

Title page**Journal: Rural and Remote Health**

Title: Development and feasibility testing of an education program to improve knowledge and self-care among Aboriginal and Torres Strait Islander patients with heart failure.

Authors Full Name	Institutional Mailing Address	Highest qualification	Email Address
*Prof Robyn A Clark	*Corresponding author Professor of Nursing (Acute Care & Cardiovascular Research) School of Nursing and Midwifery Flinders University Office: Room N212, Sturt Campus, Adelaide 5001 Phone +61 8 82013266	PhD	robyn.clark@flinders.edu.au
Prof Bronwyn Fredericks	Central Queensland University Australia, Building 33 (Room 1.32), Rockhampton QLD, Australia 4702	PhD	b.fredericks@cqu.edu.au
Ms Natahlia J Buitendyk	ATSISU, University of Queensland, Level 2, Building 4, St. Lucia, QLD 4072	BSc	natahlia.buitendyk@gmail.com
Dr Michael Adams	Australian Institute of Aboriginal and Torres Strait Islander Studies, Lawson Crescent, Acton Peninsula, Acton ACT 2601	PhD	michael.adams@aiatsis.gov.au
A/Prof Jill Howie- Esquivel	2 Koret Way, Box 0610, University of California, San Francisco, San Francisco, CA 94143 N631G, United States of America.	PhD	j.howie-esquivel@nursing.ucsf.edu
Prof Kathleen Dracup	School of Nursing, University of California San Francisco, 2 Koret Way N611E, San Francisco, California, United States of America 94143.	PhD	kathleen.dracup@nursing.ucsf.edu
Dr Narelle M Berry	Postdoctoral Research Fellow (Acute Care & Cardiovascular Research) School of Nursing and Midwifery Flinders University Office: Room N204 Sturt Campus, Adelaide 5001 Phone +61 8 82013066	PhD	narelle.berry@flinders.edu.au
Dr John Atherton	Cardiology Department, James Mayne Building Royal Brisbane and Women's Hospital, Herston QLD, Australia 4029, Queensland University of Technology School of Nursing and University of Queensland School of Medicine	MBBS	j.atherton@health.qld.gov.au
Ms Stella Johnson	CEO Kambu Medical Centre		stella.johnson@kambumedical.com.au

Conflict of Interest:

There are no conflicts of interest for any of the above authors

Sources of support for this project:

This project was supported by the Queensland University of Technology (QUT) and University of California San Francisco (UCSF) Atlantic Philanthropic Project Grant; an IHBI Collaborative Research Development Grant in 2011 and the Commonwealth Funded Health Collaborative Research Network (CQUniversity Australia & QUT) in 2013.

Abstract

Background/Aim: There is a 70% higher age-adjusted incidence of heart failure (HF) amongst Aboriginal and Torres Strait Islander people, three times more hospitalisations and twice as many deaths than non-Aboriginal people. There is a need to develop holistic yet individualised approaches in accord with the values of Aboriginal community healthcare to support patient education and self-care. The aim of this study was to re-design an existing HF educational resource (Fluid Watchers-Pacific Rim©) to be culturally safe for Aboriginal and Torres Strait Islander peoples, working in collaboration with the local community, and to conduct feasibility testing.

Methods: This study was conducted in two phases and utilised a mixed methods approach (qualitative and quantitative). Phase 1 of this study used action research methods to develop a culturally safe electronic resource to be provided to Aboriginal HF patients via a tablet computer. A HF expert panel adapted the existing resource to ensure it was evidence-based and contained appropriate language and images that reflects Aboriginal culture. A stakeholder group (which included Aboriginal workers and HF patients, as well as researchers and clinicians) then reviewed the resources and changes were made accordingly.

In Phase 2, the new resource was tested on a sample of Aboriginal HF patients to assess feasibility and acceptability. Patient knowledge, satisfaction and self-care behaviours were measured using a before and after design with validated questionnaires. As this was a pilot test to determine feasibility, no statistical comparisons were made.

Results: Phase 1: Throughout the process of resource development, two main themes emerged from the stakeholder consultation. These were the importance of identity, meaning that it was important to ensure that the resource accurately reflected the local community, with the appropriate clothing, skin tone and voice. The resource was adapted to reflect this

and members of the local community voiced the recordings for the resource. The other theme was comprehension; images were important and all text was converted to the first person and used plain language. Phase 2: Five Aboriginal participants, mean age 61.6 ± 10.0 years, with NYHA Class III and IV heart failure were enrolled. Participants reported a high level of satisfaction with the resource (83.0%). HF knowledge (percentage of correct responses) increased from $48.0 \pm 6.7\%$ to $58.0 \pm 9.7\%$, a 20.8% increase and results of the self-care index indicated that the biggest change was in patient confidence for self-care with a 95% increase in confidence score (46.7 ± 16.0 to 91.1 ± 11.5). Changes in management and maintenance scores varied between patients.

Conclusion: By working in collaboration with HF experts, Aboriginal researchers and patients, a culturally safe HF resource has been developed for Aboriginal and Torres Strait Islander patients. Engaging Aboriginal researchers, capacity-building, and being responsive to local systems and structures enabled this pilot study to be successfully completed with the Aboriginal community and positive participant feedback demonstrated that the methodology used in this study was appropriate and acceptable; participants were able to engage with willingness and confidence.

Key words: Heart failure, patient education, Aboriginal and Torres Strait Islander people

1 **Introduction**

2 Chronic health conditions are highly prevalent among Aboriginal and Torres Strait Islander
3 peoples and this places significant strain on patients, their families, communities, and the
4 health care system. Recent data demonstrated that 50% of all Aboriginal and Torres Strait
5 Islander people have at least one chronic condition, and chronic disease contributes to 80% of
6 the estimated 11.5 year life expectancy gap between Aboriginal and Torres Strait Islander
7 peoples and other Australians¹. Chronic conditions include diabetes, cardiovascular disease,
8 heart failure (HF), renal disease, pulmonary disease and mental illness.

9 HF is the second leading cause of hospitalisation in Australia^{2, 3}. There is a 70% higher
10 prevalence of HF amongst Aboriginal and Torres Strait Islander peoples compared to non-
11 Aboriginal Australians². Their age-adjusted hospitalisation rates are three times higher and
12 their HF mortality is twice as high of that of non-Aboriginal and Torres Strait Islander people
13 with HF^{2, 3}. However, most Aboriginal and Torres Strait Islander people who have HF have
14 more than one chronic condition. These data highlight the need for holistic yet individualised
15 approaches^{1, 4, 5} in accord with the values of Aboriginal and Torres Strait Islander community
16 healthcare. HF patients who effectively manage their symptoms through lifestyle
17 modification and adherence to medications have fewer hospitalisations. Nurse-led programs
18 that teach and support self-care have also been shown to reduce hospitalisations⁶.

19 Although evidence indicates that self-care improves outcomes compared to usual care, 50%
20 of patients experience minimal benefit from these interventions.⁷ The variance in effect on
21 reducing hospital admissions (0%-45%)^{8, 9} seems to indicate that one size does not fit all.
22 The variance is undoubtedly partly attributable to differences in patient characteristics. Little
23 is known about factors that distinguish patients who successfully manage their HF self-
24 care from those who do not or which elements of self-care lead to optimal outcomes. Even

25 less is known about HF self-care strategies in Aboriginal and Torres Strait Islander peoples.
26 Research has indicated that Aboriginal and Torres Strait Islander HF patients have
27 significantly lower self-care behaviours ($p < 0.001$)¹⁰. Continuous quality improvement
28 programs, such as The Audit and Best Practice for Chronic Disease (ABCD) project, have
29 shown positive results in improving outcomes for chronic disease and implementing evidence
30 based practice in urban and rural community clinics¹¹.

31 Fluid management is a key component of symptom monitoring and management for HF
32 patients. Telemonitoring data have shown that signs and symptoms of fluid overload begin
33 around 8 days prior to an emergency hospital admission for acute decompensated HF¹².
34 These data suggest that there was sufficient warning time for action and prevention.

35 Current guidelines recommend patients weigh themselves daily and commence a prescribed
36 fluid management plan if 2 kilograms over 2 days is gained with associated hand, ankle or
37 abdominal swelling¹³. Monitoring and managing these simple signs of HF can prevent the
38 deterioration that leads to acute decompensated HF and pulmonary oedema, and can prevent
39 consequent readmission^{6, 12, 14}.

40 Self-management programs assisted by information technology and telephone follow-up may
41 assist in the effective management of HF patients. A systematic review and meta-analysis
42 indicated that these programs are highly effective in reducing mortality and hospitalisation
43 and in improving HF knowledge and medication adherence¹⁵. The use of tablet computers is
44 one way of providing educational materials to help improve patient care¹⁶, and has the
45 potential to be adapted for a range of different conditions and populations

46 The educational intervention called Fluid Watchers© developed in the USA by Caldwell and
47 colleagues, educates patients about the signs, symptoms, causes and consequences of HF in
48 their self-management and in particular, fluid monitoring by keeping a daily weight record¹⁴.

49 The intervention is specifically aimed to reduce the anxiety which many HF patients
50 (especially women) associate with weighing themselves due to adipose weight gain¹⁷. The
51 program gives patients an action plan in the case of fluid gain and addresses perceived
52 barriers that would prevent adherence to this action plan. Fluid Watchers© has been shown to
53 improve HF knowledge and self-care behaviour in rural patients and participation in this
54 program has been shown to lead to reduced rates of hospital readmission and mortality
55 among these patients^{14, 18}.

56 Therefore, the purpose of this study was to create a tablet computer based educational
57 resource, adapted from the Fluid Watchers© program to provide culturally safe HF education
58 to Aboriginal and Torres Strait Islander peoples. There were two phases of this project which
59 aimed to: 1) Engage expert HF stakeholders and the local Aboriginal and Torres Strait
60 Islander community healthcare workers and patients to participate in the redesign of existing
61 Fluid Watchers-Pacific Rim© HF educational materials to be culturally safe for the local
62 Aboriginal and Torres Strait Islander community and; 2) Conduct a feasibility study with a
63 purposeful sample of Aboriginal and Torres Strait Islander HF patients to gather feedback
64 regarding the tools developed to improve HF knowledge and self-care behaviours.

65 **Methods**

66 *Study Design*

67 This study was conducted in two stages utilising a mixed methods design to create the
68 educational resource and test its feasibility including action research and pre-intervention
69 post-intervention knowledge and self-care questionnaires. The first stage was the
70 development of a culturally safe version of Fluid Watchers-Pacific Rim© HF educational
71 materials for use on a tablet computer.

72 The Queensland University of Technology University Human Research Ethics Committee
73 approved the study and written, informed consent was provided by all participants.

74 Community consent was sought through initial discussions with local Elders before initiating
75 the study or contacting participants. Aboriginal and Torres Strait Islander HF patients were
76 sent letters inviting them to participate in the study. The letters stated study objectives and
77 intended outcomes, participant inclusion criteria, a prompt to participate, incentives,
78 notification to receive a call in the next few days and contact details for further information
79 and explanation.

80 *Development of Educational Resource*

81 Action research methods were used to develop the new resource using materials provided by
82 Fluid Watchers^{©19}. Two working groups were established to accomplish this. An expert HF
83 panel, consisting of a cardiologist, a HF nurse practitioner, HF research academics, and a
84 cardiac nurse, Aboriginal researchers and community nurses as well as an IT team provided
85 advice on appropriate modification of the resources. A Following the action research cycles
86 of Plan, Act, Observe and reflect.

87 During the planning phase the expert panel took the Fluid Watchers resource and proposed
88 modifications to ensure that 1) the curriculum was delivered according to evidence-based
89 guidelines provided by the Australian National Heart Foundation and American Heart
90 Association Self-management Guidelines for patients^{13, 20}; 2) the applicability of
91 psychometric tools were appropriate; 3) the language and format was accommodating to
92 Aboriginal and Torres Strait Islander patients' culture and literacy; 4) images and
93 interactivity reflected Aboriginal and Torres Strait Islander culture and gender.

94 The IT team then actioned (Act) the proposed modifications into a new Aboriginal and Torres
95 Strait Islander specific resource. The expert panel then reviewed the modifications (Observe)

96 and then proposed further modifications. Case notes were kept during the development stage
97 for subsequent analysis. This was repeated through two cycles.

98 The resource was then taken to a broader group of stakeholders consisting of representatives
99 including university and medical researchers, staff from the Aboriginal and Torres Strait
100 Medical Service, technology developers and two Aboriginal and Torres Strait Islander HF
101 patients. This was a key component of the reflection stage of action research. Bringing in
102 Aboriginal and Torres Strait Islander medical staff and HF patients allowed for questions
103 relating to cultural appropriateness and shared understanding to be addressed. The outcomes
104 of these discussions were also fed back into the resource development to reach the final
105 product.

106 The Fluid Watchers© program included an illustrated PowerPoint™ featuring a HF patient
107 (male or female, whichever the patient chose) and patient diary for adaptation. The larger
108 stakeholder group alongside the expert panel prepared the adaptations and gave feedback
109 verbally, in written or electronic form. Information collected was integrated to produce the
110 next version of the teaching tool. Specific feedback regarding illustrations of Aboriginal body
111 shape, facial features, choice of clothing, colours, skin tone and environment were
112 communicated to the graphic designer.

113 ***Feasibility and acceptability testing***

114 The second stage involved pilot-testing the feasibility and acceptability of the newly designed
115 resource with a group of HF patients based at an Aboriginal and Torres Strait medical service
116 in central Ipswich, Queensland, Australia. To be included in the feasibility study participants
117 had to be of Aboriginal or Torres Strait Islander descent, aged over 18 years and have a
118 clinical diagnosis with NYHA function class II-IV symptoms. Potential participants were

119 excluded if they were a resident of a nursing home or institution as these patients generally do
120 not perform self-care.

121 Eligible participants identified by the Aboriginal healthcare worker were introduced to the
122 researcher. An Aboriginal researcher explained to the HF patients the purpose of the study, an
123 Aboriginal themed diary for recording daily observations and a Heart Foundation 'Living
124 each day with my heart failure' booklet was given to each patient in appreciation for their
125 time and contribution.

126 *Intervention*

127 Prior to viewing the resource, participants completed questionnaires on their knowledge of
128 heart failure and self-management behaviours. Participants then spent approximately one
129 hour trialling and reviewing the resource. After this, they then had one attempt to complete
130 the knowledge and self-management questionnaires again as well as a satisfaction survey
131 related to their experience with the resource.

132 *Instruments*

133 Three validated questionnaires were used in this study to evaluate Aboriginal HF patients'
134 knowledge, self-management behaviour and satisfaction levels with receiving education via
135 the adapted Fluid Watchers© program. All questionnaires were embedded in the program and
136 appropriate permission to use the questionnaires was obtained from each of the original
137 authors. Patients answered the questionnaires by touching their answers on the tablet
138 computer. A HF knowledge questionnaire¹⁴ and Self-Care Heart Failure Index (SCHFI) V6.2
139 questionnaire²¹ were used as pre- and post-intervention measures. Aboriginal HF patients'
140 satisfaction level with the program and its contents was measured by satisfaction survey²²
141 adapted for heart failure. All questionnaires were converted into plain, conversational

142 language as advised by the Aboriginal and Torres Strait islander members of the expert panel.

143 A consistent layout with large text and images were used wherever feasible.

144 Examples of content adaptation of the questionnaires included “Symptoms are vague or come

145 on gradually” changed to “I feel this (symptom) all the time or don’t notice a change,”

146 “Overall how do you feel about keeping yourself free of heart failure symptoms?” changed to

147 “Do you feel you can look after you, so that your heart failure doesn’t give you trouble?” and

148 “How quickly did you recognise it as a symptom of heart failure?” changed to “When did you

149 know it (the symptom) was because of your heart failure?”

150 *Heart Failure Knowledge*

151 The questions for assessing HF knowledge were initially developed based on the Rapid Early

152 Action for Coronary Treatment (REACT) study in the acute myocardial infarction

153 population²³. The questionnaire was modified for a HF population^{14, 19} and content validity of

154 the modified questionnaire was established by HF experts. Internal consistency and reliability

155 for the modified questionnaire was 0.83¹⁴. The modified HF knowledge questionnaire

156 covered basic HF physiology, recognition of HF signs and symptoms and barriers to seeking

157 care¹⁴. The 20-item questionnaire allowed patients to choose what they perceive as the correct

158 answer from multiple choice, yes / no or true / false options. In this survey, the correct answer

159 for each question accrued one point (the wrong answer has zero points). Therefore, the

160 questionnaire had a minimum score of 0 and a maximum score of 20 points¹⁴.

161 *Self-Care Heart Failure Index (SCHFI)*

162 Self-management behaviours were measured using the Self-Care Heart Failure Index

163 (SCHFI) V6.2 questionnaire²¹. The SCHFI evaluates patient self-management behaviour by

164 assessing the following skills: frequency of self-care behaviours such as daily weighing,

165 physical activity, medication concordance (maintenance), ability to confidently manage HF
166 (confidence) and the ability to evaluate the importance of symptoms, recognise changes in
167 health status, take required actions to relieve symptoms and to evaluate the effectiveness of
168 self-management and treatment (management). Each of these components has been tested for
169 reliability (Maintenance: coefficient alpha=0.553, Confidence: coefficient alpha=0.827 and
170 Management: coefficient alpha=0.597).²¹ Scores for maintenance, confidence and
171 management were calculated in accordance with the authors instructions²¹. Patients with
172 higher scores are considered to have a greater ability to self-manage.

173 ***Satisfaction Survey***

174 To examine the level of satisfaction with receiving education via the adapted Fluid
175 Watchers© program, a satisfaction survey was administered following exposure. This survey
176 evaluated the ease of navigation and useability of the resource. A previously validated
177 satisfaction survey²² that determined participant satisfaction for receiving healthcare via
178 telephone interaction was modified to be appropriate for the tablet computer based program.
179 The finalised questionnaire included 29 items with a 5-point Likert scale (1=strongly
180 disagree, to 5= strongly agree). Open ended questions were also asked to collect qualitative
181 data on acceptance, comprehension and impact of the program.

182 ***Data Analysis***

183 Microsoft Excel 2010™ was used to collate and analyse data. To describe the process of
184 resource development, summaries of field notes were used and data were reported using the
185 method proposed by Huberman and colleagues, (1994) to identify emerging patterns and
186 themes²⁴.

187 Quantitative Data are reported using descriptive statistics, including means (standard
188 deviations). Due to the small sample size, statistical comparisons for the pre- and post-
189 knowledge and SCHFI questionnaires were not performed.

190 **Results**

191 *Stakeholder Feedback*

192 Two main themes emerged from stakeholder feedback while adapting materials for
193 Aboriginal patients: identity and comprehension. Identity was an important concept to portray
194 in the new teaching tools. Stakeholders felt that illustrations should accurately reflect
195 Aboriginal people of the same gender as the patient and from the local community. Feedback
196 was given to alter the skin tone, choice of clothing, facial features and body shape of original
197 illustrations and the program was voiced by members of the local Aboriginal community. The
198 environment in which the Aboriginal people appeared was also important and was changed to
199 reflect one to which the community could relate. Finally, symbolism was added to reflect the
200 Aboriginal cultures. Reviewers saw symbolism as necessary to reflect identity, and
201 Aboriginal flags were featured where possible, and text and background colours changed to
202 represent those of the flags. Figure 1 shows selected screen shots of the completed
203 PowerPoint slides.

204 Comprehension was also a theme that emerged to be of importance to stakeholders.
205 Reviewers considered it important that illustrations be created to portray an action; for
206 example, additional fluid accumulation in the abdominal region was illustrated by a man
207 having difficulty doing up his belt. Images complemented text and provided another aid to
208 dependence upon reading ability and text was converted into plain language. Researchers also
209 changed the tense of language; in most instances first person was used so as to closely
210 identify with the person reading it. For example, in a questionnaire, the original wording
211 read: “*A primary cause for symptoms of heart failure is too much fluid*” and this was changed
212 to, “*Too much fluid in my body causes heart failure*”. Acronyms were removed and complex
213 nouns and verbs were replaced with simple descriptive language. Simplifying language

214 therefore occurred in this manner within the PowerPoint™ and questionnaires, and
215 illustrations were developed to aid comprehension.

216 IT experts constructed the technology interface with the following additional features: simple
217 animated anatomy and physiology to teach concepts of the normal heart and HF; voice-over
218 presented by members of the local Aboriginal community; user-friendly interface;
219 simultaneous login; secure method of data retrieval and analysis to retrieve patient responses
220 with a shortcut key to provide ease of searching and data categorisation; secure settings for
221 patient confidentiality with data unable to be accessed in the public domain.

222 ***Patient Feedback***

223 ***Participants***

224 The Aboriginal medical clinic patient database produced a list of eleven potential
225 participants. Five of these patients agreed to participate in the program and the other 6
226 declined to participate due to an inability to commit the time to the project. All five
227 participants that trialled the program were Aboriginal people, born in Australia and spoke
228 English as their primary language. The mean age of participants was 61.6 ± 10.0 years. Three
229 participants had a NYHA classification of Class III and two participants had a classification
230 of Class IV.

231 ***Acceptance***

232 Two participants (female) expressed having enjoyed their experience stating “*I liked it all*”
233 and thought the teaching tool was “*good*” and they “*enjoyed it*”. One patient (male, NYHA
234 Class IV) became tired during the program and at the end stated that overall “*it was alright*”.
235 Another (male) appreciated the concept of providing information via this teaching method

236 stating, *“That is a good idea, instead of just talking or asking about it, the iPad just tells*
237 *you.”*

238 All five participants had never used a tablet computer before. One person (female) described
239 the experience as having initially made her nervous – *“at first I was scared”* but then
240 reflected that she found the experience *“enjoyable”*. Another participant (male) reflected
241 upon the teaching tool as *“simply moving with technological advancements”* stating that *“we*
242 *need to keep up”*. Most participants used the tablet computer touch screen with ease, however
243 one participant (male) had repeated difficulty utilising a gentle touch and stated that it was
244 not easy to use the touch screen. Another participant (female) stated the general organisation
245 of the teaching materials was easy to navigate from the home screen and that the video was
246 *“very helpful”*.

247 When asked, all participants agreed they would use this teaching tool on the occasion they
248 visit the AMS. Three participants (two female, one male) stated they would like to use the
249 teaching tool to refresh their knowledge in the future, stating *“I would use that again”*, *“I*
250 *would like to watch it again”* and *“I would use something like that again”*.

251 ***Comprehension***

252 Participants commented that the teaching tool was very easy to understand with *“no big*
253 *words”* (female) and another noting the message was *“not complicated with jargon”* (male).
254 Another (female) stated that before, they did not know much about their HF, but *“seeing that*
255 *really did make me realise”*. From this it appears that participants were able to comprehend
256 the information presented.

257

258 ***Impact***

259 When referring to the overall message one participant stated, “*this is something I will never*
260 *forget*”. One patient stated that exposure to the messages of the teaching tool “*came at a good*
261 *time*” and described having begun a health overhaul in the New Year by participating in the
262 local walking group, eating more fresh fruit and vegetables.

263 One participant was particularly motivated after participating, stating, “*its now up to me to do*
264 *this*”. This participant returned to the clinic later in the day to show the research team
265 alternative low salt items they had purchased.

266 ***HF Knowledge and SCHFI***

267 There was a 20.8% increase in HF knowledge (Table 1) with the percentage of correct
268 responses increasing from $48.0 \pm 6.7\%$ to $58.0 \pm 9.7\%$.

269 The results of the SCHFI questionnaire are described in Table 2. Despite the intervention and
270 survey completion only taking 60 minutes two participants did not complete the follow-up
271 questions on this survey related to maintenance as they became too fatigued to finish the
272 questionnaire. Of the three participants that did complete this section there was a 26.1%
273 increase in maintenance score (from 46.7 ± 6.7 to 58.9 ± 25.5 possible range 0-100). All five
274 respondents completed the management and confidence questions and there was a 1.9%
275 increase in management (from 53.0 ± 12.5 to 54.0 ± 6.5 possible range 0-100) and a 95.1%
276 increase in confidence (from 46.7 ± 16.0 to 91.1 ± 11.5 possible range 0-100).

277 ***Satisfaction***

278 Participant satisfaction was 83.0% (Figure 2). Greatest satisfaction was with the inbuilt video
279 demonstration and in having questions answered. All participants indicated willingness to
280 adopt lifestyle changes (daily weighing) and endorse its use to educate others with HF.

281 **Discussion**

282 The results of the present study demonstrate that by working in collaboration with HF
283 experts, Aboriginal researchers and patients, a culturally safe HF resource has been
284 developed for Aboriginal and Torres Strait Islander patients. Engaging Aboriginal
285 researchers, capacity-building, and being responsive to local systems and structures enabled
286 this research to be successfully completed with the Aboriginal community and the positive
287 participant feedback shows that the methodology used in this study was appropriate and
288 acceptable; participants were able to engage with willingness and confidence.

289 Currently, limited information is available on health promotion using a tablet or computer
290 that has been developed specifically for Aboriginal and Torres Strait Islander people with HF.
291 Participants rated their satisfaction with the program at 83%. They commented that the
292 information was easy to comprehend and all endorsed its use to educate others with HF.
293 Previous researchers have expressed that existing teaching resources for Aboriginal and
294 Torres Strait Islander peoples' HF self-management are unsuitable and practical self-care
295 teaching resources are needed with key messages communicated simply and visually²⁵. The
296 stakeholder group emphasised that health promotion pictures and messages are needed to be
297 contemporary and reflective of Aboriginal and Torres Strait Islander communities in the
298 modern setting²⁶.

299 Community organisations are viewed as vehicles for enhancing social connection and cultural
300 expression among Aboriginal and Torres Strait Islander peoples²⁷. The waiting room of an
301 Aboriginal medical clinic has previously been described as creating opportunity for valued
302 and important aspects of daily life to take place – sharing health information and spending
303 time with friends and family²⁸. During feedback time, all participants agreed they would be
304 happy to use the tool upon subsequent visits to the clinic. Although all participants had never

305 used a tablet computer, most became familiar and confident in using it during the trial and
306 only one participant displayed limited dexterity while using the touch screen. Utilisation rates
307 of Internet-based programs are low among some Aboriginal and Torres Strait Islander
308 communities with a notable 'digital divide'²⁹. One participant stated that few persons of his
309 generation used this type of technology on a daily basis; however all agreed that they would
310 be happy to refresh their knowledge using the technology upon visits to the clinic.

311 Use of touch-screen technology can therefore be regarded as an alternative (or substitute)
312 way of presenting health information to more conventional mechanisms such as verbal
313 advice, posters, leaflets, books etc. in the appropriate health care provider setting²⁹. The
314 education tool has the potential to assist health professionals to provide a more positive
315 experience for Aboriginal and Torres Strait Islander patients with HF through cultural
316 recognition and consideration. After receiving the education, participants verbally expressed
317 motivation to implement lifestyle changes and expressed gratitude; one participant positively
318 stating, "*This is something I will never forget*". Most notably participants had greater self-
319 efficacy, showing a measurable improvement of 95.1% in confidence to ably manage their
320 symptoms.

321 Other studies that have measured changes in knowledge and self-care in Australian HF
322 patients have shown similar results to the present study. Boyde and colleagues (2013)
323 demonstrated improvements in HF knowledge (14% increase) as measured by the Dutch
324 Heart Failure Knowledge Scale and increases in SCHFI maintenance (7% increase),
325 management (28% increase) and confidence (11% increase)³⁰. In addition, Caldwell and
326 colleagues (2005) has demonstrated a similar (3 point) improvement in HF knowledge over
327 three months along with significant improvements in self-care behaviour.¹⁴

328 *Limitations and future directions*

329 As this was a pilot program, the number of participants was not sufficient to allow for the
330 determination of statistically significant differences. The small number of participants was
331 due to the use of one clinic for recruitment. Instead, the results support the need for further
332 research, with participant numbers which allow for greater analysis of effect, future studies
333 will seek to recruit a greater number of participants.

334 Notwithstanding this limitation, it has been reported that changes in the SCHFI of ≥ 0.5 of a
335 standard deviation may be considered clinically relevant²¹ and thus scores on maintenance and
336 confidence show improvements over and above 0.5 of the standard deviation and could be
337 considered as clinically relevant, but this needs to be explored further in a larger population.

338 In addition, it is not known whether the results of this study will be transferable to wider
339 community, which may have different levels of literacy.

340 Results may not necessarily equate to longer-term behaviour change or reduced hospital
341 admissions. Prolonged effects were not measured as post-test questionnaires were distributed
342 immediately after the education session^{19,30}.

343 Further adaptations may be required for different Aboriginal and Torres Strait Islander
344 communities, and in this case should utilise an Aboriginal and Torres Strait Islander
345 Reference Group from the community for which they are developing the resource. Our
346 findings support the need for future studies with longer follow-up time¹⁴ in a larger cohort
347 with administrative blinding to measure longer term behaviour change and the effect on
348 clinical outcomes including quality of life, hospitalisations and health care utilisation.

349

350 **Conclusion**

351 This project utilised a mixed-methods design to adapt and evaluate educational tools for
352 Aboriginal and Torres Strait Islander HF patients that incorporated interactive voice over and
353 visual aids into a tablet computer-based resource. Consistent with previous studies in non-
354 Aboriginal populations, favourable trends were observed in knowledge and self-care and
355 participants expressed a high level of satisfaction with the resources. Further research is
356 required to measure long-term behavioural change and effects on hospital admissions.
357 Additional adaptation may be required to be transferable to other Aboriginal and Torres Strait
358 Islander communities.

359 **Acknowledgments**

360 The research team would like to thank the following individuals: Vikki Blacka, Noel Hicks,
361 Kay Mundraby for their input and fabulous voices for the app, Dr Johannes Moolman, Chris
362 Horton and Nazli Bashi for their clinical heart failure expertise and research support.

References

1. Australian Institute of Health and Welfare. *Life expectancy and mortality of Aboriginal and Torres Strait Islander people*. Canberra: Australian Institute of Health and Welfare 2011.
2. Australian Institute of Health and Welfare. *Cardiovascular Disease: Australian facts*. Canberra: Australian Institute of Health and Welfare, 2011.
3. Woods JA, Katzenellenbogen JM, Davidson PM, Thompson SC. Heart failure among Indigenous Australians: a systematic review. *BMC Cardiovascular Disorders*. 2012;12(1):99.
4. Australian Health Ministers' Advisory Council. *Aboriginal and Torres Strait Islander Health Performance framework report*. Canberra: Australian Health Ministers' Advisory Council, 2010.
5. Australian Institute of Health and Welfare. *The Health and Welfare of Australia's Aboriginal and Torres Strait Islander People: an overview*. Canberra: Australian Institute of Health and Welfare, 2011.
6. Jaarsma T, Halfens R, Abu-Saad HH, Dracup K, Gorgels T, Van Ree J, et al. Effects of education and support on self-care and resource utilization in patients with heart failure. *European Heart Journal*. 1999;20(9):673-682.
7. Riegel B, Moser DK, Anker SD, Appel LJ, Dunbar SB, Grady KL, et al. State of the science promoting self-care in persons with heart failure: a scientific statement from the American Heart Association. *Circulation*. 2009;120(12):1141-1163.

8. Riegel B, Carlson B, Glaser D, Romero T. Randomized controlled trial of telephone case management in Hispanics of Mexican origin with heart failure. *Journal of Cardiac Failure*. 2006;12(3):211-219.
9. Stewart S, Marley JE, Horowitz JD. Effects of a multidisciplinary, home-based intervention on planned readmissions and survival among patients with chronic congestive heart failure: a randomised controlled study. *The Lancet*. 1999;354(9184):1077-1083.
10. Schnell-Hoehn KN, Naimark BJ, Tate RB. Determinants of self-care behaviors in community-dwelling patients with heart failure. *Journal of Cardiovascular Nursing*. 2009;24(1):40-47.
11. Si D, Bailie R, Cunningham J, Robinson G, Dowden M, Stewart A, et al. Describing and analysing primary health care system support for chronic illness care in Indigenous communities in Australia's Northern Territory—use of the Chronic Care Model. *BMC Health Services Research*. 2008;8(1):112.
12. Spaeder J, Najjar SS, Gerstenblith G, Hefter G, Kern L, Palmer JG, et al. Rapid titration of carvedilol in patients with congestive heart failure: a randomized trial of automated telemedicine versus frequent outpatient clinic visits. *American Heart Journal*. 2006;151(4):844. e841-844. e810.
13. National Heart Foundation of Australia. *Living well with chronic heart failure: a guide for patients and their families* 2008 [08/May/2014]. Available from: <http://www.heartfoundation.org.au/SiteCollectionDocuments/Living-well-with-chronic-heart-failure.pdf> .

14. Caldwell MA, Peters KJ, Dracup KA. A simplified education program improves knowledge, self-care behavior, and disease severity in heart failure patients in rural settings. *American Heart Journal*. 2005;150(5):983. e987-983. e912.
15. Inglis S. Structured telephone support or telemonitoring programmes for patients with chronic heart failure. *Journal of Evidence-Based Medicine*. 2010;3(4):228-228.
16. Suhling H, Rademacher J, Zinowsky I, Fuge J, Greer M, Warnecke G, et al. Conventional vs. Tablet Computer-Based Patient Education following Lung Transplantation—A Randomized Controlled Trial. *PloS one*. 2014;9(3):e90828.
17. Riegel B, Carlson B. Facilitators and barriers to heart failure self-care. *Patient Education and Counseling*. 2002 4//;46(4):287-295.
18. Dracup K, Moser DK, Pelter MM, Nesbitt T, Southard J, Paul SM, et al. A Randomized Controlled Trial to Improve Self-Care in Patients with Heart Failure Living in Rural Areas. *Circulation*. 2014 (IN PRESS accepted for publication May 9, 2014).
19. Howie J, Banks A, Caldwell MA, Dracup K. A pilot educational intervention improves knowledge of symptoms of heart failure. *American Journal of Critical Care*. 2003;12(3):278.
20. Adams K, Lindenfeld J, Arnold JMO, Baker D, Barnard D, Baughman K, et al. HFSA 2006 comprehensive heart failure practice guideline. *Journal of Cardiac Failure*. 2006;12(1):e86-e103.
21. Riegel B, Lee CS, Dickson VV, Carlson B. An update on the self-care of heart failure index. *The Journal of Cardiovascular Nursing*. 2009;24(6):485.
22. Clark RA, Yallop JJ, Piterman L, Croucher J, Tonkin A, Stewart S, et al. Adherence, adaptation and acceptance of elderly chronic heart failure patients to receiving healthcare via telephone-monitoring. *European Journal of Heart Failure*. 2007;9(11):1104-1111.

23. Simons-Morton DG, Goff DC, Osganian S, Goldberg RJ, Raczynski JM, Finnegan JR, et al. Rapid early action for coronary treatment: Rationale, design, and baseline characteristics. *Academic Emergency Medicine*. 1998;5(7):726-738.
24. Huberman AM, Miles MB. Data management and analysis methods. 1994.
25. Kowanko I, Helps Y, Harvey P, Battersby M, McCurry B, Carbine R, et al. *Chronic Condition Management Strategies in Aboriginal Communities*. Flinders University and the Aboriginal Health Council of South Australia, Adelaide: 2012.
26. Baunach E, Lines D, Pedwell B, Lange F, Cooney R, Taylor HR. The Development of Culturally Safe and Relevant Health Promotion Resources for Effective Trachoma Elimination in Remote Aboriginal Communities. *Aboriginal & Islander Health Worker Journal*. 2012;36(2).
27. Reilly RE, Doyle J, Bretherton D, Rowley KG, Harvey JL, Briggs P, et al. Identifying psychosocial mediators of health amongst Indigenous Australians for the Heart Health Project. *Ethnicity & Health*. 2008;13(4):351-373.
28. Jowsey T, Yen L, Ward N, McNab J, Aspin C, Usherwood T, et al. It hinges on the door: Time, spaces and identity in Australian Aboriginal Health Services. *Health Sociology Review*. 2012;21(2):196-207.
29. Doessel DP, Travers H, Hunter E. The Use of Touch-Screen Technology for Health-Related Information in Indigenous Communities: Some Economic Issues 1. *Prometheus*. 2007;25(4):373-392.
30. Boyde M, Song S, Peters R, Turner C, Thompson DR, Stewart S. Pilot testing of a self-care education intervention for patients with heart failure. *European Journal of Cardiovascular Nursing*. 2013;12(1):39-46.

Figure 1: Examples of slides from the patient education material for the tablet computer.

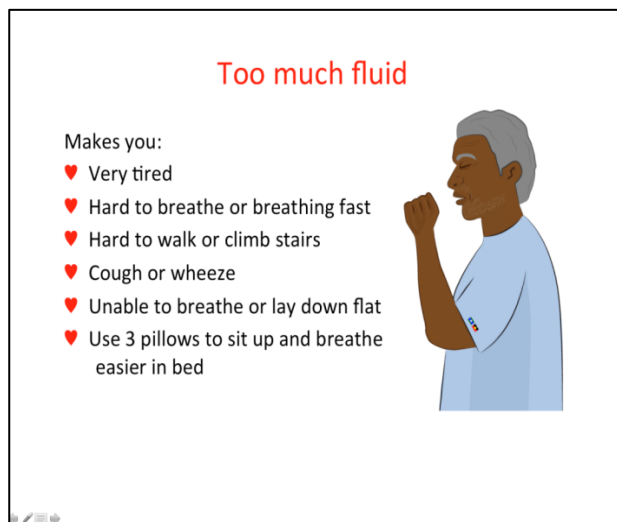
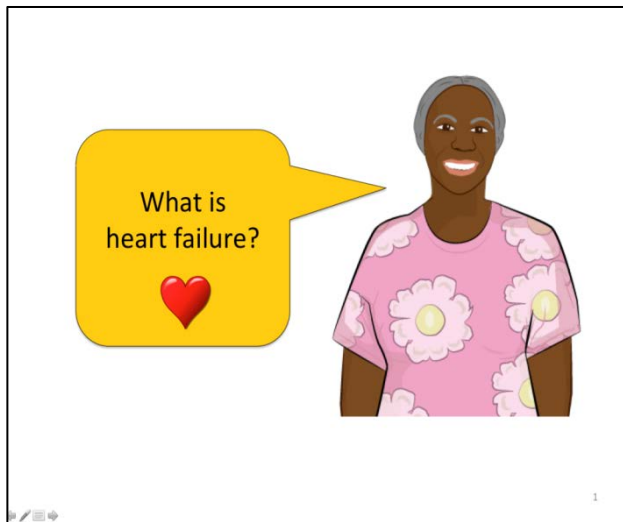


Figure 2. Results of patient satisfaction with the resource. Participants were asked to rate each of the following statements out of 5 is 1=strongly disagree, 2=disagree, 3= do not agree or disagree, 4=agree and 5=strongly agree. Where questions were negative, scores were reversed.

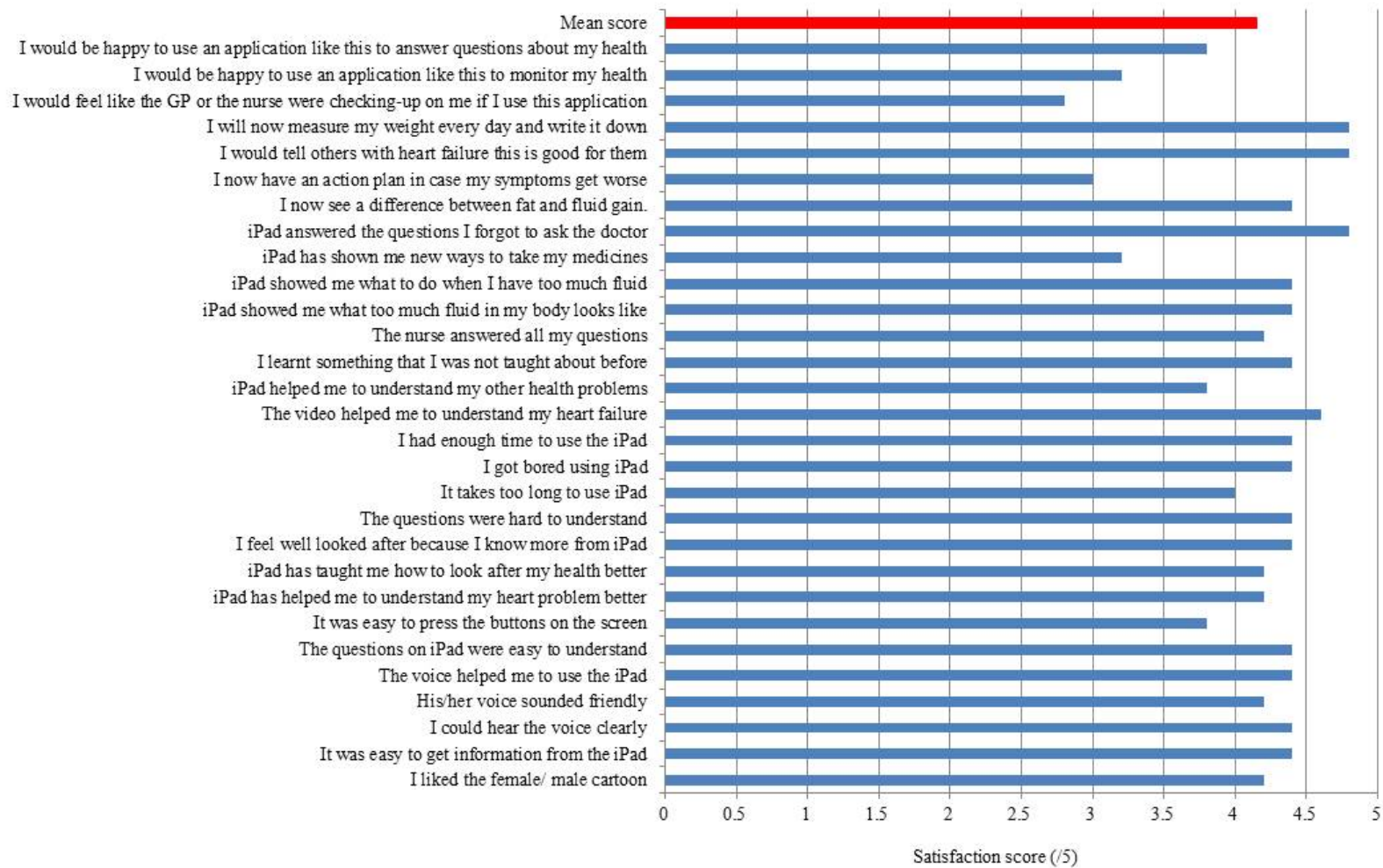


Table 1. Changes in Heart failure Knowledge score (out of a possible 20) for each participant.

Patient	Pre-Intervention		Post-Intervention		Percentage Change
	Score (/20)	Percent correct	Score (/20)	Percent correct	
1	9.0	45.0	11.0	55.0	2.0
2	11.0	55.0	11.0	55.0	0.0
3	8.0	40.0	14.0	55.0	3.0
4	9.0	45.0	10.0	50.0	1.0
5	11.0	55.0	15.0	75.0	4.0
Mean (SD)	9.6 (1.3)	48.0 (6.7)	11.6 (1.9)	58.0 (9.7)	2.0 (1.6)

Table 2. Changes in Self-Care Heart failure Index (SCHFI) Questionnaire, possible range for scores was 0-100.

Patient	Management (/100)			Confidence (/100)			Maintenance (/100)		
	Pre	Post	Change	Pre	Post	Change	Pre	Post	Change
1	55.0	50.0	-5.0	44.4	88.9	44.5	56.7	-	-
2	70.0	50.0	-20.0	66.7	100.0	33.3	50.0	-	-
3	55.0	55.0	0.0	50.0	94.4	44.4	43.3	36.7	-6.7
4	50.0	50.0	0.0	22.2	100.0	77.8	40.0	53.3	13.3
5	35.0	65.0	30.0	50.0	72.2	22.2	43.3	86.7	43.3
Mean (SD)	53.0 (12.5)	54.0 (6.5)	1.0 (18.2)	46.7 (16.0)	91.1 (11.5)	44.4 (20.8)	46.7 (6.7)	58.9 (25.5)	16.7 (25.2)

- = missing data