the participants ask that they too walk in each other's shoes and share kindness instead of critique. The written messages in *Walking in These Shoes* are specific to this. In *Sam's Story*, they expose the ills of social media and intimate that despite hardships, young people can find solace in new opportunities for friendships, provided they accept them when they present themselves. The videos offer blueprints for how to live that are literal and metaphorical, pragmatic, and morally emphatic. They are in and of themselves distinct and actionable provocations: essentially, to be courageous and face the metaphorical dragons and ghosts that inhabit everyone's lives.

This commentary is of particular interest because, despite their freedom to suggest anything, the groups universally chose pragmatic and generally attainable solutions, informed by their own experiences. Despite some early discussions amongst the participants that hinted at utopian and grandiose ideas, their suggestions (in my opinion) help to dispel any myths that children and young people will present radical or unattainable solutions if given the chance to propose or initiate change. On the contrary, these 29 young people created video artefacts that share their experiences and provide insights into potential solutions that are realistic and fit for purpose—solutions that could easily be considered and adopted or promoted by anyone within the spheres of influence in health and education.

Significance of This Research

This project has pulled together forms of praxis that are not traditionally associated with health research—those of creative, narrative processes expressed in participatory video artefacts. Although there are some international examples of participatory video or drama being used with children and young people, they are relatively few and far between when compared with the expanse of adult-centric projects, in particular those that aim to improve adult experiences and health outcomes. The key significance of this project is that it is, by all accounts, the first health-specific participatory video and drama project with young people in Aotearoa New Zealand. It therefore stands as a future template to gather young people's perspectives and ideas, whether here in Aotearoa New Zealand or in other international contexts.

While the paucity of youth voice and participation in Aotearoa New Zealand healthcare (and arguably wider society) is under some scrutiny, it still remains relatively unattended. In the face of increasing youth health needs, particularly those related to youth mental health, the widening gaps between adult- and child-centric approaches to the design and delivery of healthcare are failing to serve young people well (UNICEF Office of Research, 2022; United Nations Children's Fund, 2021). I find it haunting that the young people in this project have, in 2021, echoed UNICEF's findings that Aotearoa New Zealand young people have relatively poor mental health outcomes with the highest

rates of self-harm and youth suicide of the 41 high-income countries surveyed (UNICEF Office of Research, 2016, 2017).

There are increasing calls internationally to include young people's voices in research, policy development, and the evaluation of policy outcomes (Martinez, Richards-Schuster, Teixeira, & Augsberger, 2018). The participatory video methods used in this project demonstrate ways in which adults can apply their agency as allies—getting alongside young people and keeping the focus on them in order to diminish power differentials. Participatory video also brings into focus the powerful capacity of metaphors and storytelling to keep young people's needs at the forefront of decision making. This project therefore provides a tenable example of how participatory video can help young people enhance their ideas and amplify their voice using creative, narrative, symbolic, and embodied methodologies to produce powerful research and understandings. This approach opens doors for greater inclusion of youth voices and thus serves as a unique contribution to child and youth voice in and about Aotearoa New Zealand healthcare.

On Pursuing a “Good Life”

The topics of bullying, poor mental health, and a need for better sex and health education in schools identified by the participants generally align with the findings in the Aotearoa New Zealand Children's Commissioner's *What Makes a Good Life?* (2019) report. The report identifies an ongoing need for children and young people in Aotearoa New Zealand to be kept safe, to have increased mental health support, and to have improved educational outcomes. UNICEF has criticised successive Aotearoa New Zealand governments for not fully monitoring or attending to children's needs since the social and economic reforms of the 1980s negatively and disproportionately impacted on the young (Blaklock et al., 2002). Despite the relative prosperity of Aotearoa New Zealand, child health outcomes continue to remain near the bottom of the international comparative tables, specifically relating to issues of equality and youth suicide (UNICEF Office of Research, 2013, 2014, 2016, 2017).

Given the congruence of the themes that arose in this project with the Aotearoa New Zealand Children's Commissioner's survey findings, the insights provided through this project's creative

artefacts may prove to offer valid and valuable potential solutions to the health challenges facing Aotearoa New Zealand's young people. In some cases, these solutions may be direct requests for change, such as the call for changes to sex and health education in schools in 8-Ball Production's *The Change We Need*. In other cases, the solutions may be more reflective and introspective, such as in the messages shared by Just a Label Productions; in that group's *Quest for Courage*, the solutions include accepting that there will always be interpersonal hardships such as bullies, sadness, and anxiety and that the sources for these tensions are both extrinsically and intrinsically located. This requires both individual behavioural changes and supportive policy advancements that promote young people to "follow the path" to overcome adversity.

Overall, the video stories are a tangible representation of the potential for policymakers, educators, and healthcare providers to empower young people to share their insights into what they need to achieve a "good life." Participatory video and drama methods provide a practical model for youth collaboration and empowerment and are valuable tools for fostering young people's participation and pursuit of a good life.

New Tools for Change

This project aims to amplify the participants' voices and, importantly, to do so in perpetuity. With the video artefacts now hosted on a youth-centric [Creating Space Project YouTube channel](#), once the channel has been made public, anyone capable of watching a short video will be able to view the participants' stories. For today's generation of digital natives who are fluent in video-based online platforms—from YouTube to Instagram to TikTok to Snapchat—this outcome exemplifies research with young people for young people. Video and digital storytelling methods are valid tools for sharing ideas between young people. Furthermore, because video makes information far more accessible than traditional academic methods for disseminating findings—such as through journals or thesis repositories, which are often inaccessible to young people (Egli et al., 2019)—it also facilitates sharing ideas between young people and policymakers, health professionals, and educators. The video artefacts presented in the YouTube channel thus hold the potential to encourage mutual and reciprocal

exchanges both between young people and between young people and the adults who develop policies that can address the issues they raise.

The project has focused as much on building the capacity of the participants to reflect on and share their experiences as it has on determining any specific absolute findings to be acted upon, epitomising the importance of pursuing process over product that participatory video and ethnographic filmmakers identify as an epistemological necessity (Asadullah & Muniz, 2015; Benest, 2010; Benjamin-Thomas et al., 2019; Gruber, 2016; Harris, 2008; Lunch & Lunch, 2006). The reflexivity and reciprocity that the process delivers is a means of constructing a bridge between young people and adult world views. This is vital if we are to develop new and meaningful ways of embracing youth participation and facilitating their input into policy and other decision-making processes (Stoecklin, 2012).

The skills that the participants gained also create the potential for them to share more of their views, enabling them to climb higher up the rungs of Hart's ladder of participation (see Figure 24 [page 127]). They are now capable of initiating and disseminating their own projects rather than relying on those initiated by adults such as this one. As described in the "[A Surprise Worthy of Note](#)" section (page 166), one success of this project was receiving a feedback and thank you video from the participants, which exemplifies their adoption of the methods. The sincere yet playful thank you messages (they suggested I find a way to control the weather!) were created without solicitation and I believe provide some evidence that working creatively with young people to build their capacities (for reflection, analysis, expression, and communication) can deliver future unconstrained opportunities for them to act of their own volition to instigate change, thereby fostering agency well beyond the immediate research space and time. In this way, the project has, at least to some degree, met the aspects of the Freirean goal of liberation that underpinned its planning (Freire, 1982; Richardson-Ngwenya, 2012).

An Online "Playground": Voices Amongst the Chatter

Digital storytelling is a powerful and useful tool for learning, particularly for the YouTube generation (Dreon, Kerper, & Landis, 2011). According to the Organisation for Economic Co-

operation and Development (OECD) Programme for International Student Assessment (PISA), Aotearoa New Zealand young people spend more time on the internet than young people in any other country in the world with the exception of only Denmark, Sweden, and Chile (Sutcliffe & Webber, 2021). Ninety-seven per cent of 15-year-olds in Aotearoa New Zealand have open unfettered access to a mobile phone and the internet, meaning that digital platforms are endemic to the young people of Aotearoa New Zealand and, with the expansion of online learning, literally ingrained and promoted within the education system itself.

During the time of this research, the volume of online learning has accelerated rapidly under the COVID-19 response, which has left young people isolated and locked out of face-to-face schooling for months at a time (Menzies et al., 2020; United Nations, 2020). With digital platforms now serving as both obligatory learning spaces and exploratory social playgrounds, it should be noted that these are not playgrounds solely populated by the young, nor are they monitored. The flow of information and the access that young people have to information and misinformation are unlike anything that previous generations have had to navigate. Most social media spaces do little more than ask for a self-declaration of age to participate, which means that despite the potential benefits of online social and knowledge spaces, we should not expect only positive outcomes for young people (Sadagheyani & Tatari, 2020).

On the contrary, to bring positive outcomes, we must continually assess and attend to the landscapes that young people inhabit, recognising that we cannot know them without asking about and listening to young people's perspectives. Young people's online and offline worlds are fast-changing geographies that, based on the video artefacts from this project, they need and want support to navigate. While the use of creative methods to explore the participants' portraits and landscapes has been successful in this project, to improve all young people's health outcomes is entirely relational and reliant upon creating many more spaces that can facilitate ongoing dialogue and reciprocal listening and learning.

New Ways of Learning and Collaborating

As just mentioned, we have seen a rapid shift to online learning and communication from responses to the COVID-19 pandemic (Maxon et al., 2021). This has effectively increased the gap between those who have access to information and social connection and those who do not (United Nations, 2020; Webb et al., 2020). Considering the comments made by the participants about feeling invisible in school, I can't help but worry that the more that learning moves online, the more potential there is for many young people to become invisible. As a lecturer myself, I have found it very isolating to deliver content online and much more difficult to create learning moments for students than when we are physically together in a room. An online space, where people are often hidden behind filters and avatars, makes it difficult to determine who is participating and, in my opinion, dulls the world to two dimensions and removes the cues we rely on to actually “see” each other.

This matters because young Aotearoa New Zealanders have almost unequalled access to digital devices and internet platforms such as YouTube, Instagram, Facebook, Messenger, and so many others that hold both potential risk and potential benefit to their well-being. As UNICEF's Tseng and Wang (2021) point out (and as is evident in *Sam's Story*), it is becoming “increasingly hard [for young people] to disentangle offline experiences from those online” (p. 108). The almost ubiquitous access to the online world, to some extent, is removing the necessity of gathering in real spaces to share ideas or to work together to enhance them. The participants have noted in their stories that they see the risks of social media in terms of isolation and poor mental health outcomes and they want us all to understand that they need support and, in some cases, specific change to ensure their well-being.

Importance of Reciprocal Relationships With Young People

The answer to better youth health outcomes lies, I believe, within the philosophical positioning of this project itself. It is one of unconditional regard for young people's perspectives and potential. It starts from a strengths-based approach to collaboration rather than one of a predetermined or illusory deficit. The participants identified that they often determine their level of interaction with adults based on the adults' attitude. Jenna (14) claimed that when they are treated as “just a kid” (see

the “[Helping Other ‘Invisibles’?](#)” section [page 100]), young people stop asking questions. I believe we need to listen intently if we want them to participate, and this relies upon developing trusting and reciprocal relationships with clear and open communication.

This project, by and from its very design, has relied on intensive collaboration with young people. From the very first discussions through to the completion of the participants’ videos, this project spanned three years and included 20 children and young people aged 5 to 16 years as youth advisors who guided the initial formation and refinement of the project methods; 28 young people aged 8 to 16 years who allowed me to be part of their theatre troupes as an observer; and 29 young people aged 11 to 17 years as participants. We are now undertaking the iterative process of facilitating and promoting the sharing of the videos in order to make the participants’ perspectives more visible. I do not yet know to what extent we will be able to share their perspectives but, as the Lunch brothers point out, participatory video is relational work that often doesn’t have a clear end point and is reliant on acting together but from different positions (Lunch & Lunch, 2006).

Although the COVID-19 pandemic had a negative impact on the timing of the workshops and final screening of the participants’ videos, it also highlighted the significant power of participatory video for the genesis of discussion and dissemination of young people’s ideas in both real world and virtual spaces. The usefulness of digital communications to privately consider content and foster co-creation can’t be overlooked and, once again, supports the idea that we can adopt methods that incorporate capacity building and relational constructs at the inception point of projects with young people. As Lunch and Lunch (2006) and Asadullah and Muniz (2015) explain, successful participatory video projects rely on fostering strong relationships with the communities we are working with. This is not only to determine what they need but also to enable future follow-up to see if the desired outcomes have been achieved and what new perspectives have formed (Benjamin-Thomas et al., 2019; Lunch & Lunch, 2006; Milne et al., 2012; Richardson-Ngwenya, 2012; Shaw & Robertson, 1997; White, 2003).

This is an ongoing point of tension in this work as there remains much to be done with the video artefacts that the participants created. The [Creating Space Project – Supporting Youth Voice](#)

YouTube channel will become publicly available upon my completion of the Doctor of Health Science (DHSc) programme, and any impacts on future policy development or praxis will need to be tested after that point.

Chapter 6: Future Possibilities: Where to From Here?

This section provides my recommendations for further research and action, outlines the limitations to this study, and presents my closing thoughts.

Recommendations

This project has identified that young people perceive mental health issues to be the key barrier to their living healthy lives. The participants have suggested a need for adults and young people alike to address the prevalence of bullying online and in schools and have asked for changes in how sexual health and health education is taught in schools. They have also requested improved access to mental health support by way of affordable and easily accessible counselling services.

The following recommendations are separated into the four categories most relevant to the project findings: policy, education, health systems, and research.

Policy

Based on the findings of the project, I recommend that the Aotearoa New Zealand government (1) works to embed United Nations Convention on the Rights of the Child (UNCRC) rights into law and (2) lobbies for improvements in tracking child health outcomes by seeking standardisation of UNICEF reporting.

Embed UNCRC Rights Into Law. The UNCRC Monitoring Group (UNCRCMG) has identified that child and youth health outcomes in Aotearoa New Zealand are subpar, with the Health and Disability Commissioner stating that they require “urgent attention” (2017, p. 6). It is unclear what defines an urgent response, and I find it remarkable that despite such longstanding warnings, something so “urgent” has spanned generations of young people. Without concrete change, there is little reason to believe that health outcomes will improve for the next generation of Aotearoa New Zealand’s young people.

As discussed in the “[Legislative Influence and Constitutional Confluence](#)” section (page 53), Aotearoa New Zealand has no written constitution, and the UNCRC rights are not embedded into domestic law. This creates a need to establish accountability for the maintenance of children and young people’s rights to participation in our country, including in the policies and decisions that have

a direct impact on their health. Young people and their advocates currently have no legal recourse to address long-running failures to ensure that health policies are non-discriminatory, represent the best interests of the child, foster children's survival and development, and establish opportunities for children's participation. Not only does this lack of accountability and legal mandate continue to silence the experiences of the young and slow any progress towards honouring the commitments made by the nation through the signing of the UNCRC, it effectively ensures a perpetuation of less positive outcomes for individuals (including children) and society as a whole.

I believe that Aotearoa New Zealand could make significant progress in improving child health outcomes if laws required policies to consider their impact on children and young people before their adoption and implementation. Such legal mandates would make governments and institutions legally accountable for policies that result in breaches of young people's rights. Take, for example, the repeated failure of the Aotearoa New Zealand government to produce disaggregated child health data to UNICEF, which impacts on its very ability to accurately measure our country's successes and failures in relation to the UNCRC. If Aotearoa New Zealand were to take the path that Scotland has and embed children's rights directly into domestic law, I believe this could light a path towards mitigating inequities in health.

Seek Standardisation of UNICEF Reporting. The UNICEF Innocenti Report Cards and associated league tables are arguably the best tools available for gauging the status of children and young people's health and well-being at the country level against the expectations of the UNCRC. Unfortunately, each report has a specific focus intended to contextualise the global state of child well-being. Whether the focus is on the impact of the global economic crisis on children (UNICEF Office of Research, 2014), on child health outcomes in the context of the United Nations (UN) Sustainable Development Goals (UNICEF Office of Research, 2017), or on the risks of unhealthy environments for children's well-being (UNICEF Office of Research, 2022), the changing lens used in UNICEF's approach to reporting data, by prioritising new domains, means that they do not publish comparable measures from report to report. This obfuscates a nation's overall progress (or lack thereof) when it

comes to child health and well-being. The paucity of comparative assessments across time makes establishing accountability at a national level difficult and stepwise refinement almost impossible.

Given this, I recommend lobbying UNICEF's Office of Research – Innocenti to seek changes to the Innocenti Report Cards—specifically, to request a standardised reporting protocol for the domains being explored. A move to standardised and repeatable measures would allow Aotearoa New Zealand (and other nations) to hold their leaders and institutions to account should they continue to fail to make progress on areas previously identified as subpar in terms of health outcomes for our children and young people.

Education

I believe that before we can realise improvements in child health outcomes, we must work to bring both young people's rights and young people's perspectives on healthcare to the foreground, and education around this will be key. My recommendations include (1) raising health professionals and educators' awareness of young people's rights under the UNCRC; (2) creating new modalities for sharing children's perspectives on health issues with policymakers, health professionals, and teachers; and (3) fostering ongoing collaboration with young people.

Raise Health Professionals and Educators' Awareness of Young People's Rights Under the UNCRC. The fundamental right of young people to be heard and considered in relation to things that affect them has not yet been instantiated into Aotearoa New Zealand's healthcare or educational practice. There is a need to educate health professionals, teachers, and the wider public about the specific rights of young people under the UNCRC. This would facilitate faster integration of these rights into practice and potentially support a move to instantiate these rights into law. In relation to healthcare and education, both fields have regulatory bodies responsible for overseeing curricula delivery. For example, the Nursing Council of New Zealand has a separate state exam that nurses must pass to attain professional registration. Regulatory bodies such as this could be used to ensure that health and education practitioners have appropriate knowledge of young people's rights before they gain their registration. I recommend that the regulatory bodies responsible for medicine, nursing, and education review their curricula to ensure that they incorporate the UNCRC principles and,

further, that they require individuals seeking registration in these fields to demonstrate understanding and competence in applying the principles in practice to qualify for registration.

Create Spaces to Share Children's Perspectives on Health Issues With Policymakers, Health Professionals, and Teachers. To realise the intent of the UNCRC (1989), policymakers, health professionals, teachers, and others involved in decision making about children's health need input from children directly on the health issues most salient to them. Based on the findings of this project, these include mental health issues overall, with a specific focus on bullying, anxiety, and misdirected sexual health and health education. The [Creating Space Project YouTube channel](#) is an example of a platform that can serve to provide ready access to the views of children and young people on health issues. It can also provide a template for other such platforms and, importantly, provide an educational mechanism for policymakers, health professionals, and teachers. While a substantial amount of statistical data is available that highlights the relatively poor mental health experienced by many young people in Aotearoa New Zealand (Menzies et al., 2020), the same is not true for direct accounts from young people on their experiences of mental health. The ability for those involved in the care of young people and those developing policies that may affect young people to learn about their perspectives directly is important. The type of video-based platform created through this study has the potential to serve as an educational forum that amplifies young people's voices while minimising how much adults act as interpretive intermediaries and may help shift a prevalent attitude that dismisses young people's capacity to participate in decision making related to their healthcare.

Foster Ongoing Collaboration With Young People. To establish positive outcomes in the long term, I do not believe it is enough to simply share young people's views from a singular or static moment in time. For real impact, there needs to be lasting, reciprocal relationships between young people and the entities responsible for policies that affect them. More specifically, the Aotearoa New Zealand Ministry of Health and Ministry of Education should adopt collaborative practice in a triad with young people. Only then can young people provide real-time (or a close approximation of real-time) insights into their experiences and perspectives for policymakers to consider and use to inform

potential change. This project has shown how relationships can be built with organisations that serve young people and then sustained beyond singular points of contact. Iterative work can take place even as the original participants transition away from childhood and new young people enter the process as participants.

Above all else, governmental institutions and organisations should consider the “essence” of youth participation to ensure that the needs of young people are understood within their mandates and thereby assure that they meet the principles of the UNCRC (1989). The more meaningful and reciprocal the communications regarding matters relevant to young people, the more likely the health outcomes will be positive. For example, if, as Menzies et al. (2020) point out, both school and online environments are proving detrimental to young people’s mental health, then more focus must be placed on the geographies and landscapes of those spaces in order to address the root causes. It is illogical to continue taking a passive approach, because young people are, by nature, transitional, so policy and funding decisions should not be ad hoc or deferential, but rather timely, intentional, and specific to the needs being identified directly by young people. To achieve this, decision makers need ongoing, regular opportunities to hear and learn from young people about their concerns, challenges, and priorities for their health.

As this study identifies, face-to-face and online bullying and inadequate health education are currently a significant concern for young people and clear drivers of poor mental health outcomes, which increasingly include depression and suicidality and thus demand genuine attention. Acknowledging this problem and subsequently resourcing schools, educators, and healthcare providers to build truly reciprocal, collaborative, and responsive relationships with and around young people as a way of learning about and addressing their health needs will better inform strategic responses.

Health System

My recommendations relating to the Aotearoa New Zealand health system reflect both the primary question and sub-questions of this study:

- *Primary question: How can participatory video and drama facilitate collaboration with young people to empower their voices in healthcare policy and provision?* In my opinion, the video artefacts from the workshop demonstrate that a participatory approach most definitely *can* empower young people's voices regarding healthcare, and therefore my first health-related recommendation is to establish and support independent child and youth advisory panels for health policy and research that incorporate these methods.
- *Sub-questions: What do young people see as the most important issues and challenges they face in relation to their health and well-being? What ideas do young people have that might help resolve the issues they face in relation to health and well-being?* The participants in this study identified mental health issues as the most important health issues that they currently face and point to appropriate and accessible counselling services as key to helping resolve these. My second recommendation is therefore to collaborate with youth advisors to co-design counselling services that best meet their expectations and needs in the health setting.

Establish and Support Independent Child and Youth Advisory Panels for Health Policy and Research. This project created three separate child and young person advisory groups to guide the choice of methods. Although I believe the contributions of these groups served young people's interests well, there was no formal youth advisory voice involved in the ethics approval granted by the Auckland University of Technology Ethics Committee. Similarly, as I identify in the "[Children's Voice in Aotearoa New Zealand Healthcare](#)" section earlier (page 47), Aotearoa New Zealand district health boards (DHBs) rely heavily on adult advisory groups to inform their policy changes but do not apply the same inclusivity for young people because "including children is difficult." Many "difficult" things are done in healthcare every day (take cardiac surgery, for example), and I do not believe that just because something is difficult, it is acceptable for it to be continually overlooked, particularly when that means displacing the rights of children. On the contrary, in keeping with the spirit of the UNCRC and its principle of inclusion, our health systems should allocate more resources to establish,

develop, and maintain iterative and long-running collaborative spaces for young people as a form of advisory panel to help guide healthcare policy and research decisions in areas that affect them.

These spaces should be designed to enable the young people on the panels to independently contribute their perspectives and ideas. Wherever possible, and in particular when it comes to healthcare policy, the approach should incorporate participatory methods (such as participatory video and drama). This format would both allow young people's own voices to inform policy and research decisions and help develop the personal capacity of each young person involved, so that as they themselves become adults, they can in turn foster the inclusion of the next group of young people.

Collaborate With Youth Advisors to Co-design Counselling Services. In the video artefacts produced through this study, the participants portray counselling services in a positive light. Furthermore, the personal stories they shared with me of actually using counselling services reinforce these favourable accounts. Unfortunately, the challenges they face in gaining access to counselling—such as having to get a referral from doctors or, in some cases, their teachers—taint this positivity. At the root of this recommendation is young people's desire to have timely and barrier-free access to counselling to help them manage their anxieties, stress, and emotions.

A 2020 government report on youth mental health identifies that the number of young people being diagnosed with mental health issues has almost doubled since 2012 (Cooke, 2021). The report was criticised by the government opposition party as having been “sanitised” because key data points such as wait times and suicide rates were available but omitted from the report. This aligns with the concerns raised by UNICEF that Aotearoa New Zealand governments often fail to provide reliable disaggregated data, which limits the extent to which child health issues in the country can be assessed accurately (see the “[Measuring the Effects of Discrimination: Comparisons and Layering](#)” section [page 41] for a more detailed discussion on this issue). However, another source shows that as of November 2020, the national average time for a young person to gain access to mental health services was 33 days (Cooke, 2021). This figure does not take into account the anecdotal increases now being linked to systemic problems arising from the COVID-19 pandemic and lockdowns. Furthermore, this

figure does not include data from a number of DHBs known to have long waiting times, as they did not provide disaggregated data that would allow for specific analysis of young people's experiences.

The participants in this study were well aware of the problems facing young people in accessing mental health services, and their call for timely and appropriate clinical mental health services for young people is in keeping with broader awareness of the problem. I therefore recommend establishing and resourcing a collaborative approach to co-design a service that can provide affordable, appropriate, and easy-to-access counselling and mental health services for young people.

Research

From my perspective, the participatory methods used in this project effectively provided valuable and actionable insights while also highlighting topics that would benefit from further exploration. I recommend that similar participatory methods be used to undertake research (1) with young people to specifically explore the prevalence and nature of bullying in schools and on social media; (2) with young people who regularly engage with acute health services to assess their level of participation in decisions made about their care; and (3) with intermediate and secondary school teachers to understand their perspectives on health and sexual health education in Aotearoa New Zealand.

Undertake Participatory Research With Young People to Explore the Prevalence and Nature of Bullying in Schools and on Social Media. The participants in this study have made it clear that bullying is a significant concern for young people today, describing it as pervasive and affecting them both in school and online, leaving few safe spaces. Furthermore, they describe the responses of adults to this environment of bullying as apathetic. Research using participatory methods (such as participatory video and drama) to explore the specific experience of being bullied—and potentially of being a bully—could help identify what young people believe are contributing factors while answering specific questions, such as:

- How can teachers, parents, and young people address the feelings of isolation and invisibility that the participants describe?

- How can schools better respond to bullying behaviours to reduce their occurrence and support students who are being bullied?

Ideally, these additional research projects would include a wider variety of ages (5 to 18 years) than represented in this study to provide a broader picture and greater understanding of the causes of the problem and potential solutions for it.

Undertake Participatory Research With Young People to Assess Their Level of Participation in Acute Care Decisions. The initial goal of this project was to determine whether participatory video and drama methods could serve to amplify young people’s voices to inform health policy. To a great extent, the project successfully achieved this goal, as it resulted in video artefacts that will be available for practitioner and policymaker consideration. The workshop process, and in particular the participatory storytelling methods that it employed, proved an effective way to engage with young people and unveiled specific aspects of young people’s involvement with health services that might benefit from additional participatory exploration and analysis. In particular, the participants’ contributions show that young people often feel invisible to adults and choose to not engage with them—and more specifically to not ask them questions about matters related to their health—when those adults treat them as “just a kid” (refer to the “[Helping Other ‘Invisibles’?](#)” section [page 100]). A participatory research project could be used to better understand young people’s experiences of healthcare (particularly the experiences of those who regularly engage with acute health services) and how they are or are not included in the decisions that surround it. Such a project should explore how young people are or are not consulted on their care and whether within such care their inclusion or marginalisation is by accident or design.

Undertake Participatory Research With School Teachers to Understand Their Perspectives on Health and Sexual Health Education. An Education Review Office (ERO) report (2018) found that only 19.8 per cent of schools audited in Aotearoa New Zealand delivered sexual health education “very well.” The same report found that 28 per cent of schools delivered it “not at all well.” Given the concerns raised by the participants in this study about sexual health education, it does make me wonder where the various schools that the participants attend ranked within the report.

Even without the context of this ERO report, using their own personal experiences the young people in this study provided insights that align with the report's sobering statistics. They relate that the health and sexual health education in their schools does not meet their needs, while the report states that "the social and technological context around sexuality and sexuality education has shifted quickly and profoundly. Overall, the quality of schools' sexuality education programmes have [*sic*] not kept pace with this shift" (p.18).

Given these coinciding insights, I recommend undertaking participatory research with intermediate and secondary school teachers who provide health and sexual health education for young people to identify what they perceive as barriers to and enabling factors in creating positive learning environments in this area. This research could be adult centric, but alternatively it could be conducted in collaboration with young people who have participated in health and sexual health education at school themselves, which might enable reciprocal learning and ultimately inform future educational praxis.

Limitations and Considerations

The findings and recommendations expressed in this and previous chapters should be considered within the context of the limitations of this study. As an overarching observation, I initiated this participatory action research (PAR) project in part to fulfil an academic qualification and in part to address questions arising from my personal experiences in clinical practice. As a result, certain aspects were constrained to fit the requirements of the academic programme, including the topic (health), available resources, budget, and timelines. This is in contrast to the ideals of PAR, in which the participants/co-researchers provide the initial impetus to investigate and have input into most aspects of the research design.

Young People Are Not a Homogenous Group

It is important to consider that young people are not a homogenous group and therefore the views of the participants and the project's findings may not be directly transferable to all young people in all contexts. These participants have, for example, all had some degree of training in youth theatre companies and therefore may not represent all young people's experiences of education or

socialisation. For example, the stories from the participants who identified concerns relating to health and sexual health education may resonate with many other young people, but equally may not align with those who attend the 19.8 per cent of schools in Aotearoa New Zealand that are reported as teaching sexual education “very well” (Education Review Office, 2018). It is essential to consider that even when grouped together, young people are always a collection of unique individuals who may not be representative of all young people in a given community or wider collective (such as a nation).

Recruitment May Have Left Some Still “Invisible”

Although the analysis of the participant portraits provides some evidence that the participants represent the cultural and ethnic diversity typical of Aotearoa New Zealand society, I did not undertake specific recruitment processes to ensure this. I did not purposefully select for or consider characteristics such as ethnicity, sexuality, disability, and literacy in the recruitment process. By recruiting participants from a theatrical background, the study may have unintentionally excluded other equally important perspectives. For example, if I were to have recruited participants from a sporting club or activist organisation and then run the same creative, narrative process, using the same research questions, the participants might have identified altogether different health priorities. Given this potential limitation, it is possible that some young people may not see themselves within the video artefacts produced through this project.

Similarly, although I subsidised the fees for the summer school programme for several participants to preclude cost as a barrier to their participation, I did not use any specific recruitment methods or criteria to ensure that there was representation across all socioeconomic groups. I therefore cannot assume that the participants are representative of the socioeconomic diversity across Aotearoa New Zealand, which could potentially alter what these young people see as the most salient health issues to young people.

Collective Versus Individual Perspectives

While the methods used in this project consist of layered and reflexive processes, not all individual participant’s stories and contributions are distinctly visible within the video artefacts. By design, the study brought the participants together to develop and agree on shared stories within a

group context using democratic processes. This give-and-take process, which filmmakers know well, leaves some components “left on the cutting room floor.” In other words, inevitably many significant ideas that members of the group raised were not included in the final stories. The resulting video artefacts feature subtle and valuable insights woven together through the creative process to produce a coherent, singular narrative. The collective development of stories is therefore a potential limitation of the study, as not all aspects of each final fictional video artefact can be traced back to its specific inception point or the individual account that informed it.

(As Yet) Unknown Ability to Inform

The video artefacts within the [Creating Space Project YouTube channel](#) can only be made public upon completion of the academic qualification that it supports. Thus, despite my belief in the potential of the video artefacts to inform policymakers, health professionals, and educators about young people’s concerns and ideas regarding their health, the actual impact of these artefacts cannot yet be qualified or quantified. I will not be able to assess the ability of these video artefacts to reach people and inform their thinking and, perhaps more importantly, their actions until I can make the YouTube channel available to the public and actively promote it through my professional networks, publishing (such as through journals), and future workshops. With this in mind, the project’s findings that participatory video and drama constitute a valid platform and appropriate way to support and enhance young people’s participation and collaboration remains theoretical.

Final Comments

This project has been a tremendously rewarding and eye-opening time both for me and, anecdotally, for many of the participants. It has confronted my assumptions about young people’s capacity to contribute meaningfully to research and, according to some of the participants, has challenged their belief that adults don’t see them as anything more than problems to be solved. I found the resilience and hope within these young people infectious and believe that they produced insights that adults alone could not attain.

The participants identified key issues that affect their health and call out their “invisibility” and lack of inclusive spaces as contributing to negative health outcomes. The video artefacts that

capture their creative, narrative processes and the stories they have shared point to the real and present danger of youth isolation, bullying, anxiety, inappropriate or misguided health education, and the unpredictable but all-encompassing nature of social media. Feeling invisible to adults and “awkward” when participating in health education, young people can tell when nurses, teachers, or other adults genuinely care about their perspectives or are simply doing a job. As they try to figure out who they are and who they can trust, young people need adults to acknowledge that these issues are important and in need of sincere consideration. To minimise negative health outcomes for young people, we must address their feelings of alienation and make concerted efforts to facilitate collaborative and inclusive spaces.

I hold myself fortunate to have had the opportunity to work alongside these talented young people, and while each participant is unique, I believe as a group they are fundamentally representative of most young people. They are generous and adept problem solvers who want to belong and contribute. They want to make things better—to make a difference.

In a world beset with polarising narratives and counternarratives so often promoted through “click bait” titles, the participants have identified the tensions of navigating social and political issues, whether online or at school. This project has demonstrated that participatory video methods are a valid and effective means of engaging with young people for reflective exploration and creative expression of the geographical and metaphorical landscapes they inhabit. The participatory video process has enabled them to make their thoughts on health literally visible and, for all intents and purposes, universally accessible, while also maintaining the authenticity of their voice. It provides a platform that places their perspectives centre stage, where they can receive the attention they deserve and help effect change.

While facilitating the participants’ self-reflections, I too have had to reflect on the myriad things that make us who we are. I have had to reflect on how I experienced childhood and left it behind, and how I now perceive young people and why. Some of their stories resonate with my own lived experiences and have awoken memories and thoughts that can only be described as commensurate with theirs. As a result, I remain concerned for young people’s futures, not only

because of a sense of paternalistic duty I feel to protect them, but because I believe that their well-being is an integral aspect of everybody's well-being. I hope that their work through this project awakens people's ability to see the potential that young people have to tell it like it is and to solve problems creatively. In each and every one of us exists an entire community of players—all the different ages that we have been or are yet to become. Caring for and being inclusive of young people in how we function as a society is thus fundamentally caring for and enhancing who they will become: us.

Unfortunately, Aotearoa New Zealand has not yet adopted a practice of including young people universally in the processes and decisions that affect them. A commitment to upholding their rights to participation and to having their perspectives considered in policy decisions—so that we might all benefit from their unique offerings—is akin to accepting that children are, indeed, literally our future. This perspective could be dismissed as an unactionable cliché, but for me, having now worked with these young participants as closely as I have, I am unreservedly certain that their contributions are as important to improving their health outcomes as they are to improving our own. If we want young people to live well and ultimately transition to become healthier, more capable, and more enlightened adults than we are, nothing can be lost by our listening to them. As they have suggested, this is “the change we need.”

References

- Aasgaard, H. S., Borg, M., & Karlsson, B. (2014). Emancipation or symbolic participation: How can we 'do' action research as a democratic process? *International Practice Development Journal*, 2(1), 7.
- Aickin, R., & Jellyman, T. (2012). *ADHB/WDHB Child Health Improvement Plan 2012-2017*.
<https://www.adhb.health.nz/assets/Documents/About-Us/Planning-documents/Auckland-DHB-Annual-Plan-2020-21.pdf>
- Alderson, P. (2007). Competent children? Minors' consent to health care treatment and research. *Social Science & Medicine*, 65(11), 2272–2283.
<https://doi.org/10.1016/j.socscimed.2007.08.005>
- Aldridge, J. (2015). *Participatory research: Working with vulnerable groups in research and practice*. Policy Press.
- American Psychological Association. (2017a). *Clinical practice guideline for the treatment of PTSD*.
<https://www.apa.org/ptsd-guideline/ptsd.pdf>
- American Psychological Association. (2017b). *What is exposure therapy?* <https://www.apa.org/ptsd-guideline/patients-and-families/exposure-therapy>
- Amnesty International. (2016). *History of human rights: Key human rights milestones throughout history*.
https://www.amnesty.org.nz/sites/default/files/History%20of%20human%20rights_0.pdf
- Aperio, M. (2015, March 28). *American exceptionalism - Explained and evaluated* [Video]. YouTube.
<https://www.youtube.com/watch?v=em3T5KnLAX0>
- ARTICLE 19. (2021a). *International annual report 2020: Defending freedom of expression and information around the world*. <https://www.article19.org/wp-content/uploads/2021/05/Annual-Report-2020-low-res-1.pdf>
- ARTICLE 19. (2021b). *The global expression report 2021: The state of freedom of expression around the world*. <https://www.article19.org/wp-content/uploads/2021/07/A19-GxR-2021-FINAL.pdf>

- Asadullah, S., & Muniz, S. (2015). *Participatory video and the most significant change: A guide for facilitators*. <https://insightshare.org/resources/participatory-video-and-the-most-significant-change/>
- Auckland District Health Board. (2015). *2015/16 annual plan: Incorporating the statement of intent and the statement of performance expectations*.
- Auckland District Health Board. (2022). *Health service co-design toolkit*.
<https://www.healthcodesign.org.nz/assets/Health-co-design/2010-07-HCD-Toolkit-17.1MB.pdf>
- Auckland District Health Board, & Waitemata District Health Board. (2012). *Child Health Improvement Plan*.
- Auerbach, J., & Castronovo, R. (Eds.) (2013). *The Oxford handbook of propaganda studies*. Oxford University Press. <https://doi.org/10.1093/oxfordhb/9780199764419.001.0001>
- Babich, B., & Ginev, D. (Eds.). (2014). *The multidimensionality of hermeneutic phenomenology*. Springer. <https://doi.org/10.1007/978-3-319-01707-5>
- Bamberg, M. (1997). Language concepts and emotions: The role of language in the construction of emotions. *Language Sciences*, 19(4), 309–340.
- Bamberg, M. (2011). Who am I? Narration and its contribution to self and identity. *Theory & Psychology*, 21(1), 3–24. <https://doi.org/10.1177/0959354309355852>
- Bay of Plenty District Health Board. (2016). Bay of Plenty District Health Board annual plan 2017: Incorporating the statement of intent and statement of performance expectations.
- Benest, G. (2010). *A rights based approach to participatory video: Toolkit*. InsightShare.
- Benjamin-Thomas, T. E., Rudman, D. L., Gunaseelan, J., Abraham, V. J., Cameron, D., McGrath, C., & Kumar, S. V. K. (2019). A participatory filmmaking process with children with disabilities in rural India: Working towards inclusive research. *Methodological Innovations*, 12(3).
<https://doi.org/10.1177/2059799119890795>
- Blaiklock, A. J., Kiro, C. A., Belgrave, M., Low, W., Davenport, E., & Hassall, I. B. (2002). When the invisible hand rocks the cradle: New Zealand children in a time of change. *Innocenti*

- Working Paper No. 93*. UNICEF Innocenti Research Centre. <https://www.unicef-irc.org/publications/pdf/iwp93.pdf>
- Blazek, M. (2017). Participatory video with children and young people. In T. Skelton, R. Evans, & L. Holt (Eds.), *Methodological approaches*. Springer. https://doi.org/10.1007/978-981-287-020-9_20
- Blazek, M. (2018). Children and young people's emotional geographies. In: T. Skelton & S. Aitken (Eds.), *Establishing geographies of children and young people. Geographies of Children and Young People, Vol I* (pp. 1-21). Springer. https://doi.org/10.1007/978-981-4585-88-0_9-1
- Blazek, M., & Hraňová, P. (2012). Emerging relationships and diverse motivations and benefits in participatory video with young people. *Children's Geographies*, 10(2), 151-168. <https://doi.org/https://doi.org/10.1080/14733285.2012.667917>
- Boyd, H., McKernon, S., Mullin, B., & Old, A. (2012). Improving healthcare through co-design. *The New Zealand Medical Journal*, 125(1357), 76–87.
- Boyd, H., McKernon, S., & Old, A. (2010). Health service co-design: Working with patients to improve healthcare services guide and toolkit. Waitamata District Health Board.
- Bradbury-Jones, C., Isham, L., & Taylor, J. (2018). The complexities and contradictions in participatory research with vulnerable children and young people: A qualitative systematic review. *Social Science & Medicine*, 215(10). <https://doi.org/10.1016/j.socscimed.2018.08.038>
- Bray, L., Carter, B., Kiernan, J., Horowicz, E., Ridley, J., & Dixon, K. (2021). *Rights based standards for children undergoing clinical procedures: An international collaborative good practice statement*. <https://www.edgehill.ac.uk/wp-content/uploads/documents/Rights-based-standards-for-professionals-compressed.pdf>
- British Medical Association (BMA). (2016). Cutting away at our children's futures: How austerity is affecting the health of children, young people and families. British Medical Association. <https://www.bma.org.uk/media/2060/cutting-away-at-our-childrens-futures-austerity-child-health-guuk-2016.pdf>
- Campbell, J. (1993). *The hero with a thousand faces*. Fontana Publishing.

Cancel culture. (2022, May 11). In *Wikipedia*.

https://en.wikipedia.org/w/index.php?title=Cancel_culture&oldid=1087196770

Canosa, A., Graham, A., & Wilson, E. (2018). Reflexivity and ethical mindfulness in participatory research with children: What does it really look like? *Childhood*, 25(3), 400–415.

<https://doi.org/10.1177/0907568218769342>

Canosa, A., Wilson, E., & Graham, A. (2016). Empowering young people through participatory film: A postmethodological approach. *Current Issues in Tourism*, 20(8), 894–907.

<https://doi.org/10.1080/13683500.2016.1179270>

Carter, B. (2009). Tick box for child? The ethical positioning of children as vulnerable, researchers as barbarians and reviewers as overly cautious. *International Journal of Nursing Studies*, 46(6),

858–864. <https://doi.org/10.1016/j.ijnurstu.2009.01.003>

Carter, B., Bray, L., Dickinson, A., Edwards, M., & Ford, K. (2014). *Child-centred nursing*. Sage.

Carter, B., & Ford, K. (2012). Researching children's health experiences: The place for participatory, child-centered, arts-based approaches. *Research in Nursing & Health*, 36, 95–107.

<https://doi.org/10.1002/nur.21517>

Carter, B., Jackson, D., Hayter, M., & Nyamathi, A. (2012). Children out of place: Vulnerability and risk in the countryside? *Contemporary Nurse*, 42(2), 298–300.

Chandler, D., & Munday, R. (2020). *Oxford dictionary of media and communication* (3rd ed.).

<https://www.oxfordreference.com/view/10.1093/acref/9780198841838.001.0001/acref-9780198841838>

Chapple, S. (2009). Child well-being and sole-parent family structure in the OECD: An analysis.

OECD social, employment and migration working papers, no. 82. OECD Publishing.

<https://doi.org/10.1787/225407362040>

Charlton, J. (1998). *Nothing about us without us: Disability oppression and empowerment*. University of California Press.

Chevalier, J. M., & Buckles, D. J. (2019). *Participatory action research: Theory and methods for engaged inquiry* (2nd ed.). Routledge. <https://doi.org/10.4324/9781351033268>

Child Poverty Action Group. (2017). *A New Zealand where all children can flourish: Briefing paper to the incoming government.*

<https://www.cpag.org.nz/publications/17102620cpag20201720election20briefing20paper20v8webpdf>

Child Poverty Action Group. (2021). *2021 briefing to incoming ministers: Health.*

<https://static1.squarespace.com/static/60189fe639b6d67b861cf5c4/t/62cfd20f4e6b3453d19aa194/1657786900524/CPAG+Health+Briefing+to+Incoming+Minister+Final+for+Web.pdf>

Children Act 1989 (UK). <https://www.legislation.gov.uk/ukpga/1989/41/contents>

Children and Young Persons Act 2008 (UK). <https://www.legislation.gov.uk/ukpga/2008/23/contents>

Children's Commissioner. (2015). *Giving children the best health care possible: Submission on the update of the New Zealand Health Strategy.* Manaakitia A Tatou Tamariki/Office of the Children's Commissioner.

Children's Commissioner. (2017a). *Child and youth voices on bullying in Aotearoa: Engaging children and young people in matters that affect them.* Office of the Children's

Commissioner. <https://www.childrenandyoungpeople.org.nz/documents/48/2017-Mai-World-Bullying-Report2.pdf>

Children's Commissioner. (2017b). *A new chapter for children's rights in New Zealand* [Press release]. Office of the Children's Commissioner.

<http://www.scoop.co.nz/stories/PO1711/S00154/a-new-chapter-for-childrens-rights-in-new-zealand.htm>

Children's Commissioner. (2019). *At a glance: What makes a good life? Children and young people's views on wellbeing.* <https://www.occ.org.nz/publications/reports/what-makes-a-good-life>

Coad, J., & Evans, R. (2007). Reflections on practical approaches to involving children and young people in the data analysis process. *Children & Society*, 22(1), 41-52.

<https://doi.org/10.1111/j.1099-0860.2006.00062.x>

- Coad, J. E., & Shaw, K. L. (2008). Is children's choice in health care rhetoric or reality? A scoping review. *Journal of Advanced Nursing*, 64(4), 318–327. <https://doi.org/10.1111/j.1365-2648.2008.04801.x>
- Constitutional Advisory Panel. (2013). *New Zealand's constitution*.
- Cooke, H. (2021). Wait times for youth mental health services balloon out under Labour, despite huge investment. <https://www.stuff.co.nz/national/politics/300271651/wait-times-for-youth-mental-health-services-balloon-out-under-labour-despite-huge-investment>
- Cortez, F. G. (2016). The overcoming of violence: Paulo Freire on the use of violence for social transformation. *Philosophy of Education*, 10(2), 68–83. <https://doi.org/DOI:10.25138/10.2.a.6>
- Cotterell, G., John, S. S., Dale, C., & So, Y. (2017). *Further fraying of the welfare safety net*. Child Poverty Action Group.
- Coyne, I. (2008). Children's participation in consultations and decision-making at health service level: A review of the literature. *International Journal of Nursing Studies*, 45(11), 1682–1689. <https://doi.org/10.1016/j.ijnurstu.2008.05.002>
- Coyne, I., & Carter, B. (2018). *Being participatory: Researching with children and young people—Co-constructing knowledge using creative techniques*. Springer Publishing.
- Craig, C. J. (2018). Metaphors of knowing, doing and being: Capturing experience in teaching and teacher education. *Teaching and Teacher Education*, 69, 300–311. <https://doi.org/10.1016/j.tate.2017.09.011>
- Crane, P. R. (2010). *Participatory action research workbook*. Social Work and Human Services, Faculty of Health, Queensland University of Technology. <https://eprints.qut.edu.au/216157/>
- Crotty, M. (1998). *The foundations of social research: Meaning and perspective in the research process*. Allen & Unwin.
- Cumming, J. (2022). Going hard and early: Aotearoa New Zealand's response to Covid-19. *Health Economics, Policy and Law*, 17(1), 107–119. <https://doi.org/10.1017/S174413312100013X>

- D'Souza, A. J., Signal, L., & Edwards, R. (2017). Patchy advances in child health hide a systematic failure to prioritise children in public policy. *New Zealand Medical Association*, 130(1450), 12–15.
- de Waal, F. B. (2008). Putting the altruism back into altruism: The evolution of empathy. *Annual Review of Psychology*, 59, 279–300.
<https://doi.org/10.1146/annurev.psych.59.103006.093625>
- Dearfield, C. T., Bamum, A. J., & Pugh-Yi, R. H. (2017). Adapting Paulo Freire's pedagogy for health literacy interventions. *Humanity & Society*, 42(2), 182–208.
<https://doi.org/10.1177/0160597616633253>
- Debski, S., Buckley, S., & Russell, M. (2009). Just who do we think children are? New Zealanders' attitudes about children, childhood and parenting: An analysis of submissions on the Bill to Repeal Section 59 of The Crimes Act 1961. *Social Policy Journal of New Zealand*, (34), 100–112. <https://www.msd.govt.nz/about-msd-and-our-work/publications-resources/journals-and-magazines/social-policy-journal/spj34/34-think-children-are.html>
- Depoy, E., & Gitlin, L. N. (2019). *Introduction to research: Understanding and applying multiple strategies* (6th ed.). Elsevier.
- DH/NHS Finance Performance and Operations. (2011). *The operating framework for the NHS in England 2012/13*.
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/216590/dh_131428.pdf
- Dickinson, A., Wrapson, W., & Water, T. (2014). Children's voices in public hospital healthcare delivery: Intention as opposed to practice. *New Zealand Medical Journal*, 127(1405).
- Donnetto, S., Tsianakas, V., & Robert, G. (2014). *Using experience-based co-design (EBCD) to improve the quality of healthcare: Mapping where we are now and establishing future directions*. National Nursing Research Unit.

Dreon, O., Kerper, R. M., & Landis, J. (2011). Digital storytelling: A tool for teaching and learning in the YouTube generation. *Middle School Journal*, 42(5), 4–10.

<https://doi.org/10.1080/00940771.2011.11461777>

Duncanson, M., Richardson, G., Oben, G., Wicken, A., van Asten, H., & Adams, J. (2020). *Child Poverty Monitor 2020: Technical report (Child Poverty Monitor Series)*. New Zealand Child and Youth Epidemiology Service. <http://hdl.handle.net/10523/10585>

Education Review Office. (2018). *Promoting wellbeing through sexuality education*.

<https://ero.govt.nz/our-research/promoting-wellbeing-through-sexuality-education>

Egli, V., Carroll, P., Donnellan, N., Mackay, L., Anderson, B., & Smith, M. (2019). Disseminating research results to kids: Practical tips from the Neighbourhoods for Active Kids study.

Kōtuitui: New Zealand Journal of Social Sciences Online, 14(2), 257–275.

<https://doi.org/10.1080/1177083x.2019.1621909>

Emmison, M., Smith, P. D., & Mayall, M. (2013). *Researching the visual*. Sage.

Everdell, W. R. (2000). *The end of kings: A history of republics and republicans* (2nd ed.). University of Chicago Press.

Farrar, J. (Ed.) (2022). *Evolution: What does it mean to be human?*

<https://www.bbcearth.com/news/what-does-it-mean-to-be-human>

Farrell, H. (2018). It's no accident that Facebook is so addictive. *The Washington Post*.

<https://www.washingtonpost.com/news/monkey-cage/wp/2018/08/06/its-no-accident-that-facebook-is-so-addictive/>

Farrington, C. (2016). Co-designing healthcare systems: Between transformation and tokenism.

Journal of the Royal Society of Medicine, 109(10), 368–371.

<https://doi.org/10.1177/0141076816658789>

Fernando, J. W., Burden, N., Ferguson, A., O'Brien, L. V., Judge, M., & Kashima, Y. (2018).

Functions of utopia: How utopian thinking motivates societal engagement. *Personality and Social Psychology Bulletin*, 44(5), 779–792. <https://doi.org/10.1177/0146167217748604>

- Fitzgerald, M. & Perrie, L. (n.d.). *The significance of the silver fern*. Museum of New Zealand/Te Papa Tongarewa. <https://www.tepapa.govt.nz/discover-collections/read-watch-play/ferns-and-lycophytes/significance-silver-fern>
- Fletcher, A. (2021). *Wonderworks: The 25 most powerful inventions in the history of literature*. Simon & Schuster.
- Fogo Island Inn. (n.d.). *The Fogo Process*. <https://fgoislandinn.ca/our-island/the-fogo-process/>
- Frank, A. W. (1995). *The wounded storyteller: Body, illness, and ethics*. University of Chicago Press.
- Frank, A. W. (2002). Why study people's stories? The dialogical ethics of narrative analysis. *International Journal of Qualitative Methods*, 1(1), 7–27.
- Frank, A. W. (2005). What is dialogical research and why should we do it? *Qualitative Health Research*, 15(7), 964–974.
- Frank, A. W. (2010). *Letting stories breathe: A socio-narratology*. The University of Chicago Press.
- Freire, P. (1982). Creating alternative research methods: Learning to do it by doing it. In B. Hall, A. Gillette, & R. Tandon (Eds.), *Creating knowledge: A monopoly? Participatory research in development. Participatory research network series no. 1* (pp. 29–37). Society for Participatory Research in Asia, New Delhi (India).
- Freire, P. (2000). *Pedagogy of the oppressed* (30th anniversary ed.). Continuum International Publishing Group.
- Gear, A. (2021). *Powerful poetry: Read, write, rejoice, recite poetry all year long*. Pembroke Publishers.
- Gibbon, M. (2002). Doing a doctorate using a participatory action research framework in the context of community health. *Qualitative Health Research*, 12(4), 546–558.
- Gillam, L. (2016). The zone of parental discretion: An ethical tool for dealing with disagreement between parents and doctors about medical treatment for a child. *Clinical Ethics*, 11(1), 1-8. <https://doi.org/10.1177/1477750915622033>
- Gilljam, B. M., Arvidsson, S., Nygren, J. M., & Svedberg, P. (2016). Promoting participation in healthcare situations for children with JIA: A grounded theory study. *International Journal of*

Qualitative Studies on Health and Well-being, 11, 30518.

<https://doi.org/10.3402/qhw.v11.30518>

Goswami, U. (2020). *Cognitive development and cognitive neuroscience: The learning brain* (2nd ed.). Routledge.

Gruber, M. (2016). Participatory ethnographic filmmaking: Transcultural collaboration in research and filmmaking. *Visual Ethnography*, 5(1). <https://doi.org/10.12835/ve2016.1-0057>

Gunn, W., Otto, T., & Smith, C. (2013). *Design anthropology: Theory and practice*. Bloomsbury Academic.

Hamza, W. A., & Pierce, N. (2019). Why the world needs the youth revolution more than ever.

<https://www.weforum.org/agenda/2019/08/the-youth-revolution-is-more-powerful-than-ever/>

Harris, U. (2008). Bridging the divide with participatory video. *Fijian Studies: A Journal of Contemporary Fiji*, 6(1/2), 146–165.

Harris, U. (2009). Transforming images: Reimagining women's work through participatory video.

Development in Practice, 19(4). <https://doi.org/10.1080/09614520902866405>

Hart, R. A. (1992). Children's participation: From tokenism to citizenship. *UNICEF International Child Development Centre*, 4, 1–39.

Hatab, L. J. (2014). Dasein, the early years. *International Philosophical Quarterly*, 54(4), 379–391.

<https://doi.org/10.5840/ipq201410619>

Health and Disability System Review. (2020). *Final report: Pūrongo whakamutunga*.

www.systemreview.health.govt.nz/final-report

Health Quality & Safety Commission New Zealand. (n.d.). *Adult hospital inpatient experience*.

<https://www.hqsc.govt.nz/our-programmes/health-quality-evaluation/projects/patient-experience/adult-inpatient-experience/>

Healthcare Ethics and Law. (n.d). *Consent for Children - Gillick v West Norfolk and Wisbech AHA* 1986. [https://www.healthcareethicsandlaw.co.uk/consent-healthcare-ethics-](https://www.healthcareethicsandlaw.co.uk/consent-healthcare-ethics-law/gillickcompetence)

[law/gillickcompetence](https://www.healthcareethicsandlaw.co.uk/consent-healthcare-ethics-law/gillickcompetence)

Heidegger, M. (1962). *Being and time*. Harper.

Hickel, J., & Haynes, N. (2018). *Hierarchy and value: Comparative perspectives on moral order*.

Berghahn Books.

Hill, D. A. (2005). The poetry in portraiture: Seeing subjects, hearing voices, and feeling contexts.

Qualitative Inquiry, 11(1), 95–105. <https://doi.org/10.1177/1077800404270835>

Hogenboom, M. (2015). The traits that make human beings unique. *BBC Future*.

<https://www.bbc.com/future/article/20150706-the-small-list-of-things-that-make-humans-unique>

Hopwood, B., & Tallet, A. (2011). Little voice: Giving young patients a say. *Nursing Times*, 107(49), 18–20.

Horton, J., & Kraftl, P. (2006). What else? Some more ways of thinking and doing ‘Children’s

Geographies’. *Children’s Geographies*, 4(1), 69–95.

<https://doi.org/10.1080/14733280600577459>

Immigration New Zealand. (n.d.). *Family friendly*. [https://www.newzealandnow.govt.nz/why-choose-](https://www.newzealandnow.govt.nz/why-choose-nz/family-friendly)

[nz/family-friendly](https://www.newzealandnow.govt.nz/why-choose-nz/family-friendly)

InsightShare. (n.d.). *Living cultures*. <https://insightshare.org/network/>

International Crisis Group. (2022, July 18). *Turkey’s PKK conflict: A visual explainer*.

<https://www.crisisgroup.org/content/turkeys-pkk-conflict-visual-explainer>

Johnson, D. J., Agbényiga, D. L., & Hitchcock, R. K. (2013). *Vulnerable children: Global challenges in education, health, well-being, and child rights*. Springer.

Kemp, S. (2022). *Digital 2022: New Zealand*. DataReportal [https://datareportal.com/reports/digital-](https://datareportal.com/reports/digital-2022-new-zealand)

[2022-new-zealand](https://datareportal.com/reports/digital-2022-new-zealand)

Kidd, S. A., & Kral, M. J. (2005). Practicing participatory action research. *Journal of Counseling*

Psychology, 52(2), 187–195.

Kim, J. (2016). Youth involvement in participatory action research (PAR): Challenges and barriers.

Critical Social Work, 17(1).

Kohler, R. (2008). *Jean Piaget*. Bloomsbury Academic.

Kotare Trust and AWEA. (2014). *Freire at the flaxroots: Analysis and action in Aotearoa*.

<http://kotare.org.nz/freire-at-the-flaxroots/>

Krassoi, P., & Cording, J. (2018). *Multiple disadvantage among sole parents in New Zealand*. Social Policy Evaluation and Research Unit.

Langhout, R. D., & Thomas, E. (2010). Imagining participatory action research in collaboration with children: An introduction. *American Journal of Community Psychology*, 46(1-2), 60–66.

<https://doi.org/10.1007/s10464-010-9321-1>

Lansdown, G. (2001). *Promoting children's inclusion in democratic decision making*. UNICEF Innocenti Research Centre.

Lansdown, G. (2010). The realisation of children's participation rights: Critical reflections. In B. Percy-Smith & N. Thomas (Eds.), *A handbook of children and young people's participation: Perspectives from theory and practice*. Routledge.

Lansdown, G. (2011). *Every child's right to be heard: A resource guide on the UN Committee on the Rights of the Child general comment no.12*. Save the Children Fund.

Lawrence-Lightfoot, S. (2005). Reflections on portraiture: A dialogue between art and science. *Qualitative Inquiry*, 11, 3–15. <https://doi.org/10.1177/1077800404270955>

Lawrence-Lightfoot, S. (2016). *Growing each other up: When our children become our teachers*. University of Chicago Press.

Lawrence-Lightfoot, S., & Davis, J. H. (1997). *The art and science of portraiture*. Jossey-Bass Inc.

Lawton, G. (2013). Can adults ever really understand children? *Childhood Education*, 16(8), 341–346. <https://doi.org/https://doi.org/10.1080/00094056.1940.10724475>

Lepore, J. (2021). Facebook's broken vows: How the company's pledge to bring the world together wound up pulling us apart. *New Yorker*(August 2).

<https://www.newyorker.com/magazine/2021/08/02/facebooks-broken-vows>

Lewin, K. (1946). Action research and minority problems. *Journal of Social Issues*, 2(4), 34–46. <https://doi.org/10.1111/j.1540-4560.1946.tb02295.x>

- Lloyd, K., & Emerson, L. (2017). (Re)examining the relationship between children's subjective wellbeing and their perceptions of participation rights. *Child Indicators Research*, 10(3), 591–608. <https://doi.org/10.1007/s12187-016-9396-9>
- Lloyd, W. (2013). How can we understand our children? *Childhood Education*, 15(2), 53-55. <https://doi.org/https://doi.org/10.1080/00094056.1938.10724270>
- Longtin, Y., Sax, H., Leape, L. L., Sheridan, S. E., Donaldson, L., & Pittet, D. (2010). Patient participation: Current knowledge and applicability to patient safety. *Mayo Clinic Proceedings*, 85(1), 53–62. <https://doi.org/10.4065/mcp.2009.0248>
- Lunch, N., & Lunch, C. (2006). *Insights into participatory video: A handbook for the field*. InsightShare.
- Lundy, L., Kilkelly, U., Byrne, B., & King, J. (2012). *The UN Convention on the Rights of the Child: A study of legal implementation in 12 countries*. Queens University Belfast; UNICEF.
- Lundy, L., & McEvoy, L. (2012). Childhood, the United Nations Convention on the Rights of the Child, and research: What constitutes a ‘rights-based’ approach? In M. Freeman (Ed), *Law and childhood studies: Current legal issues (volume 14)* (pp. 75–91). Oxford Academic. <https://doi.org/DOI:10.1093/acprof:oso/9780199652501.003.0006>
- Lwin, S. M. (2019). *A multimodal perspective on applied storytelling performances: Narrativity in context*. Routledge. <https://doi.org/10.4324/9781351059992>
- MacDonald, C. (2012). Understanding participatory action research: A qualitative research methodology option. *Canadian Journal of Action Research*, 13(2), 34–50.
- Mahuika, N. (2019). A brief history of whakapapa: Māori approaches to genealogy. *Genealogy*, 3(2). <https://doi.org/10.3390/genealogy3020032>
- Mandıracı, B. (2019). *Assessing the fatalities in Turkey’s PKK conflict*. International Crisis Group. <https://www.crisisgroup.org/europe-central-asia/western-europemediterranean/turkey/assessing-fatalities-turkeys-pkk-conflict>

- Martens, S. B. (2021). Michael Ure, Nietzsche's the gay science: An introduction. Cambridge introductions to key philosophical texts. Cambridge: Cambridge University Press, 2019. *Foucault Studies*(30), 101–105. <https://doi.org/10.22439/fs.vi30.6258>
- Martinez, L. S., Richards-Schuster, K., Teixeira, S., & Augsberger, A. (2018). The power of prevention and youth voice: A strategy for social work to ensure youths' healthy development. *Social Work*, 63(2), 135–143. <https://doi.org/10.1093/sw/swx059>
- Maslow, A. H. (2012). *Toward a psychology of being: A psychology classic*. Start Publishing.
- Maxon, D., Bacalso, C., & Serban, A. M. (2021). *Beyond lockdown: The 'pandemic scar' on young people. The social, economic and mental health impact of COVID-19 on young people in Europe*. European Youth Forum. <https://www.youthforum.org/files/European20Youth20Forum20Report20v1.2.pdf>
- McHugh, S. (2015). Audio storytelling: Unlocking the power of audio to inform, empower and connect. *Asia Pacific Media Educator*, 24(2), 141–156. <https://doi.org/10.1177/1326365x14555277>
- Menzies, R., Gluckman, P., & Poulton, R. (2020). *Youth mental health in Aotearoa NZ: Greater urgency required*. The University of Auckland. <https://informedfutures.org/wp-content/uploads/Youth-Mental-Health-in-Aotearoa-NZ.pdf>
- Merriam-Webster. (n.d.). Catch-22. In *Merriam-Webster.com dictionary*. Retrieved May 4, 2022, from <https://www.merriam-webster.com/dictionary/catch-22>
- Milne, E.-J., Mitchell, C., & De Lange, N. (2012). *Handbook of participatory video*. AltaMira Press.
- Minister of Health. (2016). *New Zealand Health Strategy: Future direction*. Ministry of Health. <https://www.health.govt.nz/system/files/documents/publications/new-zealand-health-strategy-futuredirection-2016-apr16.pdf>
- Ministry of Health. (2016). *Emergency department use 2014/15*. https://www.health.govt.nz/system/files/documents/publications/emergency-department-use-2014-15-aug16_0.pdf

Ministry of Health. (2019). *Annual update of key results 2018/19: New Zealand Health Survey*.

<https://www.health.govt.nz/publication/annual-update-key-results-2018-19-new-zealand-health-survey>

Ministry of Health. (2021). *Annual update of key results 2019/20: New Zealand Health Survey*.

<https://www.health.govt.nz/publication/annual-update-key-results-2019-20-new-zealand-health-survey>

Ministry of Social Development. (2003). *Involving children: A guide to engaging children in*

decision-making. <https://www.msd.govt.nz/documents/about-msd-and-our-work/publications-resources/archive/2003-involving-children.pdf>

Ministry of Social Development. (2015). *Wraparound programme: Service specifications*.

<https://www.msd.govt.nz/documents/about-msd-and-our-work/publications-resources/service-guidelines/wraparound-programme-specification.pdf>

Miranda, L.-M. (2016). Hamilton: an American musical. In J. McCarter (Ed.), *Hamilton: the revolution* (pp. 23–26). Grand Central Publishing.

Neufeld, M. (2016). *Paediatric ketamine sedation: Stories from healthcare professionals* [Masters thesis, Auckland University of Technology]. Tuwhera. <http://hdl.handle.net/10292/10194>

Neufeld, M., Spence, D., & Water, T. (2017). Working in the dark: A hermeneutic inquiry into healthcare professionals' stories of ketamine sedation with children. *Contemporary Nurse*, 53(5), 545–557. <https://doi.org/10.1080/10376178.2017.1362956>

Neufeld, M., Water, T., & Godbold, R. (2012). *The ethical implications of the use of dissociative analgesia (ketamine) in paediatrics*. HRC.

New Zealand Bill of Rights Act 1990.

<https://www.legislation.govt.nz/act/public/1990/0109/latest/DLM224792.html>

New Zealand Family Violence Clearinghouse. (2017). *Data summary: Child and youth affected by family violence*. <https://nzfvc.org.nz/sites/nzfvc.org.nz/files/DS3-Children-and-Youth-2017.pdf>

Newell, M. (2005). *Harry Potter and the goblet of fire* [Film]. Warner Bros. Pictures.

- Newhook, S. (2009). The godfathers of Fogo: Donald Snowden, Fred Earle and the roots of the Fogo Island Films, 1964-1967. *Newfoundland and Labrador Studies*, 24(2), 1719–1726.
- Nietzsche, F. (1974). *The gay science: With a prelude of rhymes and an appendix of songs* (W. Kaufmann, Trans.). Random House.
- Noelle-Neumann, E. (1993). *The spiral of silence: Public opinion, our social skin* (2nd ed.). University of Chicago Press.
- Noelle-Neumann, E. (2013). Public opinion and social control. In W. Donsbach, C. T. Salmon, & Y. Tsfati (Eds.), *The spiral of silence: New perspectives on communication and public opinion*. Routledge. <https://doi.org/10.4324/9780203125007>
- Notes on Irish folklore. (1916). *Folklore*, 27(4), 419–426. <http://www.jstor.org/stable/1255596>
- Nowell-Smith, G. (2017). *The history of cinema: A very short introduction*. Oxford University Press. <https://doi.org/10.1093/actrade/9780198701774.001.0001>
- Nuffield Council on Bioethics (UK). (2015). Children and clinical research: Ethical issues. *Jahrbuch für Wissenschaft und Ethik*. <https://doi.org/10.1515/jwiet-2017-0124>
- Office of the Children's Commissioner, the Paediatric Society New Zealand, & Ko Awatea – Centre for Health System Innovation and Improvement. (2013). *The child and youth health Compass questionnaire tool: Supporting innovation, good practice and equity*. <https://www.occ.org.nz/documents/89/The-Compass-questionnaire-tool.pdf>
- Office of the Children's Commissioner. (2017). *A new chapter for children's rights in New Zealand* [Press release]. <http://www.scoop.co.nz/stories/PO1711/S00154/a-new-chapter-for-childrens-rights-in-new-zealand.htm>
- One Hundred Years of Cinema. (2016a, May 1). *The invention of cinema (1888 to 1914)* [Video]. YouTube. <https://www.youtube.com/watch?v=zH0VCY5CYQQ>
- One Hundred Years of Cinema. (2016b, August 9). *1925: How Sergei Eisenstein used montage to film the unfilmable* [Video]. YouTube. https://www.youtube.com/watch?v=g5WbeoP_B8E
- One Hundred Years of Cinema. (2018, January 22). *1935: Triumph of the will – The power of propaganda* [Video]. YouTube. <https://www.youtube.com/watch?v=p7hJVatTW45M>

- Pallant, C., & Price, S. (2015). *Storyboarding: A critical history*. Palgrave Macmillan.
- Percy-Smith, B., & Thomas, N. (2010). *A handbook of children and young people's participation: Perspectives from theory and practice*. Routledge.
- Peterson, J. (2002). *Maps of meaning: The architecture of belief*. Taylor and Francis.
<https://www.perlego.com/book/1607797/maps-of-meaning-pdf>
- Peterson, J. (2018). *12 rules for life: An antidote to chaos*. Random House Canada.
- Pink, S. (2007). *Visual interventions applied visual anthropology*. Berghehn Books.
- Plush, T. (2012). Fostering social change through participatory video: A conceptual framework. In E.-J. Milne, C. Mitchell, & N. de Lange (Eds.), *Handbook of participatory video* (pp. 67–84). AltaMira Press.
- Punch, S. (2002). Research with children: The same or different from research with adults? *Childhood*, 9(3), 321–341. <https://doi.org/10.1177/0907568202009003005>
- Pytell, T. (Ed.). (2015). *Viktor Frankl's search for meaning: An emblematic 20th-century life*. Berghahn Books.
- Qvortrup, J. (1994). “Childhood matters: An introduction”. In J. Qvortrup, G. Bardy, M. Sgritta, & H. Wintersberger (Eds.), *Childhood matters: Social theory, practice and politics*. Avebury.
- Qvortrup, J., Corsaro, W., & Honig, M. (Eds.). (2009). *The Palgrave handbook of childhood studies*. Palgrave Macmillan London.
- Radford, B., & McKelvie, C. (2022, January 19). *Dragons: A brief history of the mythical, fire-beathing beasts*. <https://www.livescience.com/25559-dragons.html>
- Richardson-Ngwenya, P. (2012). The affective ethics of participatory video: An exploration of interpersonal encounters. *ACME: An International E-Journal for Critical Geographies*, 11(2), 250–281. <https://acme-journal.org/index.php/acme/article/view/933>
- Robert, A. (2020). Lessons from New Zealand's COVID-19 outbreak response. *The Lancet Public Health*, 5(11), 569–570. [https://doi.org/10.1016/s2468-2667\(20\)30237-1](https://doi.org/10.1016/s2468-2667(20)30237-1)

- Rogers, C. (1959). A theory of therapy, personality and interpersonal relationships as developed in the client-centered framework. In S. Koch (Ed.), *Psychology: A study of a science. Vol. 3. Formulations of the person and the social context* (pp. 184–256). McGraw-Hill.
- Rogers, C. (1961). *On becoming a person: A therapist's view of psychotherapy*. Houghton Mifflin.
- Rogers, C. (2012). *Carl Rogers on person-centered therapy* [Video]. Kanopy.
<https://aut.kanopy.com/video/carl-rogers-person-centered-therapy>
- Rowling, J. K. (2000). *Harry Potter and the goblet of fire*. Bloomsbury.
- Rowling, J. K. (2017). *Fantastic beasts & where to find them*. Bloomsbury.
- Rummel, R. J. (1995). Democracy, power, genocide, and mass murder. *Journal of Conflict Resolution*, 39(1), 2–26. <https://doi.org/10.1177/0022002795039001001>
- Saadia, V. (2021). The hero's journey of patients and health professionals.
<https://victorsaadia.medium.com/the-heros-journey-of-patients-and-health-professionals-8775a8371052>
- Sadagheyani, H. E., & Tatari, F. (2020). Investigating the role of social media on mental health. *Mental Health and Social Inclusion*, 25(1), 41–51. <https://doi.org/10.1108/mhsi-06-2020-0039>
- saed. (2021). Anti-communism and the hundreds of millions of victims of capitalism. *Capitalism Nature Socialism*, 32(1), 1–17. <https://doi.org/10.1080/10455752.2021.1875603>
- Sanders, E., & Stappers, P. (2008). Co-creation and the new landscapes of design. *CoDesign*, 4(1), 5–18. <https://doi.org/10.1080/15710880701875068>
- Santos, P. M., Silva, L. F., Depianti, J. R., Cursino, E. G., & Ribeiro, C. A. (2016). Nursing care through the perception of hospitalized children. *Revista Brasileira de Enfermagem*, 69(4), 646–653. <https://doi.org/10.1590/0034-7167.2016690405i>
- Schmidt, K., Merrill, S., Gill, R., Miller, G., Gadermann, A., & Kobar, M. (2021). Society to cell: How child poverty gets “under the skin” to influence child development and lifelong health. *Developmental Review*, 61. <https://doi.org/https://doi.org/10.1016/j.dr.2021.100983>

- Shakespeare, W. (1987). *The complete works of William Shakespeare: Complete and unabridged*. Chatham River Press.
- Sharp, I. (2007). *Our favourite poems: New Zealanders choose their best-loved poems*: Craig Potton Publishing.
- Shaw, J., & Robertson, C. (1997). *Participatory video: A practical approach to using video creatively in group development work*. Routledge.
- Shilling, D. (2013). Knowledge doubling every 12 months, soon to be every 12 hours. Retrieved June 13, 2021, from <https://www.industrytap.com/knowledge-doubling-every-12-months-soon-to-be-every-12-hours/3950>
- Shipman, D. (1993). *Cinema: The first hundred years*. Weidenfeld and Nicolson.
- Shonkoff, J. P., & Garner, A. S. (2012). The lifelong effects of early childhood adversity and toxic stress. *Pediatrics*, 129(1), e232-246. <https://doi.org/10.1542/peds.2011-2663>
- Skyrme, S. L., & Woods, S. (2018). Researching disabled children and young people's views on decision-making: Working reflexively to rethink vulnerability. *Childhood*, 25(3). <https://doi.org/10.1177/0907568218769365>
- Snowden, D. (1984). *Eyes see; ears hear*. Memorial University. https://www.participatorymethods.org/sites/participatorymethods.org/files/eyes%20see%20ears%20hear_snowdon.pdf
- Soderback, M., Coyne, I., & Harder, M. (2011). The importance of including both a child perspective and the child's perspective within health care settings to provide truly child-centred care. *Journal of Child Health Care*, 15(2), 99–106. <https://doi.org/10.1177/1367493510397624>
- Solzhenitsyn, A. (2001). *The Gulag Archipelago 1918-56: An experiment in literary investigation (abridged)* (T. P. Whitney & H. Willets, Trans.). Vintage Random House.
- Stalberg, A., Sandberg, A., Soderback, M., & Larsson, T. (2016). The child's perspective as a guiding principle: Young children as co-designers in the design of an interactive application meant to facilitate participation in healthcare situations. *Journal of Biomedical Informatics*, 61, 149–158. <https://doi.org/10.1016/j.jbi.2016.03.024>

- Stoecklin, D. (2012). Theories of action in the field of child participation: In search of explicit frameworks. *Childhood*, 20(4), 443–457. <https://doi.org/10.1177/0907568212466901>
- Sutcliffe, R., & Webber, A. (2021). *PISA 2018: Digital devices and student outcomes in New Zealand schools*. Ministry of Education.
https://www.educationcounts.govt.nz/_data/assets/pdf_file/0008/208799/PISA18-Digital-devices-and-student-outcomes-in-New-Zealand-schools-web-accessible.pdf
- Te Aka. (n.d.-a). Pūkana. In *Te Aka Maori dictionary*. Retrieved May 4, 2022, from <https://maoridictionary.co.nz/search?keywords=pukana>
- Te Aka. (n.d.-b). Whānau. In *Te Aka Maori dictionary*. Retrieved November 25, 2022, from <https://maoridictionary.co.nz/search?idiom=&phrase=&proverb=&loan=&histLoanWords=&keywords=whanau>
- Te Taumata Toi-a-Iwi. (2021). *Annual review July 2020–June 2021*.
<https://www.tetaumatatoiaiwi.org.nz/wp-content/uploads/2021/10/Annual-review-2020-2021.pdf>
- Thabrew, H., Fleming, T., Hetrick, S., & Merry, S. (2018). Co-design of eHealth interventions with children and young people. *Frontiers in Psychiatry*, 9.
<https://doi.org/10.3389/fpsyt.2018.00481>
- Thorne, B., & Sanders, P. (2012). *Carl Rogers* (3rd ed.). Sage.
- Tim Bray Theatre Company. (n.d.) *Extraordinarily creative*. <https://timbray.org.nz/youth-theatre/>
- Tseng, P. E., & Wang, Y. H. (2021). Deontological or utilitarian? An eternal ethical dilemma in outbreak. *International Journal of Environmental Research and Public Health*, 18(16).
<https://doi.org/10.3390/ijerph18168565>
- Tyson, L. (2011). *Using critical theory: How to read and write about literature* (2nd ed.). Routledge.
- UN Committee on the Rights of the Child. (2016). *Concluding observations on the fifth periodic report of New Zealand CRC/C/NZL/CO/5*. 2016.
<https://digitallibrary.un.org/record/856035?ln=en>

- UN Convention on the Rights of the Child Monitoring Group. (2017). *Getting it right: The children's convention in Aotearoa*. <https://www.occ.org.nz/publications/reports/getting-it-right-nov-2017/>
- UNICEF. (2000). A league table of child poverty in rich nations. *Innocenti Report Card* no 1. <https://www.unicef-irc.org/publications/226-a-league-table-of-child-poverty-in-rich-nations.html>
- UNICEF. (2007a). Child poverty in perspective: An overview of child well-being in rich countries. *Innocenti Report Card* no. 7. <https://www.unicef-irc.org/publications/445-child-poverty-in-perspective-an-overview-of-child-well-being-in-rich-countries.html>
- UNICEF. (2007b). Law reform and implementation of the Convention on the Rights of the Child. *Innocenti Publications*. <https://www.unicef-irc.org/publications/493-law-reform-and-the-implementation-of-the-convention-on-the-rights-of-the-child.html>
- UNICEF. (2010). The children left behind: A league table of inequality in child well-being in the world's richest countries. *Innocenti Report Card* 9. <https://www.unicef-irc.org/publications/619-the-children-left-behind-a-league-table-of-inequality-in-child-well-being-in-the.html>
- UNICEF Office of Research. (2013). Child well-being in rich countries: A comparative overview. *Innocenti Report Card* 11. <https://www.unicef-irc.org/publications/683-child-well-being-in-rich-countries-a-comparative-overview.html>
- UNICEF Office of Research. (2014). Children of the recession: The impact of the economic crisis on child well-being in rich countries. *Innocenti Report Card* 12. <https://www.unicef-irc.org/publications/733-children-of-the-recession-the-impact-of-the-economic-crisis-on-child-well-being-in.html>
- UNICEF Office of Research. (2016). Fairness for children: A league table of inequality in child well-being in rich countries. *Innocenti Report Card* 13. <https://www.unicef-irc.org/publications/830-fairness-for-children-a-league-table-of-inequality-in-child-well-being-in-rich-countries.html>

- UNICEF Office of Research (2017). Building the future: Children and the Sustainable Development Goals in rich countries. *Innocenti Report Card 14*. https://www.unicef-irc.org/publications/pdf/RC14_eng.pdf
- UNICEF Office of Research. (2020). Worlds of influence: Understanding what shapes child well-being in rich countries. *Innocenti Report Card 16*. <https://www.unicef-irc.org/child-well-being-report-card-16>
- UNICEF Office of Research. (2022). Places and spaces: Environments and children's well-being. *Innocenti Report Card 17*. <https://www.unicef-irc.org/publications/1417-rc17-places-and-spaces-environments-and-childrens-well-being.html>
- United Nations. (2020). *Policy brief: Education during COVID-19 and beyond*. https://www.un.org/sites/un2.un.org/files/sg_policy_brief_covid-19_and_education_august_2020.pdf
- United Nations Children's Fund. (2021). *The state of the world's children 2021: On my mind—Promoting, protecting, and caring for children's mental health*. UNICEF. <https://www.unicef.org/media/114636/file/SOWC-2021-full-report-English.pdf>
- United Nations Convention on the Rights of the Child. (1989). *Convention on the Rights of the Child*. <http://www.ohchr.org/Documents/ProfessionalInterest/crc.pdf>
- United Nations High Commissioner for Refugees. (2008). *UNHCR guidelines on determining the best interests of the child*. <https://www.unhcr.org/protection/children/4566b16b2/unhcr-guidelines-determining-best-interests-child.html>
- United Nations Inter-agency Group for Child Mortality Estimation (UN IGME). (2017). *Levels and trends in child mortality: Report 2017*. <https://www.un.org/development/desa/pd/sites/www.un.org.development.desa.pd/files/un-igme-child-mortality-report-2017.pdf>
- United Nations. (1948). Universal declaration of human rights. <https://www.un.org/en/about-us/universal-declaration-of-human-rights>

van Rooyen, A., Water, T., Rasmussen, S., & Diesfield, K. (2015). What makes a child a 'competent' child? *New Zealand Medical Journal*, 128(1426).

Waksler, F. C. (1991). Studying children: Phenomenological insights. In Waksler, F. C. (Ed.), *Studying the social worlds of children: Sociological readings* (pp. 60–71). Falmer Press.

Water, T., Rasmussen, S., Neufeld, M., Gerrard, D., & Ford, K. (2017). Nursing's duty of care: From legal obligation to moral commitment. *Nursing Praxis in Aotearoa New Zealand*, 33(3).
<https://doi.org/10.36951/NgPxNZ.2017.010>

Waugh, T., Baker, M., & Winton, E. (2010). *Challenge for change: Activist documentary at the National Film Board of Canada*. McGill University Press.

Webb, S., Kingstone, S., Richardson, E., & Flett, J. (2020). *Rapid evidence and policy brief: COVID-19 Youth Recovery Plan 2020-2022*. Te Hiringa Hauora/Health Promotion Agency.
<https://www.hpa.org.nz/sites/default/files/Rapid%20Evidence%20and%20Covid-19%20Youth%20Recovery%20Plan%202020-2022.pdf>

White, S. A. (Ed.) (2003). *Participatory video: Images that transform and empower*. Sage Publications.

Wilczek, F. (2015, September 10). Einstein's parable of quantum insanity. *Quanta Magazine*. Retrieved May 1, 2021, from <https://www.quantamagazine.org/einsteins-parable-of-quantum-insanity-20150910>

Wilkinson, W., & Wilkinson, S. (2018). Principles of participatory research. In I. Coyne & B. Carter (Eds.), *Being participatory: Researching with children and young people—co-constructing knowledge using creative techniques* (pp. 15–35). Springer Publishing.

Williams, J. N. (2007). Propositional knowledge and know-how. *Synthese*, 165(1), 107–125.
<https://doi.org/10.1007/s11229-007-9242-1>

Willis, J. W., & Edwards, C. (2014). *Action research: Models, methods and examples* (Vol. 2). Information Age Publishing.

World Health Organization. (2016). *World health statistics 2016: Monitoring health for the SDGs, sustainable development goals*. <https://apps.who.int/iris/handle/10665/206498>

Wright, M. (2003). *Newfoundland and Labrador history in Canada: 1949-1972*. Royal Commission on Renewing and Strengthening Our Place in Canada.

<https://www.gov.nl.ca/publicat/royalcomm/research/history.pdf>

Yang, E. (2021). Young people are particularly vulnerable to lockdowns. *American Institute for Economic Research*. <https://www.aier.org/article/young-people-are-particularly-vulnerable-to->

[to-](https://www.aier.org/article/young-people-are-particularly-vulnerable-to-)

[lockdowns/?gclid=CjwKCAiA9tyQBhAIEiwA6tdCrGUS30GO01LERf10_KhdXxzbcBmM2Ze_3TVSumJDsohPkFSAJkTuoBoCdTkQAvD_BwE](https://www.aier.org/article/young-people-are-particularly-vulnerable-to-lockdowns/?gclid=CjwKCAiA9tyQBhAIEiwA6tdCrGUS30GO01LERf10_KhdXxzbcBmM2Ze_3TVSumJDsohPkFSAJkTuoBoCdTkQAvD_BwE)

Young, A. (2010, March 25, 2010). Some welfare reforms do breach rights, says Bennett. *NZ Herald*.


http://www.nzherald.co.nz/nz/news/article.cfm?c_id=1&objectid=10634153

Young, A. (2018, January 31). Jacinda Ardern announces targets with plan to halve child poverty within 10 years. *NZ Herald*.

http://www.nzherald.co.nz/nz/news/article.cfm?c_id=1&objectid=11985561

[Zak, P. \(2013\). *The moral molecule: How trust works*. Penguin Group.](#)

Appendix A: Ethics Approval



Auckland University of Technology Ethics Committee (AUTC)

Auckland University of Technology
 D-88, Private Bag 92006, Auckland 1142, NZ
 T: +64 9 921 9999 ext. 8316
 E: ethics@aut.ac.nz
 www.aut.ac.nz/researchethics

TE WĀNANGA ARONUI
O TĀMAKI MAKAU RAU

19 March 2021

Dr Catriona Conry
 Faculty of Health and Environmental Sciences

Dear Catriona,

Re Ethics Application: **20/42 Creating space for young people to inform health care policy in New Zealand through a participatory video approach**

Thank you for providing evidence as requested, which satisfies the points raised by the Auckland University of Technology Ethics Committee (AUTC).

Your ethics application has been approved for three years until **19 March 2024**.

Standard Conditions of Approval

1. The research is to be undertaken in accordance with the [Auckland University of Technology Code of Conduct for Research](#) and as approved by AUTC in this application.
2. A progress report is due annually on the anniversary of the approval date, using the EA2 form.
3. A final report is due at the expiration of the approval period, or, upon completion of project, using the EA3 form.
4. Any amendments to the project must be approved by AUTC prior to being implemented. Amendments can be requested using the EA2 form.
5. Any serious or unexpected adverse events must be reported to AUTC Secretariat as a matter of priority.
6. Any unforeseen events that might affect continued ethical acceptability of the project should also be reported to the AUTC Secretariat as a matter of priority.
7. It is your responsibility to ensure that the spelling and grammar of documents being provided to participants or external organisations is of a high standard.

AUTC grants ethical approval only. You are responsible for obtaining management approval for access for your research from any institution or organisation at which your research is being conducted and you need to meet all ethical, legal, public health, and locality obligations or requirements for the jurisdictions in which the research is being undertaken.

Please quote the application number and title on all future correspondence related to this project.

For any enquiries please contact ethics@aut.ac.nz. The forms mentioned above are available online through <http://www.aut.ac.nz/research/researchethics>

(This is a computer-generated letter for which no signature is required)

The AUTC Secretariat
Auckland University of Technology Ethics Committee

Cc: j.neufeld@aut.ac.nz; Tipoka.Watg@aut.ac.nz

Appendix B: Participant Information Sheet



Participant Information Sheet

Information sheet for participants aged 11 to 18

Date Information Sheet Produced: 05/01/2021

Project Title

Creating space for children and young people to inform Healthcare policy in New Zealand using Participatory Video

An Invitation

My name is Mike Neufeld and I am a Registered Nurse and Child Health researcher. I am currently studying to become a Doctor of Health Science and would like to invite you to take part in a creative video project.

This information sheet will tell you why I am doing this project and what will happen during it.

What is the purpose of this research?

I want to understand more about what it is like for young people accessing healthcare and to hear your ideas about health and what you think a perfect health care experience might be like.

If we can understand more about what it is like for young people accessing healthcare, we may be able to help make visiting the hospital or seeing a Doctor or Nurse better for young people in the future.

How was I identified and why am I being invited to participate in this research?

You are being invited to participate because you are a young person between the ages of 11 and 18 and you live in New Zealand.

You may have been offered this information sheet because you or someone you know has seen an advertisement or announcement at school, or you may be part of an organisation that is wanting to participate in the project.

How do I agree to participate in this research?

If after reading this sheet you would like to take part in this project, then you can sign the consent form and email or call / text me on the numbers below. If you are under 16, you can sign the Parental consent and assent form and get a parent or guardian to sign it and either send it to me via email or return it to me at your next Kids 4 Drama session.

It is important for you to know that your participation in this research is voluntary (it is your choice) and whether or not you choose to participate will neither advantage nor disadvantage you. You can withdraw from the study at any time and if you choose to withdraw from the study, you will be offered the choice between having any contributions you have made that are identifiable as belonging to or including you, removed or allowing it to continue to be used in the project. However, once the final video/film has been produced, removal of your contributions may not be possible.

What will happen in this research?

This research is a Participatory Video/Drama Project where you will learn how to use video and audio equipment to plan, film and edit a short film. We will use creative and fun ways to explore your thoughts and ideas about health care. You will have the opportunity to work in small groups with other young people to learn theatrical/filmmaking and collaboration skills to create a short film that shares what you think is most important when it comes to your health and when receiving care from Doctors, Nurses or other health professionals.

This will take place during School Holidays and will be a 5 day workshop running Monday to Friday. Food and refreshments will be provided and we will finish with a celebration and public screening of your film(s) for friends, family and anyone you might like to attend.

What are the discomforts and risks?

Taking part in the project will take up some of your time as the sessions are full days just like school. It is also using audio and video equipment, so you may be asked to do things like interview other participants (like a journalist) or talk to the camera yourself. It could be that thinking about times when you or someone you love has been unwell or injured or been in hospital could be difficult or make you feel upset.

How will these discomforts and risks be alleviated?

Participatory video is a way to create a fun, creative and friendly space to explore ideas while also teaching skills that you can use in the future. If you choose to participate, you can choose which parts of the workshop you wish to take part in and if at any point you experience discomfort, can stop immediately. There will be no pressure placed on you to participate should you find it unenjoyable.

What are the benefits?

You will get to meet other young people interested in participatory video and learn filmmaking techniques. The things we learn from this project may also contribute to shaping better health experiences and outcomes for young people in New Zealand. This project will also benefit me directly as it will complete the requirements for my Doctoral qualification. Because it is a participatory project, you will be considered a co-researcher, so will have a say in what we do and create. If you enjoy the project, and would then like to continue learning about research and advocacy skills, you will have the opportunity to present the work we have done publicly and be part of a youth advisory group for future projects.

How will my privacy be protected?

Only your mum/dad/carer and the other participants will know you are taking part, until the final video is shown at a public screening. If you prefer not to be filmed or have your images and voice in the final videos, you can tell me and we will work together to find ways for you to contribute and have fun without being identifiable. If you do not want your name used, we can use a pseudonym (pretend name) and you can make the decision as to what can and cannot be included in the final video. Anything I write about the study will not include your real name and other details will not be shared unless you say it is ok.

What are the costs of participating in this research?

There is no cost to participate other than your time. As this will take place over 4 to 5 days, it is a significant amount of time, however if you have specific needs regarding time, everything possible will be done to help schedule things so you can participate as fully as possible. Food and refreshments will also be provided during the workshops.

What opportunity do I have to consider this invitation?

You can take as much time as you need to consider the invitation. The first sessions are planned to start on the 3rd or 4th Thursday in August, 2020. It would be best to know your answer before the start date to allow time to plan activities, equipment etc., but if you need more time, just let me or Stephen Dallow know and we can work towards a solution.

Will I receive feedback on the results of this research?

Yes. As you are considered 'co-researchers' in this project, you will be directly involved in determining the 'results'. At the completion of the project, you will receive a Flash Drive that contains the material you have created during the workshops and the final video that has been created. You may also wish to help present the works to policy makers and health professionals after the project has completed.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this study should be notified in the first instance to the Project Supervisor, Dr Cath Conn cath.conn@aut.ac.nz, 921 9999 Ext 7407.

Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTC, ethics@aut.ac.nz, (+649) 921 9999 ext 6038.

Whom do I contact for further information about this research?

Please keep this Information Sheet and a copy of the Consent Form for your future reference. You are also able to contact the research team as follows:


Researcher Contact Details:

Michael Neufeld

email: michael.neufeld@aut.ac.nz

Phone 09 921 9999 x7402

Appendix C: Parent Information Sheet



TE WĀNANGA ARONUI
O TĀMAKI MAKAU RAU

Parent Information Sheet

Information sheet for parents

Date Information Sheet Produced: 05/01/2021

Project Title

Creating space for young people to inform health care policy in New Zealand using participatory Video

An Invitation

My name is Michael Neufeld and I am a Registered Nurse and a child and youth health researcher. I am currently studying to achieve my Doctor of Health Science and would like to invite your child to take part in a fun participatory drama and video project.

This information sheet will explain why I am doing this project and what will happen during it.

What is the purpose of this research?

Children are not often included in the design and delivery of healthcare, but there is evidence that suggests when they are, they have better health outcomes that last a lifetime. I want to understand more about what it is like for young people accessing healthcare in New Zealand and to hear your child's ideas about health and what they think a perfect health care experience should be like.

If we can understand more about what it is like for young people accessing healthcare, we may be able to inform policy makers and health professional's actions, thereby making accessing healthcare better for all young people.

How was my child identified and why are they being invited to participate in this research?

Your child is being invited to participate because they are a young person between the ages of 11 and 18 and living in Auckland New Zealand.

You may have been offered this information sheet because you or someone you know has requested information, or you or your child are members of a youth group, theatre company, school, or other organisation that has expressed an interest in participating.

How do I agree for them to participate in this research?

After reading this sheet and discussing it with your child, if you are interested in them taking part you can either sign the attached **Participant Consent/Assent and Release form** and have your child bring it to their next Kids 4 Drama class, or if you have any questions, email me at michael.neufeld@aut.ac.nz or call/txt me on the numbers in the contact details below.

If your child is under 16, they will also need to sign the form (this ensures that they themselves want to take part).

It is important for you to know that your child's participation in this project is completely voluntary and whether they choose to participate or not will neither advantage nor disadvantage them. They can withdraw from the project at any time and if they do withdraw, they will be offered the choice between having any contributions they made during the project removed, or allowing these contributions to be used in the performances/videos. However, once the final drama and video content has been produced, removal of their specific contributions may not be entirely possible.

What will happen in this research?

This research is a Participatory Drama and Video Project where participants will explore health contexts during their weekly drama classes in a weeklong school holiday programme. They will develop short theatrical shows/skits based on their experiences, thoughts and ideas. This is similar to the processes already being used in Kids4drama classes, but with a distinct focus on Health and healthcare. In addition to their usual theatrical learnings, participants will also be given the opportunity to learn how to use video and audio equipment to plan, film and edit a short film based on their performances.

Much like their usual classes, we will use creative and fun ways to explore thoughts and ideas about health care, working together to learn how to collaborate and extend their theatrical and filmmaking skills. Ultimately, they will

work with each other to create performances and a short film or films that share what is most important to young people when it comes to health and receiving care from Doctors, Nurses and other health professionals.

This will take place over 4 or 5 Thursday night Classes and a catered weekend session that will culminate in a celebration of their accomplishments and a performance / screening to friends, family and invited guests.

What are the discomforts and risks?

Taking part in the project will take up some of their time as the sessions will be done during some of their weekly Kids4drama Thursday evening sessions in Term 3, and a Friday evening and Saturday, Sunday in the last week of the project in term 4.

Kids4 Drama and I will work with the group to schedule the weekend session to suit everyone as best as possible, keeping in mind their commitments to school and study. If you have specific needs, please let me know.

In the event that participants cannot attend all sessions but still wish to participate, that is ok, we will work to make whatever time they can participate as enjoyable as possible.

The only other consideration regarding potential 'discomfort' is that your child will be performing and using audio and video equipment. They may be asked to do things like interview other participants (like a citizen journalists) or be asked to talk to the camera themselves. Although not expected, for some children, reflecting on times when they or someone they love has been unwell or injured, could make them feel upset. If this were to occur, they can stop at any time, and they will be supported by me or their acting coach in the first instance, and you would be notified.

How will these discomforts and risks be alleviated?

This project is an extension of the usual programme and processes at Kids 4 Drama. Participatory drama and video are ways to create a fun, creative and friendly space to explore ideas while also teaching real skills that young people can use in the future. If your child participates, they can choose which parts of the activities they wish to take part in and if at any point they experience discomfort, they can stop immediately. There will be no undo pressure placed on them to participate should they find it unenjoyable, and Stephen Dallow and I will work with them to find ways of meeting their individual expectations.

What are the benefits?

This project is important to me as it will help to complete my Doctoral qualification. The most positive benefit however is that participants will get to share their ideas and thoughts and learn hands on techniques of creating performances and video. Because it is a participatory project, the young people will be considered co-researchers, and 'experts' in their own lives, so will have a very strong say as to what we do and create. If they enjoy the project and would like to continue learning about research and advocacy skills, they will also have the opportunity to co-present the work to policy makers and Health professionals, becoming part of a youth advisory group who can give feedback on future child and youth health research projects.

How will privacy be protected?

The participatory nature of this project means that participants work together with me and Kids4 drama to decide what does or does not get included in the final production and video creations. As such, they can decide whether or not they are in the performances or video(s), or how they are represented in these. For example, if they wish to be anonymous, this can be achieved via filming techniques and/or the use of pseudonyms (pretend names). This will be discussed with each participant as the material is being created, and most importantly, during regular integrated review and feedback opportunities that ensure participants make the decision as to what can and cannot be included. After the workshops are completed, anything I subsequently write or present about this work will not include anyone's names or other specific details unless they have expressly asked to be credited for the work they have produced.

What are the costs of participating in this research?

There is no cost to participate other than time and possibly transport to the workshop location. As this will take place over a number of sessions, it is a significant time commitment, however it is on the usual Kids 4 Drama schedule. If you or your family have specific needs regarding time, everything possible will be done to help schedule things so your child can participate as fully as possible.

What opportunity do I have to consider this invitation?

You can take as much time as you need to consider the invitation, but the first sessions will hopefully commence in the 3rd Thursday of August, and the sooner we have consent the better to allow time to plan the activities and arrange any food, refreshments or equipment necessary. If you need more time, or wish to discuss any aspect of the project with me, please let me know and we can look at how we might be able to make it work for you and your family.

Will I receive feedback on the results of this research?

Yes. In this project, the young people are considered 'co-researchers', so will be aware of 'results' as they emerge. At the completion of the project, you and your child will also receive a Flash Drive that contains all the material they created during the workshops and a recording of the performance and any film(s) that create. You child may also be invited to help present the works to policy makers and Health professionals should they wish to.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this study should be notified in the first instance to the Project Supervisor, Dr Cath Conn cath.conn@aut.ac.nz, 921 9999 Ext 7407.

Any concerns regarding the conduct of the research or researcher should be notified to the Executive Secretary of AUTC, ethics@aut.ac.nz, (+649) 921 9999 ext 6038.

Who do I contact for further information about this research?

Please keep this Information Sheet and a copy of the Consent Form for your future reference. You are also able to contact the researcher as follows:

Researcher Contact Details:


Michael Neufeld

email: michael.neufeld@aut.ac.nz

Phone 09 921 9999 xt 7402

Approved by the Auckland University of Technology Ethics Committee on March 20th, 2020, AUTC Reference number 20/42

Appendix D: Participant and Parental Consent and Waiver Form



AUT

TE WĀNANGA ARONUI
O TĀMAKI MAKAU RAU

Participant Consent/Assent and Release Form

Participants aged 11-15 years

Project title: *Creating space for children and young people to inform Healthcare policy in New Zealand using Participatory Video*

Project Supervisor: *Dr Cath Conn*

Researcher: *Michael Neufeld*

☐ I have read and understood the information provided about this research project in the Parent and Participant Information Sheets dated 05.08.2020.

☐ I have had an opportunity to ask questions and to have them answered.

☐ I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without being disadvantaged in any way.

☐ I understand that if I withdraw from the study then I will be offered the choice between having any data/contributions that are identifiable as belonging to me removed or allowing it to continue to be used. However, once the findings and creative works have been produced, removal of my data may not be possible.

☐ I permit the researcher to use any photographs, artworks, audio or videos that are part of this project and/or any other reproductions or adaptations from them, either complete or in part, alone or in conjunction with any wording and/or creative work solely and exclusively for (a) the researcher's portfolio; and (b) exhibition and examination purposes; and (c) all forms and media for advertising, trade, sharing of the findings or other lawful purposes as stated on the Information Sheet.

☐ I understand that any material created in the working sessions is deemed to be owned by the researcher and that I do not own copyright of any of the work.

☐ I agree to take part in this research project.

Participant Assent:

(If you are under 16, a Parent/Guardian must also sign the consent form, but by signing your 'assent' you confirm that you yourself wish to participate)

Participant Name: Age

Participant signature :

Date:

Contact Details (if applicable)

Phone.....

Email

Parent/Guardian signature of consent (If Participant is under 16 years of age)

Contact Details

Name:

Phone.....

Email

Date:

Approved by the Auckland University of Technology Ethics Committee on March 19th, 2020 AUTEK Reference number 20/42

Note: Participants should retain a copy of this form.

Aug 2020
page 1 of 1
This version was last edited in Aug 5th 2020