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Building a Sense of Identity Belonging and Culture Through Place-Making and Creative Co-Design: Practices within New Zealand's Educational Context

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Abstract: The key role and the importance of arts and culture in shaping today's creative economy and bringing vibrant range of creative and cultural activities to the public has been steadily growing in the past few years. This paper investigates the question of how design research contributes to belonging and wellbeing, specifically in the context of Aotearoa, New Zealand. Through a proposed three-folded structure: a) Toi Whītiki in Action, b) Aotearoa – New Zealand and Education Context, and c) Student Case Studies, this paper delves deeper into student creative projects and city co-design practices to enhance a city's status of wellbeing and engagement with diverse culture.

Keywords: aotearoa; arts and culture; design research; collaborative practices; placemaking; wellbeing

1. Introduction

The creative industry sector is gaining more and more momentum, and perhaps it will hit 'pick creativity' in the next years to come. The arts are contributing as well towards the creative entrepreneurship, as the CreativeNZ surveys shows: "New Zealanders believe the arts make their communities better places to live and agree they should be a part of everyone's education" ("New Zealanders and the arts summary report", 2017, p.5). Furthermore: "Eight out of ten New Zealanders have participated in the arts or attended an arts event, or both, in the last 12 months resulting in a record high for arts engagement (80%)" ("New Zealanders and the arts summary report", 2017, p.6). The benefits of the arts, as stated in the survey, are plentiful: boost of confidence, creativity, a sense of belonging; all the signifying badges of well-being and effective impact. "New Zealanders recognise the positive contribution the arts make to supporting strong, thriving communities and the development of happy, confident young New Zealanders,' said Creative New Zealand Chief Executive Stephen Wainwright" ("New Zealanders and the arts summary report", 2017, p.1).



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'Art for the many, not for the few', as the New Zealand Prime Minister and Minister for Arts, Culture and Heritage voiced in an opinion piece (Ardern, 2018). Taking the framework of the Auckland Council document *Toi Whītiki: Auckland's Arts and Culture Strategic Action Plan* (2015), this paper looks into the question of how design research contributes to belonging and wellbeing, specifically in New Zealand. Through a proposed two-folded structure: a) *Toi Whītiki in Action*, b) *Aotearoa – New Zealand and Education Context*, and c) *Student Case*, this paper delves deeper into student creative projects and city co-design practices to enhance a city's status of wellbeing and engagement with diverse culture.

2. How Tāmaki Makaurau - Auckland Plans to be the Most Liveable and Culturally Diverse City

In the period between 2015 and 2025, Tāmaki Makaurau - Auckland, will face the need to respond to continued growth, changing demographics, and increasing international competitiveness in the creative sector. In order to address those areas in need of support and make the most of opportunities, Auckland Council and its subsidies having been planning the future of the creative sector to make Auckland the most liveable city. There are several strategic initiatives which contributes to this government goal such as the *Toi Whītiki Arts and Culture Strategic Action Plan* ("Toi Whītiki Strategic Action Plan", 2015). This strategic plan has set goals and key objectives for the duration of ten years to develop and grow arts and culture in Auckland. Currently the Auckland, Tourism, Events and Economic Development (ATEED) are calling out to the Auckland community to have a say on how the city can grow the potential of the creative sector through a "Creative Industries Strategy" towards 2030 ("Creative Auckland 2030"). The Auckland Co-Design Lab is another example of an Auckland Council supported organisation that is calling for community engagement. This initiative aims to work with central government and community partners to apply co-design principles and a perspective view to complex social issues. This paper situates *Toi Whītiki* in relation to the New Zealand government goals for the creative sector, looking into what is the new data and target goals in the field, and how enhancing wellbeing through creative means, will further expand the impact of arts, culture and a sense of belonging.

The key role and the importance of arts and culture in shaping today's creative economy and bringing vibrant range of creative and cultural activities to the public has been steadily growing in the past few years. Case example is Tāmaki Makaurau - Auckland, which through the Auckland's Arts and Culture Strategic Action Plan (*Toi Whītiki*) strives to achieve the vision of becoming the "world's most liveable city". As it is stated in *Toi Whītiki*:

Arts and culture play a key role in the cultural, social and economic life of Auckland, making it a more dynamic and attractive place to live, work and visit. It connects and strengthens our communities, gives us a sense of identity and pride, improves individual and community health and well-being, and contributes to a strong economy. (2015, p.4)

Toi Whītiki aims to deliver on the vision and outcomes of the Auckland Plan (the key strategic document for Auckland Council), which includes the integration of arts and culture into

everyday lives, and to address the challenges and opportunities in the ever-growing and increasingly diverse city. Following on from the strategic directions in the Auckland plan, Toi Whītiki is a core strategy recognising the importance of people's engagement with arts and culture and boosting participation in shaping stronger communal bonds, wellbeing, and sense of partaking an active role in shaping Auckland to be truly a liveable and multi-cultural city. The action plan has a 10-year timeframe in order to allow time to measure the impacts and outcomes and has been developed by Auckland Council in collaboration with the arts and culture sector. Commented upon by councillor Alf Filipaina: "Public engagement on Toi Whītiki, led by Auckland Council, clearly showed that Aucklanders understand that arts and culture are fundamental to a healthy society and a good quality of life" ("Toi Whitiki Strategic Action Plan", 2015, p.3). To support this statement, the Action Plan gives the figures that 88% of Aucklanders believe that the arts are good for you, 86% agree the arts help to improve society, and 90% agree that they learn about different cultures through the arts ("Toi Whitiki Strategic Action Plan", 2015, p.4). In 2014, over 90% of Aucklanders attended or participate in at least one arts event. The number of people participating in arts and cultural activities is growing exponentially each year, which is evident from the numbers and figures provided by Creative New Zealand (Figure 1). The action plan recognises the importance that the creative sector plays in bringing wider economic, cultural, and social benefits, and supports opportunities to maximise the sector's contribution to the vision of greater Auckland.

In relation to the Toi Whītiki plan, Auckland Council is looking at South Auckland as becoming "the first New Zealand Maker City, known to for intergenerational creativity, entrepreneurship and innovation" ("Toi Whitiki Strategic Action Plan", 2015, p.5). Through the official strategy *South Auckland: City of Makers Strategy* (2018), the Auckland Council puts in focus how "in the next five years, we will be focusing on strengthening the maker movement and growing the ecosystem of spaces, people, knowledge and infrastructure" ("South Auckland: City of Makers Strategy" 2018, p.6). This plan operates in the broader scope of The Southern Initiative (TSI), which was launched in 2012, with the goal to "plan and deliver a long-term programme of co-ordinated investment and actions to bring about transformational social, economic and physical change in this area" ("South Auckland: City of Makers Strategy", 2018, p.6). Tamaki Makaurau - Auckland, is already a city that exhibits qualities of a strong leader in the creative economy, following the statistics that "with nearly 18, 000 people working in concentrated clusters, supported by some of the world's best talent - 49% of the country's creative jobs are based here, contributing \$1.8 billion in gross domestic product (GDP) annually or 2.3% of Auckland's GDP" ("Toi Whitiki Strategic Action Plan", 2015, p.54). Overall, working within the framework of the South Auckland Maker City plan, Auckland Council puts forward few points that will focus on: "Celebrating South Auckland successes locally and nationally"; "creating market opportunities by jumpstarting key initiatives"; and to "work with communities, government and private sector to promote south Auckland as a hub for learning and innovation" ("South Auckland: City of Makers Strategy", 2018, p.54).

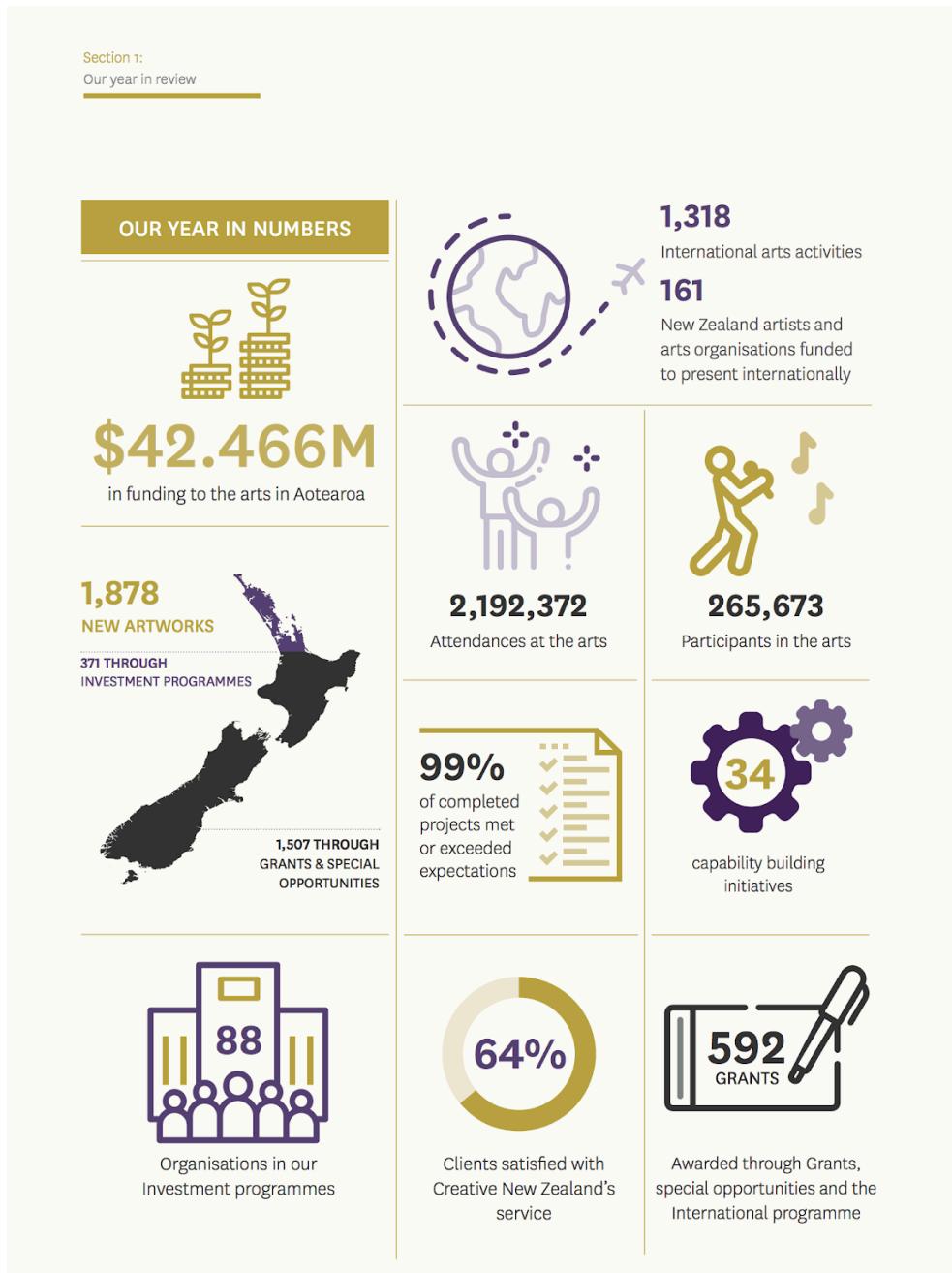


Figure 1 Creative New Zealand Annual Report 2017

The vision for arts and culture in Toi Whītiki is focused on six key categories: Participation; Investment; Infrastructure; Place-making; Identity; and Creative Economy. In order to get a better grasp of why and how these key points are included in the action plan and what role they play; they will be discussed further below. Starting from the very first one - Participation.

Participation is the rudimentary founding block of the Action Plan. What participation means for the vision of the Auckland Plan is that “all Aucklanders can access and participate in

arts and culture" ("Toi Whitiki Strategic Action Plan", 2015, p.18). The participation aspect consists of three Action Plan points: a) increase opportunities for Aucklanders to experience and participate in arts and culture; b) better communicate what's on offer; c) remove barriers to access and participation ("Toi Whitiki Strategic Action Plan", 2015, p.20). The vital role that participation has is to ensure that indeed all Aucklanders, despite age, cultural background, and mobility, can partake in engaging with the arts and culture activities: "research shows that while Aucklanders value arts and culture in all their forms, many do not engage with them, and access and participation are not equitable across the region" ("Toi Whitiki Strategic Action Plan", 2015, p.24). In order to address these barriers, the three sub-points need to be put in action to ensure that participation is accessible to all Aucklanders.

Another important aspect that needs to be taken deeper look into is 'place-making' (point four of the Action Plan) and the role of arts and culture as intrinsic elements to Auckland's place-making agenda. Auckland plays a vital role as a creative incubator for place-making, and strives to enhance further the engagement and liveability of the city:

We've heard that Aucklanders want to improve the liveability, beauty, vitality and sustainability of the region and its people through creativity and innovation. While 76% of them agree that the arts help define who we are, we know we need to do better in communicating the key role that arts and culture, and specifically public art, have in making a great city. Making it easier to create art in public places will go some way towards encouraging more people to be part of the transformation. (Toi Whītiki, 2015, p.43)

Following from this statement, in order for the city to indeed do better in communicating the key role that arts and culture, including public art, have in making a significant impact, there are two major points Action Plan points put down for consideration: a) the narrative - tell people's stories by encouraging unique and distinctive public art that reflects and responds to place-making; and b) make it easier to plan, create and deliver innovative art and design in public places ("Toi Whitiki Strategic Action Plan", 2015, p.44). This links as well to the next point of the six major Action Plan categories, which is 'Identity' (point five). Auckland celebrates a unique cultural identity and the status of the city as a melting pot of different cultures and the standout feature which is the vibrant *Māori culture* ("Toi Whitiki Strategic Action Plan", 2015, p.48). To be able to stand out on the global stage, Auckland Council is firmly supporting and putting in action the vision of strong local identities, which gives the unique flavour of the arts and culture produced here:

Combined with our strong European heritage, robust Pacific cultures and growing Asian identities and their festivals, Aucklanders are increasingly enjoying cultural experiences. An exciting blend of artistic styles, techniques and performance arts is emerging and can be supported by helping these groups to network. Auckland's indigenous culture and strong contemporary art practice are already growth areas in its visitor economy, and this can be built on. ("Toi Whitiki Strategic Action Plan", 2015, p.48)

An example of growing Asian identities and for other cultures to embrace the Asian community through fostering enjoyable cultural experiences is the Chinese Lantern Festival in Auckland. In 2019 the festival celebrated its 20th anniversary, providing for its visitors the

experience of “hundreds of handmade Chinese lanterns, music and dance performances, martial arts demonstrations, traditional Chinese art and craft – there’s a range of activities for all ages” (“Lantern Festival” [APA], n.d). Another big major festival, celebrating robust Pacific cultures, is the Pasifika Festival. Running since 1993, is the “largest Pacific Island cultural festival of its kind in the world” (“Lantern Festival” [APA], n.d) festival of its type in the world and attracts over 200,000 visitors annually. The festival consists of “...11 distinctly different villages, each with a performance stage and market, to show the diversity of the Pacific cultures represented. The villages represent the Cook Islands, Fiji, Niue, Aotearoa, Hawaii, Samoa, Tahiti, Tuvalu, Tonga, Tokelau and Solomon Islands” (“Lantern Festival” [APA], n.d).

New Zealand is evolving through place-making, creative co-design and inclusiveness values - it is hoped there will be a “synergy”, “the coming together of people” and substantial social impact. Opening opportunities for the community to shape ‘their’ city is a real strategic approach. The Auckland Council strategic plans support the significance of community participation shaping stronger communal bonds, wellbeing, and sense of partaking through people’s engagement with each other via the arts and culture as well as advocate Auckland to truly be a liveable, harmonious and multi-cultural city.

3. Aotearoa - New Zealand and Education Context

Historically, biculturalism has been central to New Zealand’s self-conception. This has evolved with the Treaty of Waitangi which, in 1840 promoted “We are one people now” (Sinclair, 1971) and then 150 years later became “Two peoples, one nation” (Bathurst, 2011). However, New Zealand’s growing polyethnic diversity, is proving that both biculturalism and multiculturalism play a role in New Zealand’s evolving identity and are necessary for strong and healthy ethnic relations in New Zealand (Ward, & Liu 2012). For example, the recent mosque terrorist shooting in Christchurch this year, radically defined New Zealand’s national identity in solidarity and unity against racism.

In the 2016 Social Report, the Ministry of Social Development (“MSD”, 2016) stated that under the section of Cultural Identity, a desired outcome was to value the cultural diversity in New Zealand. (Ministry of Social Development, n.d.) Thus, this raised the question: How do we promote the preservation of a multicultural national identity?

Ethnic groups in Tāmaki Makaurau

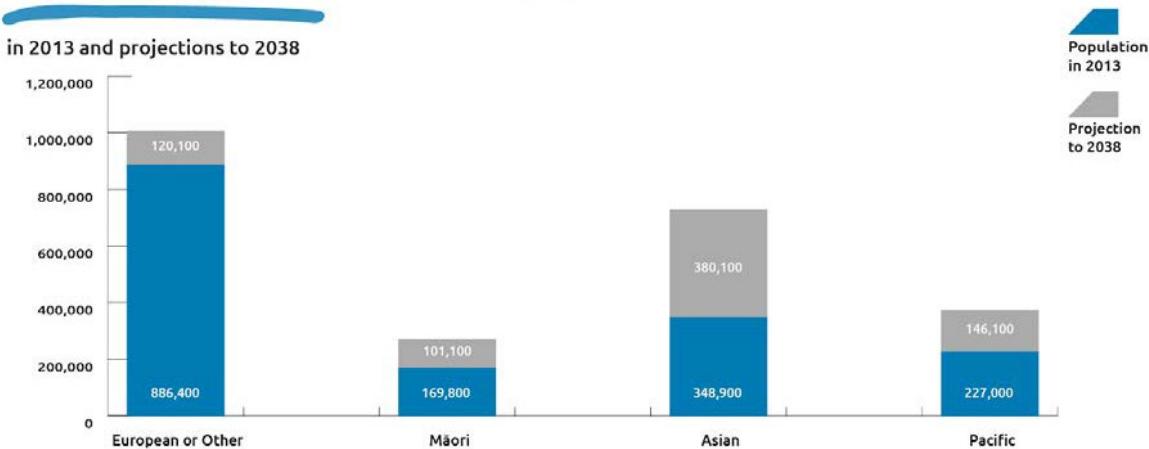


Figure.2 Source: Stats NZ, subnational ethnic population projections.

Auckland University of Technology (AUT) is the second largest and one of the leading universities of New Zealand, in the field of innovation and technology. As a young millennial university who will be celebrating its 20th anniversary in 2020, it is one of the world's best modern universities – Times Higher Education has ranked AUT as the top millennial university in Australasia and in the top 1% of universities in the world. The university's mission is simply "Great Graduates" [AUT, n.d] with a vision to respond to its place in the world through exceptional learning experiences and to contribute wellbeing and prosperity through discovery and application of knowledge. Fundamental to its vision to be a place where people love to work and learn are its values: "Tāwhaitia te ara o te tika, te pono me te aroha, kia piki ki te taumata tiketike - The path of integrity, respect, and compassion; scale the heights of achievement" [AUT, n.d]. As a university in Aotearoa - New Zealand, AUT is committed to the rights and obligations articulated in New Zealand's founding document The Treaty of Waitangi. The university advocates Māori presence and participation in all aspects of university life including the AUT Values framework and AUT authentically integrating Mātauranga Māori within research, teaching and learning. Furthermore, the emphasis put on The Treaty of Waitangi in relation to teaching and learning practices can be summed up in the following way: "The Treaty of Waitangi principle puts students at the centre of teaching and learning, asserting that they should experience a curriculum that engages and challenges them, is forward-looking and inclusive, and affirms New Zealand's unique identity" [AUT, n.d].

Students who study in Aotearoa - New Zealand will be submerged into a curriculum where the Treaty of Waitangi principles places students at the centre of teaching and learning, supporting that they should experience a curriculum that engages and challenges them, is forward-looking and inclusive, and affirms New Zealand's unique identity. An amalgamation of the Treaty of Waitangi and Mātauranga Māori has shaped AUT to be committed to building a safe, positive, and inclusive higher learning environment characterised by the free exchange of diverse ideas, skills and cultural perspectives. This

is evident through a range of student's projects that explore identity, culture, sense of belonging and wellbeing.

4. Case Studies

AUT programmes such as the Creative Technologies attracts diverse students who aspire to be entrepreneurial by hacking singular approaches to disciplines, technologies, methodologies and collaboratively innovate through transdisciplinary. The programme sits within the Faculty of Design and Creative Technologies and is recognized as a highly visible place for the development of critical and creative skills, amongst the creative industry and students. This highly visible place, which can be better framed as "creative place-making" (Markusen 2014), is an "inherently restless, unfinished process", that seeks and supports the continuous flow of creativity, and preparing the students for "pursuing the chimera of creative entrepreneurship" (Schlesinger, 2016, p.6). As an example of establishing strong co-design practices and a sense of collaborative place-making, the faculty paper Mahitani (Collaborative Practices) serves as an initiative across the DCT Schools, in order to better understand each other's background and culture and to provide the space and tools to connect with the community through an interdisciplinary community or industry project. All DCT students must take the paper as a prerequisite, which includes ethics and guiding principles of tikanga and mātauranga Māori, in order to instil the sense that they can co-create and co-design as a community and not simply as individual learners and makers. The paper description of Mahitani states:

Introduces concepts of collaborative work, in a wider context of students' work futures, that are underpinned by the guiding principles of tikanga (customary lore, practices and traditions) and mātauranga Māori (Māori-knowledge of the Māori world). Examines a relevant conceptual or thematic issue affecting Aotearoa/New Zealand through the design and completion of a small-scale collaborative project across disciplines. Explores how these concepts of collaboration relate to emerging workplaces and evolving digital work futures. (AUT Documentation)

It is important as well to highlight the learning goals and outcomes of the paper and how they relate to the above-mentioned principles of tikanga and mātauranga Māori. This is achieved through the students working together to identify and select effective collaboration strategies that include decision making and risk taking; an interdisciplinary approach to exploring data and analysing problems; reflect on the collaboration performance using a tikanga and mātauranga Māori framework; reflect on how the practice relates to the future of work across disciplines and digital environments. The project brief is dependent on a real-life client from either a community organization or a company, which provides the students with an external real-life practical learning experience.

Another one of the programme papers in the Creative Technologies - 'Integrative Practice', states as its aim to: "Explore concepts, issues and problems from more than a single disciplinary perspective. Introduces methodologies for integrating knowledge and practices

from different disciplines and allows students to both comprehend and directly address complex issues". Emphasis is put on interdisciplinary approaches and collaboration, to foster comprehension and skills "from more than one disciplinary perspective". This approach is reflected through the student practices and their creative works. Two student cases will be discussed here: Continuum (2018) and Tāngatai Tāngata (2019).

4.1 Continuum (2018)

The project 'Continuum' aims to prompt self-awareness on the performativity of heritage through facilitating conversation between two participants. This is done through an interactive and performative kinetic table. This work arose from the creator's personal desire to understand her own heritage, and to explore and understand the performativity of heritage and remembering. The work's original purpose aimed to embody the creator's journey of self-discovery of her heritage. Also, to prompt others to reconsider and 'remember' their own intangible heritage. However, it was soon realised that these were two separate projects. Thus, the purpose was refined to prompt self-awareness that their relationship with the heritage and past, influences the performance of their identity. The key message being heritage is performative.



Figure.3 'Continuum', Talia Pua (2018)



Figure.4 'Continuum', Talia Pua (2018)

DESIGN PROCESS

When heritage and memory are understood through the frame of active remembering, they are performative. As Harrison (2012) argues, "heritage is primarily not about the past, but instead about our relationship with the present and the future." (p. 4) In this way, heritage and remembering has the power and stimulate to inspire us inspire and influence our actions. From this perspective, like performativity, focus is shifted off the objects of heritage and memory, and onto the process, experience and produced effects of remembering. For the aesthetics, the layout of the table drew inspiration from family tree diagrams. The arcs of the family tree diagram were adapted to represent the continuums. The table design took inspiration from antique Chinese tables so that the participants would feel a sense of heritage before interacting with the work. Furthermore, by reinterpreting a tangible heritage artefact into a kinetic table, participants are symbolically transforming the way they relate with heritage through physically manipulating the composition of the table surface. Regarding performativity, the work drew inspiration from existing performer driven displays and performative surfaces. These included, Reuben Margolin's kinetic sculpture, 'Connected' (Margolin, 2011), MIT's kinetic tabletop, 'Transform' (Ishii, Leithinger, Follmer, Zoran & Schoessler, 2014), and Andreas Vang's 'Tectonic Clock' (Vang, 2015).

The work was developed through extensive prototyping and playtesting of all aspects of the design so to prove the design's fulfilment of the project's intention. The interaction design came from an early role-playing workshop that play-tested different performance approaches to exploring the concepts. From this, the continuum exercise was then further refined through playtesting multiple paper prototypes and cardboard mock-ups that focussed

on different elements of the exercise. For example, the wording and order of the questions, the instructions, the layout and group vs. individual context.

The physical mechanisms and design of the table were all prototyped on low-risk scales first. For example, using cardboard mock-ups, using CAD software for 3D modelling, and paper concepting. This then progressed onto a medium-risk scale where the design of the mechanisms was tested and finalised on a small scale using the chosen materials and methods e.g. plywood and laser-cutting. This progression from low-risk to high-risk scale prototyping was done to minimise costs, i.e. time, money and resources, and maximise the success-rate of the final design by proving that it works beforehand.

All feedback received and decisions made were critically assessed alongside design pillars. These pillars outlined the three key concepts the work needed to engage with, and the three-key aesthetics of play for the desired experience. The play aesthetics were informed by Hunicke, Leblanc and Zubek's (2004) MDA framework for game design. The design pillars were then adapted into a methodology flowchart which assisted in the decision-making process. This evolved an exploration of how to encourage self-expression and reflection, using theories of performativity, Tactile User Interfaces (TUI), and social play.

IMPLEMENTATION OF CONTINUUM

Talia Pua was contacted by an AUT initiative called "Wiser" - an "intimate space designed for conversation, connection, and reflection on the ups and downs of being human", consisting of a "programme of talks, workshops, rituals, and social events to explore how we can develop better self-knowledge and a greater sense of purpose and meaning in our lives", to work with them on implementing Continuum as part of Wiser's programme of workshops and events at AUT in 2020. The curatorial team are currently looking at designing a workshop around 'Continuum' that will focus on heritage and identity. As the artistic director of Wiser stated:

Continuum has a lot of value for people. I have done work with a lot of individuals who have expressed that they feel disconnected to parts of who they are and their cultural heritage. And I think that Continuum gives them an opportunity to work through some of that. The tactile nature of Continuum, the ability to touch and feel, as well as have a conversation is a really great way to open people up and help them express what they want to say. (Pua, 2018)

As a recognition of the success of the project, it won the Designers Institute of New Zealand Best Design Award, in the category of Student Public Good. This is what the Best Awards Judges stated:

This thoughtful, tactile experience stood out against a deluge of digitally based entries. We loved the way that the design returns users to a slower, more personal and connected interaction, and we imagine, a deeper conversation about heritage and identity. Wifi-free gamification meets culture in a compelling and beautiful package. (Designers Institute of New Zealand Best Design Awards, 2019)

4.2 Tāngatai Tāngata (Person in People)

Serving as an example is the collaborative duo-project ‘Tāngatai Tāngata’ (Hobman & Pua, 2019) sought to address New Zealand’s multicultural national identity by asking: “what does it mean to be a New Zealander?” Through the development of this project, it became important to find how to conceptualise identity within a New Zealand-specific lens. This led onto drawing on Māori *tikanga*, way of doing, such as *Pepeha* and the *Au to Whakawhanaungatanga* framework. To make these frameworks accessible to the public, ‘Tāngatai Tāngata’ drew on other disciplines including tangible user interface design, play and interaction, participatory art and data physicalization. “By creating and contributing their own personal ‘pepeha tile’, participants are encouraged to self-reflect on their own identity within a New Zealand-specific framework, and reflect on how they connect to the wider collective” (Hobman & Pua, 2019).

RELEVANT THEORIES

Initially Pua and Hobson considered theories on social sustainability as being equity between generations (McKenzie, 2004). Specifically, they considered this within a cultural and collective context: how can we sustainably build and maintain collective and cultural identities across generations? Other theories on nationality, identity and social sustainability were also considered within the design and development.

While national identity has been defined as being united in assimilation (Bobro, 2018), ‘Tāngatai Tāngata’ intends to contribute that national identity is built upon the preservation of its diverse collectives. Identity markers are “a characteristic associated with an individual that they might choose to present to others to support a national identity claim” (Kiely, Bechhofer, Stewart, & McCrone, 2001). For this process to develop, there is a need for more fluid national identity rules to assess identity markers.

PROJECT INCEPTION

The design and development were initially inspired by the research question - “How do we preserve a multicultural national identity?” The phrase “This is how New Zealand introduces itself - *Koinei tā Aotearoa whakamihī*” (*pepeha.nz*) was the main catalyst in the ‘Tāngatai Tāngata’ project that prompted to consider: “What would New Zealand’s *pepeha* be?”



Figure.5 *Au to Whakawhānaungatanga framework diagram (TKI & Ministry of Education, n.d.)*

Through practice as research, it was discovered that contrary to rigid notions about national identity and nationality, “New Zealand-ness” manifests in numerous ways (see images below). Moreover, from discussing with a cultural advisor Pua and Hobson were challenged with how to create a National Pepeha that would represent and relate to everyone.

Thus, it was endeavoured to discover how to create a system in which theoretically the populace could collectively create their own national pepeha. In doing so, how principles could be applied from collaborative and participatory art practices were explored. The Au to Whakawhānaungatanga framework, which was applied to the format to highlight the connection between self and the collective.

An iterative user-centred design approach was applied and throughout the process of creating tangible user interface (TUI), playtesting and interviews were conducted to progress and improve the theory. Each playtest included a follow-up interview using retrospective cognitive probes about the physical aspects, user experience, the choices made and the fundamental theory for the project. Subsequent design and development iterations of the project were through feedback and reflections.



Figure.6 'Tāngatai Tāngata', 2019 Talia Pua and Olivia Hobson



Figure.7 'Tāngatai Tāngata', 2019 Talia Pua and Olivia Hobson

5. Conclusion

Auckland Council have planned a continual growth for the next 15 years, considering the changing demographics, and increasing international competitiveness in the creative sector.

In order to support and leverage opportunities, Auckland Council and its subsidies having been planning the future of the creative sector to make Auckland the most liveable city. This paper has provided an overview of these strategic initiatives which contributes to this government goals to develop and grow arts and culture in Auckland. As New Zealand is increasingly becoming a multi-cultural and diverse city, Toi Whītiki aims to deliver on the vision and outcomes of the Auckland Plan, which includes the integration of arts and culture into everyday lives. For further development and helping to carry the mission of 'most liveable city', initiatives such as Placemaking in Practice (2018), can play a crucial role in positioning creative placemaking as the binding agent of overarching approach to improve neighbourhoods, communities, cities or towns; aiming to make arts and culture truly for all, and not just for the few. It is believed that these actions will address the challenges and opportunities in the ever-growing and increasingly diverse city. The outcomes from such initiatives will positively enhance understanding of different cultures to encourage wellbeing and a sense of belonging.

As concluding notes, it is suggested that tertiary education providers can enhance and build-up the framework for acting as testing spaces/co-designing spaces, and provide place-making approaches for council initiatives. This has been already observed on the level of the student case studies, with reference to the recognition, feedback, a part of an exhibition, and the Wiser initiative—all indications of the public engaging with the arts and culture. Embedding Mātauranga Māori within education and design research provides an open and safe place to experience and explore culture inclusiveness, our place in the world and how we engage with each other. Mātauranga Māori assists in the balance of the tension between design research, new experience design coupled with social inclusiveness. The case studies discussed illustrates how interactive activations can be a tool to unite people and culture yet also allow the participants to remember and reconnect with their heritage and for others to gain understanding and build connectedness. Allowing "the heart of people" to set the direction of the creative sector is a meaningful approach to fulfilling positive social impact, diversity, cultural acceptance, and wellbeing. As further suggestions for future research work, this paper can provide an interesting discussion and comparison with other critical design educational programs, such as that of OCAD (Ontario College of Art and Design) in Canada and draw links with placemaking projects in other cities, such as the case example of placemaking in Michigan, by the Michigan Municipal League (MML/League). In addition, AUT has recently signed a partnership with two South American Universities. The partnership includes research projects that support South American institutions to reconnect with the indigenous people through integrating cultural values and practices with learning and teaching.

6. References

- 'Art makes New Zealand a better place to live': New Zealanders [Web log post]. (2018, May 23). Retrieved December 1, 2019, from <https://tinyurl.com/tqy4sge>.

- Auckland Council. (2015). *Toi Whītiki: Auckland's Arts and Culture Strategic Action Plan*. Retrieved on November, 1, 2019, from <https://tinyurl.com/ta4g8or>.
- AucklandNZ. (n.d.). *Lantern Festival*. Retrieved from <https://www.aucklandnz.com/lantern-festival>.
- Bathurst, R. & Edwards, M.. (2011). Carrying our Future in a World of Possibility: Exploring Contemporary Implications of Maori-Pakeha Relationship in Aotearoa/New Zealand. *Tamara – Journal for Critical Organisation Inquiry*. Vol.9,(3-4), 63-74. Retrieved from: <http://www.tamarajournal.com>.
- CreativeNZ Arts Council of New Zealand *Toi Aotearoa, Summary Report. (2017). New Zealanders and the arts*. Retrieved from: https://www.creativenz.govt.nz/assets/paperclip/publication_documents/documents/606/original/new-zealanders-and-the-arts-summary-report.pdf?1526981303.
- Creative Auckland 2030*. Retrieved from: http://www.createauckland2030.co.nz/the_project.html.
- Designers Institute of New Zealand Best Design Awards*. Retrieved on November 2, 2019, from <https://bestawards.co.nz/public-good-award/student-public-good/colab/continuum/>.
- Harrison, R. (2012). *Heritage: critical approaches*. London: Routledge, 2012.
- Hayward, J. (n.d.). Principles of the Treaty of Waitangi – ngā mātāpono o te tiriti - What are the treaty principles?', *Te Ara - the Encyclopedia of New Zealand*, Retrieved on March 28, 2019 from <http://www.TeAra.govt.nz/en/principles-of-the-treaty-of-waitangi-nga-matapono-o-te-tiriti/page-1>.
- Hobman, O., & Pua, T. (2019). *Tāngata Tāngata [Board game]*. AUT: Auckland.
- Hunicke, R., Leblanc, & M., Zubek, R. (2004). MDA: A formal approach to game design and game research. *AAAI Workshop - Technical Report*. 1.
- Ishii, H., Leithinger, D., Follmer, S., Zoran, A., & Schoessler, P. (2014). *Transform [Kinetic Table]*. Retrieved from <https://tangible.media.mit.edu/project/transform/>.
- Jacinda, A. Soapbox: *Opinion piece by Jacinda Ardern. The Big Idea*. 3 September 2018. Retrieved on November 1, 2019, from <https://www.thebigidea.nz/stories/soapbox-opinion-piece-by-jacinda-ardern>.
- Kiely, R., Bechhofer, F., Stewart, R., & McCrone, D. (2001). The markers and rules of Scottish national identity. *Sociological Review*, 49(1), 33–56. <https://doi-org.ezproxy.Aut.ac.nz/10.1111/1467-954X.00243>.
- Markusen, A., & Nicodemus, A. G. (2014). Creative placemaking: how to do it well. *Community Development Investment Review*, 2, 35-42.
- Margolin, R. (2011). *'Connected' [Kinetic Sculpture]*. Retrieved March 19, 2019 from <https://www.reubenmargolin.com/waves/connected/>.
- McKenzie, S. (2004). *Social sustainability: towards some definitions*.
- Pepeha. (2018). Retrieved March 19, 2019, from <http://pepeha.nz/>.
- Placemaking in Practice. How it works? (2018). Retrieved from: <https://artintelligent.com/placemaking>
- Pua, T. (2018). *Continuum [Board game]*. AUT: Auckland.
- Sinclair, K (1971). "Why Are Race Relations in New Zealand Better Than in South Africa, South Australia and South Dakota?" *New Zealand Journal of History* 5.2 October 1971: 121-7.
- TKI & Ministry of Education. (n.d.). *Outside-school wananga*. Retrieved on March, 28, 2019, from <http://hekakano.tki.org.nz/The-programme/Outside-school-wananga>.
- Vang, A. (2015). *Tectonic Clock*. Retrieved from <http://www.andreasvang.com/?work=tectonic-clock>.
- Ward, C., & Liu, J. H. (2012). Ethno-cultural conflict in Aotearoa/New Zealand: Balancing indigenous rights and multicultural responsibilities. In *Handbook of ethnic conflict* (pp. 45-69). Springer, Boston, MA.

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Design Meets Death: Emergent Issues in a Research Study on Reimagining ‘Legacy’ in the Context of Paediatric Palliative Care

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Abstract: ‘Legacy’ is a death-centred adult-oriented concept, conventionally defined and narrowly imagined. Legacy making activities in palliative care are proven to enhance sense-making and offer therapeutic benefits. However, research around legacy and legacy making is limited in definition, outcome, and ambition. This paper reports on an exploratory, interdisciplinary, design-led study aiming to reimagine ‘legacy’, in the sensitive and heavily under-studied context of paediatric palliative care. An inclusive design approach is adopted and children and young people are focused upon as the ‘lead design partners’ with potentially distinct and largely overlooked voices and viewpoints in palliative care. Both chronological and thematic perspectives are used to outline and discuss the issues and barriers emerged throughout the study. Three overarching themes i.e. Conceptual; Ethical; and Operational are identified as key challenges. Critical reflections are summarised under three insights on Legacy, Difficult conversations, and Life design. Future opportunities for research are outlined under four recommendations.

Keywords: inclusive design; palliative care; legacy; paediatric

1. Introduction

“I don’t see the point of measuring life in terms of time any more. I would rather measure it in terms of what I actually achieve. I’d rather measure it in terms of making a difference.”

(17-year-old boy shortly before he died of cancer, 2017)

1.1 Palliative and end-of-life care

Arguments within the healthcare world around patient-centred care (Kane et al., 2015), patient-reported outcomes (Aslakson et al., 2017) and personalised medicine (Lloyd-



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Williams et al., 2008) resonate strongly with the wider recognition of the need to reclaim and reimagine end-of-life as a ‘human’, rather than a mere ‘medical’ domain (Davies, 2018), raising questions around power, control, and singular expertise in end-of-life (Author, 2019). This is further aligned with the rapidly growing evidence base in the design world, on recognition of the individuals’ right and desire to reclaim, reimagine, and design their own palliative and end-of-life experience in meaningful & desirable ways (End Well Symposium, 2019; Reimagine End of Life, 2018; HELIX, 2015; Open IDEO, 2014).

In the context of paediatric palliative care however, less is known amongst healthcare professionals about how children and young people make sense of their end-of-life experiences (Langton-Gilks, 2017; Warner et al., 2016). Approaches typically used for conducting end-of-life conversations in the adult setting have proven to be ineffective in paediatrics (Pease & McMillin, 2018) due to complexities including consent and legal authority (Thieleman et al., 2016). On the other hand, research leading to an awareness among the public and healthcare professionals of how Children and Young People (CYP) perceive their end of life experience is severely underdeveloped, and much needed (Jones & Weisenfluh, 2003). Consequently, there is, to date, no coherent framework for different disciplines in the biological, social and human sciences to work together to improve end-of-life care for CYP (Langton-Gilks, 2017; Behrman & Field, 2003).

Young adults with life limiting and life-threatening conditions have emphasised the importance of having discussions about death and dying supported by professionals and carers. Interestingly, they also note, efforts should be made to get to know them and their values prior to broaching difficult matters, further highlighting the need for engagements oriented around life, rather than death (Together for Short Lives, 2015). A need for practitioners to work more openly, proactively, and collaboratively with families has also been highlighted (Coad et al., 2014).

1.2 Legacy

A key construct in how individuals envisage their ‘end of life’ is that of ‘legacy.’ The concept of ‘legacy’ is conventionally understood in adult terms and commonly and narrowly defined as something handed down to a predecessor; the remains of a person, material and/or imagined, that lives on, once they have passed on. Hence, in its current limited definition, framed through an ‘after-death’ perspective, immediately relevant to every dying rather than living person. Such death-oriented understanding, has also been shown to permeate how adults perceive and conceive of the term when referring to children and young people’s legacy. Legacy-making activities offer a range of therapeutic benefits and have been identified as a significant enterprise with end-of-life design potentials for adults, enhancing sense-making, familial communication and positive emotional experiences (Allen, 2009).

An evidence base is beginning to emerge, which explores the meaning and impact of legacy and legacy-making in the experiences of children and young people with life-limiting and

life-threatening conditions, and their Significant Others¹ (SO) (Ackard et al., 2013). However, more often this has been gauged through the perspectives of health professionals (Foster et al., 2012) or bereaved parents (Foster, 2009). We still know little about how children and young people make sense of their own legacy, how they define and understand the term, as well as their preferences for talking about it in accessible and meaningful ways (Foster et al., 2012).

Moreover, significant differences could be anticipated in how life legacy is perceived, defined, and envisioned by CYP, compared to adults. This could be due to variances in awareness of, and adherence to socio-cultural norms and structures; imaginative and creative thinking; theories of self and personal meaning; length of life experience.

In reimagining legacy, the focus on children and young people would not only ensure their voices and visions are central to paediatric palliative care, but also add a novel and potentially significant take on the whole concept of 'legacy'. Hence, potentially enhancing, challenging and revitalising its current limited perception and potential.

1.3 Design

Beyond a process of opportunity framing and problem solving (Lawson 2007; Cross, 2006), design is an act of meaning creating (Krippendorff, K. 2006). The creative, generative, futuristic, and empathic mindset and practices of design (Johansson-Sköldberg et al., 2013) has a lot to offer to palliative and end-of-life care (Nickpour, 2019) and could inform the process of reimagining legacy. In particular, a human centred (Giacomin, 2015) and inclusive design (Clarkson et al., 2003) approach would ensure that the voices and multi-faceted experiences of users are central to every stage of the design process. Putting the extreme voices and experiences of children at the centre of reimagining legacy can be particularly helpful in challenging and innovating upon the concept for all.

An inclusive design approach implies identifying, empathising, and ultimately designing with those often ignored or excluded user groups at the peripheries, whose experiences pose the most extreme and diverse design challenges and constraints. Such focus on moving beyond the mainstream and bringing the extreme to the centre, could in turn offer rich insights, alternative novel perspectives, and lead to better-informed design challenges, re-framed opportunities, and innovative solutions that benefit all.

2. Research aims and questions

2.1 Scope and Aim

A range of gaps, limitations, and opportunities were identified within the current knowledge

¹ By 'significant others,' we refer to those individuals who are both biologically related to, and also provide tangible as well as intangible support for, the child or young person in care. Thus, this category includes parents, siblings, grandparents, aunts, uncles and cousins.

and applications of legacy in the context of palliative care. These included the narrow, death-focused, and adult-oriented existing definitions and dimensions; limited creative and generative outputs; lack of child-centred exploratory research on the topic; multiple confirmed benefits of legacy-making activities; and potential unexplored impacts of reimagined legacy-making activities on life trajectory and health outcomes.

Hence, an interdisciplinary design-led study was planned, aiming to reimagine legacy in the context of paediatric palliative care. The research study was co-defined and co-led by an interdisciplinary team of senior clinicians from a children's hospital and academics, coming from three distinct fields i.e. Paediatric palliative care, Design, and Management.

2.2 Research questions

Accordingly, four research questions were outlined;

- How might CYP receiving palliative care, reimagine their 'legacy'?
- How might CYP's SO, reimagine notions of 'legacy'?
- Based on the data from (RQ1) and (RQ2), how might CYP and their SO co-define, co-capture and co-curate 'legacy' in ways that are cognitively, emotionally, spiritually and psychologically satisfying to all concerned?
- How might legacy-making activities impact life trajectory and health outcomes in CYP and their SO?

The notion of 'legacy is for all' underpinned the exploratory research, aiming for a mentality shift in focusing on legacy as a life-centred, ongoing, dynamic, imaginative, and inclusive concept – for all those living, rather than only for those dying. CYP were seen as one progressive, distinctive and uncontaminated voice to help reimagine legacy. Furthermore, by adopting the concept of legacy as a hook, and through use of generative and creative processes and methods, the study aimed to open up spaces of dialogue around a meaningful life, what CYP wanted to achieve alongside, and how they wanted others to know about or remember them. Figure 1 captures the different approach to 'legacy' in the context of this study.

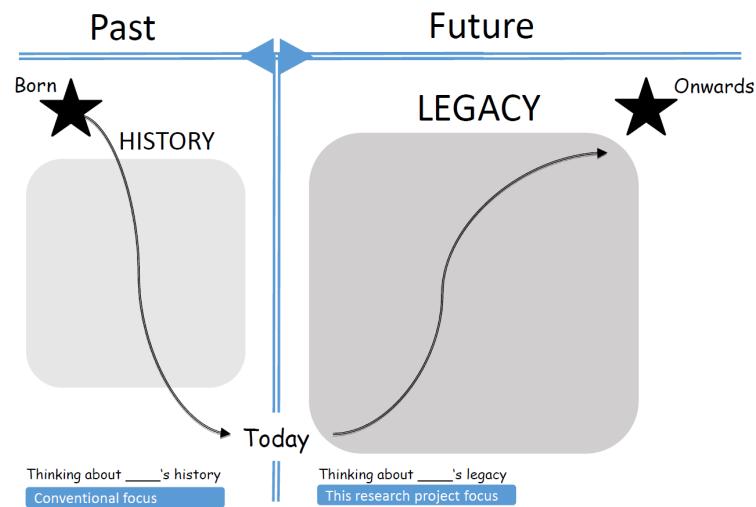


Figure 1 Legacy, a different take; LEGACY reimagined as an ongoing unending concept versus 'HISTORY' as a past concept

3. Study design and Development

Table 1 outlines the study plan comprising multiple stages, running across a 12-month period.

Table 1 Legacy Study plan running across 12 months

Stage & Activity	Length (month)
Review literature on the overarching areas of legacy, CYP, and design	3
Design Initial Legacy-making 'Creative Session', structured around RQs 1, 2 and 3, and informed by the literature review	1
Review initial session design by Steering Committee	0.5
Apply for research ethical approval	2
Recruit participants by approaching guardians for initial interest, if positive, followed by provision of information sheet, followed by a meeting with clinical team conducting the session, who will explain the study in detail and seek consent if the guardian and CYP is agreeable	2
Pilot three Legacy-making 'Creative Sessions' conducted with three eligible CYP and their SO	1
Review and finalise the 'Creative Session' by study Steering Committee	0.5
Conduct eight Legacy-making 'Creative Sessions' with CYP and their SO	8
Design 'Reflection Session' including semi-structured qualitative interviews with CYP, their SO, and facilitating staff	1
Review 'Reflection Session' by Steering Committee	0.5
Conduct 'Reflection Session' with participants involved in Creative Session	8
Data analysis	9

3.1 Ethics and Governance

A substantial ethical approval application was planned for approval by Integrated Research Application System (IRAS) which is the notional body for health, social and community care research permissions and approvals in the UK.

3.2 Sample and Recruitment

The concept of “legacy is for everyone” underpinned the recruitment strategy. Hence, all Children and Young People (CYP) diagnosed with a life limiting condition and their Significant Others (SO) who were referred to the participating hospital’s Specialist Palliative Care team, were considered eligible to participate in the research. Additionally, a clear inclusion and exclusion criteria was outlined to be carefully considered by Specialist Palliative Care team on a case by case basis. Table 2 outlines the study inclusion and exclusion criteria.

Table 2 Inclusion/Exclusion Criteria for participation in the Legacy Study

Inclusion Criteria	Exclusion Criteria
CYP with life limiting conditions referred to the Specialist Palliative Care team at the children’s hospital	Deemed too unwell/too advanced/not suitable by Paediatric Palliative Care Multidisciplinary team
SO of CYP referred to the Specialist Palliative Care team	Parent or guardian not providing informed consent
CYP Aged 4-18	CYP aged below 4 or above 18 CYP not providing assent

3.3 Stakeholders Mapping & Steering Committee

Due to the exploratory, complex, and sensitive nature of the research, an interdisciplinary group of stakeholders, who work with the target population in different capacities, were mapped. These stakeholders were also invited to join the study as the Steering Committee. They met regularly as a team, and were consulted separately where needed to review, advise, and steer the study. Figure 2 represents the Steering Committee’s spread of expertise and perspectives.

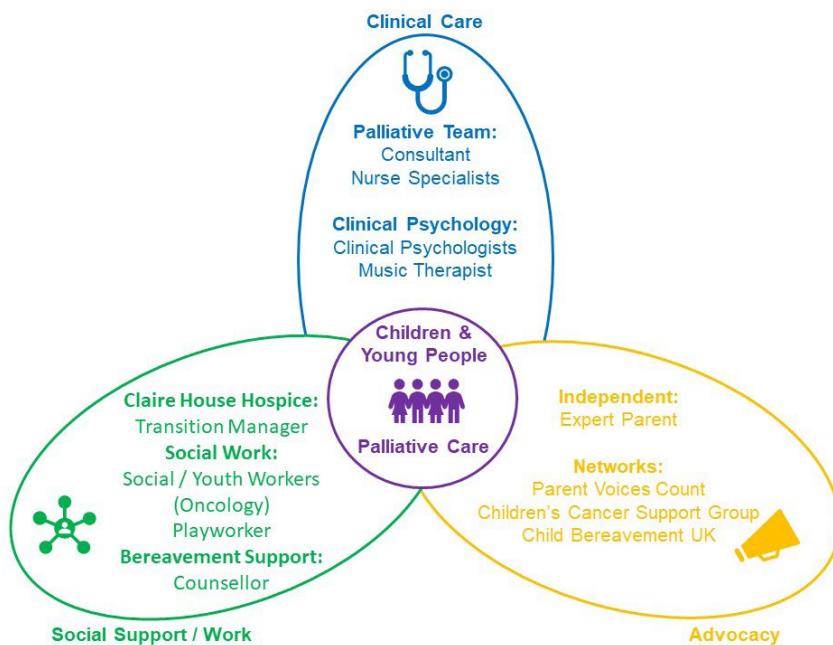


Figure 2 Legacy Study stakeholder mapping and Steering committee members

The initial study design was reviewed by committee members including two bereaved parents, a music therapist, a clinical psychologist, a patient and parent participation facilitator, and a bereavement counsellor.

4. Issues and Barriers

The study progressed into pilot phase but did not reach the Legacy-making Creative Session stage, due to a number of issues and barriers. Both chronological and thematic perspectives are used to outline these emergent issues. Firstly, an account of specific issues faced at different stages of the study is provided. Secondly, all barriers are categorised under three over-arching, inter-linking themes.

4.1 Chronological issues

CYP PROFILE

The inclusion criteria at the onset of study, included CYP aged 4-18, with normal global development and verbal communication, enrolled on a palliative pathway. This however, needed to be reviewed, in order to ensure CYP were fully involved and their distinct individual voices were captured. It was commonly understood that adolescence was the age, when children began to form their own distinct identity and voice (Briggs, 2002). However, in the context of paediatric palliative care, the confounding factors were the often multiple complex health and social difficulties that accompanied these young people, affecting their development and their ability to verbally communicate.

Accordingly, the participation age was revised as 11-18. Furthermore, a narrow band of specialties i.e. Cardiac, Duchenne Muscular Dystrophy, and Oncology was focused upon,

where CYP were more likely to have typical developmental and communication abilities, to participate with personal agency, see Figure 3. Despite the inclusive “Legacy is for Everyone” remit of the study, the time and budget limitations did not allow specialist support to facilitate participation of CYP with developmental and communication gaps. This excluded certain voices and reduced the already small number of potential participants.

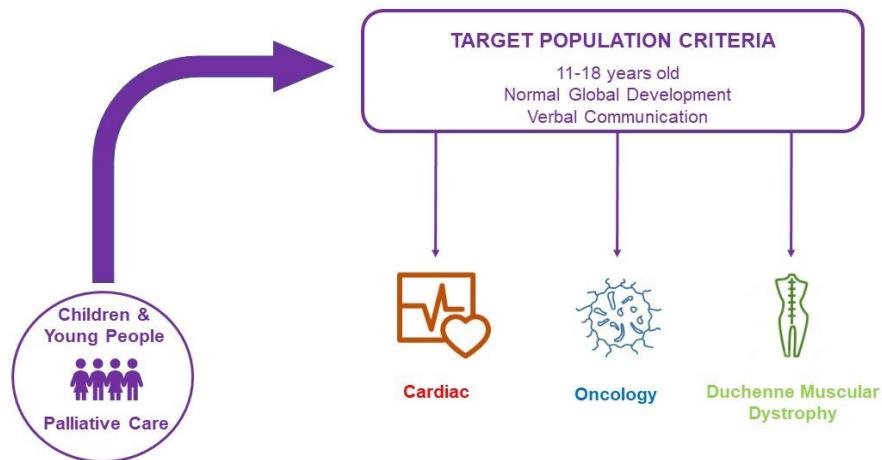


Figure 3 Re-focused CYP participant profile

PUBLIC AND PARTICIPANT FRAMING

The intention was to help reimagine legacy for everyone through an inclusive design approach. However, a necessary ethical and practical consideration in recruitment strategy, was to redress the real possibilities for misunderstanding the concept of legacy, and the overall study, in participant-facing communication.

It was acknowledged that framing the initiative through the lens of legacy, could cause negative emotions, depending on previous conversations regarding the CYP's condition, and the meaning attached to their prognosis.

From a clinical psychology perspective, the introduction of the study to a potential CYP and their family, could irrevocably challenge the understanding of the family, and the knowledge and understanding the CYP might have of their condition. Such a situation could only be mitigated through communication with the network of healthcare professionals and others involved in care of the CYP, in order to establish where a given family were in their journey, prior to approaching them for participation.

As a rejoinder to this issue, it was decided to explicitly use the term 'legacy' in communications and public framing, to maintain the project's integrity, and to keep intact transparency regarding its intentions. The project heading “Legacy is for Everyone” attempted to convey the relevance of legacy, and participant information sheets, helped to explain in positive terms, how engagement with legacy, could help people think about

what they wanted to do with their lives and their wishes and hopes. Hence, an attempt was made to challenge default perspectives, aligned to death and passing on, by including broad interpretations of the term.

STUDY DESIGN

Adding an ‘orientation’ phase

Interdisciplinary input from Steering Committee helped identify further issues around introduction, framing, accessibility and vulnerability, and gatekeeping, prior to participation in the Creative Session. Hence, an initial ‘Orientation session’ was added to the ‘Creative Session’ and ‘Reflection Session’ already planned. This was in order to better introduce the study to participants; include preparatory work to help inspire and orient both CYP and their SO; conduct a ‘pulse check’ in order to identify unique circumstances, current paths, and customise support needs; apply a sensitive stepped approach to make the study accessible and meaningful.

Separation of CYP and SO sessions

The main premise of the study was to elicit the distinct voices of CYP. However, within the sensitive and extreme context of paediatric palliative care, the parent or adult caregiver were repeatedly reported to gatekeep participation and speak on behalf of the CYP. Hence, CYP and SO sessions were separated in order to ensure CYP’s narratives. This, however, raised further issues around unsupported separation of CYP from their SO, which could put CYP, SO, and the researchers in a vulnerable position.

Framing & Format

A pilot session with teenagers in a palliative care support group, confirmed issues around framing and terminology. Young people at the group struggled with finding meaning in the concept of legacy, which needed to be further unpacked and illustrated with reference to different examples of legacy making. There was a tangible sense that legacy, was not something that was part of their everyday language and experiences, or held age-appropriate significance.

Young people also noted that the project had to be engaging and fun and provide relevant and appropriate opportunities to think through their lives, in meaningful ways. Tapping into contemporary teenage interests, popular culture e.g. music and digital games, and interesting ‘hands-on’ ways of generating information and insights, were specifically noted as potential hooks.

PILOT PHASE

Recruitment

Recruitment for pilot phase was led by stakeholder groups who worked closely with CYP and their SO. Early on, the senior consultant co-leading the project had to leave the study due to unforeseen circumstances. This significantly impacted the recruitment as the consultant was well respected as a strong authority and gatekeeper in terms of recruitment, trust and gatekeeping. This raised issues around the sensitive nature, gatekeeping, and hierarchy of

power, authority and expertise in conducting research. Targeting strategies were devised by expert stakeholders based on perceived ability to engage with the activities and appropriate resilience and coping strategies. This raised issues around sample size and purposeful sampling.

A general lack of interest and poor response rate to the pilot initiative was reported by gatekeepers. Introducing the project under the banner of 'Legacy' seemed a barrier to participation. More often the term 'legacy' was understood by parents, in terms of its 'after-death' meaning. Overall, the framing of interventions associated with end-of-life and death were not seen as sympathetic with the cultural context of oncology, for example, where narratives of hope and survivorship predominate.

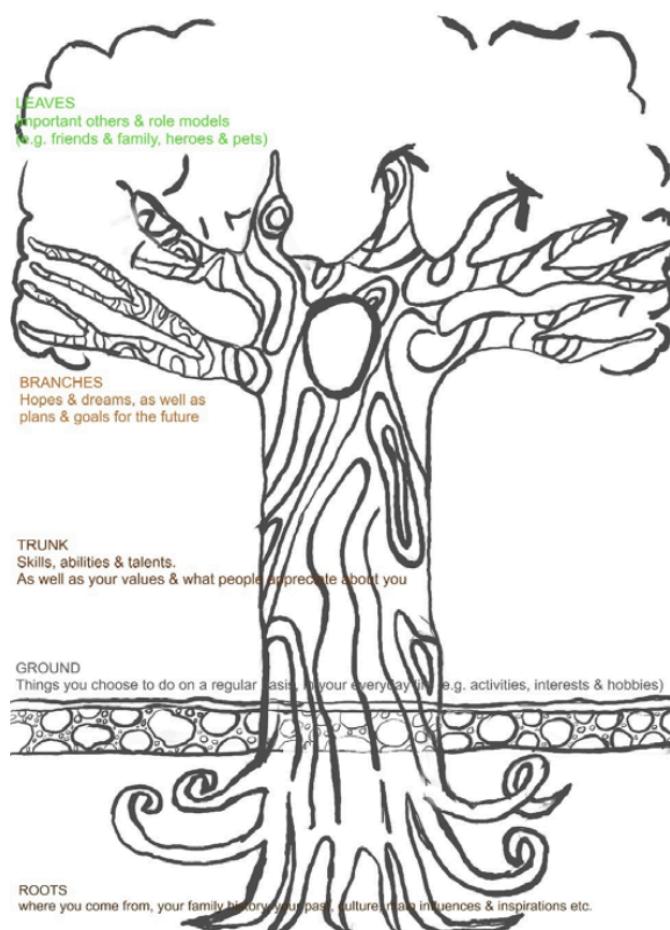
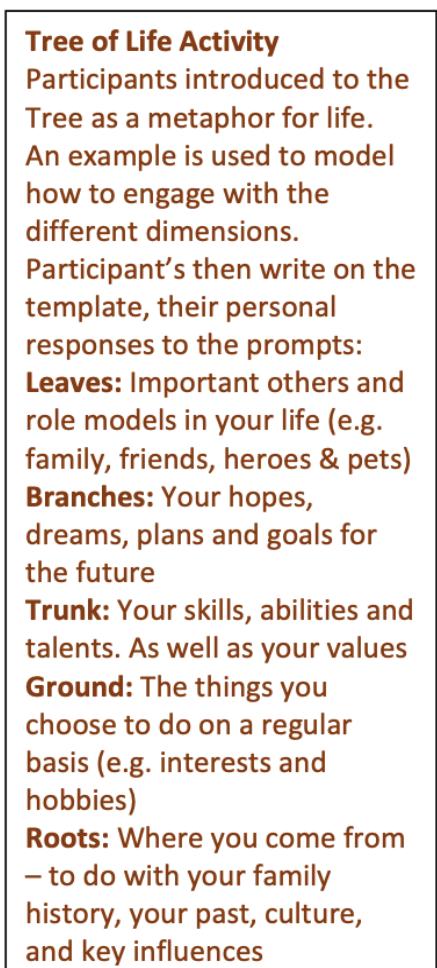


Figure 4 'Tree of Life' exercise

CREATIVE WORKSHOP

The pilot was introduced as part of a legacy project, giving an opportunity for CYP and SO to reflect on their lives, what they had done, the relationships they had made, what they wanted to do in the future and how they could make their own unique mark on the world.

Tree of Life method used predominantly in narrative therapy, (see Figure 4) was presented and participants were invited to reflect on their own lives in relation to each dimension of the tree.

The Tree of Life exercise was generally well received by the CYP as a clear, engaging and meaningful activity. CYP noted that it helped them think about matters not already considered. At the same time, they struggled with the branches level (hopes and dreams). This brought to surface, the inherently different nature of sense of future, perspective and trajectory of life in this context. And while a significant finding in itself, it was seen as a potential negative trigger, reminding CYP of their prognosis.

The small number of participants (2 CYP) was seen as a barrier. Additionally, the invasive nature and considerable level of help needed from support workers to complete typical workshop activities e.g. scribbling or drawing, impacted the information privacy and agency of CYP. Hence, the nature of data collected, was seen as major accessibility and gatekeeping challenges. CYP noted that participants should be given a choice of whether, or not to talk about their tree with the facilitator (for some, this might be considered private information).

4.2 Thematic issues

Various issues captured chronologically, are classified under three overarching themes, and discussed here.

1. CONCEPTUAL; PERCEPTIONS OF LEGACY IN PAEDIATRIC RESEARCH

There are challenges in engaging with, or implying, death in paediatric legacy interventions, which can be mis/understood as taking away hope and associated agency from the perspective of adults involved. Accordingly, researchers and practitioners using legacy interventions, have reported various difficulties in framing their work.

A key barrier, was the research focus itself, that of legacy. The impact and consequences of using legacy as an explicit framing device, was noted in both adult and CYP participant groups, across study design, gatekeeping, and recruitment.

Perspectives and attitudes towards legacy vary depending on age and position; while there is an implied onus on a post-death perspective in adult perceptions including SO (Ackard et al., 2013) and healthcare professional (Foster et al., 2012), CYP have differing viewpoints. Ackard et al. (2013) explored children with cancer's interest in legacy-making and contrary to what the research team anticipated, child participants aged 7 to 12, did not articulate or stress end-of-life concerns. Instead they expressed their wishes for others to know about: their personal characteristics; things they like to do, and; their connectedness with and love for others.

Such perception has also been uncovered in health care professional's reflections on interventions in paediatric palliative care settings (Foster et al., 2012). A thematic analysis of key perspectives noted that legacy-making activities are more often introduced at the very end of the child or young person's life, reinforcing the connection between legacy-making

and the termination of life. Interestingly, in qualifying this perspective and endorsing the need for legacy-making interventions at an earlier point, paediatric health care professionals, noted that legacy making interventions could add considerable value to child 'survivors', providing a tangible record of their journey (Foster et al., 2012), opening up new possibilities for the application of legacy interventions. This near uniform adult meaning attributed to legacy, turned the concept, in its context of vulnerability and life-limiting conditions, into something akin to a 'hot potato' that no one was particularly keen on handling.

CYP's feedback also revealed that the term didn't resonate with them and was neither a relevant term to them as teenagers, nor allowed much scope to explore and make sense of their individual life circumstances.

From a study design point of view, the time, resources, and coordination required to prepare the study sensitively for the target population were significantly increased considering the very nature of 'legacy'.

2. ETHICAL; FLEXIBILITY, GATEKEEPING AND INCLUSIVITY

The nuances and sensitivities of employing the concept of legacy in paediatric contexts, has also been discussed in relation to the ethics of practice.

Flexibility

Building on the seminal work of Bluebond-Langner (1978), Moxley-Haegart (2015) attempts to articulate to parents and primary care-givers, the CYP's capacity to talk about death, and employs alternate approaches to legacy-making that respond to, and are led by the CYP and SO. These approaches move between 'open awareness', where it is safe to talk about death and, 'mutual pretence' where CYP have trouble talking about death. This has led Moxley-Haegart to omit the term 'legacy' when working with some CYP, adopting alternative frames of reference that still enable meaningful engagement with legacy-making activities, such as: 'a project which lets others learn about us'; 'messages for family and friends'; 'a way of helping others who might have similar experiences'.

Gatekeeping

Gatekeeper refers to an adult able to control or limit researchers' access to participants. Gatekeepers have a positive function in ensuring that children are protected from research that could potentially be exploitative, invasive or coercive (Royal College of Paediatrics and Child Health Ethics Advisory Committee 2000).

The default perception in paediatric research, paints a picture of CYP as 'vulnerable' research subjects that need protection, placing responsibility onto adults to monitor and control access (Carter, 2009). While this can promote a keen and necessary safeguarding sensibility, it can also constrain and downplay children's abilities, competencies and understandings (Campbell, 2008). It also impacts on the perception of research and the position of researchers as potentially 'dangerous' (Carter, 2009).

In paediatric palliative settings, the notion of vulnerability is amplified by an order of magnitude, and argued to impact opportunities for CYP to participate and have their

voices heard (Carter, 2009). In other related research, clinical gatekeepers excluded eligible families due to: perceived burden research would place on the family and their well-being (Beecham et al., 2016; Stevens et al., 2010; Shilling et al., 2011); concerns about anticipated benefits (Westcombe et al., 2003) as well as; the likely impact on patient/family-professional relationships (Castell, 2006).

Accordingly, many studies are hampered by low rates of invitation (Hinds et al., 2007), the highest refusal rates (Gattuso et al., 2006), and identifying issues with recruitment (Tomlinson et al., 2007) due to gatekeepers deeming research with CYP and families, as inappropriate (Crocker et al., 2015).

In the context of this study, all the above were observed to be true. The explicit focus on legacy impacted most acutely on adult stakeholders' protection of perceived 'vulnerable' CYP and their SO, and monitoring and controlling access to the study.

In discussing all these ethical barriers, Tomlinson et al (2007) make a crucial point that whilst research in paediatric palliative care contexts can touch on extremely sensitive issues, none-the-less, research is still required, and perhaps more so, to better understand the context and its challenges, and to help uncover insights and strategies to support CYP and their families.

Inclusivity

Issues of accessibility and inclusion were also paramount. Some stakeholders acknowledged perceived difficulties in recruiting and bringing together CYP from different specialities in the peer-based Creative Session. In more detail, it was felt that such a scenario could bring together CYP at different stages in the journey, privy to different interpretations about the meaning of their condition, as well as create issues in group dynamics.

In addition, the stakeholders noted that the resources required to support the participation of CYP and SO, could prevent potential participants' access to and inclusion in the initiative. These were mainly due to complex and diverse range of CYP support needs, as well as logistical difficulties of bringing together CYP and their SO from across a vast geographical area.

3. OPERATIONAL; PREPARATION AND GROUNDWORK

Beecham et al. (2016) summarise operational barriers to conducting paediatric palliative care as limited time and other resources, small sample sizes, limited funding, difficulties with research ethics committees, the unpredictable nature of the illnesses and professional perceptions of the potential physical and psychological burden for participants.

Additional time needs to be afforded to setting up research in paediatric health settings (Coyne, 2010), with the groundwork required to carry out research, even more time, support and resource intensive in palliative settings (Tomlinson et al., 2007). This matched the findings from this exploratory interdisciplinary study, leading to time slippage in implementation plan. It could be argued that the effort, time and resources required to undertake research in this context were too great for an exploratory study of this size.

Early involvement of stakeholders in applied health research is understood as crucial in ensuring the relevance and cultural competence of research (NIHR, 2015). This would seem even more necessary in sensitive contexts, such as paediatric palliative care (Tomlinson et al., 2007). In assessing challenges in conducting paediatric palliative research, Tomlinson et al. (2007) identified project completion success criteria, which included engaging the opinions of key stakeholders, and crucially families, at an early stage including their involvement in study design. While the study was co-designed with key stakeholders, this was not considered detailed enough in order to hit the ground running, alluding to the highly complex, sensitive, exploratory, and interdisciplinary nature of the project. In this context, the study was deemed as ambitious, and underfunded.

5. Insights and Recommendations

5.1 Insights

LEGACY IS (NOT) FOR EVERYONE?

One major point of discussion is if and how to best communicate the explicit focus on a challenging concept such as legacy, while the aim is to reimagine that very concept. The study's underpinning "Legacy is for Everyone", attempted to convey an obvious yet sensitive insight. In the context of paediatric palliative care however, adult stakeholders and gatekeepers perceived engagement with it as too sensitive for majority of the target population. As with CYP, the concept did not seem to have enough relevance or traction.

DIFFICULT CONVERSATION ARE FOR EVERYONE?

There is evidence that timely difficult conversations can support better outcomes in paediatric palliative care (Jack et al., 2018; Coad et al., 2014; Lotz et al., 2013; Dyregrov, 2004; Scott et al., 2002). Research can pose difficult conversations that haven't happened, but could, and perhaps need to. There is an evident need for CYP and their SO to enter this conversational space.

The challenges identified in this study are not limited to its specific scope, but reflect on broader systemic and palliative care disciplinary challenges. They also reflect on the organisational culture within a children's hospital that has to deliver within extremely complex and sensitive boundaries, whilst also encourage efforts to make boundary crossings into difficult conversation spaces, worthwhile. CYP and SO need evidence and confidence that more open and potentially difficult conversations can enrich the journey. Equally, adult stakeholders and gatekeepers need evidence and support on why and how to navigate such vulnerable, yet potentially invaluable pathways. The adopted design approaches could be re-purposed to facilitate entering the difficult conversations space, in a creative and inclusive manner.

LIFE DESIGN IS FOR EVERYONE?

Beyond its 'legacy' focus and the healthy tensions embedded within it, this study intended to promote and enhance CYP's agency by adopting a human centred and inclusive design approach. Design's empathic and imaginative approach was deemed suitable in both eliciting how CYP define and evaluate their lives, as well as ideating and leading what CYP want to do with its remainder.

Design and making opportunities are not only expressive but inherently linked to connecting with others (Gauntlett, 2018). These acts of creating, making, and connecting can help CYP and SO navigate the palliative and end-of-life landscape, and communicate and develop coping resources and strategies (Foster et al., 2015). A design-led mindset to CYP life, could assert more agency about the what, when, why, how and with whom of their lives.

5.2 Recommendations

Planning for systematic, extensive and extended research co-design phase with a well-orchestrated network of interdisciplinary expert and lived experience stakeholders.

Capturing paediatric palliative care stakeholders' existing practices and experiences of engaging in difficult conversations with CYP and their SO. This will be instrumental in better adoption and adaption of design approaches to enhance and facilitate difficult conversations.

Linking challenges identified in this study to broader, deep-rooted systemic and organisational challenges in engaging paediatric service users and their significant others, within a default culture of parental and adult gatekeeping. Without acknowledgement of such systems issues, any project within similar realms, will likely fall short.

Exploring diverse and truly inclusive methods of participation where neither creativity of process or output, nor agency and privacy of CYP is compromised. Given the complexity of CYPs and SO lives on the palliative pathway, alternatives to a one size fits all data collection phase, should be considered.

6. References

- Ackard et al. (2013). From Qualitative Work to Intervention Development in Pediatric Oncology Palliative Care Research, *Journal of Pediatric Oncology Nursing*, 30 (3), 153-160.
- Aslakson RA, et a. Patient- and Caregiver-Reported Assessment Tools for Palliative Care: Summary of the 2017 Agency for Healthcare Research and Quality Technical Brief. *J Pain Symptom Manage*. 2017 Dec;54(6):961-972
- Behrman, RE, Field, MJ. (2003) When children die: Improving palliative and end-of-life care for children and their families
- Braun, V. and Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3 (2). pp. 77-101. ISSN 1478-0887
- Briggs, S (2002). *Working with Adolescents: A contemporary psychodynamic Approach*. Basingstoke: Palgrave Macmillan
- Cross, N. (2007). *Designerly Ways of Knowing* (1 edition). Boston, MA: Birkhäuser Architecture

- Coyne, I. (2010). Accessing children as research participants: examining the role of gatekeepers. Editorial. *Child: care, health and development*, 36, 4, 452–454
- Dyregrov, K. (2004). Bereaved parents' experience of research participation. *Soc Sci Med*; 58: 391–400.
- Davies EA. Why we need more poetry in palliative care. *BMJ Support Palliat Care*. 2018 Sep;8(3):266-270.
- End Well Symposium; Design for the End of Life Experience. <https://www.endwellproject.org/> (Accessed 02/12/19)
- Foster et al. (2012). Palliative nursing care for children and adolescents with cancer, *Nursing: Research and Reviews*; June, 2, 17-25.
- Giacomin, J. (2014) What Is Human Centred Design?, *The Design Journal*, 17:4, 606-623, DOI: 10.2752 /175630614X14056185480186
- Gauntlett, D. (2015). The LEGO System as a tool for thinking, creativity, and changing the world. In: *Making Media Studies: The Creativity Turn in Media and Communications Studies*, New York: Peter Lang
- Gauntlett, D. (2018). *Making is Connecting: The Social Power of Creativity, from Craft and Knitting to Digital Everything*. Cambridge: Polity Press.
- HELIX; Living well until we die <https://helixcentre.com/project-live-well> (Accessed 02/12/19)
- Hexem, K, Mollen, J, Carroll, K. (2011) How parents of children receiving pediatric palliative care use religion, spirituality, or life philosophy in tough times. *Journal of Palliative Care*
- IDEO Methods Kit <http://www.designkit.org/methods> (Accessed 02/12/19)
- IMM van der Geest, ASE Darlington, IC Streng (2014) Parents' experiences of pediatric palliative care and the impact on long-term parental grief. *Journal of Pain and Symptom Management*, Volume 47, Issue 6, June 2014, Pages 1043-1053
- Johansson-Sköldberg, U., Woodilla, J., & Çetinkaya, M. (2013). Design Thinking: Past, Present and Possible Futures. *Creativity and Innovation Management*, 22(2), 121–146. Retrieved from
- Kane PM, et al. The gap between policy and practice: a systematic review of patient-centred care interventions in chronic heart failure. *Heart Fail Rev*. 2015 Nov;20(6):673-87
- Krippendorff, K. (2006). *The Semantic Turn: A New Foundation for Design*. Boca Raton, FL.: Taylor Francis.
- Langton-Gilks, S. (2017) Follow the Child: Planning and having the best End of Life for your Chid
- Lawson, B. (2006). *How Designers Think* (4th ed.). Oxford: Elsevier
- Lloyd-Williams M, Reeve J, Kissane D. Distress in palliative care patients: developing patient-centred approaches to clinical management. *Eur J Cancer*. 2008 May;44(8):1133-8
- Moxley-Haegart (2015). 'Leaving a legacy' and 'Letting the legacy live'. *The International Journal of Narrative Therapy and Community Work*, 2, 58-69.
- Nickpour, F. (2019). Design Meets Death. A case of critical discourse and strategic contributions, *The Design Journal*, 22:sup1, 2275-2280, DOI: 10.1080/14606925.2019.1595026
- NIHR (2015). Going the extra mile: Improving the nation's health and wellbeing through public involvement in research. <https://www.nihr.ac.uk/patients-and-public/documents/Going-the-Extra-Mile.pdf> Accessed 10 October 2019
- Open IDEO. How might we reimagine the end-of-life experience for ourselves and our loved ones? <https://challenges.openideo.com/challenge/end-of-life/brief> (Accessed 02/12/19)
- Reimagine End of Life. <https://letsreimagine.org/> (Accessed 02/12/19)

- REPSSI (2007). *The mainstreaming psychosocial care and support: A manual for facilitators*. Regional Psychosocial Support Initiative.
- Scott, DA, Valery, PC, Boyle, FM, and Bain, CJ. (2002). Does research into sensitive areas do harm? Experiences of research participation after a child's diagnosis with Ewing's sarcoma. *Med J Aust*; 177: 507–10.
- Thompson, A. (2015). Paediatric palliative care. *Paediatrics and Child Health*, 25 (10), 458-462.
- Tomlinson D, Bartels U, Hendershot E, et al. (2007). Challenges to participation in paediatric palliative care research: a review of the literature. *Palliative Medicine*, 21, 435–440.
- Warner E, Kent E, Trevino K, Parsons H, Zebrack BJ, Kirchhoff AC. (2016). Social well-being among adolescents and young adults with cancer: A systematic review. *Cancer*. 1;122(7):1029-37. DOI: 10.1002/cncr.29866.

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Understanding Dynamics of Identity Navigation in Social Design

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Abstract: The aim of this paper is to initiate an interdisciplinary dialogue between social design and narrative theory in understanding how vulnerable families navigate personal and shared identities. To exemplify this, we draw upon results from a design research project that introduces board games in prisons to help children develop bonds with their incarcerated fathers. In our case study we offer a method of analysis that enable design researchers to delve into the complex field of identity navigation. Further, we offer a focused reflection arguing that the vulnerability of these families can be conceived as family identities being broken or challenged. We attempt to show that identity is constructed through family members' co-authoring of family narratives, which manifest themselves in different formats such as 'master narratives' and 'counter narratives'. Design research has the potential to examine identity formations by applying narrative theory in practice.

Keywords: social design; identity navigation; family narratives; design research

1. Introduction

Social design is characterised by participatory approaches to researching, developing, and realising new ideas that may lead to increased resilience for vulnerable groups (Armstrong et. al, 2014). The characteristic given by Leah Armstrong, Jocelyn Bailey, Guy Julier, and Lucy Kimbell consists of using participatory design activities to "make change happen towards collective and social ends, rather than predominantly commercial objectives" (2014, p.15). In this context, design researchers need analytical tools, methods and models that enable them to evaluate the impact of a given social design project and whether it offers a qualitative change to the people we design with and for (Knutz, Markussen & Lenskjold 2019; Knutz & Markussen 2019).

In this paper, we reflect upon the preliminary results of a research project aiming to



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help Danish children tackle some of the problems they experience due to their fathers' incarceration. More specifically we argue that the vulnerability of these children has to do with their family identity being broken or somehow disrupted. One way to repair their family identity is by enabling processes and situations where they get an opportunity to co-author family narratives with their fathers and other relatives. This remedying potential of storytelling is recognised by the Danish Prison and Probation Services insofar as it offers "Night Stories," an initiative for inmates who can record themselves reading fairy tales or kids' books aloud to be sent home to their children. Initiatives like these rely on the assumption that the telling and sharing of stories between parents and children play a significant role in children's identity formation and development. While "Night Stories" works for small children, there is a lack of similar initiatives for teenagers and adolescents – a group for which the question of identity formation is particularly important.

The process of identity development is a life-long process but starts during the physical changes of puberty, when a teenager starts to consider issues of identity (Erikson, 1968). In this process, the family and the stories told within a family play a crucial role in how we define ourselves and how we construct meanings of our personal and shared past (Cohler, 1982; Bruner, 1990; Fivush and Baker-Ward, 2005; McLean, 2016). Moreover, empirical studies have documented that the continuous telling and scaffolding of family stories can help children and adolescents to better cope with the separation from or loss of a parent, for instance due to secondment, illness, divorce or death (Saltzman et al. 2013).

The telling and sharing of these stories usually take place in everyday surroundings, for instance during dinnertime, bedtime or day-to-day events. However, when a parent is imprisoned for a long time, it becomes increasingly difficult to maintain and develop family narratives between parents and children, since the family no longer has the home and daily life as the natural setting for sharing stories (Arditti et al, 2003; Jewkes, 2005; Markson et al., 2015). The continuous structure of shared stories becomes increasingly fragmented or broken. To remedy this situation, we have designed a family board game with the purpose of enabling incarcerated fathers and their children (age 11-18) to re-establish the process of co-constructing family narratives by sharing stories during visiting hours. Through different gameplays the players are invited into a serious, yet playful game, where the family members can share their feelings, relive past experiences and important events as well as express their wishes and dreams for the future. The underlying assumption is that, as it helps prisoner families to maintain family narratives, the game can have a positive impact on children and adolescents' coping skills and well-being.

However, this effect study is beyond the scope of the present paper, in which we instead explore how family members, who have played this board game, talk about their experiences. In particular we focus on how the game enables participants to craft stories, how they talk about and represent themselves, how they talk about others and how they construct and navigate identities through the telling of these stories. We also look at how 'master narratives' and 'counter narratives' play a role in the formation of individual and shared identities and how these narratives sometimes conflict.

In the first part of the paper, we start out by providing some conceptual clarifications of what we mean by family, master and counter narratives and how they can serve as valuable analytical lenses for studying identity constructions. While these three forms of narrative can be a good starting point, we need however to introduce Bamberg's (2011) so-called *three dimensions of navigation* to fully grasp identity construction as a fluid and dynamic social process. By introducing these dimensions, we are able to point out some dilemmas in how family members conceive differently of their group identity.

In the second part of the paper, we move on to describe our case project: the design of a game for prisons and the research context. Moreover, we lay out a 3-step method for analysing how the game may prompt family storytelling and what kind of identity construction that takes place through it. In our analysis we identify a number of narrative categories that seem to be at play. Furthermore, we apply Bamberg's three dimensions of navigation in order to single out some dilemmas in relation to the individual and shared family identity. Based on our analysis we then present rich visual mappings that allow for a precise diagramming of how identity navigation takes place between our participants. In so doing, we get a better understanding of whether games as used for social design purposes may offer a qualitative change to the families playing the game.

2. Studying identity constructions through family, master and counter narratives

The term *family narrative* refers to the stories we tell, share and co-construct as family members. They consist of all the things we talk about as a family on a daily basis. That may be past events: stories of family members being remembered; important events like family vacations or birthdays or minor day-to-day events. Creating and sharing these stories help family members to maintain emotional bonds and help children, in particular, to create a sense of who they are and how to relate to others (Fivush et al, 2011; Fivush and Merrill, 2016). Intergenerational stories – the stories that parents and grandparents share with their children about their own past – help children to make sense of their personal and shared past and contribute to the family identity and individual well-being (Zaman and Fivush, 2011).

Inquiries into family narratives increases our knowledge of how people lead storied lives – individually and socially – and how they shape their lives according to stories. They provide a specific insight into how stories play a role in the formation of family identities. Empirical studies suggest that family narratives are important in identity formation and well-being (Bohanek et al., 2006). Furthermore, a family's ability to co-author and scaffold narratives concerning stressful or traumatic events, such as parental separation and loss, can support children and adolescents to better cope with difficult life situations (Saltzman 2013). More recently, Fivush, Bohanek & Zaman (2011) have argued that adolescents, who tell intergenerational stories from diverse perspectives show higher levels of well-being.

As argued by McLean (2016), we use narratives to make sense of ourselves and in this

process, identity is not constructed individually; we define ourselves in relation to others and others also define us. The concept of the ‘co-authored self’ as defined by McLean, allows us to explain identity as a process that is co-constructed through the stories, we tell about ourselves, through the stories we tell about others and through the stories that others tell about us. Families in this context support, counteract, maintain, and constrain identity formation and influence how we define ourselves. In this context counter narratives and dominant relationships among family members play a key role (McLean, 2015).

Master narratives within a family or a social community are stories that are shared and used time and time again by members of a community to define (for better or worse) who they are and where they belong in the social orders and hierarchies (for instance in relation to gender, sexuality, ethnicity, and age). Narratives in this regard serve a specific function, namely for passing down socio-culturally accepted values, but they also allow individuals to position their own values. According to McLean (2017) we can either agree on these narratives or we can resist, reject and counteract these by telling alternative personal stories.

Counter narratives are the stories that people tell and live, which offer resistance to master narratives (Bamberg and Andrews, 2004). In offering resistance, counter narratives contest what is assumed to be a “correct” or acceptable experience. Therefore, counter narratives always exist in relation to master narratives either in opposition to the master narrative or as minor stories relating to the master story in alternative ways, limiting it to a particularised or more personal perspective of the same event (Throsby, 2002). Yet, counter narratives can manifest themselves at various levels ranging from the personal, group and institutional level, for instance when staff members contest managerial decisions and strategies communicated through preferences, values, beliefs etc. (Frandsen et al., 2016). They may also diverge into minor stories or as disruptive powers that infuse people’s personal stories and lived experiences with new meanings, identities and complexities (Bamberg, 2006; Bamberg and Georgakopoulou, 2008).

By analysing what people tell (about themselves and others) and how they react (e.g. assimilate or accommodate) to what others say we can apply the concept of master and counter narratives to *family narratives* and thus study how stories play a role in the formation of individual and shared family identities.

3. Dimensions of identity navigation

Family, master and counter narrative may easily give the impression that identity constructions come in a more or less stable or fixed form. However, identity constructions often involve a fluid and dynamic social process of negotiating multiple roles of identity and self-other relationships. Bamberg (2011) has suggested that this process can be properly understood by introducing what he refers to as three dimensions of navigation. As the dimensions do not follow in a certain hierarchical or logical order, we have taken the liberty to introduce them here reversely to how they are found in Bamberg’s original text.

The first dimension of identity navigation is that of *agency*. In this dimension the speaking

subject is perceived as “a bodily agent” that speaks with the body, which allows for non-verbal and embodied actions to be part of the analysis. Here identity can be navigated between the two terminal points of acting as an active “agent” (taking action, acting powerfully, taking responsibility) or as a passive “undergoer” (taking no action, acting powerless, taking no responsibility). Speaking subjects with high agency are experienced as being in control (positioning a heroic sense of self), whereas speaking subjects with low agency are experienced as being not in control (positioning a victimized sense of self). In both cases the speaker foregrounds certain events and places him/herself in these events as an “agent” in relation to others.

The second dimension concerns *constancy and change* across time. In this dimension the speaking subjects navigate their identity dilemma “by positioning who-they-are in terms of *some* form of continuity, constructing their identities in terms of *some* change against the background of *some* constancy (and vice versa)” (Bamberg 2011, p. 103). Stories in this dimension can give shape to identity constructions that can be plotted as sudden changes, slow transformations or even give shape to a sense of self that indicates no change at all.

The third dimension concerns *sameness versus difference* and positions the speaking subjects in relation to others (Bamberg 2011, p. 104), either aligning with others (“we are the same as”) or positioning themselves as a contrast to them (“we are different from”). Stories in this dimension can give shape to an individual sense of self (“I am not like …”) or they can be plotted as a sense of self in terms of belonging to a certain group, community or social category (“my friends and I always …”). Navigations can happen through aligning with or rejecting the values, behaviours or actions of others.

By coding our narrative data according to these three dimensions we will identify dilemmas of navigation in relation to the individual participants (e.g. the father being a parent as well as a prisoner); family members (e.g. father versus sons/daughters) but also dilemmas of the shared family identity vis-à-vis the institutional system (e.g. the participants being “family” as well as being part of a prison system they must comply with). In so doing we get to understand families of prisoners and whether the game that we have designed offers a qualitative change to the families playing this game during visiting hours.

4. Case study: A prison game

The game *Captivated* (see fig. 1) has been designed for the Danish Prison and Probation Service’s visiting program to help children and adolescent (age 11-18) to maintain and develop social relationships with their incarcerated fathers. The game, which is today fully implemented in the visiting rooms in all Danish prisons, is a result of the three-year funded design research project *Social Games against Crime* (2015-2018) that involved a cross-disciplinary research team from Denmark, the Netherlands and UK, including design researchers, ethnographers, criminologists, experts in narrative theory and sociologists.

Even though much has been done to make in-visits facilities in Danish Prisons more family-friendly, initiatives are still lacking for teenagers and adolescents. The fieldwork we

conducted as part of a pilot study in prisons from 2013–2015 revealed that visiting spaces rarely offer initiatives to this age group. Additionally, in a report made by The Danish National Centre for Social Research (Oldrup et al., 2016), it was subsequently observed that one of the reasons why children ages 11–17 are reluctant to visit their fathers in prison is due to this lack of meaningful initiatives. This report also showed that the wellbeing of these children is lower as compared to prisoners' younger children. If they lose contact with their fathers in prison, it was further stipulated that they are at higher risk of ending up in psychiatric treatment, placement with a foster family, or that it will significantly reduce their educational performance (Oldrup et al., 2016: pp. 5–14).

To address the unmet needs of this age group, the authors carried out a three-year funded research and intervention study from 2015–2018 to investigate whether a board game designed for children and their incarcerated fathers has the potential to help them maintain family relations. The overall purpose of the game is to use game elements as prompts for restoring family narratives that are challenged or broken due to paternal incarceration. In particular, the game attempts to enable the players to share personal stories through bodily interactions and dialogue concerning the fathers' and the children's daily lives. In so doing, it is assumed that the game will help prisoner fathers and their teenage children to maintain a relationship to the benefit of the children's wellbeing and development (although the study of this impact was beyond the scope of the 3-year project).

The project is targeting families of prisoners, because imprisonment is known for having negative collateral effects on families' wellbeing. These families are vulnerable in several respects. First of all, imprisonment makes it difficult to maintain and develop family bonds between parents and children (Arditti et al, 2003; Markson et al.2015). Secondly the family structure is complicated, since many of the parents in these families are divorced or children have been placed in foster care, which means that children do not visit their fathers in prison together with their mothers, but with grandparents, foster parents or others. For these reasons the continuous construction of shared family stories is challenged.

During the process of designing the game, which lasted 1.5 years, several participatory activities and co-design workshops have been organised, including workshops with children, mothers and incarcerated fathers as well as workshops with prison officers and family therapists. These workshops have helped the researchers to shape game characters and to construct a game world that aligns with the actual needs and dilemmas of the families of prisoners (see previous articles focusing on the participatory design process, Knutz et al. 2016; Knutz et al. 2019).

4.1 The design of the prison game

The final version of the game has a game mechanic similar to that of the board game Monopoly, the difference being that the players do not move around in a city but in a prison with certain places (workspaces, kitchen, visiting room), characters (prisoners and prison staff) and situations that the players learn about. All characters in the game have families and

identities. The players may win the game by collecting certain characters and performing acts triggered by the question cards. The game includes three different types of cards (see Figure 1).

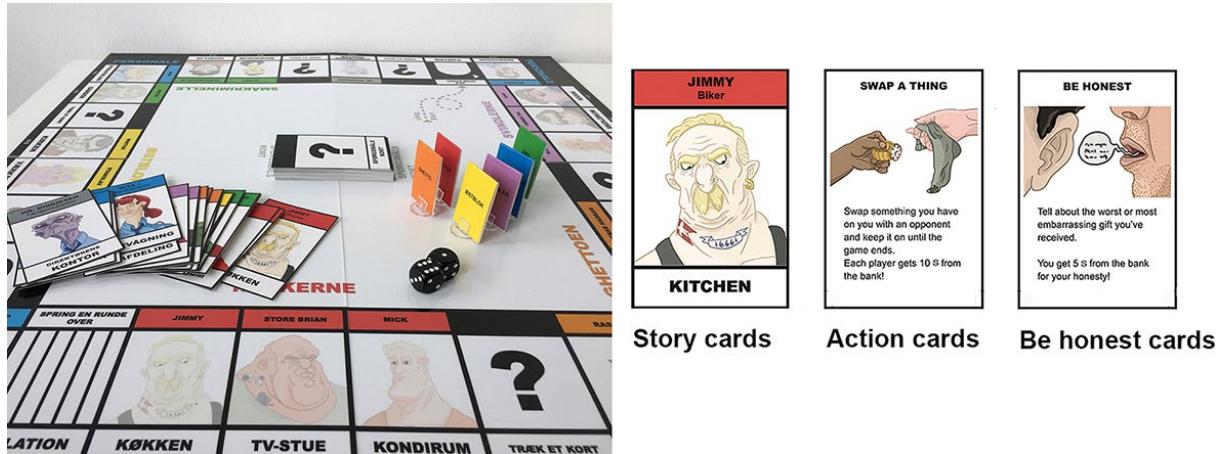


Figure 1 The prison game "Captivated". The game includes three different types of cards: Story cards (stories about the prison), action cards (that encourages physical interaction) and be honest cards (that foster interpersonal communication between the players).

Story cards include illustrated stories about the prison and the prisoners. For example, a story card about a particularly muscular prisoner practicing bodybuilding, says; “Oops! Your pants have shrunk and now everyone can see your *Hello Kitty* tattoo”. These ironic and “teasing” anecdotes about prisoners have been collected during the co-design workshops with prisoners and children and bring parts of the prisoners’ life that is normally not talked about into the parent-child interaction and conversation.

Action cards include eight different actions, for instance “Exchange something you wear with another player;” “Challenge one of your opponent players in arm wrestling;” or “Give one of your opponent players a tattoo” (for this purpose the game contains a black permanent marker). These cards are designed with the purpose of encouraging physical or embodied interactions between children and their imprisoned fathers.

Be honest cards are the third type of cards, which include nine different challenges that encourage the players to open up and talk about past memories, future wishes or personal feelings. For instance, one card says, “Talk about something that makes you angry or sad,” another one says, “Talk about the most embarrassing gift you have received.” These cards are designed to enable the sharing of emotions, embarrassing events and as well as hopes and dreams for the future. Furthermore, they attempt to bring personal identity stories of the real world into the family narrative. With the assistance of family therapists working within the criminal justice system, we carefully considered the design of these cards to avoid intimidating fathers and children or eliciting unwanted emotions.

After completing the final game prototype, the game was pilot tested with two families who played the game during visiting hours together with the research team.

Based on this experience the evaluation study was planned and set up.

4.2 Evaluation study

The evaluation study was conducted in two Danish maximum-security prisons and lasted eight months. Five families participated in the evaluation study and played the game during their prison visits. Due to prison regulations the research team was not allowed access to the visiting rooms, since no form of monitoring was permitted. Hence follow-up interviews played a central role in the evaluation study.

The families who participated went through the following process: The family played the game during visiting hours without being monitored. After having played the game, the father and child were interviewed separately by two researchers. The interview with the father took place in the prison under the supervision of a prison officer. The children were interviewed at home, usually with their mother or foster parent present (see Figure 2). All interviews were conducted in Danish, audio-recorded, transcribed and translated.

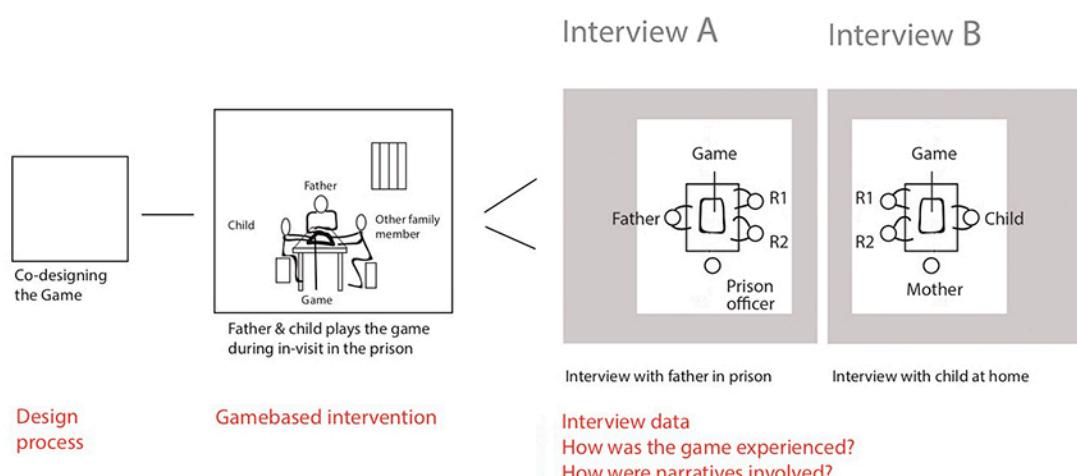


Figure 2 The evaluation study design

During the interviews the board game played a key role, as a research tool enabling dialogue. The two researchers listen to how the participants recalled the game experience of, for instance, what happened when a player got a particular card (e.g. the be honest cards) or landed on a particular place on the game board (e.g. the “visiting room”). This part of the study was not designed to try to reconstruct their authentic game-based interaction, rather, the interview setting itself was conceived as a context for family storytelling, yielding data for analyzing the stories that fathers and children told about their family visit. The empirical data is analysed according to a series of analytical steps (see below).

Due to the limitations of this paper, we focus on excerpts from interviews with one particular family and two of its members (for a more extensive study, see also Markussen & Knutz 2020a; 2020b forthcoming). The family in question consists of 11-year old Oskar and his

incarcerated father John who has been in prison for 14 years. John is a leading member of a criminal gang and is the father of three children. Oskar is his youngest son. John is divorced from Oskar's mother and therefore Oskar visits John with John's new girlfriend.

5. Method of Analysis

In the following we focus on the conversation with John (Interview A) and the conversation with Oskar (Interview B). We will provide examples from excerpts of how John talks about himself, how he talks about Oskar, and how he talks about being in prison. Likewise, we will give examples of how Oskar talks about himself, how he talks about his father and how he talks about the prison. Furthermore, we provide examples of how the prison officer Henry addresses John during the conversation as parent or prisoner. Our aim is to identify different identity constructions and navigations, which are perceived through the various ways in which the participants talk, interact and perform, based on the materiality of the prison game.

Our method of analysis follows a series of analytical steps that enable us gradually to tap into the identity navigation:

- **Step 1: Detecting identity construction in relation to roles**

In this step we apply Bamberg's first dimension by looking at the speaking subjects as "agents" that may take on certain roles (e.g. the concerned father, the powerful prisoner etc.) and we attempt to identify a number of these.

- **Step 2: Foregrounding relevant narrative categories**

This step allows us to identify a number of counter-, master- or family narratives manifested in the personal relationship between the participants

- **Step 3: Plotting identity navigation in relation to dimensions and narrative categories**

In this step we activate the dimensions of *constancy and change* across time as well as the dimension of *sameness versus difference*. This final step allows us to make a comparative analysis of the two interviews in relation to a particular game card/topic that was activated during the game sessions and talked about in both interviews. We will refer to these mappings as "plottings" (see Figure 4 and 5).

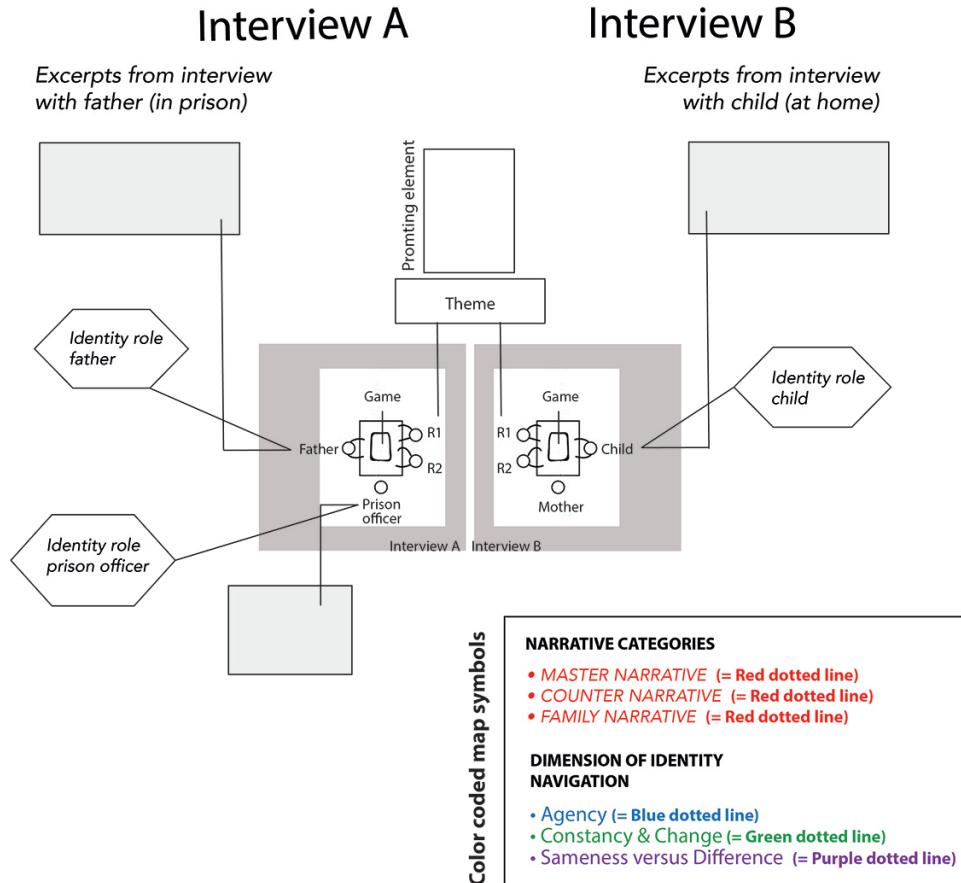


Figure 3 *Model of analysis. Step 3 will result in visual mappings that attempt to diagram the identity navigation taking place between the participants*

6. Analysing the “talk”

6.1 Examples of the participants positioning different identities that engage in different narrative categories (step 1 and 2)

When John talks about his son Oskar and how they played the game, he says that Oskar, during the game session, drew a be honest card, which made Oskar talk about how much he misses his dad. To this John adds: “I was a little nervous that it came to close” and “then I hurried on so that he didn’t get too sad”. John says about the be honest cards, that they are “good” but also a bit “offensive”. He further explains that he is afraid “to step into something that hurts”. During the interview John poses questions about the game and about his son’s involvement in the project: “Have psychologists been involved?”; “Can the drawings made with the marker be washed off?”; and “I’ve talked to his [Oskar’s] mother. He is willing to talk about these things.” About his own participation in the project John says: “I will do everything to help when it has something to do with our children.”

In these excerpts John positions himself both as the responsible father but also worried and protective father who is concerned about his son getting upset or sad when he draws the be

honest cards; or whether the black marker can be washed off, and that he is on good terms with his ex-wife, Oskar's mother ("we have talked about these things"). The prison officer sometimes supports and co-constructs John's responsible father identity, for instance by remarking: "But it's also great that he [Oskar] can tell you that he misses you." In so doing, the prison officer positions himself as "the caring prison officer" who empathises with the prisoner and supports him in assuming his parenting role.

A second identity role of John is that of being a prisoner and a gang leader. When talking about the story card that reveals the "Hello Kitty tattoo," John jokes about confronting his gang members "checking their ankles." He later explains, "there is a conflict between us and another group", which causes some violence, but he adds that this is a "business risk." And he confirms his role as a gang leader by indicating that within his group he is the one who controls ("in our group it's just me who decides"). A third identity construction is the funny-friend identity. John says: "Me and my 11-year-old son we manage a lot by using humour. We do a lot of really funny stuff together." This statement indicates that he looks at his bond with his son as a kind of partnership or friendship built around "having fun together."

If we compare this with Oskar's account about his father, the funny-friend identity seems to mirror his father's positioning: "I know everything about my father," he says and continues "We know each other well." Oskar also says that they have fun together and points out that he and his dad's girlfriend "always cheat on Dad," when they play the game. This indicates that Oskar and his father seem to share a family identity of "being friends" and a family narrative that points towards "having fun together." But Oskar's personal narrative does not always align with the shared family narrative of "having fun."

Oskar repeatedly expresses a need to be heard, seen and felt. He says about the be honest cards that "It was nice that you could just say things as they are...and that you can say something that you do not really talk about, for instance if your mum or dad is not listening." It seems as if Oskar doesn't want everything to be "just fun". His account seems to counteract how he defines himself within the family and his experiences of the be honest cards seem to represent a counter narrative to his father's perception about the cards as being "too hard" and as something that makes his son "sad."

During both interviews Oskar and his father look back at the old prison where John was previously imprisoned. Here the children could walk in and out of the visiting rooms. Oskar says: "I actually got to know somebody there." John also comments several times on the old prison. It was better, according to him, because the children could experience an open door "and play with the other children." "We are family people," John continues. "I want to get to know my brothers' children."

These statements express multiple identity constructions. John speaks both as "the responsible family father" and as a leader of his criminal gang and his so-called "brothers" whose children he wants to know better. John seems to switch seamlessly between two different positions: that of the "the responsible father" and that of a "leading member of a criminal gang." Through these excerpts we also learn how the old prison is part of Oskar's

and John's shared family narrative and that its visiting facilities are assessed as "good" or "better" compared to those in the new maximum-security prison.

John and Oskar's narratives are counter narratives to the prison officer Henry's conception of "the good visit". Henry believes that the doors to the visiting room must be closed, so that the family can have some privacy. "It is best for the family," he repeatedly states. As John continues to insist on the open door, Henry explains that it would never work because "our security system would explode completely." Henry's identity construction is caught between two competing master narratives that exist within the Danish criminal justice system: one master narrative that articulates incarceration as a process of rehabilitation and care and another that emphasises imprisonment as a matter of punishment, control and security. Both John and Oskar seem to reject Henry's conception of "the good visit" and they construct a counter narrative that aligns with their shared family narrative: the narrative about the good (old) prison that allows prisoners and their families to meet freely during visiting hours.

During his talk about the old prison Oskar is asked what it was that made these visits good. To this Oskar replies, "I just think it was...it was because it was my mom and my dad and me who were together." This does not represent a counter-narrative as such, but it does indicate that Oskar and his mother have their own alternate family narrative and shared understanding of what made these previous visits "good:" they were together as a family.

In the first part of our analysis we have looked at the speaking subjects as "agents" that navigate identity by performing certain roles. Furthermore, we have identified a number of narrative categories that seem to be at play in the construction of personal or shared identity, including master, counter and family narratives. In the last part of our analysis we will attempt to extend the analysis to include the dimensions *constancy and change* as well as the dimension of *sameness versus difference*.

6.2 Plotting identity navigation (step 3)

This part of the analysis will be carried out visually by thematically clustering some of the excerpts that we have already presented above. In addition, we then map out the identity navigation according to the last two dimensions. We will focus on two particular topics that was prompted by the game and talked about in both interviews: the "be honest cards" and the conception of "the good visit".

The first plotting (Figure 4) concerns John and Oskar's descriptions and experiences of the be honest cards. The interview with the John ("Interview A") is placed on the left side of the figure, while the interview with Oskar is mirrored on the right side (as "Interview B"). In this plotting we have attempted to focus on identity navigation in relation to the dimension of *agency* (blue line) and *constancy and change* (green line). Master-and counter narratives are marked with red lines.

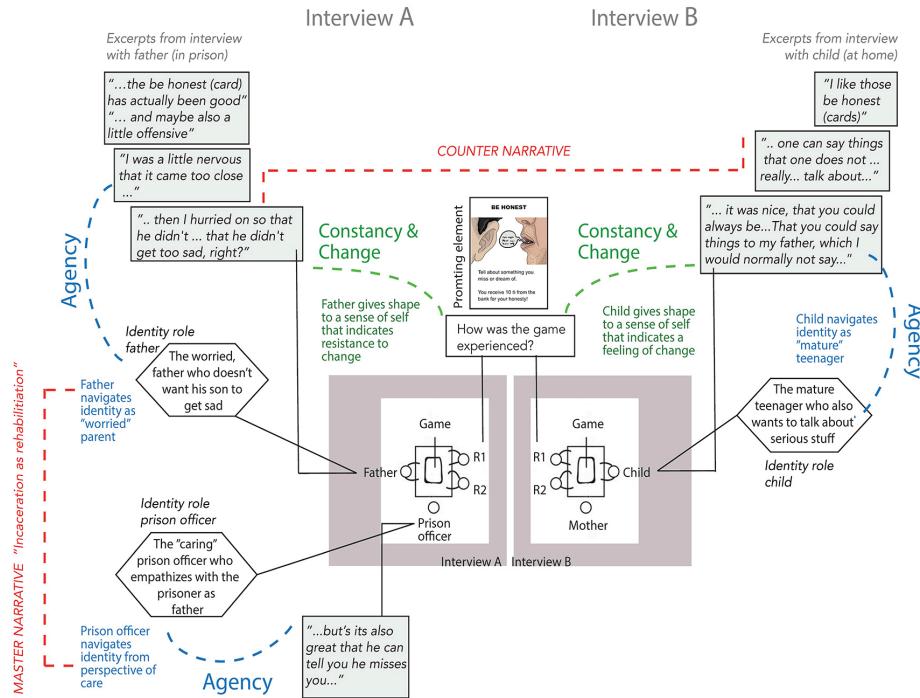


Figure 4 The first plotting concerns John and Oskar's descriptions and experiences of the Be honest cards. The identity navigation is mapped in relation to the dimension of "agency" (blue) and that of "constancy and change" (green).

In John's interview the be honest card has prompted talk about the father being concerned that the be honest card will make his son "too sad." In the dimension of *agency* (blue line) the father is positioning himself as "the worried father" (afraid of Oskar getting too sad). The prison officer supports and scaffolds this identity formation by positioning himself as "the caring prison officer" who empathises with the prisoner and supports him in his parenting role. In their identity process both father and prisoner assimilate with the institutional master narrative within the Danish criminal justice system that articulates incarceration as a process of rehabilitation and care.

If we compare John's concern about the be honest card making his son "too sad" with Oskar's reflection on the same game card, then he is positioning himself rather differently. For John's son the be honest cards seem to open up for a possibility to "say things" to his father that he "would not normally say." Here the son is positioning himself as "the mature teenager" - an identity role that does not align very well with how the father defines him within the family (as a small child that needs attention or protection). Oskar's account represents a counter narrative in terms of how the be honest card is experienced and valued as well as how his father defines him within the family narrative.

In the dimension of *constancy and change* (green line) the father gives shape to a sense of self that indicates a resistance to go into things that gets too emotional ("I was a little nervous that it came too close."). The son, on the contrary, expresses a sense of self that

indicates a feeling of something being different than before ("one can say things ...that one does not really talk about"). Based on this we argue that Oskar feels that a change has happened (between him and his father) and that the be honest card has prompted this change.

The second plotting (Figure 5) concerns the participants' experience and description of the "good" prison visit. In this plotting we focus on identity navigation in relation to the dimension of *agency* (blue line) but we will add *sameness versus difference* (purple line) to get a more profound understanding of how the father and son navigate identity in relation to other groups (their own family versus other prisoner's families).

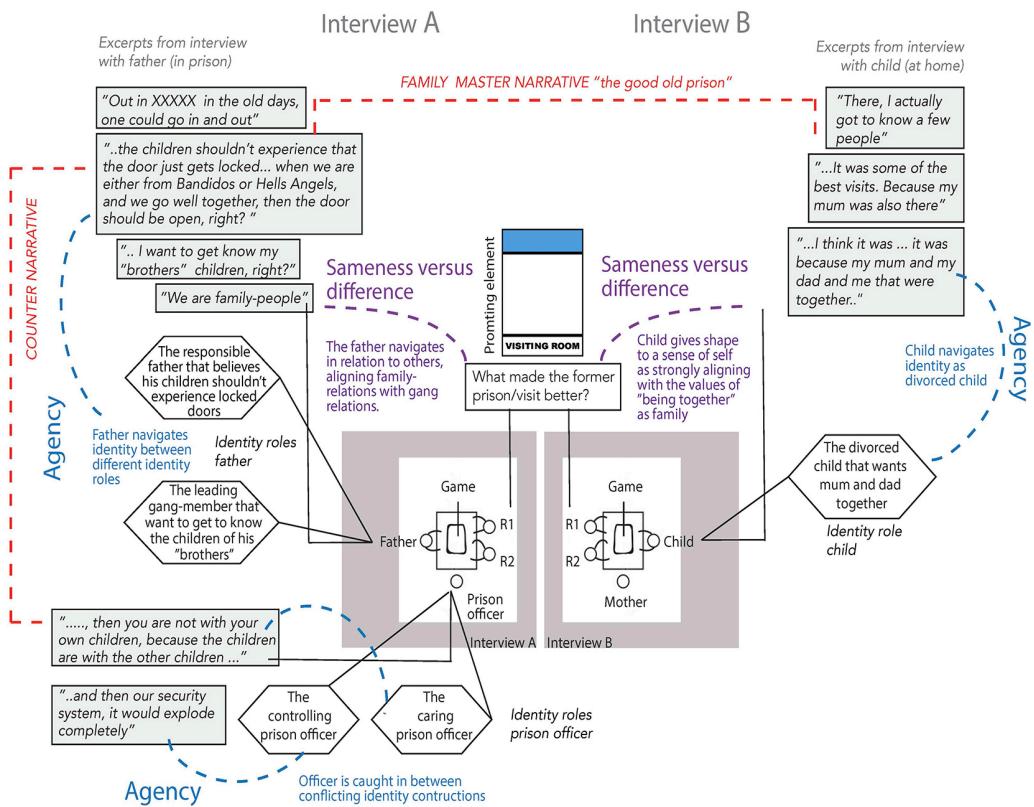


Figure 5 The second plotting concerns John and Oskar's descriptions and experiences of the "good" prison visit. The identity navigation is mapped in relation to the dimension of "agency" (blue) and that of "sameness versus difference" (purple)

In interview A and B, the game has prompted family talk about the difference between past visits and present visits. In both interviews, the father and child (independently of each other) seem to share the idea of the old prison somehow having been better than the present one. But this family narrative about the "good old prison" is more complex than that.

If we apply the dimension of *agency* as well as the dimension of *sameness versus difference*, John positions two different identity roles; "the responsible family father" ("the children shouldn't experience that the door just get locked") and "leading gang-member" ("I want

to get to know my “brothers’ children”). In the dimension of *sameness versus difference* John seems to navigate his identity by equating family relationships with gang-relations. If we activate the same dimensions in the interview with Oskar we get a different insight into why these past events have relevance for the child’s experience of the past (“It was some of the best visits. Because my mum was also there”). The child positions the identity role as “divorced child” and the self-other differentiation in the dimension of *sameness versus difference* is navigated by giving shape to a sense of self that strongly aligns with the value of the three of them (him, his dad and his mum) being together “as a family”. This navigation tells us that even though both father and son share a family narrative about the “old” prison as “better”, they might not share *what more precisely* made these visits “good”.

The prison officer is countering the father’s family narrative of the “good visit” (the visit with open doors) and the plotting visualizes his identity dilemma; he is caught between two conflicting identity roles. One that aligns with “care” (“then you are not with your own children”) and another that aligns with “control” (“our security system would explode”). Whereas the father navigates rather unproblematic between “responsible dad” and “leading gang-member”, the prison officer has more difficulties in navigating between “care” and “control”.

7. Conclusion

Through our case study we analyse the various narrative categories that are involved in a family’s co-construction of identity and how these narratives work in a social context. Here master narratives as well as counter narratives play a central role in how families navigate individual and shared identities. For instance, Oskar and his father have a shared family narrative that offers resistance to the Prison & Probation Service’s Master narrative of the “good visit”. But Oskar also give shape to a sense of self that indicates that the good visit for him positions different values and preferences than those of his father.

Identity constructions are complex matters as they often involve a dynamic social process of negotiating multiple roles of identity and self-other relationships. By applying the dimensions of navigation and turning these into visual plottings we gain a more profound understanding of the dynamics of identity formation and how these work across time (e.g. in relation to present or past family visits); how these works in relation to group-identity (e.g. criminal gang relations versus family relations); or between family members. For instance, Oskar expresses a sense of self that indicates a feeling of something being different than before and that a change has happened between him and his father, through the activation of the be honest cards.

We state that design researchers need analytical tools, methods and models that enable them to evaluate the impact of a given social design project and whether it offers a qualitative change and value for the people interacting with the design. Value in this context, can be a matter of giving families the opportunity to share ‘family narratives’ and to negotiate and navigate identities. By co-designing a game world particularly for families

of prisoners, narratives can be shared and at the same time this storytelling space can allow individual family members to position their own values and preferences in relation to past, present and future events. Our contribution is a method of analysis that enable design researchers to examine identity navigation. This method forms the first step in developing a more extensive theoretical framework and interdisciplinary dialogue between social design research and narrative theory.

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8. References

- Arditti, J. A., Lambert-Shute, J., & Joest, K. (2003). Saturday morning at the jail: Implications of incarceration for families and children. *Family relations* 52(3), 195-204.
- Armstrong, L., Bailey, J., Julier, G., & Kimbell, L. (2014). *Social design futures: HEI research and the AHRC*. University of Brighton.
- Bamberg, M. (2006). Stories: Big or small: Why do we care?. *Narrative inquiry*, 16(1), 139-147
- Bamberg, M., & Andrews, M. (Eds.). (2004). Considering counter-narratives: Narrating, resisting, making sense (Vol. 4). John Benjamins Publishing.
- Bamberg, M., & Georgakopoulou, A. (2008). Small stories as a new perspective in narrative and identity analysis. *Text & Talk*, 28(3), 377-396
- Bamberg, M. (2011). Narrative practice and identity navigation. In J. A. Holstein J. F. Gubrium (eds.) *Varieties of narrative analysis*, 99-124. Los Angeles: Sage.
- Bohanek, J. G., Marin, K. A., Fivush, R., & Duke, M. P. (2006). Family narrative interaction and children's sense of self. *Family process*, 45(1), 39-54.
- Bruner, J. S. (1990). *Acts of meaning*. Cambridge, MA: Harvard University Press.
- Cohler, B. J. (1982). Personal narrative and life course. *Life span development and behavior*, 4, 205-241.
- Erikson, E. (1968). *Youth: Identity and crisis*. New York: WW Norton & Company.
- Fivush, R., & Baker-Ward, L. (2005). The search for meaning: Developmental perspectives on internal state language in autobiographical memory. *Journal of Cognition and Development*, 6(4), 455-462.
- Fivush, R., Bohanek, J. G., & Zaman, W. (2011). Personal and intergenerational narratives in relation to adolescents' well-being. *New directions for child and adolescent development*, 2011(131), 45-57.
- Fivush, R., Habermas, T., Waters, T. E., & Zaman, W. (2011). The making of autobiographical memory: Intersections of culture, narratives and identity. *International Journal of Psychology*, 46(5), 321-345
- Fivush, R., Habermas, T., Waters, T. E., & Zaman, W. (2011). The making of autobiographical memory: Intersections of culture, narratives and identity. *International Journal of Psychology*, 46(5), 321-345.
- Frandsen, S., Kuhn, T., & Lundholt, M. W. (Eds.). (2016). *Counter-narratives and organization*. London & New York: Routledge.
- Jewkes, Y. (2005). Loss, liminality and the life sentence: Managing identity through a disrupted lifecourse. In A. Liebling & S. Maruna (eds.) *The effects of imprisonment*, 366-388. London & New York: Routledge.

- Knutz E, Lenskjold T & Markussen T (2016) Fiction as a resource in participatory prototyping. In *Proceedings of the 50th Design Research Society conference*, Brighton, UK, 27–30 June 2016. London: Design Research Society.
- Knutz, E., Markussen, T. & Lenskjold, T. (2019): Navigating care in social design: a provisional model. In *Proceedings of the 8th biannual Nordic Design Research Society conference*. Helsinki: Aalto University.
- Knutz, E. & Markussen, T. (2019): The ripple effects of social design: a model to support new cultures of evaluation in design research. In Rodgers, P. (ed.). Lancaster: Lancaster University.
- Markson, L., Lösel, F., Souza, K., & Lanskey, C. (2015). Male prisoners' family relationships and resilience in resettlement. *Criminology & Criminal Justice*, 15(4), 423-441.
- Markussen, T. & Knutz, E. (2020a, forthcoming). Boardgames as a New Method for Studying Troubled Family Narratives – Framing Counter Narratives in Social Design Research. In Lueg, K. (ed.) *Routledge Handbook of Counter Narratives*. London & New York: Routledge.
- Markussen, T. & Knutz, E. (2020b, forthcoming). Playing games to re-story troubled family narratives in Danish maximumsecurity prisons. *Punishment & Society*.
- McLean, K. C. (2016). The co-authored self: Family stories and the construction of personal identity. Oxford: Oxford University Press.
- McLean, K. C., & Syed, M. (2015). Personal, master, and alternative narratives: An integrative framework for understanding identity development in context. *Human Development*, 58(6), 318-349.
- Oldrup, H., Frederiksen, S., Henze-Pedersen, S. & Olsen, R. F. (2016). Indsat far – udsat barn (Incarcerated father – vulnerable child. Copenhagen: The Danish Center for Social Science Research.
- Saltzman, W. R., Pynoos, R. S., Lester P., Layne, C. M. & Beardslee, W. R. (2013). Enhancing family resilience through family narrative co-construction. *Clinical Child and Family Psychology Review* 16(3): 294-310.
- Throsby, K. (2002). Negotiating “normality” when IVF fails. *Narrative Inquiry*, 12(1), 43-65.
- Zaman, W., & Fivush, R. (2011). Intergenerational narratives and adolescents' emotional well-being. *Journal of Adolescence*, 21, 703-716.

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