

Title

0020by **Kelsey Chapman** in **Inclusive Health Research 2024****Original Submission**

Score	n/a
1. The Entry	
1 1. Lead organisation or Institution chiefly responsible for submitting this entry	Griffith University
Registered Address	2.12 G27 Parklands Drive Southport QLD 4222 AU
Type of Organisation	Academic/research institution
Website URL	https://inclusivefutures.griffith.edu.au/hub-page/the-dignity-project
1.2 Chief Contact Person	Kelsey Chapman
Chief Contact Person's Job Title/Post	Dignity Project Research Fellow
1.3 Name of project or programme	The Dignity Project
1.4 Date that the project or programme began	January 2017
1.5 Countries in which research / implementation was undertaken	Australia
1.6 About partners and collaborators	Here you should name up to three collaborating organisations and provide a contact email address for each one that you name. We will then send a request for a supporting statement, which will be taken into account in the scoring of this application.
Partner organisation/institution #1	The Hopkins Centre
Website URL	https://www.hopkinscentre.edu.au/
Partner organisation/institution #2	Health Equity Unit, Metro South Health
Website URL	https://metrosouth.health.qld.gov.au/
Partner organisation/institution #3	Queenslanders with Disability Network
Website URL	https://qdn.org.au/

The Case Study

1.8 The Title of Your Case Study

1.9 Simple Summary

The Dignity Project (DP) is a place where data (e.g., stories, perspectives, ideas and solutions) can be collected in partnership with citizens with disability and collated to inform the design and delivery of dignified services and system interfaces to improve health outcomes and health equity. Specifically working in rehabilitation, healthcare, and other social services, at the centre of the DP is a bespoke digital engagement platform designed and moderated by citizen science leaders with disability who were embedded into the academic project team. We employ creative methods of digital storytelling that help to disrupt overt, covert, deliberate and unconscious barriers that prevent or limit citizens with disability from participating in research and service (re)design. The DP provides a safe, accessible, and inclusive online space for citizen scientists with disability to share, reinterpret and analyse their collective health experience to create more inclusive and equitable health outcomes for people with disability.

1.10 Introduction

The Dignity Project commenced in 2017 by Griffith University researchers. The ongoing partnerships with Metro South Health, The Hopkins Centre, and Queenslanders with Disability Network were initiated by a successful collaborative grant from the Office of the Queensland Chief Scientist in 2019. These partners together undertook scoping work to design a citizen science framework and scope an initial program of research that would embed dignity into the way systems are designed and delivered to improve health and wellbeing outcomes for people with disability. Our key partners have served as funders, as partners in successful grant and commercial research, and as key collaborators across all of our 25+ research campaigns and projects. While the Dignity Project is driven and led by Griffith University research fellow, Dr. Kelsey Chapman, members from all partner organisations are regularly engaged to design and deliver integral Dignity Project research.

1.11 Key Words

people with disability; citizen science; Australia; disability and rehabilitation; dignity;

Which category best fits this project or programme?

Building a better research ecosystem

3. Better Research Ecosystem Case Study

The case study structure below is provided for those applications which relate to the introduction of a new or modified policy, working practice or process that supports a more inclusive research ecosystem. The ultimate beneficiaries should still be those with current or future unmet health needs. We are seeking case studies that can be published as a piece of writing, so please write your entry as a summary, rather than a series of statements addressing the questions. You do not need to repeat information across sections. We do not expect everyone to be able to address all of the questions, as not all will be relevant.

3. 1. The Context

The Dignity Project started at Griffith University in 2017 in response to a decade of research in partnership with people with disability revealing instances of undignified treatment and inequities in health systems that could be easily prevented if solutions were designed by people with lived experience. The Dignity Project was established to ensure that: (1) future disability, rehabilitation and healthcare research addresses the topics of most concern to people with disability; (2) people with disability are respectfully engaged in research beyond superficial forms of participation; (3) research delivers meaningful outcomes and social change that promotes dignity; and (4) long term health and wellbeing outcomes are improved for the 40% of Australians living with chronic conditions, disability and impairment.

Using citizen science, the Dignity Project regards people with disability as experts in their own life experiences. Academic researchers, therefore, play a supportive role, providing methods, training and opportunities that can enable important challenges to be identified from lived experiences and solutions with real impact to be explored. Citizen science, when conducted by people with disability, is a form of emancipation and enablement. Our method of citizen science is maximally inclusive with emancipatory goals. It goes beyond the notion of 'amateurs' assisting qualified researchers in data collection and analysis, but embeds citizens as integral drivers of all phases of research.

Griffith University is a natural host for The Dignity Project, with its long-standing reputation as a civic social justice institution, built on a history of interdisciplinary solutions to complex challenges. For more than 30 years, Griffith has been respected as a leader in the disability and rehabilitation sector. The Dignity Project is able to leverage the multi-level engagement infrastructure in place within the university to partner closely with other research centres, including The Hopkins Centre, Queenslanders with Disability Network, The Queensland Government, and Metro South Health and Hospital Service. Our partners engage with us to address real-time clinical and social challenges for people with disability, driven by teams of clinician-researchers, researchers with disability and academics in partnership. Currently, The Dignity Project has funded grants with all partner organisations and is collaborating on a widespread program of work to improve the health and wellbeing of people with disability.

3.2. The Initiative

The Dignity Project is the only research project of its kind in Australia, designed to address disability challenges, particularly in healthcare, using extreme citizen science. It is innovative in multiple ways: (1) it re-positions the role of citizen scientists as drivers of knowledge creation; (2) it involves a novel use of citizens' lived experience of disability to inform the focus of research, the method, and the translation; (3) it has developed and applied an innovative framework for citizen science, using it to conduct research in areas of priority for people with disability; (4) it provides an innovative digital space where solutions can be generated by and for people with disability in partnership with academic researchers.

While the importance of consumer and community engagement in research is growing, as are the popularity of methods like co-design, The Dignity Project set out to respond to both unmet health needs for people with disability as well as the long history of tokenism and inequitable participation in research. We prioritise diverse types of knowledge and different epistemological understandings of knowledge production, including lived experience. Extreme citizen science is highly salient to citizens with disability, for whom research has typically been problematic or tokenistic. Historically, citizens from marginalised groups, like people with disability have been poorly represented in research, leading to poor health outcomes and solutions. Extreme citizen science is needed to address this entrenched exclusion of people with disability from science, particularly health science. Empowering citizens with disability to use their experiential knowledge to impact change can have positive outcomes for individuals, researchers, and whole communities. After realising there were a dearth of frameworks through which citizen science can be inclusive and equitable for people with disability, The Dignity Project created and trailed one in partnership with people with disability. From there, people with disability identified the need to define dignity and develop a model through which dignity and human rights can be protected, maintained, and enhanced within healthcare systems and other mainstream systems in order to result in equitable, quality health outcomes.

3.3. Engagement

The Dignity Project harnesses innovative digital engagement techniques and methods (e.g. digital storytelling, GIS mapping, and video) to facilitate accessible and inclusive opportunities for engaging people with disability in research and citizen science. The project uses recognised and well-tested participatory research methods (e.g. digital storytelling) that have been shown to promote critical dialogue to bring about change by developing civic engagement among marginalised populations. Disability is not homogenous, even among citizens with the same diagnosis, and so safeguarding dignified, authentic and transparent citizen science must be based on accessibility and inclusion and responsive to diversity and intersectionality. Barriers to inclusion in citizen science are particularly problematic for citizens with disability, who experience higher levels of economic inequality, lack of appropriate transportation, time constraints and unfamiliarity with scientific methods. Digital engagements was important to overcome many of these barriers, but inclusion and accessibility required further commitment to atypical and flexible working patterns and ensuring online environments and data collection mechanism could be accessed and understood by citizens with diverse impairments.

In response, the Dignity Project created an online platform, co-designed in collaboration with people with disability, which aimed to: (1) contribute to a valid database of ideas and develop a population of active citizen scientists who are confident about sharing and engaging with evidence; (2) link citizen scientists with senior researchers to provide capacity building and training; (3) enable citizen scientists with disability to participate accessibly and inclusively in digital storytelling and forums.

Following a successful pilot from 2020-2022, The Dignity Project improved digital infrastructure and engagement capabilities to extend our capacity. Our platform is WCAG2.1 compliant and is successfully used by people with a range of disability, including people with physical, sensory, psychosocial, cognitive, and intellectual disability. We also engage meaningfully with our partner organisations to ensure that the research conducted using citizen science methods is implementable and translatable to health, government, and other mainstream service system contexts.

3.4. The Impact

The Dignity Project has offered a number of benefits that have been realised, specifically within the last four years, including: (1) improved knowledge about the experiences of people with disability in navigating rehabilitation and health service systems; (2) better understanding of the challenges associated with engaging in rehabilitation, sustaining social networks and participating in society; and (3) improved awareness of the utility and benefit of engaging end-users in service planning, design, delivery and implementation.

The Dignity Project has undertaken a suite of research grants and commercial research, valued at more than \$1.1 million, all designed to understand what dignity means for people with disability and how to ensure that people with disability have dignified experiences and outcomes in their interactions with mainstream systems and services, particularly in healthcare contexts. This knowledge creation as led to the development of a model for dignity and key recommendations for action by policymakers, service providers and system decision-makers: (1) recognise people with disability and their right to make informed decisions about their lives and care; (2) improve system navigation and informed decision-making with complete, accessible and inclusive information; (3) eliminate or minimise access barriers using co-design and universal design; (4) improve training and support for frontline clinical staff to increase their capability, opportunity, and confidence to provide respectful, disability aware interactions; (4) create spaces to support the expression of voice, choice and independence of people with disability. Our citizen scientists have partnered with our academic staff to publish 6 peer-reviewed journal articles in Q1 journals, 5 The Conversation articles, and were selected as finalists for the 2022 Eureka Prize for Innovation in Citizen Science. We also launched a citizen science, "Research 101" micro-credential and digital badge training in June 2023 to assist the more than 100 currently enrolled students to professional their lived experience through research. In the past 12 months alone, the Dignity Project has tripled in citizen science memberships on the platform, with more than 350+ people with diverse disability, 70% of whom are women with disability. Thirteen of our citizen scientists are now employed as research assistants and research partners across initiatives at Griffith University, the Summer Foundation, and Queensland Health. At a system level, results of Dignity Project research are being embedded in policy and practice across Queensland Government departments, including in their respective accessibility and inclusion action plans and strategies, and to provide enhanced dignified care for their patients.

3.5. The Future

The future plans for the Dignity Project includes driving continual impact for people with disability, their families and carers, and the organisations and services that support them. Continued expansion including creating more meaningful opportunities for the employment of disabled researchers and scholars; increasing capacity and engagement in research by people with disability; and earning competitive grants to support our growth. We will continue to tackle significant challenges that restrict people with disability in society, amplifying their voices and driving campaigns that will contribute to improved health and wellbeing outcomes.

Significantly, the Dignity Project is working with the Queensland Government to develop a evidence and implementation alliance focused on disability health equity, building on our current research findings and outcomes. This program of work will: (1) ensure that consumer voice continues to be central to our work; (2) focus on establishing the root causes of health inequity, particularly in regional and rural areas; (3) eliminate knowledge silos and build interdisciplinary and cross-sectoral evidence to support the delivery of more effective practices; and (4) address knowledge mobilisation, translation and implementation strategies to improve healthcare design, delivery and policy for people with disability.

We are also continuing to apply for significant grant funding to expand our ongoing "Voice of Queenslanders with Disability" project which measures baseline data for Queenslanders with disability, their family and carers, across the 7 policy areas of Australia's Disability Strategy. We are hoping to take this initiative to a national level and innovate on methods for engaging with people with disability who are most vulnerable to poor health outcomes, those living in group homes and who are not typically verbal.

4. The Prize Fund

We would use the funds to increase our overall impact, by: (1) investing in training and capacity building for our citizen scientists to enhance their skills and knowledge in research methodologies; (2) improve engagement through attending international conferences to increase the impact and translation of our existing research and develop partnerships for new research; (3) invest in small-scale pilot projects that serve as proof of concepts for larger initiatives, specifically around developing citizen led models for peer support in healthcare and testing new methodologies for engaging people who are not typically verbal.

5. Your advice to others

Our key advice is to focus on translating research into real-world impact by engaging end-users actively, creating accessible resources and using citizen science principles. Explore innovative approaches like digital training initiatives and celebrate achievements, including increased citizen science memberships and employment opportunities.

6. Supporting Evidence

6.1. Funders

The Queensland Government and Queenslanders with Disability Network. The Voice of Queenslanders with Disability (2023 and 2024). \$44104 GBP
Metro South Hospital and Health Service. SERTA Project Grant, The Dignity Project: Disability-led innovation to improve the patient journey. \$64805 GBP

6. 2. Academic/Professional Publications	<p>(1): The Australian Occupational Therapy Journal. 2023. The Dignity Project Framework: An extreme citizen science framework in occupational therapy and rehabilitation research. Kelsey Chapman, Angel Dixon, Kevin Cocks, Carolyn Ehrlich, Elizabeth Kendall. https://onlinelibrary.wiley.com/doi/full/10.1111/1440-1630.12847</p> <p>(2): Qualitative Health Research. 2023. Dignity and the Importance of Acknowledgement of Personhood for People with Disability. Kelsey Chapman, Angel Dixon, Carolyn Ehrlich, Elizabeth Kendall. https://journals.sagepub.com/doi/full/10.1177/10497323231204562</p>
6.3. Other publications	<p>(1): 2023. The Queensland Government and Queenslanders with Disability Network. The Voice of Queenslanders with Disability: Final Report 2023. https://qdn.org.au/wp-content/uploads/2023/06/Voice-of-Queenslanders-with-Disability-report.pdf</p> <p>(2): February 20, 2023. The Conversation. Disability and dignity - 4 things to think about if you want to 'help'. https://theconversation.com/disability-and-dignity-4-things-to-think-about-if-you-want-to-help-198993</p> <p>*The Conversation article was also published in the "2023 a Year of Consequence" yearbook by The Conversation.</p>
6.4. Other forms of communication, including conferences	<p>(1) August 17, 2023. ABC News (TV, Online and Radio). "Ivy struggled to find a job, then she did a Brisbane internship for people with disabilities". https://www.abc.net.au/news/2023-08-17/qlld-disability-workforce-employment/102735458?utm_campaign=abc_news_web&utm_content=link&utm_medium=content_shared&utm_source=abc_news</p> <p>(2) 2021. With, Not For, a podcast by the Centre for Inclusive Design. "The Dignity Project with Angel Dixon and Kelsey Chapman". https://podcasts.apple.com/us/podcast/the-dignity-project-with-angel-dixon-and-kelsey-chapman/id1557096826?i=1000534418139</p>
6.5 Other Evidence	<p>The Dignity Project selected as finalists for the Eureka Prize for Innovation in Citizen Science (2022) https://www.griffith.edu.au/research/inclusive-futures-reimagining-disability/blog-posts/the-dignity-project-finalist</p>