Streamlining chronic disease management in the Torres Strait: review of current practice and recommendations for improvement

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Introduction

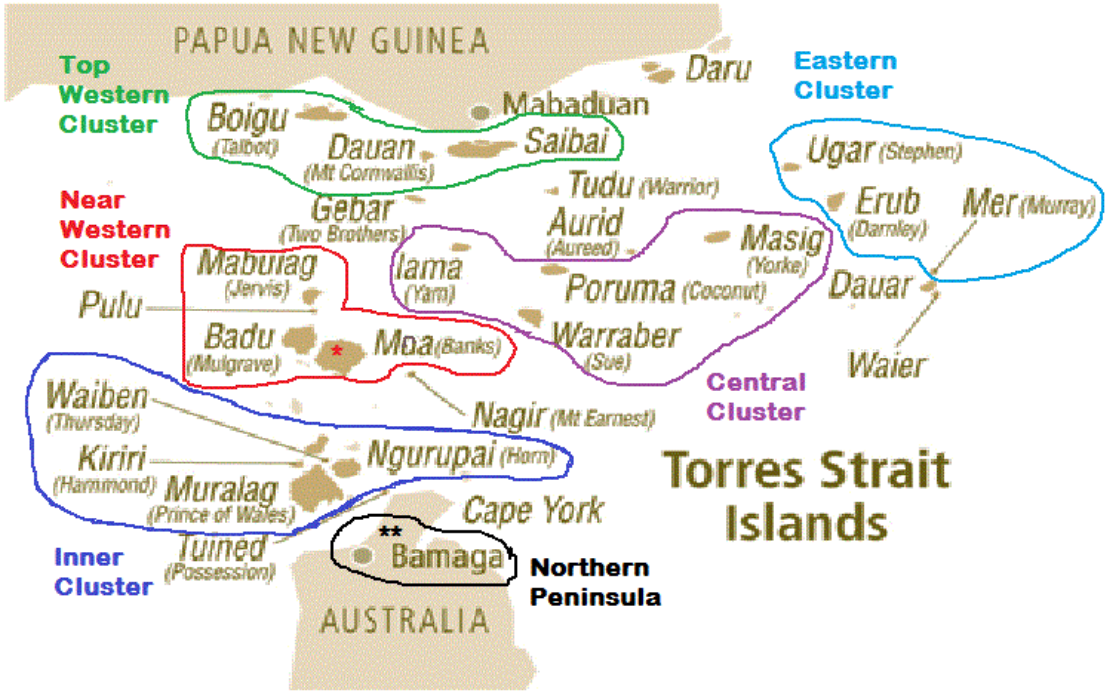
Burden of disease

Aboriginal and Torres Strait Islander (ATSI) people have long been recognised to have an increased burden of chronic diseases compared to non-indigenous Australians.

In remote areas the situation was worse; ATSI people were more than five times as likely as all non-Indigenous people to have diabetes and nearly four times as likely to have kidney disease[1].

The Torres Strait is a remote area consisting of 17 inhabited islands and two communities located between the tip of Cape York and the coast of Western Province, Papua New Guinea[2] (see Figure 1.). The region has been divided into six clusters (Figure 1.). The unique geography of the Torres Strait Islands entails many challenges for the local healthcare system.

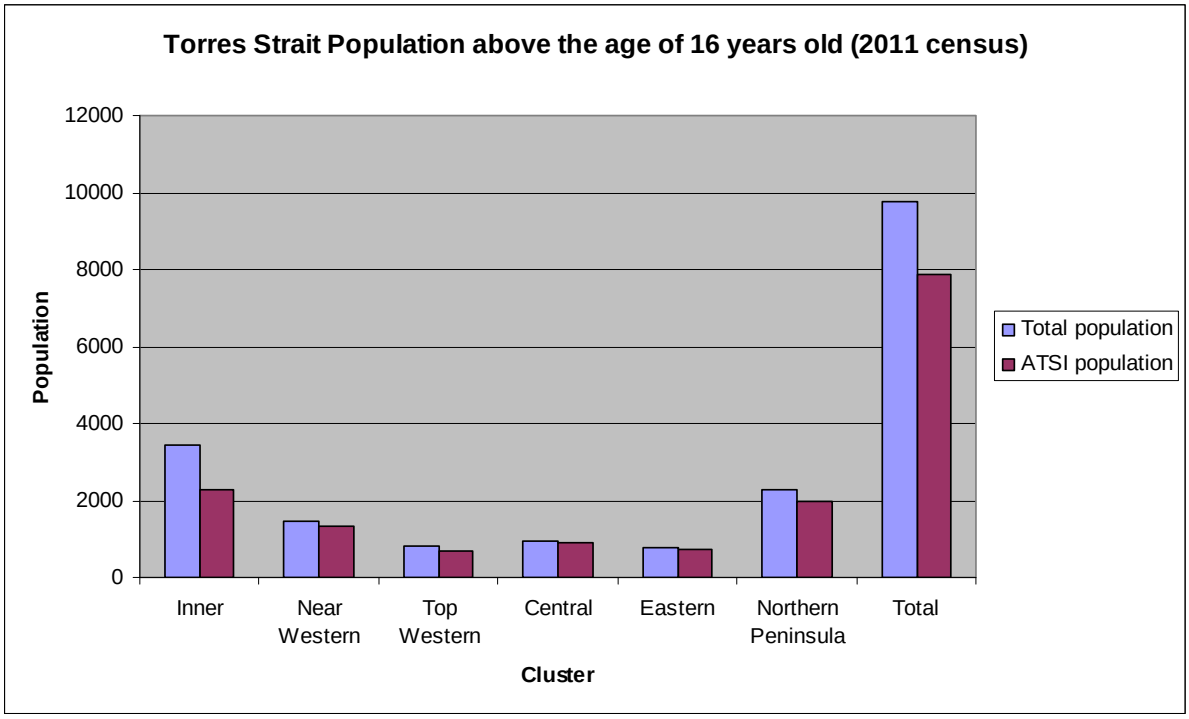
Figure 1 Torres Strait regional map and clusters division



*Kubin and St Pauls are two settlements located on Moa Island in the Near Western Cluster
**Injinoo, New Mapoon, Seisia, Umagico are four settlements located near Bamaga in the Northern Peninsula.

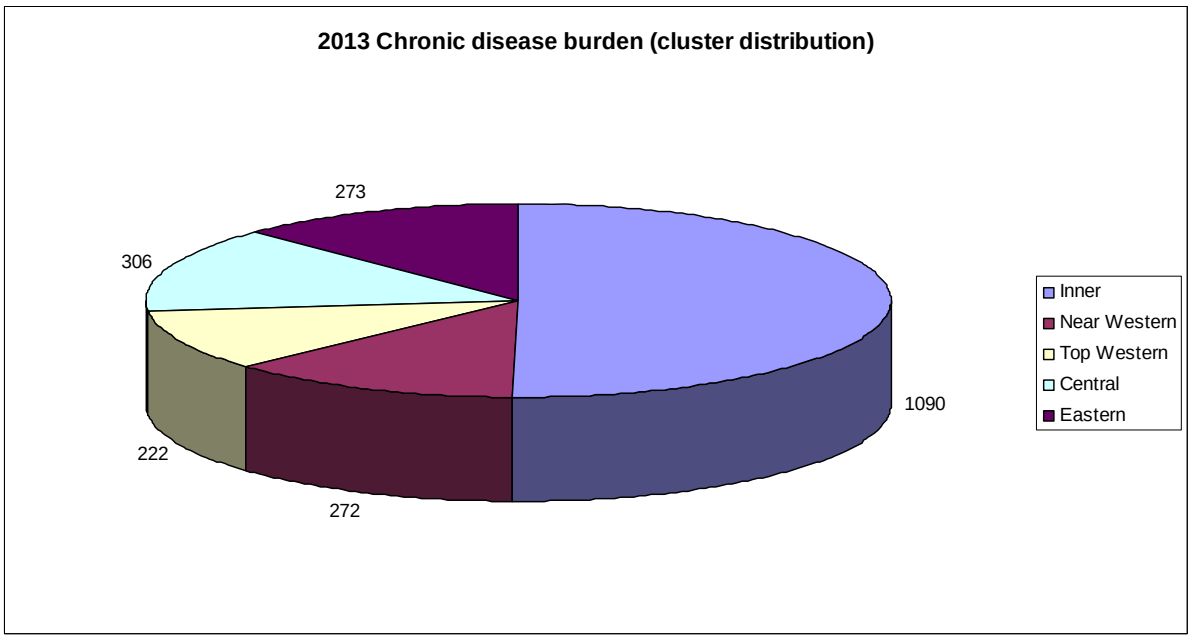
In this project, the focus is on the population above the age of 16 years old as this is the age group where the majority of chronic diseases occur. According to the census in 2011[3], there were 9744 people above the age of 16 yo in the Torres Strait, and 7872 (80.79%) of whom have identified themselves as ATSIs. (See Figure 2)

Figure 2 Torres Strait Population above the age of 16 years old



Locally-generated statistics (see methodology) record 2180 patients (22.2%) suffering from 1 or more chronic diseases. In figure 2, the total number of chronic disease patients in each cluster is shown.

Figure 3 2013 Chronic disease burden cluster distribution (does not include Northern Peninsula)



Note: The number of patients with 1 or more chronic diseases in each cluster

Figure 4 2013 percentage chronic disease patients (CDC) and the percentage of ATSI in each cluster

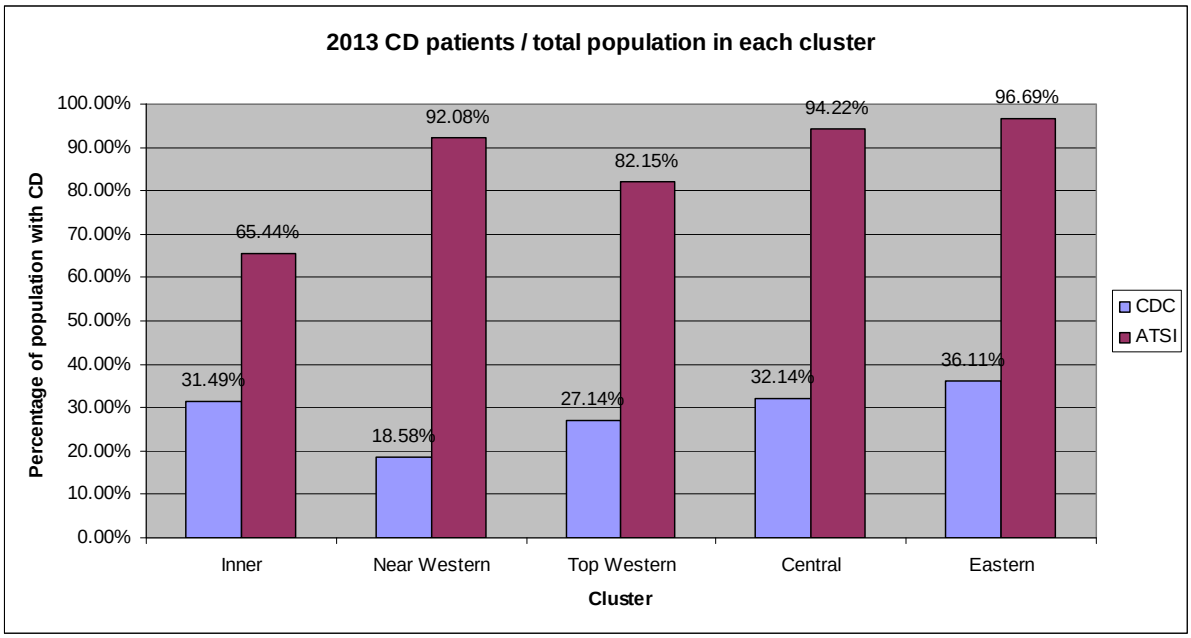
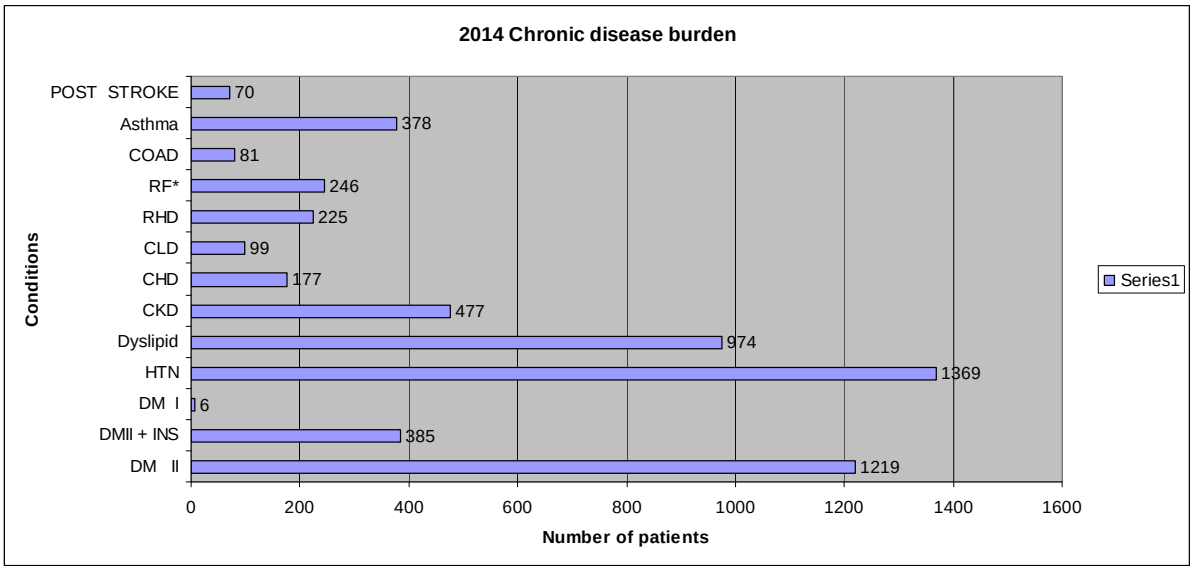


Figure 4 depicts the proportion of patients in each cluster who a) have one or more chronic diseases and b) are indigenous. This figure attempts to demonstrate that there are more chronic disease patients when there are more ATSI people in the region. However, the results are somewhat varied between the clusters. More statistical analysis would be required to test this hypothesis.

In 2014, the most common chronic diseases recorded were hypertension (HTN), Type II Diabetes Mellitus (DMII) and dyslipidaemia accordingly. The numbers of patients with these chronic diseases are shown below (See Figure 5.).

Figure 5 2014 Chronic disease burden



RF = Rheumatic fever, RHD = Rheumatic Heart disease, CLD = Chronic liver disease (mainly hepatitis B), CHD = Chronic Heart Disease, DMII + INS = Diabetes Mellitus, type II on insulin.

The very high prevalence of chronic diseases in the Torres Strait makes chronic disease management the overarching health priority within the local health system.

Past system, current system

Traditionally, medical records were fragmented across islands, with patients often having multiple "hard copies" of their medical records, often incomplete. Chronic disease management proved difficult due to disruption of continuity of care. The Holt's database was a unique, local, Microsoft based electronic medical record (EMR) established in the early 1990s in an attempt to connect all the medical records together.

Project FERRET was established at around the same time as a complementary chronic disease registry and recall system of sorts[4]. As most of the medical records were handwritten, it required manual input into FERRET. The project became labour intensive and time consuming. The database was also built on Disk Operating System (DOS), thus it became obsolete with advancement of technology.

A new project was started in 2011 to install an EMR in the Torres Strait to improve the current system. The new system that was installed was Best Practice, a software mostly used predominantly in the general practice setting elsewhere in Australia. This software allows health professionals to update patient information during consultations and insert reminders for investigations, immunisations, cancer screening and treatments. The current registries on the system include those for immunisations, Pap smears and diabetes mellitus.

However, the FERRET database is still in use on some islands in conjunction with Best Practice. Most clinicians have been using Best Practice for the past three years. The information in FERRET is out of date on many islands.

There are also two hand written registries on Thursday Island, including an International Normalised Ratio (INR) registry and the "Bicillin injection book" registry. They are each managed by one nurse or health worker for recording and recall of patients.

Current services

The current management of chronic diseases in the Torres Strait Islands mainly relies on the routine care provided by the local medical team, consisting of rural generalists clinicians, nurses, health workers, one diabetic educator and one podiatrist.

Other health personnel dedicated to various aspects of chronic disease management includes nurses and health workers in the Diabetic clinic. Several visiting physicians and specialist teams also manage other chronic diseases, which include CKD, RHD, DMII, COPD, Asthma and general medical conditions.

Thursday Island Post Acute Rehabilitation and Aged Care Team (PARAC) follow up with patients after discharge from the hospital, especially for those who may require more intensive, community-based services. They perform home visits to these patients who require high care. They also arrange and recall them for follow up appointments and investigations. This team manages the INR registry and the "Bicillin book" by recording and recalling patients who are on Thursday Island for regular blood tests on their INR and Bicillin injections for those who suffered from Rheumatic Heart Disease (RHD).

Individual recall systems have been setup in a relatively ad-hoc fashion in different locations in the Torres Strait. These are mainly for patients with hypertension, dyslipidemia, chronic kidney disease and diabetes mellitus type II, but vary among each island depending on local strategies and idiosyncraces e.g. the number of local staff members. The methods that these systems use for recalls include: phone calls, appointment cards, mail, home delivery of appointment reminders and home visits.

Gaps in services

According to the Australian Institute of Health and Welfare (AIHW)[5], the national health priority areas for chronic diseases include:

- arthritis and musculoskeletal conditions
- asthma

- cancer control
- cardiovascular health
- diabetes mellitus
- injury prevention and control
- mental health
- obesity.

Furthermore, all the screening performed in the region largely relies on patients presenting at the service, often for an acute medical problem or unrelated condition.

Thus there are multiple systems in place for chronic disease management in the region that may be considered comparable in some ways to “disease registries”, however, these are still not connected via a common system. The Best Practice software was an EMR installed for connecting the all the medical records together. Until now there are some of the registries that are not fully updated on this software, e.g. INR registry, “Bicillin book”.

The issue of patient recalls represents a significant challenge. The postal system is often slow in the Torres Strait region and not everyone has a mailbox. Some Islands are very large and more densely populated, hence home visits or delivery of appointment reminders are often not possible. Some islands also do not have mobile phone services, so SMS may not reach all patients. Thus, some patients inevitably miss follow-up appointments, tests etc.

Medical workforce retention has also been a major challenge in the region, which is ongoing. This makes the continuity of care very difficult.

Aims of this project

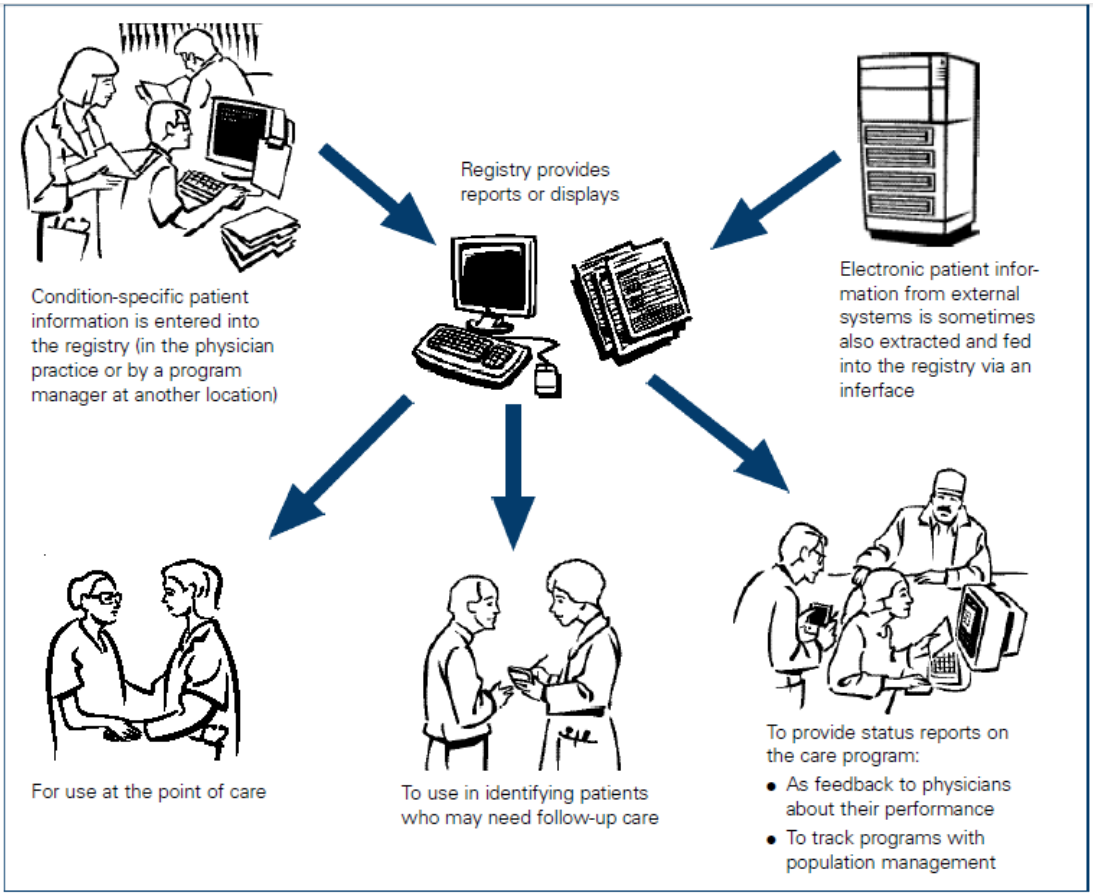
In the Torres Strait, management of chronic diseases are the predominant health concern and have been faced with many challenges. This project tries to identify some of the most significant obstacles to effective long term chronic disease management and areas for improvement.

Health information technology has proven to be beneficial to chronic disease care[6,7]. Computerised disease registries have commonly been used and are relatively simple to setup[8].

In the USA, four health centers have successfully implemented chronic disease management systems (CDMS) for population-based care management[9]. According to the article[9], a CDMS tracks multiple chronic conditions and can collect and present data for thousands of patients at a time. This is also known as an advanced registry or population health management system[9]. It is shown that CDMS require a lower cost to setup and has better ability to support chronic disease management compared to an EMR[10].

In this project, a CDMS will be called a chronic disease registry (CDR), which is defined as a computerised system incorporating the ten most common chronic diseases in the Torres Strait region and other relevant medical information. Other existing registries which relates to the management of chronic diseases would also be included in this system.

Figure 6 Basic functions of a chronic disease registry[11]



A CDR allows information to be kept up-to-date between all staff members and integrates specialist expertise and primary care[11]. Hence, such systems maintain better continuity of service at the primary care level. This then allows the system to be more proactive in preventive health, e.g. by providing timely reminders for physicians and patients[11]. A registry should also be able to generate disease statistics to identify relevant subpopulations for care such as those identified as suffering from a higher burden of chronic disease in the Torres Strait (see Figures 3 & 4 above). With a unified system in place, standardized guidelines and care plans can be implemented to ensure a standardized treatment for all patients. Thus, streamlining the whole process and increasing efficiency of chronic disease management. A CDR can also monitor performance of the healthcare providers[11].

Methodology

Population statistics of the Torres Strait were generated from the ABS census in 2011[3].

Statistics on the burden of diseases of the Torres Strait were generated by James Candy (Clinical Nurse Consultant, Thursday Island Primary Healthcare Centre) by manual comparison between records in FERRET database and the use of search engine in Best Practice. Only patients who were aged 16+ were included in the statistics. Patients who appeared in both records were removed for redundancy. The 2013 statistics do not include Northern Peninsula region but the 2014 statistics do.

An interview comprising a nine question survey (Appendix 2), surrounding chronic disease management in the Torres Strait was conducted. It was aimed at finding areas of improvement in the community for different chronic diseases in the Torres Strait Islands.

The people being interviewed included four doctors, seven nurses and four ATSI health workers who have worked in the Torres Strait Islands for at least three years. The semi-structured interviews lasted for 30-60 mins. As most islands do not have a residing doctor, only the nurse or health worker was interviewed.

Responses were transcribed and analysed for common themes.

Results

Table 1 The best and worst managed chronic diseases in the Torres Strait region

Best managed		Worst managed	
DMII	11	Obesity	7
RHD	9	Oral health	5
CKD	8	DMII	5
HTN	4	CKD	4
Asthma	1	Hepatitis B	4
Mental health	1	Dyslipidemia	3
Chronic ear infections	1	HTN	2
Chronic wounds	1	Chronic heart disease	2
Chronic heart disease	1	STIs	2
Diabetic retinopathy	1	Chronic ear infections	1
		Chronic wounds	1
		Rheumatological diseases + arthritis	1
		Post stroke	1

DMII = Diabetes Mellitus, type 2, CKD = chronic kidney disease, RHD = rheumatic heart disease, HTN = hypertension.

Table 2 Challenges faced by clinicians when managing chronic diseases in the Torres Strait region

Challenges	
Environmental	
Limited options at supermarket	4
Lack of facilities and human resources	2
Remoteness, distance	1
Desalination of water	1
Hot climate deters patients to exercise	1
Patient	
Getting patients motivated	6
Poor patient compliance	4
Cultural values, affecting eating habits	4
Lifestyle, poor eating habits	3
Lack of knowledge to the importance of health, poor understanding	2
Lack of health education and access to technology for more health knowledge	1
Clinician	
Lack of continuity of care	5
Lack of coordination, teamwork, consistency	5
Lack of time, human resources	4
Multiple systems for recording data	3
Lack of recall system	3
Lack of effort in non-medical side, e.g. health promotion	3
Lack of standardisation of management	2

Table 3 Factors that clinicians think are affecting patient follow up

Factors that clinicians think are affecting patient follow up	
Fear to western medicine, medications, doctors	4
Patient non-compliance	4
Cultural values, affecting understanding of importance of health	3
Lack of education on health	3
Work, family issues	3
Poor previous experience	2
Remoteness, distance	2
Fragmentation of health services (different doctor every time)	2
Language barrier	1
Confidentiality in small community	1

All respondents agreed that setting up a chronic disease registry would help with the current chronic disease management. The advantages and disadvantages are recorded below (see table 4.). 14 out of 15 would prefer the use of Best Practice as a platform for the registry to be setup. The reason that the one respondent who preferred FERRET over Best Practice, was that FERRET could generate population statistics.

Table 4 Advantages and disadvantages of setting up a chronic disease registry

Advantages
Research and statistics
Greater appreciation of burden of disease
Generate data to work strategically for certain regions, maximise effectiveness
Better transitional care, and planning
Allows performance data
Enhance care to patient --> can see trajectory of disease development
Client satisfaction enhanced
Disadvantage
Didn't work before, problem with input of information

Table 5 Information to include in chronic disease registry

Information to include in chronic disease registry
Diagnosis
Staging / severity of disease
Cycle of care
Last review
Investigations
Last specialist review
Differentiation between coronary heart disease (e.g. STEMI, NSTEMI, Angina)
Differentiation between HTN, DMII, dyslipidemia or is it a combination
Patient compliance
Colour coded reminders (e.g. red = overdue, blue = pending, green = done)
Reminder of obese children, adolescence

Discussion

In summary, all the respondents thought that setting up a CDR would help improve chronic disease management in the Torres Strait. The majority of respondents would prefer the new CDR to be built on top of the current Best Practice software. The best and worst managed chronic disease were considered to be DMII and obesity, respectively. The major environmental challenge perceived by respondents, with respect to chronic disease burden, was the limited options for health food choices in the supermarkets. The most frequent response for patient related challenges was difficulty in getting patients motivated. The perceived clinician challenges focused on lack of continuity of care, consistency, coordination and teamwork. Factors that clinicians thought affected patient follow up were fear of western medicine and patient non-compliance.

Regarding the clinician related challenges; the findings of this project suggest that a CDR could address those issues. A CDR would allow clinicians to have the most up-to-date information at the point of primary health care, even if clinicians change over relatively frequently within the region. This can improve continuity of care and consistency. The coordination between clinicians may also be improved by such a system, as clinicians can see updated information from other clinicians. With a better continuity and consistency of care, patient satisfaction may also be expected to increase.

It is interesting to note that, at least one interviewee mentioned that “DMII seems to be the chronic disease that we put most amount of effort in, but I am not sure whether it is well managed”. This suggests that clinicians are not sure whether their work is actually improving the chronic disease burden in the Torres Strait. A CDR capable of generating population statistics would be valuable in understanding the performance data.

Respondents also mentioned other potential advantages of the system’s ability to generate statistics. It may allows greater appreciation of the burden of the diseases in each region, thus enabling strategic planning, e.g. where to input more resources. By allowing a better allocation of resources, improved efficiency of chronic disease management may be possible.

A CDR with an effective recall system could allow a more proactive way of tackling chronic disease. Acute-on- chronic problems can be prevented. This saves time for the clinicians. As one respondents said “the doctors are often overwhelmed by treating the acute problem of a patient with chronic disease” and “they are just bandaiding these acute presentations”.

Regarding obesity as the chronic disease that some clinicians felt was the worst managed in the Torres Strait, it suggests the importance of knowing the percentage of population who are obese in the Torres Strait. Screening for every patient for obesity, by measuring BMI and waist circumference may be helpful. This should commence at an early age. According to the AATSIHS[12], almost one-third of (29.7%) ATSI children aged 2–14 years are overweight (19.6%) or obese (10.2%) according to their BMI. ATSI children aged 2–14 years were also significantly more likely than non-Indigenous children to be obese.

Concerning the CDR design, the input of data into a registry had been a major challenge in the past. It was a concern among the health professionals, as it was labour intensive to update the FERRET database. They all agreed that the system would be most ideal if it was connected to Best Practice, so the information can be updated as the consults were performed.

Limitations of the study

The limitations of this study included the lack of patient feedback and perspectives, making this project highly clinician-focused. The population and disease data in this project only included the past two years. A broader timeframe would be more useful to analyse the disease trend in a long term fashion. Moreover, a larger number of survey respondents would improve the robustness of the results.

Progress and technical issues

Paula Marshall, who is responsible for setting up Best Practice in the local region has started the process of upgrading the software. Moreover, she has asked Best Practice for support on holding

tutorials for training the use of Best Practice in the Torres Strait region. More licenses for Best Practice have been applied, allowing more staff members to access the software.

According to Best Practice technical support, at the moment the software cannot allow users to create a customized disease registry. If we were to create a new registry on the software, it will have to be done through Best Practice. However, it is possible to build a disease registry on a separate database then connect it to Best Practice. This way the information input during consultations can be updated on the database simultaneously. Furthermore, the database can be used for other purposes, e.g. gathering population and disease statistics.

The findings of this project have been presented to the senior medical officer team and met with significant interest and approval.

Conclusion

The respondents from the interviews are very supportive for a comprehensive and unified chronic disease registry to be setup. It may be able to improve the current chronic disease management service in the Torres Strait. The most important thing for the CDR to be successful is the information needs to be up to date and a unified system is crucial for this to happen.

Below is a list of recommendations (1-8 is CDR focused, 9-19 is related to other areas of chronic disease management in the Torres Strait):

CDR focused

1. Unifying the databases, transfer of information from FERRET to Best Practice.
2. Use Best Practice as the basis for setting up the CDR, ensure all medical records to be input through Best Practice to avoid gaps of information in the CDR
3. More training in the use of Best Practice for all local health professionals to ensure proper use of Best Practice for medical information recording
4. Input of INR, bicillin registry into Best Practice to update the information.
5. Using the SMS reminder system on Best Practice to enhance recall system.
6. Setup CDR that is capable of generating population and disease statistics
7. Strategic planning of chronic disease management according to disease burdens in different clusters or islands
8. Increase screening and recording for obese children. Alerts to be shown in red for adolescents who are obese.

Chronic disease management related:

9. More human resources in diabetes management, especially diabetic educators and podiatrist
10. More training for health workers on chronic diseases
11. More health promotion, e.g. health week
12. Ensure continuity of health promotion programs
13. Increase use of public media for health promotion, e.g. local radio, newspapers, television, public announcements, community flyers, posters
14. More exercise, weight loss, healthy eating classes
15. Personal trainers to design customised exercise plans for individual

16. Games after work, e.g. basketball, rugby, AFL, soccer

17. Starting a garden in the local schools to promote eating fruits and vegetables, also to promote self-sufficiency instead of relying on the local supermarkets

18. Healthier choices in the supermarkets, lowering the price of healthy foods in the supermarkets

19. Education on the concept of preservatives in food

Acknowledgment

Thank you for the following people who have helped contribute to the project.

- Dr. Lachlan McIver – preceptor, project design
- Paula Marshall (clinical nurse consultant, specialists project Best Practice coordinator) – technical issues, Best Practice
- Glenise Koch (AO3 Best Practice administration) – information on FERRET, Holt's database, HIBCS
- James Candy (Thursday Island Primary Health Care Centre) - Torres Strait Island statistics
- Dr. Sam Jones
- Dr John Cooper (Med Super – Thursday Island Primary Healthcare Centre)
- Karen Maguire (Registered nurse) – PARAC team
- Interview List (Appendix 2)
- Best Practice technical support

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Presenter

Alfred Liu is currently a fourth-year medical student at the University of Queensland. Before entering medical school, he graduated from the University of Wisconsin – Madison in 2009 with a Bachelor's degree in Natural Sciences, majoring in Biochemistry. During his undergraduate studies, he participated in molecular biology research focusing on eukaryotic protein expression and purification with various cell lines. During his second year in medical school, he participated in paediatric leukaemia research under Dr Andrew Moore at the UQ Child Health Research Centre. The study looked at a novel therapeutic strategy of treating acute myeloid leukaemia by targeting the protein Survivin with a chemical YM155 (Sepantronium Bromide), and was recently published in the journal of Leukaemia Research. In 2014, he had the opportunity to visit the Torres Strait Islands for a clinical rotation. During his six weeks stay, he conducted a qualitative study to address chronic disease management issues in the Torres Strait region.

Appendix 1

Survey

1. What chronic diseases do you think are managed the best / poorest in Torres Strait Islands? (Name 3)
    - Best
    - Poorest
2. What are some challenges faced for the management of chronic diseases in Torres Strait Islands?
3. What are some areas of improvement for the management of chronic diseases in Torres Strait Islands?
4. What factors do you think affects patients from returning to follow up consultations?
5. Do you think having a chronic disease registry will help? (Yes/No)
    - Reason?
6. What information do you think is pertinent to include in the chronic disease registry?
7. What is done to ensure that patients with chronic diseases are being followed up?
8. What mechanism / system would you prefer when establishing a chronic disease registry?
9. From your experience, what are the lessons learnt from management of chronic diseases in Torres Strait Islands?

Appendix 2

Interview list:

Senior medical officer team

- Dr. Wynand Bertynbach
- Dr. Jack Sloss
- Dr. Oscar Whitehead (Director of Medical Services)
- Dr. Irene Tjiung

Clinical nurse consultants

- Vickie Tamvoy
- Cathy Parker (Horn Island)
- Christine Perrett (St Paul's)
- Robyn Whyte (Yorke Island)
- Angela Mills (Darnley Island)
- Keiva Kovak (Thursday Island Primary Health Care Centre)

Registered Nurses

- James Candy (Thursday Island Primary Health Care Centre)

Health workers

- Salome Gaiden (Yam island)
- Fred Tamu (Warraber)
- Tomi Newie (St Pauls)
- Norma Whap (Mabuiag)