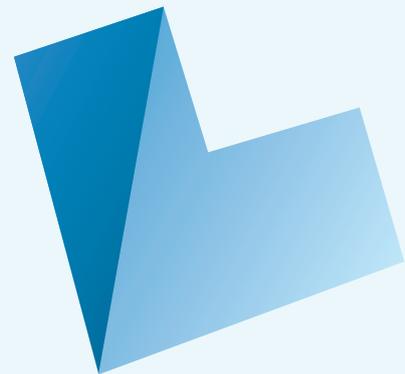


synergistiq

**EAST
TIMOR
HEARTS
FUND**

Australians supporting a
healthy Timor-Leste

Social Return on Investment Study Completed for East Timor Hearts Fund



October 2015

www.easttimorheartsfund.org.au



Contents

Overview and key findings	5
Executive summary	6
Introduction	8
Methodology	10
Identified need, assumptions and variables	12
Findings	14
Free treatment	14
Benefits	15
Feedback on the ETHF program	18
Strengths	19
Future ways to enhance the work	19
Conclusion	20
Case studies	21
Appendices	23
Appendix 1: Project Logic	23
Appendix 2: Interview schedules	25
Appendix 3: Guide for East Timor partners	26
Appendix 4: Participant information	28
Appendix 5: Consent form	29

AT A GLANCE

KEY STUDY FINDINGS

Estimated
additional
years of life

AVERAGE
32 YEARS

Average
quality of
life increase

AVERAGE
89%

Additional
'quality of
life years'

AVERAGE
28 YEARS

Value of
additional years
of life per patient

AU\$66,304
per patient
(Australian
equivalent
\$1.3 million)

Social
return on
investment

AU\$1: AU\$9

For every dollar invested, the ETHF program generates \$9 in social return on investment.

Overview and Key Findings

East Timor Hearts Fund (ETHF) is an Australian based medical aid charity providing cardiac screening services in Timor-Leste (East Timor), life-saving heart surgery and procedures in Australia for young Timorese and follow up monitoring and support.

Due to a lack of specialist cardiac facilities, these patients have no treatment options in Timor-Leste.

Surgery and medical procedures are provided by leading hospitals in Australia, at no cost to the patient. East Timor Hearts Fund also provides transport, accommodation, warm clothing and social support via a volunteer patient support team.

Patients range in age from 11–33 years, and generally have rheumatic heart disease (caused by childhood rheumatic fever, which is rife in Timor-Leste) or congenital conditions such as ASD or “hole in the heart”. Typically by the time they are identified for treatment by East Timor Hearts Fund they are gravely ill, with a life-expectancy of between one and five years. Their quality of life is severely compromised by their condition, with symptoms including breathlessness, lethargy and pain.

After their procedure or surgery patients’ symptoms typically rapidly disappear, and they are able to resume normal activities, including returning to school, university and work and family and community responsibilities.

This study has found that patients who have received treatment from the ETHF program enjoy an average of 32 years of additional life, with an average of 89 per cent quality of life improvement.

This tallies with anecdotal evidence. Patient Joantina Faria, who was 19 when she had her procedure in November 2013, said afterwards:

PATIENT JOANTINHA FARIA

“I can breathe easier, I do not feel tired any more, I can walk long distances, I can do my running (exercise) without feeling breathless, my appetite is back, and more importantly I am back to school and doing really well.”

Joantina returned to Melbourne in July 2014 to complete the Run Melbourne fun run to raise funds for ETHF.

This study found that the additional years of life could be valued at AU\$66,304 per patient (Australian equivalent \$1.3 million).

The social return on investment from the program is AU\$1 : AU\$9. This means that for every dollar invested, the ETHF program generates \$9 in social return on investment.

Executive Summary

Rheumatic heart disease has largely been eradicated in developed countries but is still prevalent in the developing world. Rheumatic heart disease is acquired from a bacterial infection of the throat or skin, which is usually not treated in poorer societies and results in longer term damage to the heart valves. This is common in Timor-Leste (known in Australia as East Timor) and patients are usually not diagnosed until late, when they are very sick.

As Timor-Leste currently lacks specialist cardiac facilities, these heart conditions cannot be treated locally. East Timor Hearts Fund (ETHF) is an Australian community-based medical aid charity providing free heart surgery in Australia, specifically valve replacement surgery and mitral balloon procedures to patients from Timor-Leste. As at 2015 East Timor Hearts Fund was providing surgery or procedures to between 5–10 patients a year, who had an expected life expectancy of between one to five years.

ETHF contracted Synergistiq to complete a Social Return on Investment (SROI) analysis of the heart operations or medical procedures provided to people from Timor-Leste. A SROI is a social cost-benefit tool designed to bring together the value of the health and social impacts created by ETHF for individual patients. This value is compared to the net financial and in-kind contribution from ETHF, resulting in a final dollar figure representing the overall health and social return for each Australian dollar invested. Therefore, the SROI provides measures of the aggregated social impact of the heart operations and procedures provided by ETHF. In summary, as a SROI is a beneficiary-centred analysis, it seeks to identify the value achieved through the money, volunteer time, technical resources and expertise invested to deliver the heart operations or medical procedures to East Timorese young people.

The SROI used objective metrics and financial proxies to place an average monetary value on the number and quality of increased life years for six patients after the heart operation or medical procedure.

This study found that post surgery or procedure; the outcomes for individual patients were substantial. First, patients lived and received an average of 32 additional years of life with an average 89 per cent improvement in the quality of these additional years. We were able to identify the total change in the number of 'quality life years' gained as a result of the operation or procedure for each patient. We did this by discounting the average additional years of life gained through the operation or procedure, by the average increase in the 'quality of life' for each patient. We found that this varied across the six patients from 21–35 years with an average of 28 'quality life years'.

Patients and ETHF partners also identified additional major benefits including dramatic and quick positive improvements to their physical health; increased engagement and contribution to their families including having children and increased energy and enthusiasm to engage with school, employment and community. These intangible benefits are un-costed and are in addition to the financial returns.

The heart operation or medical procedure provided by ETHF saves the lives of patients suffering life-threatening heart disease. Therefore the SROI is based on estimates of the financial benefit of the heart operation or medical procedure provided to a patient from Timor-Leste. To enable this calculation, the SROI commences with the estimates completed by the World Bank, whereby individual lives in different countries are valued differently, depending on each person's estimated contribution to the Gross Domestic Production (GDP) or their capacity to purchase goods or what is known as their Purchasing Power Parity [PPP] within that individual country.

In Timor-Leste for example, the estimated average contribution of an local person to GDP was calculated as AU\$2,368. Using the same calculations, in Australia, the average contribution of an Australian person was calculated as AU\$46,631 (GDP PPP). These calculations demonstrate the cultural and economic differences between Australia and Timor-Leste which is a key factor influencing the SROI.

The current model used by the ETHF is for patient from Timor-Leste to receive a free heart operation or medical procedure in Australia. The free medical treatment and 'in kind' donations resulted in the ETHF expending only \$7,358.33 per patient. This expenditure was divided by the estimated financial benefit arising from the operation for each patient, resulting in a SROI estimate that for each AU\$1 expended by the ETHF, the patient receives the equivalent of AU\$9 in health benefits in Timor-Leste. Thus a SROI figure of AU\$1 : AU\$9

Key findings

The medical procedures, surgery and health care provided by the ETHF program is provided free by individual medical practitioners, the partner health service in Timor-Leste and Victorian public health services.

In Timor-Leste, on average, the surgery resulted in a life being saved and patients living an estimated additional 28 "quality of life years" for each patient. Based on international modelling, these additional years of life represent an economic value of AU\$66,993 for each patient. If the patient lived in Australia, on average the surgery would result in an estimated economic value of AU\$1,247,768 for each patient.

Due to the donated medical treatment and other 'in-kind' resources, the ETHF reported total direct patient expenditure of \$44,150 at December 2014. When this expenditure was divided by the number of patients, the ETHF actually spent \$7,358.33 per patient to deliver heart operations and medical procedures to six East Timorese patients.

When the actual expenditure per patient was divided by the average financial benefit received for each patient, the social return on investment calculations used for this study estimate

for every AU\$1 of expenditure, an East Timorese patient received the equivalent of AU\$9 of health benefits, in Timor-Leste.

Therefore the ETHF SROI figure is AU\$1 : AU\$9

When the free operations and medical procedures, provided in both Australia and Timor-Leste, were costed, it was estimated that each patient received medical care and treatment worth AU\$33,291.

In addition to the overall benefit of additional years of life, the following quotes from patients who had received medical treatment, illustrate the qualitative value of the service provided by the ETHF.

INTERVIEWEE #5

"Since the surgery I do not feel tired any more, the pains I had on my chest are gone, I can breathe so much easier now. I feel wonderful! I am now a mother of a 3 month old baby daughter. When I look at her I thank God and ETHF for giving me the second chance in life."

INTERVIEWEE #6

"I am now back to normal life. I can breathe well, I can play with my friends without feeling tired, I go to school, I eat well and I also help around the house and sometime I look after my sister's kids."

Introduction

Due to poverty, poor health infrastructure and inadequate resources, many people from Timor-Leste have limited access to financial and other resources to meet their basic needs including nutritious food, clean water, adequate housing and health care. Some suffer life-threatening health conditions that could be readily treated with the right clinical expertise and medical facilities, both of which are not currently available in Timor-Leste (known in Australia as East Timor). Children and young people are specifically vulnerable to health issues, with research indicating that the risk of infectious disease in Timor-Leste is very high.¹

Congenital heart and rheumatic valve disease are two life-threatening conditions that affect some East Timorese children and young people. Rheumatic valve disease is acquired from a bacterial infection of the throat or skin, which is usually not treated in poorer societies and results in longer term damage to the heart valves. This is common in Timor-Leste and patients are usually not diagnosed until late, when they are very sick. As Timor-Leste currently lacks specialist cardiac facilities and specialist cardiac staff, these heart conditions cannot be treated locally.

Open heart surgery or mitral balloon procedure can have major positive impacts on the lives of young people in Timor-Leste. The primary benefits include extended years of life and improved

quality of life for each individual patient. Patients are able to return to school, work, their family and community. They are able to contribute to their community through employment and community activities.

In addition to the primary benefits for individuals who receive the operation or procedure, there is considerable research detailing how a healthier population can contribute more to the long term economic, cultural and social development of their community.²

East Timor Hearts Fund (ETHF) is an Australian community-based medical aid charity providing free heart surgery in Australia, specifically valve replacement surgery and mitral balloon procedures to East Timorese patients. ETHF was established informally in 2010 and registered as a company in 2012.

From 2010 to February 2015, the ETHF provided operations or medical procedures to 25 people. ETHF provides clinics in Dili, the capital of Timor-Leste, and in outlying areas including Baucau and Baguia in the north-east of Timor-Leste.

As at 2015 ETHF was providing surgery or procedures to between five to 10 patients a year, whose life expectancy was between one to five years.

In brief, the surgery or procedures is provided through the following process. A volunteer medical team conducts twice-yearly clinics in Dili, working collaboratively with Bairo Pite Clinic, a Timor-Leste partner organisation. During the clinic, prospective patients are screened as to their suitability for treatment in Australia. If selected, patients and a health support worker/interpreter from Bairo Pite Clinic (and a family member in the case of children) are flown to Melbourne, Australia, where the patient undergoes heart surgery or medical procedure and receives medical and social support during their recovery. After patients return to Timor-Leste they receive monitoring and care delivered by Bairo Pite Clinic and the ETHF medical team.

The ETHF contracted Synergistiq to complete a Social Return on Investment (SROI) analysis of the heart operations or medical procedures provided to its patients from Timor-Leste. A SROI is a social cost-benefit tool designed to bring together the value of the health and social impacts created by the ETHF for individual patients. This value is compared to the net financial and in-kind contribution from the ETHF, resulting in a final dollar

figure representing the overall health and social return for each Australian dollar invested. Therefore, the SROI provides measures of the aggregated social impact of the operations or medical procedures provided by the ETHF.

In summary, as a SROI is a beneficiary-centred analysis, it seeks to identify the value achieved through the free time, technical resources and expertise invested to deliver the heart operations or medical procedures to East Timorese patients.

In addition to the monetary value placed on the changes achieved through the work of the ETHF, this report also presents specific qualitative evidence on the intangible and un-costed benefits gained from the operation or medical procedure. This evidence was collected from patients who had received the operation or procedure and key ETHF partners who contributed to the delivery of the program. This evidence informs readers as to the types of changes that occurred as a result of the heart operation or procedure, in addition to the key enabling factors that contributed to such changes.

Introduction

Methodology

Synergistiq used the following methodology to enable the quantification of health benefits from the heart operations or medical procedures provided by the ETHF. The methodology included a number of steps briefly summarised below:

- 1** The identification of a project logic for the ETHF which was jointly developed in a meeting with a representative from the Fund on 8 December 2014 (Appendix 1).
- 2** Synergistiq developed a data collection framework which included specific tools and documents for interviews with patients and key stakeholders. This framework was submitted to the Fund's Board for review and ethics approval on 16 December 2014 and approved in January 2015. Prior to the recruitment of patients for interviews, the partner representatives received a guide which provided information about the project, recruitment and process of obtaining consent (Appendix 3).
- 3** Review of the patient data demonstrates that approximately 50 per cent of patients underwent open heart surgery and 50 per cent underwent mitral balloon procedures. Therefore, the patient data sample included three patients who had previously received open heart surgery and three who had received a mitral balloon procedure. Key indicators included: date of birth; date of treatment, life expectancy prior and post treatment and quality of life prior and post operation or procedure. This data was included in the Social Return on Investment analysis.
- 4** In addition to the quantitative patient data, EHTF approached six patients who had previously undergone surgery in Australia and invited them to participate in a semi-structured interview. Of the six patients, the data for four was included in the SROI calculations. Prior to agreeing to be interviewed, patients received an explanatory statement and consent form. This information was originally developed in English and translated into Tetum, the major local language in Timor-Leste, by a qualified translator in Timor-Leste (Appendices 4 & 5). Once the patient consented to the interviews, they were interviewed by representatives from Bairo Pite Clinic, the partner organisation in Timor-Leste (Appendix 2.1). The data collected during the interview was translated back into English and provided to Synergistiq. All interviews were conducted as semi-structured conversations.
- 5** Synergistiq also conducted interviews with three representatives from partner organisations in Timor-Leste and Australia (Appendix 2.2). The partners provided additional evidence on the key benefits, challenges and unexpected outcomes from the medical treatment.
- 6** The Fund and its partner the Bairo Pite Clinic, also provided financial data on both the costs of delivering open heart surgery and mitral balloon procedures and the actual expenditure and 'in-kind' contributions from the ETHF. These costs are detailed in the following section.
- 7** The Fund also provided a description of its activities, a description of the context in Timor-Leste e.g. the current lack of medical facilities, which provided additional information that assisted in the development of a counter-factual account of what would occur to patients if the Fund did not provide its services.

The project aligned with the seven principles of SROI.³ Table 1 details how the chosen methodology addressed each principle.

TABLE 1: PRINCIPLES AND METHODOLOGY

PRINCIPLE	METHODOLOGY
1 Involve stakeholders	Six patients and two representatives from the Timor-Leste partner organisation along with one representative from a Melbourne partner were interviewed and their feedback included in the report.
2 Understand what changed	Qualitative data was collected through semi-structured interviews with patients and representatives from partner organisations. The data was analysed and the findings included in the report.
3 Value the things that matter	Patients and representatives identified the outcomes that were achieved. These outcomes were linked to financial proxies from broadly accepted international research. For example, in 2012, the World Bank estimated that each year an East Timorese person has AU \$2,368 (East Timor Gross Domestic Product (GDP) Purchasing Power Parity). ⁴ In addition, the World Health Organisation provided estimates for life expectancy in Timor-Leste. ⁵
4 Only include what was material	The study includes analysis of quantitative and financial data along with a thematic analysis of the qualitative data collected from patients and key representatives. This analysis enabled the identification of key health, economic and social outcomes for patients.
5 Do not over-claim	All the estimates are conservative. In addition, evidence is provided to illustrate the possible outcome for patients if they did not receive the medical treatment.
6 Be transparent	The report includes the methodology, level of involvement of stakeholders, the data collected and the financial proxies and qualitative data substantiating the outcomes achieved.
7 Verify the result	The company that completed the SROI was an independent contractor.

¹ World Health Organisation (WHO). (2015). Timor Leste: Statistical profile. Retrieved from <http://www.who.int/countries/tls/en/>.

² Department of Foreign Affairs and Trade. (2015). Overview of Australia's aid program in Timor-Leste. Retrieved from <http://dfat.gov.au/geo/timor-leste/development-assistance/pages/development-assistance-in-timor-leste.aspx> 5 May 2015; World Health Organisation. (2013). The economics of social determinants of health and health inequalities. Retrieved from http://apps.who.int/iris/bitstream/10665/84213/1/9789241548625_eng.pdf?ua=1&ua=1.

³ Social Ventures Australia Consulting. (2012). Social Return on Investment: Lessons learnt in Australia. The Centre for Social Impact, Social Ventures Australia and Price Cooper Waterhouse; Social Ventures Australia. (2014). 'Getting the most out of SROI', Retrieved from <http://svaconsultingquarterly.com/2014/06/13/getting-the-most-out-of-sroi/>; SROI Network, (2014). 'Starting out on SROI'. Retrieved from <http://www.sroinetwork.org/>.

⁴ See Footnote 1.

⁵ See Footnote 2.

Introduction

» A key element of the SROI methodology is to account for the following three issues: Deadweight; Displacement and Attribution.

Deadweight

'Deadweight' refers to the need to ensure the identification of all other possible outcomes that would occur without the contribution from the ETHF. The estimated life expectancy of each patient was between one to five years. Therefore, it is assumed that without the heart operation or medical procedure, each patient would have died within a five year period.

Displacement

The issue of 'displacement' refers to the possibility that a key problem was moved, instead of being changed through the program or service under review for the SROI. As discussed previously, the heart operations or medical procedures were successful and all the patients had increased life expectancy and quality of life.

Attribution

Third is the issue of 'attribution'. This study indicates that at the time of writing, the Government of Timor-Leste Ministry of Health, local medical services and international non-government organisations working in Timor-Leste, do not currently have the medical equipment and personnel to provide the specific operations and medical procedures provided through the ETHF program.

Identified need, assumptions and variables:

This study is based on estimates of the costs and benefits of heart surgery provided to six of the 25 East Timorese patients who received heart operations and medical treatment provided by the ETHF from December 2010 to February 2015. The patients were diagnosed by staff at Bairo Pite Clinic and the ETHF medical team as suitable candidates for heart surgery. The patient data that was provided for the SROI calculations included three patients who underwent open heart surgery and had heart valves replaced and three patients who underwent mitral valvuloplasty (commonly referred as a mitral balloon procedure) which did not require open heart surgery.

The SROI calculations included the total cost of providing open heart surgery to three patients and the mitral balloon procedure to three patients. This total cost was divided by six patients which provided an average cost for each patient. This average cost was multiplied by six to provide an average cost of providing medical treatment for six patients in Timor-Leste and Australia. The average cost was divided by the annual patient expenditure by ETHF. The figures used in the SROI are discussed further in the 'Findings' section.

The SROI is based on a number of assumptions and estimates for each of the six patients, which were provided by an expert medical physician from the ETHF. Key examples included:

- Life expectancy prior to treatment
- Life expectancy post the treatment
- Quality of life prior to the treatment
- Quality of life years post the treatment.

The patients were aged six to 18 years of age at the time of the operation or medical procedure and of the six, five were female and one was male. Prior to the surgery, patients suffered from a range of serious heart conditions including:

- Severe mitral stenosis – which is the narrowing of the mitral valve orifice of the heart
- Pulmonary hypertension – which is when the tiny arteries in the lungs are blocked
- Severe mitral regurgitation – when the mitral valve does not close properly and blood leaks in the heart
- Severe aortic stenosis which is the abnormal narrowing of the aortic valve in the heart
- Mild arrhythmia when there is an irregular heartbeat or abnormal heart rhythm
- Sub aortic membrane, when the membrane blocks the aortic valve in the heart.

All patients experienced extreme difficulties when breathing and drawing enough oxygen into their bodies for their basic needs. The medical term for this condition is exertional dyspnoea. In addition, all patients suffered fatigue. At the time of the medical treatment, the expected life expectancy for the six patients varied from one to five years. The life-threatening nature of the conditions was highlighted by one interviewee who noted that some East Timorese patients had been assessed as suitable for surgery in Australia, but had died prior to the heart operation or medical procedure (Interviewee #7).

All the six patients who were interviewed shared very similar challenges and symptoms of poor chronic cardiac health. Patients reported that both they and their families suffered physically, emotionally and financially as a result of their declining cardiac health. Patients described how they were always sick, exhausted, moody, depressed, angry, and unable to do simple things like cook, clean or walk short distances. Many were no longer able to work or go to school because of their declining health. All became bed-ridden and were afraid of the possibility of dying.

THE SROI

IDENTIFIED NEED,
ASSUMPTIONS
AND VARIABLES:

Life expectancy
prior to treatment

Life expectancy
post the treatment

Quality of life
prior to the treatment

Quality of life
years post the treatment.

Findings

Free treatment

The ETHF provided a detailed list of expenses and free contributions that enabled each patient to receive the heart operations or medical procedures in Australia.

The ETHF reported direct patient expenditure of \$44,150 as of December 2014.⁶ Therefore, the ETHF expended \$7,358.33 to deliver the heart operations and medical procedures to the six patients.

In addition to this reported expenditure, patients benefited from the following services which provided pro bono in Timor-Leste:

- An Australian medical team who travelled to Dili for a three day field trip twice a year to complete medical diagnosis and provide follow up treatment. The medical team included a cardiologist, translator and medical administrator and two medical students
- Key medical and social work staff from Bairo Pite Clinic in Dili, and
- Use of a cardiac diagnosis machine.

The estimated cost of each field trip to Timor-Leste was \$27,750. During each trip, the medical team would diagnose and screen approximately 100 patients referred from Bairo Pite Clinic. During the clinic, approximately six patients would be diagnosed as suitable for medical treatment in Australia and/or past patients would receive follow up assessment and referral to Bairo Pite Clinic for further care if needed. Therefore, it is estimated that during each trip, each of the six patients received \$277.50 worth of pro bono medical care.

Patients commented positively on the work of the ETHF medical team working in Dili, with one patient stating that:

INTERVIEWEE #2

“Since my operation in Melbourne last year, today is my first time that I came to do the follow-up check-up by Dr Noel Bayley. I like the fact they (ETHF) run those clinics here in Dili twice a year to do a follow up check-up on previous patients and also to identify new critical patients for heart surgery in Melbourne.”

The six patients who travel to Australia for the heart operation or medical procedure received the following pro bono services:

- The presence of a health support worker/interpreter from Bairo Pite Clinic and other volunteer social support
- Flights and other transport
- Food and accommodation: pre and post-medical treatment
- Open heart or mitral balloon procedure – including all staff ie: cardiac surgeon, surgical registrar, anaesthetist and nursing.
- Medicines and pathology services
- Medical care in an Intensive Care Unit
- Medical care in Recovery.

It was estimated that each of the three patients who underwent open heart surgery received free medical treatment and other benefits in both Timor-Leste and Australia estimated to be worth \$39,787.50. Each of the three patients who underwent mitral balloon procedures received free medical treatment and other benefits estimated to be worth \$18,332.85.

The service delivery model described above is extremely time consuming and complex involving multiple partners and complex activities. As one interviewee commented:

INTERVIEWEE #7

“People don’t understand the logistics it takes to make this work. It is a real challenge but now we have people with the experience to make this work.”

All recipients of ETHF medical assistance described going through whole process of getting heart surgery in a positive and almost identical manner. The whole process is as follows: patients with symptoms of poor cardiac health and their families visit the Bairo Pite Clinic to meet Dr Dan Murphy, Head Physician at the Bairo Pite Clinic and Dr Noel Bayley, honorary medical adviser to ETHF, who runs the clinics twice a year. All of the interviewees had never travelled overseas before and reported that they were somewhat nervous. However all interviewees appreciated the support and company of Bairo Pite staff as ‘chaperones’ during the return journey from Timor-Leste to Melbourne, before, during and after the operation or procedure.

In addition patients were supported throughout the process in Melbourne by the accompanying health support worker/interpreter, ETHF volunteers and Timorese community members. Patients appreciated the support and reported that it made them feel much safer and reassured about the operation or procedure. None of the patients interviewed for this study made any negative comments about the process. All patients expressed appreciation, excitement and joy after receiving the surgery.

INTERVIEWEE #1

“At the beginning it all sounded very scary as I’ve never been overseas and let alone going for a big surgery. After a few briefs with the ETHF team, my family and I felt much better as the ETHF team had explained the process of the surgery and what to expect once I was in Melbourne. Looking back, it was the best decision that my family and I had done. When I was in Melbourne, I was very well looked after by the hospital team and the ETHF volunteers. I also received some support from the Timorese community there.”

<p>BENEFITS</p> <p>The individual benefits are grouped into key themes including:</p>	<p>1 >></p>	<p>Increased life expectancy</p>
	<p>2 >></p>	<p>Improved health outcomes</p>
	<p>3 >></p>	<p>Improved education, employment, community and social outcomes.</p>

1. INCREASED LIFE EXPECTANCY

The SROI estimates the economic benefits of the investment provided by the ETHF for each patient, specifically the benefit from the additional years of life and increased quality of life.

The ETHF’s honorary medical adviser, a qualified cardiologist with many years of experience, provided expert estimates as to the benefits of the operation or medical procedure. The adviser provided estimates as to the number of additional years of life for each patient (change in life years). These estimates varied between 27–39 years, with an average of 32 years. In addition,

the ETHF medical adviser also provided estimates as to the expected adjustment to each patient’s quality of life after the operation or procedure. These varied between 85–90 per cent with an average of 89 per cent. When the average additional life increase is adjusted by the average increase in quality of life, we are able to identify a total change in ‘additional quality of life’ years, post treatment, for each patient. These varied from 21–35 years with an average of 28 quality life years.

The heart operation or procedure provided by the ETHF saves the lives of patients. Therefore the SROI is based on estimates of the financial benefit of the heart operation or medical procedure provided to the patient from Timor-Leste. To enable this calculation, the SROI commences with the estimates completed by the World Bank, whereby individual lives in different countries are valued differently, depending on each person’s estimated contribution to the Gross Domestic Production (GDP) or their capacity to purchase goods or what is known as their Purchasing Power Parity [PPP] within that individual country. In Timor-Leste for example, the estimated average contribution of an East Timorese person to GDP was calculated as AU\$2,368.⁷ Using the same calculations, in Australia, the average contribution of an Australian person was calculated as AU\$46,631 (GDP PPP).⁸

By multiplying the total change in quality life years with the annual expected contribution to the GDP in Timor-Leste for each East Timorese patient, we were able to identify an average total financial benefit gained for each patient as a result of the operation or medical procedure. The increased number of productive life years results in an average direct benefit of AU\$66,304 (economic value measured at Timor-Leste income levels), for each patient.

ETHF expenditure and pro bono contribution

Based on the audited financial report, the ETHF received \$280,382 in financial donations and expended \$44,150 on direct patient costs. Therefore the average expenditure per patient was \$7,358.33.

As detailed above in Table 2, the increased number of productive life years results in an average direct benefit of AU\$66,304 (economic value measured at Timor-Leste income levels) for each patient.

Findings

When we divide the average total benefit at Timor-Leste income levels by the total expenditure, the result is a Social Return on Investment (SROI) of 1:9. Therefore we estimate that in Timor-Leste, for every AU\$1 invested, an East Timorese patient receives the equivalent of AU\$9 of health benefits, in Timor-Leste.

As a result of the free treatment, each patient who underwent an open heart operation received approximately \$39,735 of free medical treatment and other support. Each patient who received a mitral balloon procedure received approximately \$18,332 of free medical treatment and other support.

When both are multiplied by 3 and added, the total annual pro bono contribution to the ETHF was \$174,201. When divided by 6 patients, the average was \$29,033 per patient (regardless of the type of operation or procedure). When this annual pro bono contribution of \$174,201 was added to the reported direct patient expenditure of \$44,150, the ETHF annually contributes a total of \$218,351 of financial and pro bono contribution to patients requiring heart operations or mitral balloon procedures.

When this figure is divided by the six patients who received treatment, each patient received approximately \$36,391 worth of actual and in-kind contributions from the ETHF.

2. IMPROVED HEALTH OUTCOMES

Once the patients returned to Timor-Leste after their surgery almost all were greeted by an elated family at airport. Although recovery did not happen overnight, both patients and their families reported immediate positive changes in the health and wellbeing. All patients describe feeling like a 'new person'.

INTERVIEWEE #5

“Since the surgery I do not feel tired any more, the pains I had on my chest are gone, I can breathe so much easier now. I feel wonderful! I am now a mother of a 3 month old baby daughter. When I look at her I thank God and ETHF for giving me the second chance in life.”

INTERVIEWEE #8

“Speaking on behalf of patients, families and staff of Bairo Pite Clinic we are encouraged that 100 per cent of patients have survived in better health, which would likely not be the case if East Timor Heart Fund was not actively involved.”

INTERVIEWEE #7

“For most of these people who have a bad valve in their heart their life span is affected. They can get clots which lead to an aneurism and they die. We try to pick the most in need. This operation gives them their life back. For those who we can't assist we treat them with medication. However there is only so much you can do with medicine when there is a mechanical [heart valve] problem. It is so precarious that we have had people die waiting for their date in Australia.”

3. OTHER INTANGIBLE BENEFITS: IMPROVED EDUCATIONAL, EMPLOYMENT, FAMILY, COMMUNITY AND SOCIAL OUTCOMES

All the patients reported a full recovery and improved lives as a result of the life-saving surgery. They all reported positive changes in all areas of their lives (physically, emotionally, socially and financially) compared to how they were prior to the surgery. Patients also told us that they were leading happy, health and successful lives. They also reported that they were now able to do the things they were unable to do prior to surgery. Many had returned to work or study and were able to engage in physical activities again.

TABLE 2: AVERAGE RESULTS FOR EAST TIMORESE PATIENT

CATEGORY		AVERAGE RESULT FOR EAST TIMORESE PATIENT
1	Average life expectancy of East Timorese person.	66 years⁹
2	Patient – Life expectancy prior to the operation or medical procedure.	Additional 2.3 years
3	Life expectancy post treatment.	44 years
4	Increased additional number of life years the identification of key health, economic and social outcomes for patients.	32 years
5	Change to quality of life.	89 per cent
6	Total change to “quality of life” years (# number of life years adjusted by change to quality of life).	28
7	Financial benefit for the patient living in Timor-Leste (AU\$2,368, the value of one year [GDP PPP] Timor-Leste, multiplied by total change to life years).	AU\$66,304
8	Average total value of medical treatment received by each patient (average of patients receiving open heart or mitral valvuloplasty procedures).	AU\$36,391
9	Financial benefit if the patient was living in Australia (AU\$46,631, the value of one year [GDP PPP] in Australia, multiplied by total change to life years).	AU\$1,305,668

⁶ ETHF (2014) Audited Financial Report

⁷ The World Bank. (2012) GDP (PPP) Retrieved from <http://data.worldbank.org/country/timor-leste?display=graph>

⁸ International Monetary Fund. (2014) 2014 GDP (PPP) Retrieved from <http://www.imf.org/external/pubs/ft/weo/2014/02/weodata/weorept.aspx?pr.x=76&pr>.

⁹ The World Bank. (2012). Life Expectancy. Retrieved from <http://data.worldbank.org/country/timor-leste?display=graph>.

Findings

INTERVIEWEE #6

“I am now back to normal life. I can breathe well, I can play with my friends without feeling tired, I go to school, I eat well and I also help around the house and sometime I look after my sister’s kids.”

INTERVIEWEE #7

“One patient came from a far village. When he got back he was considered a local hero. They threw a party. That’s how important it is. It gives hope to a community ...This can transform society.”

INTERVIEWEE #8

“They can return back to normal life and continue their daily activities in school, work and life. Benefits from ETHF because surgery is not available in Timor-Leste, prognosis without surgery is not good.”

One interviewee from a partner organisation noted that not only did the operation or treatment enable a ‘dramatic improvement’ in people’s lives, but that it ‘opens up and changes their outlook on life’ (Interviewee #8), including one patient who reported that they now wanted to work in the health sector.

Feedback on the ETHF program

The recipients of the operations or medical procedures were extremely thankful for the ETHF. They and their families spoke about their gratitude for the in-kind donations of the doctors, medical staff, hospitals and the work of ETHF. Patients extended this gratitude to all involved from the doctors to the staff of the fund, the hospital staff, and East Timorese community in Melbourne. One man even participated in the Run Melbourne fun run and described the experience as a ‘real privilege’ to be able to represent all the previous patients who had previously benefited from the heart surgery in Melbourne. All of the interviewees spoke about how the ETHF gave them a second chance in life. They also hoped that the ETHF could receive more financial support so it could offer additional operations or medical procedures to more people.

All the patients and partners highlighted the overall significant and positive contribution of Dr Noel Bayley, ETHF honorary medical adviser, as founder and key contributor to the program. As one interviewee stated:

INTERVIEWEE #8

The program is the brainchild of Noel Bayley and is largely due to his dedication and enthusiasm.

Strengths

This study highlights a number of key strengths of the ETHF program. These include first, the partnership with a local medical service in Timor-Leste who assist with the identification of possible patients and support the Australian medical team in Dili. Second, the volunteer medical staff who conduct the medical trips, screen and select patients in Timor-Leste and provide check-ups and referrals to the Bairo Pite Clinic and follow up medical care of past patients. Third, the support provided by the East Timorese health worker/interpreters and family members who accompany patients to Australia. Fourth, the support provided by nursing, allied health, social work and other staff at the Melbourne health services. Fifth, the support provided by the East Timorese community in Melbourne. Sixth, the in-kind support provided by the participating hospitals, including follow up surgery if there are complications. Seventh, the support provided by family and members of the East Timorese community during the assessment phase, pre-treatment and during recovery.

Future ways to enhance the work

As noted previously, there are many other young people in Timor-Leste who experience heart disease and who have a poor prognosis. Consequently there is great unmet demand for the heart operations and medical procedures provided by the ETHF. There is an opportunity for the ETHF to improve and enhance its work through access to additional resources. These would enable the provision of additional treatment to more patients. This possibility was supported by a patient who commented:

INTERVIEWEE #2

“If I may I would like to ask ETHF to also run the clinics in the other districts of Timor if it’s possible. The reason being is that a lot of people in Timor do not have easy access to medical treatment and not only that the roads are so bad that people do not have easy access to come to Dili for medical treatments.”

As well as providing clinics in regional areas outside the capital of Dili, ETHF is currently exploring the possibility of providing bi-annual fly-in open heart surgical teams and equipment from Australia to provide surgery to approximately 15–20 patients, in Timor-Leste. The medical team would involve volunteer doctors, nurses and technicians who would work in partnership with local medical services and staff.

Conclusion

East Timor Hearts Fund (ETHF) provides free heart surgery in Australia, specifically valve replacement surgery and mitral balloon procedures, to approximately 10 young people from Timor-Leste each year, who prior to medical treatment, had an expected life expectancy of between one and five years.

This Social Return on Investment (SROI) analysis of the free heart operations and mitral balloon procedures provided identified the value achieved through the volunteer time, free medical treatment, technical resources and 'in kind' expertise invested to deliver the heart operations and medical procedures patients from Timor-Leste.

The medical procedures and surgery provided by ETHF are provided free by individual medical practitioners, the partner health service in Timor-Leste and Victorian public health services.

In Timor-Leste, on average, the surgery resulted in a life being saved and patients living an estimated additional 28 years of life for each patient. Based on international modelling, it is estimated that each patient would contribute an additional AU\$66,993 to the Timor-Leste GDP.¹⁰ If the patient lived in Australia, on average each patient would contribute an additional AU\$1,247,768 to the Australian GDP.¹¹

Due to the donated medical treatment and other 'in-kind' resources, the ETHF reported total direct patient expenditure of \$44,150 at December 2014. When this expenditure was divided by the number of patients, the ETHF actually spent \$7,358.33 per patient to deliver heart operations and medical procedures to six East Timorese patients.

When the actual expenditure per patient was divided by the average financial benefit received for each patient, the social return on investment calculations used for this study estimated for every AU\$1 of expenditure, an East Timorese patient received the equivalent of AU\$9.10 of health benefits, in Timor-Leste. Therefore the final SROI is AU\$1 : AU\$9.10.

When the free treatment was costed, it was estimated that each patient received medical care and treatment worth AU\$36,391.

The current model used by ETHF is for a patient from Timor-Leste to receive a free heart operation or mitral balloon procedure in Australia, which is a high-cost country.

However, the additional years of life received as a result of the medical treatment are lived in Timor-Leste, which is a low-cost country.

In addition to the SROI analysis, the study also found that post surgery; the outcomes for individual patients were substantial. First, patients lived and received an average of 28 additional years of life with an average 89 per cent improvement in the quality of these additional years. In addition, patients and ETHF partners also identified additional major benefits including dramatic and quick positive improvements to their physical health; increased engagement and contribution to their families, including having children, and increased energy and enthusiasm to engage with education, employment and community.

¹⁰ The World Bank. (2012) GDP (PPP) Retrieved from <http://data.worldbank.org/country/timor-leste?display=graph>

¹¹ International Monetary Fund. (2014) 2014 GDP (PPP) Retrieved from <http://www.imf.org/external/pubs/ft/weo/2014/02/weodata/weorept.aspx?pr.x=76&pr>.

Case Studies¹²

“I can breathe easier, I do not feel tired any more, I can walk long distances, I can do my running (exercise) without feeling breathless, my appetite is back, and more importantly I am back to school and doing really well.”

Case study 1

Joaninha da Silva Faria

DOB: 3/4/98

Before travelling from Dili to Melbourne for heart surgery, Joaninha felt very sick. Difficulties breathing, appetite loss and lethargy limited her ability to play with friends, cook and eventually prevented her from attending school. Joaninha's ill-health also led her to feel anxious and frightened for her future. Joaninha's mother had passed away at a young age, which added to Joaninha's concern that she would not recover from her illness.

East Timor Hearts Fund's volunteer medical team identified Joaninha's condition during a screening clinic in Dili in August 2013. Joaninha and her aunty were worried about the prospect of travelling to Melbourne for heart surgery, and the outcome. However, they were encouraged to learn that Joaninha would be accompanied by one of the Bairo Pite staff members, who also spoke Tetum and English.

Joaninha underwent a mitral balloon procedure at MonashHeart, a specialist cardiology service of Monash Medical Centre, in November 2013. The procedure involved



the insertion of a special balloon via a catheter which inflated a damaged valve in Joaninha's heart.

Joaninha's family greeted her at the airport upon her return home to Dili. Her family immediately noticed the positive impact of the surgery, including weight gain. Twelve months after her surgery Joaninha still feels happier and healthier. Joaninha said “I can breathe easier, I do not feel tired any more, I can walk long distances, I can do my running (exercise) without feeling breathless, my appetite is back, and more importantly I am back to school and doing really well”.

Joaninha returned to Melbourne in July 2014 to complete the Run Melbourne fun run with the ETHF team, including another former patient, Tomas Pinto.

¹² The information contained in case studies #1 and #2 was retrieved from <http://www.easttimorheartsfund.org.au/what-we-do/success-stories/>

These stories were chosen as patients had previously given consent for their photos and stories to be published.

Case Studies

“I was not scared to go to Melbourne for the surgery. All I wanted was to feel better and go back to my normal life... I was also happy to find out that one of the Bairo Pite staff would accompany me from Dili to Melbourne.”

Case study 2

Agripino Soares **DOB: unknown**

Coffee plantation worker and father of one, Agripino was very unwell prior to heart surgery in 2014. Living in the mountains in a remote area of Timor-Leste, Agripino needed to walk for almost two hours to reach his village from the main road. However with his heart condition, travelling this distance became too much. According to Agripino “I could not breathe easily, I had bad chest pains, I felt dizzy constantly and I was always very tired to the point that I just wanted to be in bed all day...I felt frustrated as I could not play with my one year old son or even help my wife around the house.”

Because the Bairo Pite Clinic established a temporary treatment centre in Agripino’s village, Agripino’s condition was able to be diagnosed by a doctor approximately a year before his illness would have claimed his life. At the Bairo Pite Clinic in Dili, Agripino was referred to ETHF for heart surgery. Agripino said:

“I was not scared to go to Melbourne for the surgery. All I wanted was to feel better and go back to my normal life... I was also happy to find out that one of the Bairo Pite staff would accompany me from Dili to Melbourne.”



The surgeons at the Royal Melbourne Hospital were able to perform a technically complex repair on Agripino’s valve, rather than replace it, as had been originally planned. Agripino’s situation when he returned to Timor-Leste highlights the challenges for residents who live outside of Dili, and the ongoing need for flexible access to clinical and rehabilitation expertise. Agripino reported that: “It was hard for me and my family. Although I felt healthier and felt like a new person, I was very sad because I could not see my family straight away as I still had to stay in Dili for a few more days for further check-ups at the Bairo Pite Clinic.”

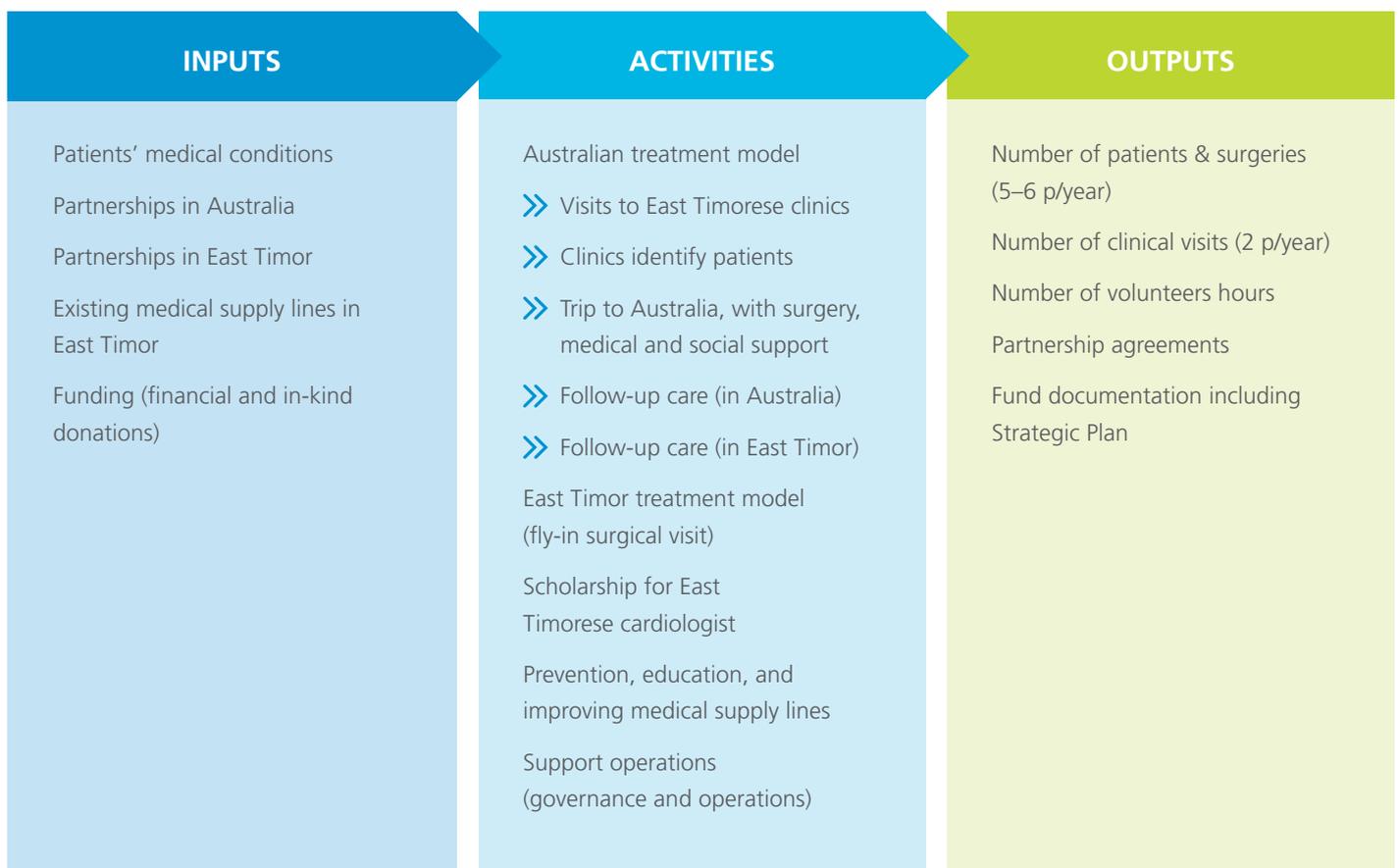
Agripino has returned to his village and is now able to undertake activities he could not do before his surgery, such as play with his son and assist his family around the house. He has also returned to work at the coffee plantation. He says he does not feel tired any more: “I can walk long distances without feeling breathless, my appetite is back [and] I do not feel chest pains any more.”

Appendices

Appendix 1: Project logic

CONTEXT:

East Timor Hearts Fund is Australia’s only medical aid charity dedicated to providing life-saving heart surgery in Australia for young people from East Timor. These patients often need relatively simple procedures to correct conditions that are the legacy of childhood rheumatic fever, a disease largely eradicated in the west but still prevalent in East Timor. There are no specialist medical facilities in East Timor that can provide this treatment.



Appendices

Outcomes:

PATIENTS' LIVES BEFORE SURGERY	PATIENTS' LIVES AFTER SURGERY
<p>PHYSICAL</p> <ul style="list-style-type: none"> » Short of breath » Palpitations » Weak » Sweating » Swelling <p>SOCIAL</p> <ul style="list-style-type: none"> » Unable to continue school/university » Reduced work capacity » Reduced ability to care for family » Reduced ability to contribute to community <p>MENTAL</p> <ul style="list-style-type: none"> » Stress » Depression » Isolation 	<p>PHYSICAL</p> <ul style="list-style-type: none"> » Previous symptoms disappear <ul style="list-style-type: none"> – (Mitral balloon procedure: symptoms disappear very quickly, generally no further medical care required) – (Value replacement procedure, symptoms disappear within a few months, sometimes can't have children, sometimes requires ongoing blood thinner, sometimes need a replacement after 10 years) <p>SOCIAL</p> <ul style="list-style-type: none"> » Ability to return to school/university » Increased work capacity » Increased ability to care for family » Increased ability to contribute to community » Advocacy for program and western medicine <p>MENTAL</p> <ul style="list-style-type: none"> » Reduced stress » Reduced depression » Reduced isolation
<p>ASSUMPTIONS</p> <ul style="list-style-type: none"> » Skilled surgical and support staff » Partnerships are durable and deliver substantial value » Support of East Timorese Government and continued country stability » Continue to raise funding 	<ul style="list-style-type: none"> » Stream of patients can be identified and consent to participate » Estimated costs are accurate for East Timor Treatment Model » Facilitates and in-country risk management for East Timor Treatment Model.

Appendix 2: Interview schedules

2.1 PATIENTS (ENGLISH)

This interview is in relation to the heart surgery you received from the East Timor Hearts Fund.

1. Can you tell us about your life before the surgery?

Prompt for:

- a. Physical
- b. Emotional/Mental
- c. Work/Education
- d. Family
- e. Community

2. Can you tell us about your experience of the whole process of having the surgery?

Prompt for:

- a. The clinic in East Timor
- b. The support before travelling to Australia
- c. The experience in Australia
- d. The support upon return to East Timor

3. Can you tell us about your life when you first returned home after the surgery?

Prompt for:

- a. Physical
- b. Emotional/Mental
- c. Work/Education
- d. Family
- e. Community

4. Can you tell us about your life now?

Prompt for:

- a. Physical
- b. Emotional/Mental
- c. Work/Education
- d. Family
- e. Community
- f. Any ongoing medical support required.

5. Is there anything else you would like to say about the surgery or the Fund?

2.2 PARTNER/ FUND REPRESENTATIVE

6. Can you tell us about your work with the East Timor Hearts Fund?

1. Can you tell us about benefits created by the Fund's work for:
 - a. Patients?
 - b. Families?
 - c. Communities?
 - d. East Timor?
 - e. Yourself?
 - f. Your organisation?
 - g. Australia?

7. What are the key factors that contribute to these benefits?

8. How else could these benefits occur without the Fund?

9. Is there anything else you would like to say about the Fund?

Appendices

Appendix 3: Guide for East Timor partners

DATE: 18 DECEMBER 2014

PRINCIPAL RESEARCHER: JED GILBERT, SYNERGISTIQ

The Fund has contracted a Melbourne based company called Synergistiq to assist it to identify the social returns on the money and work that is used to provide heart operations for East Timorese people. This process is called a 'Social Return on Investment' (SROI) analysis.

As part of the analysis, the Fund is seeking to interview four past patients who have had heart operations and ask them about their experience. The Fund wishes to use the stories and experiences of past patients to learn more about the value of the services provided. This information will be used by the Fund to examine and promote its work.

The Fund is hoping that you and your colleagues would be able to assist with this analysis by assisting with the following three steps.

- First, to determine past patients who may be willing to be interviewed.
- Second, to contact the patients and provide them with information about the process, ensure they understand this information and obtain their consent to participate in an interview. You must make it clear that whether they consent or not, it will NOT affect their treatment through your clinic in any way.
- Third, to conduct the interview and write down the patients answers to the key questions.
- Fourth, to store the information securely and provide the patients' answers back to the Fund.

We have attached copies of the questions, and the information and consent form.

WHO WILL BE INVOLVED

Ideally you and your colleagues will interview four (4) past patients. This will ideally be spread across the following characteristics:

- Sex: three females, one male
- Age at treatment: two who were 10–19, one who was 20–29 and one who was 30+
- Treatment type: two who received mitral balloon treatments, one who received MV/AV replacement/ prosthesis and one who received one of the other treatment types.

TIMING

The amount of time needed for each interview may vary, depending on someone's interest in the questions and the amount of detail they provide in their answers. However, we anticipate that the interviews could go for 45 minutes to an hour.

The Fund is hoping that the interviews could be completed during December 2014 and January 2015. The actual timing of the interviews will depend on ensuring convenience for you and the interviewees.

BENEFITS

By participating in this research, you will assist the Fund to better understand the value of their work, which may contribute to clearer marketing of the benefits being created.

RISKS

These processes and forms seek to minimise the risk for you and the interviewees. The Fund's Board have approved this research.

There is some inconvenience when participating in an interview. Please ensure the time and location of the interview is as convenient to you and the patient as possible, to minimise disruption.

We have asked you and your colleagues to conduct the interviews as you know many of the patients and have supported them during their experience. We believe this relationship will reassure them and reduce any discomfort when asked about their health and experience of the heart operation.

In addition, as women may feel uncomfortable talking to a man about personal experiences and their health, we would like to suggest that a female colleague interview the three female patients. Likewise, it may be more suitable for a male colleague to interview the male patient.

If someone decides to stop the interview and withdraws their consent to participate in the interview, we ask you to respect their decision and destroy all of the answers they provided during the interview. If this occurs, we ask you and your colleagues to identify another possible past patient who might be interested in being interviewed.

Finally, a key risk is that a patient reveals new medical information or complications from the surgery during the interview. Please be aware that this will create a responsibility on you and your colleagues to act on this information following your normal procedures. This may require treating the problem or referring the patient for treatment at an appropriate service.

CONFIDENTIALITY AND PRIVACY

The names of all participants and all information collected during the interviews will be treated as confidential.

There are a number of steps we would suggest you use to help ensure privacy and confidentiality.

- First, we suggest that you ask each interviewee to provide you with a pseudonym, which is a made up name that could be used in the report.
- Second, you and your colleagues would create a master list that has the name of the interviewee and their pseudonym. This master list will be kept in a locked filing cabinet at the Synergistiq office in Australia.

- Third, you would create a word document and write down all the information collected through the interview. You would save this document, using the interviewee's pseudonym as the title.
- Fourth, you would provide the Fund with the interview documents. The Fund team will provide the notes to Synergistiq, who will analyse the information. The original lists and all records notes will be kept in a locked filing cabinet and stored on a password protected secure electronic computer network. Documents will be kept for seven years and then deleted or destroyed in a secure manner.
- Fifth, the final report will include information collected during the interviews and any quotes from interviewees will only be identified by the interviewee's original pseudonym. Therefore, no-one reading the final report should be able to identify the participants. However, we are aware that there is a small group of people from the East Timorese community who have had heart operations. In addition, the community itself is relatively small, therefore, it is possible that some people reading the report, may try to guess who has been interviewed. You should make this clear to interviewees.

CONSENT

Patients must provide informed consent to participate in the interview. This includes carefully explaining the overall process, and the information and consent form. The patient can withdraw their consent at any time. You must also make it clear that whether they provide consent or not, it will NOT affect their ongoing treatment through your clinic in any way.

When obtaining consent, you can verbally explain the form, and have them mark the form in any way to note their signature. You can sign the form as the witness. If possible and convenient, you can also provide a copy of the full completed form to the patient.

RESULTS

The Fund will own the results of the research. If the Fund decides to publish the report, copies will be available to yourself or your colleague and community members in East Timor.

Appendices

Appendix 4: Participant information

DATE: 18 DECEMBER 2014

PRINCIPAL RESEARCHER: JED GILBERT, SYNERGISTIQ

1. Your Consent

You are invited to take part in this research for the East Timor Hearts Fund.

This form contains information about the research. Its purpose is to explain to you what is involved before you decide whether or not to be interviewed.

Please ask questions about any information in the document.

Once you understand what the research is about and if you agree to take part, you will be asked to sign the Consent Form. By signing, it means you understand the information and that you agree to participate.

You can request a copy of this form to keep.

2. Purpose and Background

The East Timor Hearts Fund wishes to know the value of the treatments it provides, including patients' health and wellbeing.

To help the Fund learn about patient's health after their surgery, the Fund has asked our East Timorese Partners to interview four past patients.

3. Procedure

If you agree, one of the Partner workers will hold an interview with you at a time and place that is convenient to you.

4. Possible Benefits

Your involvement will help the Fund research the value it is creating.

5. Possible Risks

The interview may cause you discomfort and/or distress. At any point during the interview you can request the researcher to stop the interview, and they will stop immediately.

The Partners will follow their normal procedures for any further support you require.

6. Privacy, Confidentiality and Disclosure of Information

If you give us your permission by signing the consent form, we will not write your name against anything you say in the notes or any report.

The information collected will become part of the research findings about the Fund. This report may be published more widely. Given the small number of patients, however, it may be possible for someone to guess who has been interviewed. If you are concerned about this, please tell the interviewer. All data collected will be kept in a locked filing cabinet and in a password protected hard drive for a period of 7 years after the end of the project (until 2022). After this time all information will be destroyed. It is not intended that this information will be used for any other purpose in the future.

You have a right to access your own personal information. To do so, contact Ingrid Svendsen at the East Timor Hearts Fund on mobile: 61 409 007 530 or Email: ingridsvendsen2@gmail.com

7. New Information Arising During the Evaluation

During the evaluation, the researchers might find out about new information about the risks and benefits of the evaluation. You will be informed at the beginning of the interview if this happens.

8. Results of Evaluation

The Fund will own the results of the research. They may share the results with you and others.

9. Further Information, Any Problems or complaints

If you require further information or if you have any problems concerning this evaluation, you can contact Ingrid Svendsen, Chair, East Timor Hearts Fund on mobile: 61 409 007 530 or Email: ingridsvendsen2@gmail.com

Or you can contact Jed Gilbert, Senior Consultant, Synergistiq on telephone: 61 3 9946 6800 or Email: Jed.Gilbert@Synergistiq.com

Appendix 5: Consent form

I have read, or have had read to me in my first language, and I understand the Participant Information sheet.

I freely agree to participate in this research according to the conditions in the Participant Information.

I may request a copy of the Participant Information and Consent Form to keep.

The researcher has agreed not to reveal my identity and personal details if information about this analysis is published or presented in any public form.

Participant's Name (printed): _____

Signature:

Date:

synergistiq 

**EAST
TIMOR
HEARTS
FUND**

Australians supporting a
healthy Timor-Leste

PO Box 23063, Docklands
VIC 8012, Australia

easttimorheartsfund.org.au

