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Feature

Lung health care for Aboriginal and Torres Strait Islander Queenslanders: breathing easy is not so easy

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Abstract

Objectives. In Aboriginal and Torres Strait Islander peoples in Queensland, to (a) determine the disease burden of common chronic lung diseases and (b) identify areas of need with respect to lung health services.

Methods. Literature reviews and analyses of hospitalisation and mortality data were used to describe disease epidemiology and available programs and services. Key stakeholder interviews and an online survey of health professionals were used to evaluate lung health services across the state and to identify services, needs and gaps.

Results. Morbidity and mortality from respiratory diseases in the Indigenous population is substantially higher than the non-Indigenous population across all age groups and regions. There are inadequate clinical services and resources to address disease prevention, detection, intervention and management in an evidence-based and culturally acceptable fashion. There is a lack of culturally appropriate educational resources and management programs, insufficient access to appropriately engaged Indigenous health professionals, a lack of multi-disciplinary specialist outreach teams, fragmented information systems and inadequate coordination of care.

Conclusions. Major initiatives are required at all levels of the healthcare system to adequately address service provision for Indigenous Queenslanders with lung diseases, including high quality research to investigate the causes for poor lung health, which are likely to be multifactorial.

What is known about the topic? Chronic diseases, including lung disease contribute to, and influence outcomes of, the well-known health and socioeconomic disadvantage among Aboriginal and Torres Strait Islander Australians. Nationwide, the most common reason for hospitalisation of Indigenous Australians is for lung diseases (after renal dialysis).

What does this paper add? There is currently no state- or nation-wide comprehensive review of chronic lung disease burden and the health services available to prevent, treat and manage lung disease. This review fills this gap in Queensland and has found that chronic lung disease burden is not homogenous. There are substantial gaps in, and barriers to, the provision of high quality, evidence based services and a paucity of well-designed research to inform policy and health service delivery.

What are the implications for practitioners? Evidence-based strategies are needed at the primary, secondary and tertiary levels of the healthcare system. Fourteen recommendations relevant to practitioners and policy makers were formulated.

Additional keywords: health policy, Indigenous, needs assessment.

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Introduction

Lung disorders, acute and chronic, are major causes of morbidity and mortality among Indigenous Australians. Nationally, after excluding care involving renal dialysis, diseases of the respiratory system are the leading cause of hospitalisation in this population,[1] and the fourth leading cause of mortality, accounting for 8.7% of all deaths. Mortality in Indigenous infants is 8.6 times higher than other Australian infants and conditions affecting the respiratory system are likely to be a significant contributor to this increased risk.[2] However, the importance of lung disease as a cause of acute and chronic ill-health among Indigenous Australians has not received recognition in this population comparable to that of cardiovascular disease, diabetes and renal disease.

Although there are now comprehensive national and state strategic plans to address chronic disease (including lung disease) in Aboriginal and Torres Strait Islander communities,[3–5] there have been surprisingly few efforts to document the nature and burden of lung disease or to review existing service gaps and needs.[6] Progress therefore needs to be made in order to inform the implementation and evaluation of current strategies from a respiratory health perspective. A project to address this lack of information was undertaken as part of the Queensland Government's commitment to the Australian Government's Closing the Gap initiative.[4] The project's aim was to inform the delivery of lung health services for Indigenous Queenslanders. For practical reasons, the scope of the project was limited to asthma, chronic obstructive pulmonary disease (COPD), lung cancer and obstructive sleep apnoea (OSA).

The project's objectives that are addressed in this report are:

- To summarise the available data on chronic lung diseases among Aboriginal and Torres Strait Islander peoples in Queensland; and
- To identify areas of need with respect to lung health services for Aboriginal and Torres Strait Islander peoples in Queensland

The complete report addressing all the project's objectives, including detailed reviews of past and present research, programs and strategies, is available elsewhere.[7]

Methods

The project was conducted between March and June 2010 using a mixed methodology approach. A multidisciplinary and multisectorial working group was established to oversee the project. Two project officers were employed including an Indigenous registered nurse from Queensland with extensive professional and family connections throughout the state.

Demography and disease epidemiology

Data on the profile of Indigenous Queenslanders, and burden of disease estimates, were obtained from multiple sources including the Australian Institute of Health and Welfare, the Australian Bureau of Statistics, Queensland Government Reports, research reported in the scientific literature (PubMed, Cochrane Library, ISI Web of Knowledge) and research, program and policy reports identified through various internet sites including the Indigenous *HealthInfonet*. Search strategies used the terms 'respiratory, Aboriginal, Indigenous, lung health, health services, epidemiology, asthma, chronic obstructive pulmonary disease, lung cancer, sleep apnoea'. Data were extracted from the Queensland Health Hospital Admitted Patient Data Collection and the Queensland Health Cause of Death File to calculate average annual hospitalisation and mortality rates for each of the four key diseases. Denominators used in the calculation of rates were sourced from the Australian Bureau of Statistics[8,9] and Queensland Health. Age-standardised rates were calculated by the direct method using the Australian population for aggregate Queensland data.

Health service provider perspectives

Semistructured key informant interviews were conducted with staff of respiratory and sleep departments at 12 tertiary/regional hospitals and five district hospitals, three Aboriginal Community Controlled Health Organisations (urban, regional and remote), General Practice Queensland and selected Divisions of General Practice, and Indigenous Health Program coordinators and policy officers in a range of community and corporate settings.

A deidentified online survey was conducted via Survey Monkey (Pao Alto, California) and distributed via the Queensland Health Statewide Respiratory and General Medicine Clinical

Networks, General Practice Queensland (three divisions only), Chronic Disease Coordinators and Indigenous Health Coordinators in each of the Queensland Health – Health Service Districts (HSDs) and key informants.

The interviews and survey collected data on: respondent demographics, Indigenous identification and service provision, general health service information including access to key health professionals necessary to best practice lung healthcare and management, access to resources such as spirometry, pulmonary rehabilitation and tobacco control programs. Participants were asked to identify the key gaps, system enablers and barriers and client enablers and barriers in the prevention, identification and management of chronic lung diseases. Data were analysed both quantitatively using descriptive analyses and qualitatively through the identification of common themes.

Results

Broad profile of Indigenous people in Queensland

An estimated 28% ($n = 146\,429$) of Australia's Indigenous population are resident in Queensland, equating to 3.6% of the State's total population.[9] Just over 14% of Queensland's Indigenous population identify themselves as Torres Strait Islanders only, with an additional 8.2% identifying themselves as both Aboriginal and Torres Strait Islander.[9] Approximately 51% of Queensland's Indigenous population reside outside the major cities and inner regional areas of the State (Table 1).

For almost all socioeconomic and health indicators, Indigenous Queenslanders lag behind non-Indigenous Queenslanders in all areas of the state,[3,9–13] and risk factors for chronic lung disease (overcrowding, smoking, overweight) are high.[1,12,14] Indigenous Queenslanders experienced 4.4% of Queensland's disease and injury burden in 2006.[10]

Access to healthcare remains problematic. In 2007–08 only 12.3% of Indigenous persons aged over 55, 6.3% of those aged 0–14 years and 10.8% of those aged 15–54 years had received the specific Medicare funded annual health check.[3] In 2004–05, 15% of Indigenous Queenslanders did not consult a doctor when required and 7% did not go to hospital when needed.[12] Indigenous Queenslanders are three times more likely to self-discharge from hospital than non-Indigenous Queenslanders,[3] and up to 50% less likely to have diagnostic or therapeutic procedures performed while in hospital than non-Indigenous Queenslanders.[1]

The apparent burden of ill-health is complicated by inaccuracy in official health datasets. In 2007–08, although the overall estimated level of capture of Indigenous status in Queensland acute public hospitals was 83.5%, there was marked variation by Health Service Districts (HSDs) across the State.[15] Four HSDs that collectively represent 40.2% of Queensland's estimated resident Indigenous population had an average capture rate of only 63.6%.

Providing culturally safe, competent services is hampered by the lack of Indigenous people in the health workforce. In 2006 only 2.2% of the health workforce identified as Indigenous with almost half of those being employed in operational, managerial and clerical positions.[16,17] Although there are over 60 organisations in Queensland providing Indigenous-specific health services, these are predominantly located along the coastal corridor, with few services available for Indigenous residents in the Central West and South West regions of the State.[16]

Disease epidemiology

Despite the population size and heterogeneity there are virtually no studies on the prevalence and incidence of asthma, COPD, lung cancer and OSA in Indigenous Queenslanders and only limited data from elsewhere in Australia. The exceptions are some small studies conducted in regional and remote communities or data obtained from the National Aboriginal and Torres Strait Islander Health Survey (NATSIHS).[12]

Asthma

The 2004–05 NATSIHS reported an overall age-standardised asthma prevalence of 15.3%; 10.9% (95% CI 2.7–19.1) for those in remote areas and 16.7% (95% CI 10.8–25.8) in non-remote areas.[12] A 1999 cross-sectional survey of children aged 0–17 years in five randomly selected communities in the Torres Strait and Northern Peninsula regions reported an overall prevalence of self-reported ever wheezing of 21%; 12% reported wheezing in the previous year; and 16% reported ever having asthma.[18] A follow-up study conducted in 2003 found asthma prevalence had remained high but stable.[19]

The average annual age-standardised asthma hospitalisation rates in Queensland for 2005 to 2009, and average annual age-standardised asthma mortality rates, are presented in Table 2. There was marked variation in rates between HSDs with the highest rates observed in the Mount Isa, South West, Townsville and Central West Districts (detailed data available elsewhere[7]). Overall, 4.2% of asthma hospitalisations did not have Indigenous status recorded; by HSD this ranged from 1.4 to 9.6%. Indigenous status was not reported in 2% of asthma deaths.

COPD

The prevalence of COPD among Indigenous Australians has been poorly quantified, despite mortality from chronic lung disease being 14 and 12 times higher for Indigenous males and

Table 1. Estimated resident population by Indigenous status and remoteness area, Queensland, 2006

Location	Indigenous		Non-Indigenous		All persons	
	n	%	*n*	%	*n*	%
Major city	41 097	28.1	2 398 025	60.8	2 439 122	59.6
Inner regional	30 206	20.6	866 656	30.0	896 862	21.9
Outer regional	42 612	29.1	578 226	14.7	620 838	15.2
Remote	12 523	8.6	72 230	1.8	84 753	2.1
Very remote	19 991	13.7	29 980	0.8	49 971	1.2
Total	146 429	100.0	3 945 117	100.0	4 091 546	100.0

Table 2. Average annual age-standardised hospitalisation and mortality rates per 100 000 population for asthma, chronic obstructive pulmonary disease (COPD), lung cancer and obstructive sleep apnoea (OSA), by Indigenous status, Queensland

Rates are directly age-standardised to 2006 Estimated Resident Australian population.[8] Hospitalisation rates data source: Queensland Hospital Admitted Patient Data Collection, 2005–09. Mortality rates data source: Queensland Health Cause of Death File, 2003–07. Rate ratio is a relative comparison of incidence rates between Indigenous versus non-Indigenous Queenslanders. N/P, not presented owing to data uncertainties and small numbers

	Hospitalisations Rate per 100 000 (95% CI)			
	Indigenous	Non-Indigenous	Total	Rate ratio (95% CI)
Asthma	576.4 (573.2, 579.6)	261.6 (259.4, 263.7)	281.1 (278.9, 283.4)	2.2 (1.9, 2.5)
COPD	2193.8 (2187.6, 2199.9)	507.1 (504.8, 510.1)	545.2 (542.1, 548.4)	4.3 (4.0, 4.7)
Lung cancer	494.2 (491.2, 497.2)	280.8 (278.5, 283.0)	317 (314.7, 319.4)	1.8 (1.5, 2.0)
OSA	231.1 (229.1, 233.2)	324.2 (321.8, 326.7)	344.4 (341.9, 346.9)	0.7 (0.6, 0.8)
	Mortality Rate per 100 000 (95% CI)			
Asthma	2.2 (2.0, 2.4)	1.4 (1.2, 1.5)	1.4 (1.3, 1.6)	2 (0.2, 21.0)
COPD	50.2 (49.2, 51.1)	19.3 (18.8, 19.9)	20 (19.4, 20.6)	2.6 (1.6, 4.4)
Lung cancer	53.9 (52.9, 54.9)	33.2 (32.4, 33.9)	33.7 (32.9, 34.5)	1.6 (1.1, 2.5)
OSA	N/P	N/P	N/P	N/P

females respectively than non-Indigenous males and females.[20] Surveys of lung health in Indigenous adults aged 18 years and over in remote areas of north Queensland, the NT and northern WA in the late 1990s reported prevalence ranging from 16.7 to 54%, although case definitions and case ascertainment differed between studies.[21–24]

The average annual age-standardised COPD hospitalisation rates in Queensland for 2005 to 2009, and average annual age-standardised mortality rates, are presented in Table 2. As for asthma, there was marked variation in rates between HSDs in the State with the highest rates again observed in the Mount Isa, South West, Townsville and Central West Districts. Overall, 3.7% of COPD hospitalisations did not have Indigenous status recorded; by HSD this ranged from 0.5 to 10.1%. Indigenous status was not reported in 1.8% of COPD deaths.

Lung cancer

There are currently no national data on cancer incidence in Indigenous Australians owing to poor data quality in several jurisdictions and concerns that where data have been collected, it is not accurate, although data in official registries has been improving.[25]

A comprehensive review of cancer in Indigenous Australians found they were more likely to have cancers that have a poor prognosis, were usually diagnosed with cancer at a later stage, were less likely to receive adequate treatment, and were more likely to die from cancers than other Australians.[25] A matched cohort study of all Indigenous people diagnosed with cancer in Queensland between 1997 and 2002[26] reported Indigenous patients were 24% less likely than non-Indigenous patients to receive surgery ($P < 0.0001$), 20% less likely to receive chemotherapy ($P < 0.0001$), and 9% less likely to receive radiotherapy ($P = 0.039$) than non-Indigenous patients.[26] Lung cancer incidence rates were compared in regions of Queensland according to the proportion of the population that were Indigenous;[5] rates in 2005–06 were reportedly 30% higher in areas with 1–20% Indigenous population compared with areas of less than 1% Indigenous people.[5]

The average annual age-standardised lung cancer hospitalisation rates in Queensland for 2005 to 2009, and average annual age-standardised lung cancer mortality rates, are presented in Table 2. Marked variation in rates between HSDs were observed with rates highest in the Darling Downs–West Moreton, Gold Coast, South West and Torres Strait–Northern Peninsular Regions. Overall, 10.7% of lung cancer hospitalisations did not have Indigenous status recorded; by HSD this ranged from 0 to 19.1%. Indigenous status was not reported in 0.8% of lung cancer deaths.

Obstructive sleep apnoea

There appears to be only one published study that has examined sleep health in Indigenous Australians. This study included 1650 children aged 0–17 years in five communities of the Torres Strait during 1999.[27] The prevalence of snoring was 14.2% (95% CI 12.5–15.9) and 6% (95% CI 4.9–7.2) reported restless sleep.[27]

The average annual age-standardised OSA hospitalisation rates in Queensland for the period 2005–09 are presented in Table 2. Mortality rates are not presented given uncertainties surrounding the data. OSA differed to the other diagnoses in that in all HSDs, with the exception of the Metro South region, rates were lower than non-Indigenous Queenslanders. Indigenous identification was poor; 6.6% of hospitalisations did not have Indigenous status recorded, ranging from 0.6 to 36.1% across HSDs.

All four diseases combined

As the four conditions above comprise the majority of chronic lung disease, combining the data provide an overall picture of lung health in Indigenous and non-Indigenous Queenslanders. Overall, Indigenous Queenslanders were 2.7 (95% CI 2.59–2.71) times more likely to be hospitalised for a chronic lung disease than non-Indigenous Queenslanders and 2.0 (95% CI 1.8–2.3) times more likey to die from these diseases.

Lung health services – survey findings

A total of 219 persons responded to the online survey. Most respondents worked in a public hospital or community clinic/primary healthcare centre (Fig. 1); 73% were directly involved in patient care. Of all respondents, 42.6% were nurses, 18.1% were doctors, 18.1% were Indigenous Health Workers (IHWs) and 13.3% were allied health professionals. IHWs, Indigenous Outreach Workers and Indigenous Health Coordinators were employed in 67.8, 21.7 and 34.8% of clinical settings.

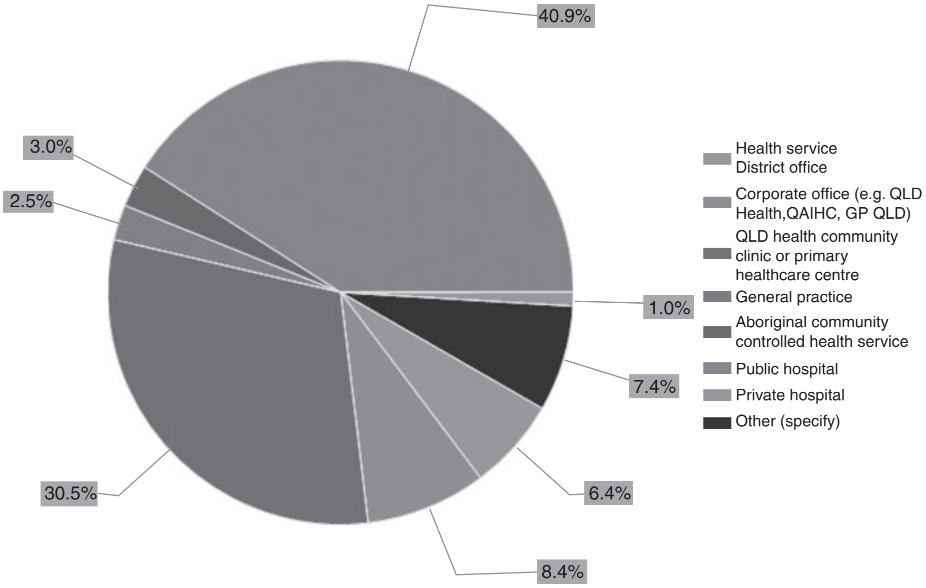

Fig. 1. Survey respondents by place of employment.

Overall access in Queensland by clinical services to key health professionals necessary to the care of Indigenous people with chronic lung diseases is presented in Fig. 2. Of note is a lack of exercise physiologists, smoking cessation facilitators, respiratory scientists, respiratory nurse specialists, chronic disease educators, IHWs with a chronic disease focus and paediatric respiratory physicians. Detailed analyses of services by HSD are available elsewhere[7]; however, those regions with the highest burden of disease were regions with the least amount of specialist services for disease prevention, detection and long-term management.

Respondents were asked to describe what, in their opinion and experience, were the key gaps in services for Indigenous people with chronic lung disease, the major system enablers and barriers to providing these services and what they perceived were the enablers and barriers for Indigenous people to receiving care. The major themes for each of these are presented in Box 1.

Lung health services – key informant interviews

Consistent messages arose during the key informant interviews that matched those described above and that are presented in Box 1, irrespective of the size of the facility and its Indigenous client base. Important priorities identified in all areas were trained lung health specialists (in all disciplines) and multidisciplinary outreach teams, smoking cessation facilitators and culturally appropriate educational resources. In almost all hospital settings, access to sleep specialists and diagnostics was limited, as were dedicated respiratory medicine beds in some of the major tertiary hospitals. Fragmentation and lack of coordination between services, particularly with respect to the referral and follow-up of people, was a major problem exacerbated in many areas by inadequate information systems. In some areas, current information systems are considered significant impediments to safe, effective and efficient healthcare.

Discussion

Although the high burden of disease in Indigenous Australians is well-known, this project is the first at any state-wide level that has examined chronic lung disease in Indigenous Queenslanders, identified programs and resources directed at addressing the burden, documented available services specific to lung health and identified health service provider perspectives. It does not address consumer perspectives, an important limitation to the comprehensiveness and representativeness of lung health needs for Indigenous Queenslanders.

Although data limitations need to be considered in the interpretation of morbidity and mortality data, overall, Indigenous Queenslanders are ~2.7 times more likely to be hospitalised with a chronic lung disease than non-Indigenous Queenslanders and 2.0 times more likely to die. There are large differences in morbidity and mortality rates within Queensland regions. The common reporting of aggregate data ignores this variation and presents a significant risk of inequitable and ineffective distribution of resources and effectively precludes an evidence-based approach to policy and funding decisions. Inadequate Indigenous identification further compounds the problem; for both hospital and deaths data there are more episodes in which Indigenous status is unknown than there are episodes in which it has been identified.

Although Queensland Health has embarked on strategies to improve Indigenous identification, comprehensive and accurate identification should be achieved as a matter of urgency. Existing data should be validated. Indigenous identification should not be considered simply the domain of admissions personnel; healthcare professionals have a responsibility to assess the

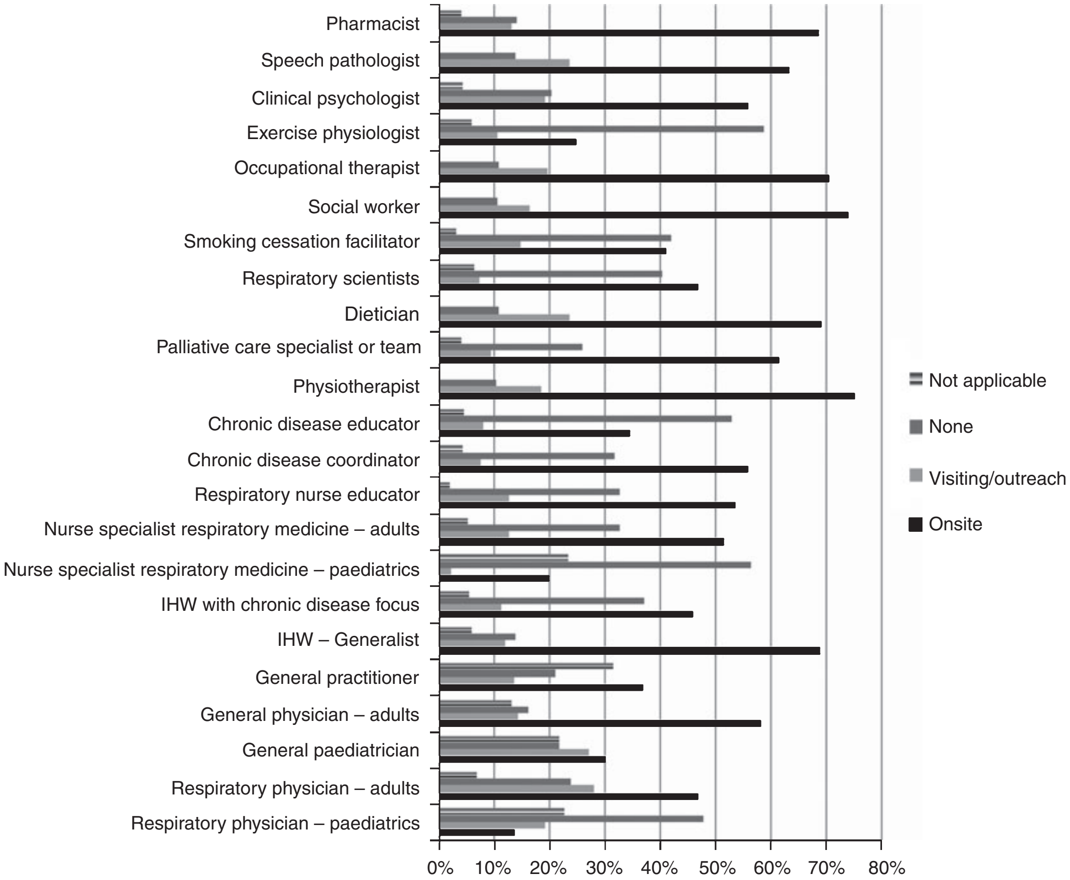

Fig. 2. Key health professionals available to clinical services in Queensland.

cultural, ethnic or religious backgrounds of all people (irrespective of Indigenous status) as part of a holistic approach and response to healthcare. This becomes particularly important in the domain of chronic diseases where long-term management and client outcomes will be dependent on a multitude of factors that define health and wellbeing.

Resources and personnel specifically dedicated to chronic lung disease detection, intervention and management are lacking and a critical need is smoking cessation facilitators and evidence-based, effective and culturally appropriate smoking interventions that go beyond one-off brief interventions. Services are sparse and those that do exist are largely considered fragmented, uncoordinated and substantially hampered by inadequate information systems that support the continuum of care.

There is a paucity of culturally appropriate educational materials and resources specific to lung disease for use with Indigenous people. Those that do exist are not well-recognised or do not account for the diversity of Indigenous backgrounds, and are not readily accessible. In many areas IHWs are not actively engaged in multidisciplinary teams or are not being effectively utilised in the care of Indigenous people. Suggested reasons for this include a lack of training, a lack of recognition of their skills and roles, devaluation of their skills and roles over time or excessive current workloads. Although limited, the available evidence suggests that the active involvement of IHWs in client care positively affects client outcomes.[28–30] Substantial efforts are required to engage IHWs and Indigenous Liaison Officers at all levels of the system and for their skills and roles to be appropriately recognised and remunerated.

The cost of chronic disease care, lack of transport to and from services, fear and distrust of services and a lack of available, culturally safe services in many regions are considered common barriers to patients accessing care. Chronic disease management is also hampered by the multiplicity of social, economic, cultural and health problems that exist among the Indigenous population and the difficulties these present when they are expected to focus on one particular problem. Although there is a range of federal, state and local initiatives underway that will, theoretically, affect lung health in Indigenous Queenslanders,[3,30,31] the evidence supporting some of these initiatives, and the data required to inform where these programs are implemented, are limited.

There is mismatch between disease burden and availability of services for chronic lung disease and lung health in Indigenous Queenslanders. Lung health should be incorporated as a priority and addressed within overarching strategic frameworks for Indigenous health. These should encompass sociopolitical strategies, improved housing and environmental health, public health measures, workforce development, education, chronic disease management and appropriate research. Fourteen key recommendations were formulated via working group consensus and with reference to those produced by the Thoracic Society of Australia and New Zealand.[6] They can be accessed in the complete project

Box 1. Health service provider and key informant perspectives on areas of need for lung health services for Indigenous Queenslanders

Major gaps in services
Lack of culturally specific programs, particularly support groups
Cultural awareness amongst staff, including Indigenous concepts of health and well being and how that affects care and management
Access to specialist services, particular respiratory specialists (nurses, doctors and allied health professionals) in outreach settings
Training and upskilling of health workers and nurses (particularly Spirometry)
Access to evidence-based preventative programs
Culturally specific smoking cessation programs and resources. Dedicated smoking cessation facilitators are a major priority
Awareness of the importance of chronic diseases and the burden and effect of these on individuals, families and the health system
Lack of coordination amongst services, particularly with respect to follow-up
More IHWs in multidisciplinary chronic disease teams

System enablers
Well trained IHWs that are an integral part of multidisciplinary teams
Collaboration between services and high quality, functioning information systems
Culturally appropriate services
The commitment of the health team, particularly senior management, to Indigenous health
Education of health professionals with respect to Indigenous health and education of the community
Good data and culturally appropriate research practices
The availability of appropriate resources

System barriers
Lack of appropriate funding, staffing and resources
Lack of well trained IHWs
Lack of cultural awareness and communication issues
Information systems that do not facilitate coordinated care and follow-up
Lack of commitment, particularly at the executive level
Lack of regular and appropriate training for all staff
Access barriers: financial, transport and physical barriers to services

Person enablers
Active engagement with proactive IHWs and ACCHOs
Wanting to learn/being actively engaged in their healthcare in environments that are culturally safe
Empowerment, self-determination and the willingness of communities to achieve better health outcomes
Accessible transport
Local, social support mechanisms
Believing they deserve good health and access to the structures and mechanisms that support and encourage this belief
Learning from others with a similar condition
Ownership of prevention, intervention and management programs
Positive ongoing feedback when things are going well and constructive, culturally appropriate feedback when things are not going well
Good quality, culturally safe care in the community

Person barriers
Lack of knowledge and education
Lack of culturally appropriate and safe services
Financial barriers and transport issues
The interplay and influence of multiple social, environmental, economic and health factors affecting health and the ability of Indigenous persons with chronic diseases to manage these and their illness

report[4] available at www.health.qld.gov.au/cpic/service_improve/clin_net_respiratory.asp.

Conflicts of interest

The authors declare that no conflicts of interest exist.

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