

# **Using Participatory Action Research to Assist Heart Failure Self-Care amongst Indigenous Australians: A Pilot Study**

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## *Abstract*

*This paper describes the initial phases of the Fluid Watchers Pacific Rim project: a participatory action research project that involves developing and trialling an iPad app to provide monitoring and self-care for Indigenous Australians with heart failure. The development phase involved working with health experts, an IT team and Indigenous heart-failure patients through three cycles of development and critical reflection. This was followed by a small pilot study to examine the app's effectiveness. In this paper, the researchers explain why IT-supported health education can be successful in decreasing re-hospitalisation and improving self-management skills. They describe the steps they took to ensure community participation and ownership of the project and present the findings of their pilot study. This pilot project suggests that an iPad app may be a practical and successful way to provide health-care support for Indigenous Australian heart-failure patients.*

## **Keywords**

Heart failure, Fluid Watchers, iPad, app, self-care, wellbeing, Indigenous, Australia, participatory action research

## **Introduction**

Indigenous people have the poorest health status of any population in Australia (AIHW, 2011). The statistics describe a life expectancy that is less than that of other Australians, coupled with increased levels of cardiovascular disease, cancer, diabetes, respiratory disease and kidney disease (AIHW, 2011). For example, Indigenous women are 11 times more likely to get coronary heart disease, and 13 times more likely to get rheumatic fever (AIHW, 2011, p. 49).

Australian estimates suggest that heart failure is experienced by 2% of the Australian population, with 13% of patients aged over 65 years. Heart failure is the leading cause of hospitalisation and a significant burden on the health care system. The stories of heart failure are similar in Australia, the USA and New Zealand (Clark, McLennan, Dawson, & Wilkinson, 2004; Massie & Shah, 1997; Riddell, 2005). In New Zealand, Maori people experience a greater burden of heart disease than non-Maori (Kerr, Penney, Barnes, & McCreanor, 2009).

In Australia, Indigenous Australians with heart failure experience a death rate that is three times higher than the non-Indigenous population (AIHW, 2003). Some of these deaths are due to poor monitoring and some deaths could be delayed with effective self-care and support. We developed the Fluid Watchers Pacific Rim project to explore ways to address this disparity within heart failure and keep people alive. We used a participatory action research method to work towards this goal. This paper describes the first phase of the action research project.

Fluid Watchers Pacific Rim involves the design and testing of an iPad application (app) designed to teach self-management strategies about heart failure. The app is focused on fluid-level monitoring, and is designed to specifically meet the needs of Indigenous people with heart failure. The first phase of Fluid

Watchers Pacific Rim had two aims: (1) to involve Indigenous patients and community health workers in developing the app, and (2) to evaluate the app's effectiveness. We were interested in two aspects of the app's effectiveness: (1) its ability to teach heart-failure knowledge and self-care behaviours (such as fluid-level monitoring), and (2) users' satisfaction with the app and opinions about its user-friendliness. The project team included researchers, clinicians and community health workers. The researchers were drawn from Queensland University of Technology (QUT), Flinders University, Ipswich Hospital, Royal Brisbane Hospital, Central Queensland University and Kambu Aboriginal Medical Service in Ipswich.

Throughout this paper, we use the term 'Indigenous Australians' to refer to both Aboriginal and Torres Strait Islander people unless we use a direct quote where Aboriginal and /or Torres Strait Islander people are mentioned.

## **Understanding heart-failure and fluid-level monitoring**

The evidence demonstrates that people with heart failure who effectively manage their symptoms will experience fewer hospitalisations (Jaarsma et al., 1999). The most appropriate management includes lifestyle modification such as careful diet, regular exercise and minimising stress, along with adherence to medicine regimens. Despite this, approximately 50% of all patients experience minimal benefit from self-care interventions (Smedley, Stith, & Nelson, 2003). There is little available evidence discussing the efficacy of self-management support. Even less is known about the efficacy of self-management support relevant for Indigenous Australian populations, despite them carrying a larger burden of the disease proportionate to population (AIHW, 2011).

Managing fluid levels is an important aspect of self-management for people with heart failure. Fluid levels are a key symptom of heart failure, so ongoing monitoring and management of fluid levels is a critical part of ongoing care (HFSA, 2006; Krum et al., 2011). There is evidence that fluid monitoring can prevent the life-

threatening consequences of emergency hospital admission for acute decompensated heart failure and pulmonary oedema (Caldwell, Peters, & Dracup, 2005; Jaarsma et al., 1999; Spaeder et al., 2006). The current guidelines for heart-failure treatment recommend that fluid levels are monitored by daily weight checks (Heart Foundation Australia, 2008). The guidelines provide advice and suggestions on what to do if the patient experiences symptoms. For example, if a patient gains two kilograms or more over two days, with associated ankle, hand and/or abdominal swelling, then the patient is advised to activate their fluid action plan and/or seek medical advice (Heart Foundation Australia, 2008).

Unfortunately, the evidence suggests that fluid monitoring is not widespread. A study with heart-failure patients in Australia revealed that less than half reported having bathroom scales. They were unable to weigh themselves, despite being advised to do so daily. Moreover, many patients in the study (especially women) were hesitant to weigh themselves daily because of the social stigma associated with being overweight and obese (Clark, Yallop et al., 2007). This suggests that social stigma is influencing the ability of patients to monitor symptoms that might save their lives.

The project being discussed in this paper, Fluid Watchers Pacific Rim, is based on a successful fluid monitoring program from the USA called Fluid Watchers©. Some of the researchers involved in the Australian project were involved in the original Fluid Watchers program. Fluid Watchers was developed with rural heart-failure patients, and demonstrated improvements in heart-failure knowledge and self-care behaviour, plus fewer re-hospitalisations and reduced mortality (Caldwell, Peters, & Dracup, 2005; Dracup & Zegre, 2009). The program is based on self-care and adult learning theories (Knowles, 1980; Jaarsma et al., 1999). It focuses on the signs, symptoms, causes and consequences of decompensated heart failure and the importance of self-management. The program involves three main strategies: (1) teaching patients to keep a diary of daily weight and develop a fluid-retention action plan, (2) addressing perceived barriers to implementing the action plan, and (3) providing a script to use when calling a health-care provider if

symptoms worsen (Caldwell, Peters, & Dracup, 2005). After viewing the evidence from this program and after much discussion, we wanted to develop a project with Indigenous Australians with heart failure in an attempt to gain health improvements and make a difference in people's lives. The aim of Fluid Watchers Pacific Rim is to adapt the original Fluid Watchers program through a participatory action research project. We want to ensure that Indigenous Australians with heart failure become more confident in differentiating between fluid and adipose weight gain during daily self-monitoring, and encourage them to respond with early action.

### *Why an app?*

The evidence suggests that self-management programs assisted by information technology are often successful. In addition, research suggests that telephone follow-up can be highly effective on outcomes such as heart-failure knowledge, medication use, reduced hospitalisation and mortality, and cost effectiveness (Clark, Inglis, McCalister, Cleland, & Stewart, 2007). Interventions using technology are able to demonstrate improvements in quality of life, reduced costs and good levels of patient acceptability. They also show improvements in patient knowledge and self care (Clark, Inglis et al., 2007).

Of course, not all information technology will be useful to heart-failure patients, and any program needs to be carefully designed and tested. Research indicates that programs with user-friendly interfaces that include simulation, animation, image and voice can be efficient ways of educating patients and improving self-management skills. Other approaches may not be as effective (Clark, Inglis et al., 2007). Clark, Inglis, et al. (2007), show that patients who receive technology-based education tend to engage and learn effectively, because they experience a sense of empowerment as self-directed learners who are taking control of their own health condition and self care. As a result, patient involvement in self care and decision making tends to increase. Our goal with Fluid Watchers Pacific Rim is to develop a form of technology that will engage heart-failure patients in self-directed

learning about their condition, thereby increasing the uptake of self care.

We decided to develop an iPad app that would be a fun and convenient IT tool. The app combines the standard characteristics of computer-based teaching tools (simulation, animation, image and voice) with the capability to create an individual avatar and use the touch-screen interface. In this case, the avatar is a visual image that represents the patient. We use a figure that in other programs might be able to be animated. We also wanted the app to collect and evaluate statistical evidence of learning and outcomes. We felt that the portability of iPads would be a great benefit to health-care workers in communities and in clinics. Our aim was to produce education and self-monitoring materials that would be engaging, interactive, easy to navigate and usable (for patients, carers and health-care workers within both hospital and Indigenous community settings).

## Methodology

We developed a participatory action research approach for the project. The research process involved a repeated cycle of developing the technology, negotiating what the device could do, and testing the technology with experts and potential users. We wanted to be able to dream and work with Indigenous heart-failure patients as part of the research process.

Drawing on the work of Reason and Bradbury (2006), Kerr et.al. (2009) identify that action research works in empowering and participatory ways 'to generate research-based solutions to problems that impact on well-being of the people and communities' (p. 2). As a process, it allows researchers to incorporate a family of research methodologies as they work with community members, groups and organisations in an attempt to seek answers and solutions to real and complex problems. The complexities involved in treating and monitoring heart failure make the topic ideally suited to participatory action research. This approach has also been extensively used in education settings to develop effective technology-based teaching strategies.

Participatory action research has been used as an appropriate research methodology with marginalised and vulnerable populations – not just in Australia, but also in other parts of the world (Giachello et al., 2003; Nelson, Ochocka, Griffin, & Lord, 1998). It is increasingly being used with Indigenous populations (Cochran, 2008; Kerr et al., 2009; Mooney-Somers & Maher, 2009). In Australia, participatory action research is often cited as a suitable approach for researchers who are seeking to work with Indigenous Australian organisations and communities (Fredericks et al., 2011; Mooney-Somers & Maher, 2009). In some cases, it is specifically chosen as an approach to bring about change (Fredericks et al., 2011; Walker, Fredericks, & Anderson, 2012).

Evidence also suggests that participatory action research used within health contexts can increase the likelihood that the developed interventions will be used and bring health benefits to the community (Leykum, Pugh, Lanham, Harmon, & McDaniel, 2009; Giachello et al., 2003; Kidd & Kral, 2005; Stringer & Genat, 2004; Viswanathan et al., 2004). Action research has successfully been used to develop interventions within Indigenous health contexts (Brough et al., 2006; Erick, Mooney-Somers, Akee, & Maher, 2008; Fredericks et al., 2011; Tsey, Patterson, Whiteside, Baird, & Baird, 2004). While there are a growing number of participatory action research studies involving Indigenous Australians, few are focused on the field of heart disease. However, the work of Kerr et al. (2009) in developing an action research project in New Zealand with Maori people experiencing heart disease is particularly relevant to this project. Heart disease amongst Maori populations is of significant concern, and its pattern is broadly similar to the experiences amongst Indigenous Australian populations (AIHW, 2011; Kerr et al., 2009).

The benefits of using action research within health contexts is best summed up by Israel et al. (1995). They explain that action research involves people from the community in all aspects of the research. The project is a co-learning process where the researchers and community members learn from each other's knowledge and expertise. Action research includes a reflective process that involves critical consciousness. It is enabling to the communities

participating in the study and works through a process that balances the goals of research, action and evaluation. The work of researchers such as Israel et al. (1995) and Reason and Bradbury (2006) highlights the benefits of action research and the need for the action research process itself to be evaluated.

The Fluid Watchers Pacific Rim project is informed by the understanding that cultural sensitivity is essential for effective heart-failure management across different populations (NHMRC, 2005). Interventions need to be adapted to suit the cultural backgrounds, socioeconomic circumstances and health literacy of the families and communities involved (NHMRC, 2005). A participatory action research approach allows us to work in a culturally appropriate and sensitive way, and to be responsive to the community's needs. We aimed to ensure that all aspects of the project involved cultural sensitivity, and demonstrated respect for history, cultural beliefs and the social determinants of health (such as inadequate resources, varying levels of education and poverty) (Anderson, Baum, & Bentley, 2007; Boyle, Fredericks, & Tweede, 2013; NHMRC, 2003).

The action research process was not easy. Developing the app took much consideration and extensive consultation. At times, we needed to challenge our decisions to make sure that we were not taking the easy option instead of thinking first about what was best for heart-failure patients, health organisations and the community while balancing what community members and patients were articulating with regards to themselves. Generally, after some discussion we would realise that we were all wanting the same thing it was in how we were talking about it that revealed the difference.

Participatory action research tends to be slow. It requires considerable reflection and more time, money and personal commitment than other approaches to research. For example, Fluid Watchers Pacific Rim involved multiple visits to the site, with time spent talking with people, reflecting on the progress, listening to feedback, and then making the changes - all before undertaking the process again.



Participatory action research involves respecting the needs of the project's various participants. For us, this meant that at times during the project, organisational and community priorities needed to take precedence. We were mindful that participatory research approaches can sometimes create tensions between individuals and groups, particularly around balancing the needs of the participants against the needs of funding bodies, the requirement to publish in academic journals, and project timelines (Kendall, Sutherland, Barnett, Nalder, & Matthews, 2011). There are examples of participants withdrawing from the research altogether because of moral distress (Kendall et al., 2011, p. 6).

Some of these issues did surface for us, and at times we struggled to balance the differing needs. We took guidance from Smith (1999), who argues that the *process* is more important than the *outcome*, and from Stringer (1999), who suggests that the quality of relationships can affect people's experiences of the project. We prioritised the developing relationships and the process itself, and this helped to direct all of our decision making. We did this by regular communication, open dialogue and always checking how everyone was travelling in the project. We sought honesty in communication and understood the privileged position we were afforded by having access to people who had such a condition. If there were issues we positioned the participants first and the organisation first and our needs as researchers second. We understood that all of the participating patients were not very well and we sought not to add to their issues in a negative way but in a positive way. Patients saw that they could not just be helping themselves, but others who came after them who had the same condition.

The project was developed according to the National Health and Medical Research Council guidelines for research with Indigenous Australians (NHMRC, 2003). On our project team, 40% of the Chief Investigators (CIs) and Associate Investigators (AIs) are Indigenous people, with the remaining members being heart-failure experts. Ethics approval was received from the Queensland University of Technology (QUT) Human Research Ethics Committee, which confirmed that our project met the requirements

of the National Statement on Ethical Conduct in Human Research (NHMRC, 2007).

This first phase of the Fluid Watchers Pacific Rim project had two key objectives:

1. To involve Indigenous patients and community health-care workers in the development of a heart-failure self-care iPad app
2. To evaluate the effectiveness of the iPad app on (1) heart-failure knowledge, (2) self-care behaviours and (3) satisfaction and user friendliness of the software.

### *Study site and size*

The Fluid Watchers Pacific Rim project is based in the city of Ipswich, west of Brisbane, in Queensland, Australia. In 2006, Ipswich had a population of just over 162,000, with 34.3% of the population in the most socioeconomically disadvantaged quintile (ABS, 2011). Compared to the wider Queensland population, Ipswich has higher rates of physical inactivity, obesity, type 2 diabetes, mental and behavioural disorders, and deaths from coronary heart disease and stroke (ABS, 2011).

The project is focused on Indigenous people with heart failure who attend either one or all of the Kambu Medical Centre in Ipswich, Ipswich Community Health Heart Failure Centre and West Moreton Health Service District. Focusing on the Ipswich site gave us a fairly defined, stable group for the trial, which helped to make the developmental stages manageable.

In the initial stages of the project, we spent time talking with staff and the Board of the Kambu Medical Centre. We needed to develop a strong working relationship with them, ensure that all stakeholders were fully informed about what was required to commence the project, and ensure they understood the process that the work would involve. We consulted with local Elders and presented education seminars relevant to our work. We wanted to develop trust and engagement between the research team and the local community. We sought to develop a relationship with Kambu Medical Centre that would provide a solid, ethical and trusting

foundation for the trial and for the subsequent large-scale project. We allowed this process to flow and extended the timeline as required. We began without a rigid timelines so we were able to extend the project with reasonable ease. We additionally worked from a basis of wait and see and develop, rather than a strict 'this is the way' process which enabled us to develop and shape the project through the input of stakeholders. This worked for us and this was the way that the Indigenous researchers had advised the non-Indigenous researchers we should best work on this project. We were able to do this since we were not governed by a grant or external agency that expected us to also stick to a timeline that was unworkable for the project.

## Developing the project

The development component of the project involved three cycles of action and reflection. Within each action research cycle, we sought feedback from three participating groups:

- Medical and clinical reviewers
- IT reviewers
- Heart-failure patient reviewers.

We sought feedback about the app's design, images, language and health content, and the level of health literacy required to use it. The app was refined and developed through each research phase. For example, the avatar's design changed to become more acceptable to our target community (Figure 1 shows one example of the IT team's work on developing the avatar). The avatar of the woman changed to be more reflective of the women in the target community who were more likely to wear dresses and have shorter hair. This image is one of a handful of images that was discussed and trialled with the participating patients and the health workers. This was a reflection of the patients themselves and not a reflection of how workers, service providers or the researchers saw the patients. This might be different in other communities. We look forward to a time when the app might be

developed to such an extent that it might allow individual patients to best reflect their individual self through the avatar.

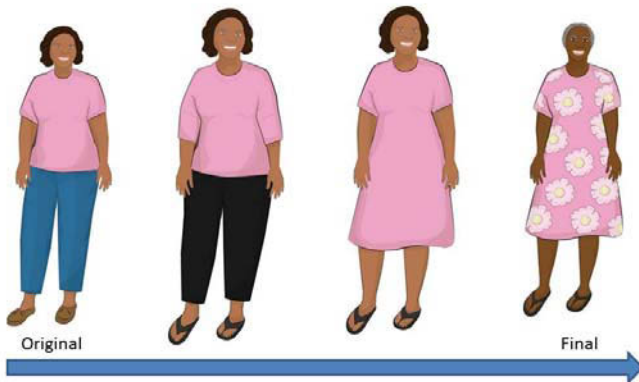


Figure 1: An example of the evolution of the app's avatar.

The third cycle of development resulted in the final version of the app that was used in the trial. Our cyclical development process was similar to the approach used by other health organisations undertaking action research projects (Fredericks et al., 2011).

#### *Input from medical and clinical reviewers*

The app was reviewed during each cycle by a medical and clinical panel that included a cardiologist, heart-failure nurse practitioner, heart-failure research academic, and cardiac nurse. The medical and clinical review panel focused on:

1. Integrity of the heart-failure messages according to evidence-based guidelines
2. Applicability of psychometric tools

3. Appropriate language and images
4. Appropriate interactivity.

#### ***Input from IT reviewers***

The IT team reviewed the app during each cycle to assess its workability and reliability.

#### ***Input from heart failure patient reviewers***

The app was reviewed by five Indigenous heart-failure patients and their carers for usability and ease of navigation. The same patients reviewed the app during each cycle. The participants for this phase were chosen as a purposeful sample based on criteria developed by the Kambu chronic disease nurse who works within a culturally safe environment and where culture is taken into account in decision making and a patients care options. Only people with heart failure who were clinically stable were approached to participate in the study. This was a group decision involving Aboriginal people, including health qualified Aboriginal people.

#### ***Trial component of the project***

Following the app's development, we undertook a small trial to assess the app's usability. We recruited five Indigenous people with heart failure who had not participated in the app's development to participate in the trial. The participants were chosen as a purposeful sample based on the same criteria as the people involved in the development phase. Only Indigenous people with heart failure who were clinically stable were approached to participate. Stability was required to minimise any clinical intervention variables during the study.

The trial phase aimed to evaluate:

1. Heart-failure knowledge
2. Self-care behaviours
3. User-friendliness of the software.

To conduct the evaluation, we used before and after validated questionnaires. Each questionnaire has been previously validated with other populations, but not with Indigenous people.

1. **Heart-failure knowledge:** We used the Heart Failure Knowledge Scale – a multiple-choice and yes/no, self-administered questionnaire (Simons-Morton, Haynie, Crump, Eitel, & Saylor, 2001). The scale consists of six items on heart failure, symptom recognition, diet, fluid restriction, medication and exercise. It provides a score of between 0 and 15 to measure heart-failure knowledge.
2. **Self-care behaviour:** We used the Self-Care of Heart Failure Index Scale (Jaarsma et al., 1999) to measure self-care behaviour, including fluid and weight management.
3. **User-friendliness of software:** We used a previously validated IT Satisfaction Survey (Clark et al., 2007), which we adapted to measure the usability and ease-of-navigation of the app, and to determine participants' level of engagement, views about the app's applicability, and satisfaction.

## Results of the trial phase

The five patients involved in the trial phase included three men and two women, with a mean age of 61.2 years. Of these patients, three were NYHA (New York Heart Assessment) Class III (an international standard that implies a high level of care is required). Four of the participants were married.

Overall, heart-failure knowledge amongst participants improved by 13%, self-care behaviours improved by 3.2%, and satisfaction with the iPad app was 86.2%. Participants said that they enjoyed participating in the project.

The outcomes of this pilot are encouraging. We are now working on how we can develop this project for a larger pilot.

## Discussion

Fluid Watchers Pacific Rim has demonstrated that the iPad app can deliver positive outcomes for Indigenous heart-failure patients. The teaching applications developed through this project can be immediately used by hospital and health-care workers who care for heart-failure patients. They can also be used by patients themselves.

The tools and materials developed in the project continue to be used by the Ipswich community, as part of our efforts to achieve sustainability and reciprocity in the project. It enabled people with heart failure to have direct input into the care of themselves. While our initial trial suggests that the app provides a valuable tool for self care and monitoring for heart-failure patients in Indigenous communities, we need to fully test the app with a larger group of patients with heart failure for reliability and validity. We believe that the PAR will offer more patients with heart failure to have a greater say in their care. Some of the issues will be the same due to the condition as it presents itself. Using PAR will add depth to what is known about Aboriginal and Torres Strait Islander people with heart failure. Even if there is some variations in future work it is adding to the evidence in so far as there is minimal evidence available. Over time with increased numbers of people participating in such work we believe we will start seeing a greater dominant themes and trends. We are planning a future trial in Ipswich which will build on the work undertaken with Kambu to date.

## Conclusion

This pilot study of the Fluid Watchers Pacific Rim project involved developing an iPad app to support self-care and monitoring for Indigenous people with heart failure. The people who participated in developing and trialling the app enjoyed their involvement in the project. They all showed improvement in knowledge and self-care (this improvement was shown by those in the development phase and those in the trial phase).

This pilot confirms that participatory action research can be used successfully in the development and trialling of an app intended for clinical interventions. The methodology was a useful way to bring together health experts, an IT team and Indigenous heart-failure patients. Together, they worked through three cycles of development and critical reflection. Through this project, we have come to believe that this approach can be used for future clinical trials that approach health care from a cultural perspective. In doing so, this offers another mechanism for working towards achievable and effective health gains for Indigenous Australians, beyond the life of the project.

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Dr Robyn A. Clark is a Professor of Nursing (Acute Care) at Flinders University. She has undertaken research of telemonitored heart-failure management in rural and remote Australia and is internationally-recognised for her research into the most effective management of patients with heart failure.

Dr Mick Adams is a Research Fellow with the Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS), Canberra, Australia. Mick is a member of the National Indigenous



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Dr John Atherton is the Director of Cardiology at the Royal Brisbane and Women's Hospital and Associate Professor, Department of Medicine, University of Queensland. His clinical and research interests include heart failure pathophysiology, quality of care in patients with acute coronary syndromes and heart failure, cardiac genetics and cardiac rehabilitation.

Ms Stella Taylor-Johnson is the CEO of the Kambu Medical Centre which provides comprehensive medical and specialist services to the Ipswich and surrounding areas and is committed to the delivery of comprehensive primary health care to Aboriginal and Torres Strait Islander peoples and supports the effective integration of services with the broader mainstream health system. Stella has been a Director of a number of organisations, including the Institute of Urban Indigenous Health (UIIH), Health Workforce Queensland and the Queensland Aboriginal & Islander Health Council (QAIHC).

Dr C-J (Jo) Wu is a Lecturer with the Queensland University of Technology (QUT). Her research interests evolved from over 16 years of clinical experience in the Coronary Care Unit where she observed differences in the progress of cardiac patients with diabetes. She is an Honorary Research Fellow with the Mater Medical Research Institute, Mater Health Services, and the Royal Brisbane and Women's Hospital.

Dr Jill Howie Esquivel is an Assistant Professor at the University of California, San Francisco, School of Nursing. Her research is inspired by her extensive clinical experience with critical care and cardiology patients, including the testing of interventions that are culturally appropriate for vulnerable populations with heart failure.

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Ms Natahlia Buitendyk is a medical student at the University of Queensland. She worked on this project as a Research Assistant at the Queensland University of Technology (QUT).

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