Royal Commission into
Victoria's Mental Health System

ATTACHMENT RB-21

This is the attachment marked '**RB-21**' referred to in the witness statement of Dr Ravi Subramanya Bhat dated 4 July 2019.

High prevalence disorders in urban and rural communities

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Objective: High prevalence disorders (anxiety, depressive and substance use) are generally assumed to be more common in urban than rural dwellers. The aims of this paper are (i) to critically review studies measuring prevalence in rural as opposed to urban location, and (ii) to argue the need to look beyond the 'quantity' question to the quality question: how does urban or rural place influence mental health?

Method: A literature review (Medline and PsychLIT) was carried out using the words 'rural, urban, mental/psychiatric, illness/disorders and prevalence', as well as a review of relevant papers and publications known to the authors.

Results: Many studies examining urban/rural differences in the rate of high prevalence disorders have been reported. Most use a 'one size fits all' definition of urban and rural, which assumes location is the key issue. The majority fail to show the purported difference in prevalence between the two settings. In general, studies have not examined interaction effects, but have simply treated the independent variables as main effects. Available data suggest that a variety of socio-demographic factors are more powerful predictors of difference in prevalence than is the location of residence.

Conclusion: Further studies are required to understand if and how rural or urban place contributes to the development of psychiatric morbidity. These studies should mirror the clinical situation by taking into account a variety of individual and community-based (including urban/rural place) risk factors which may be important determinants of mental health and mental illness, and examining the interaction between them. This may then identify the nature of any differences or what issues are specific to, or especially important, in the rural setting.

Key words: location, place, prevalence, rural, urban.

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Are high prevalence disorders (anxiety, depressive and substance use) more common among urban than rural dwellers? It is generally assumed the answer to this is yes [1,2] and that urban living is a risk factor for the development of psychiatric disorders, particularly depression and anxiety which are strongly affected by stress. Without recourse to examining the data, this view has been supported by caricatured images of urban and rural environments. Urban areas have been portrayed as environments of change, interpersonal estrangement, anonymity and conflicting values, seen as a focus of technological development and social dislocation, viewed by some as crime-ridden, riot-torn havens for individuals without strong loyalties and consistent values. By contrast, rural areas have been depicted as environments of social stability, integration, supportive

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interpersonal networks, and consensus about moral and political issues; and, in addition, as aesthetically superior to large cities [2,3].

There are several compelling reasons for re-examining whether urban or rural residence is a risk factor for psychiatric disorder, and if so, why. First, several authors' vision of cities as evil and rural areas as peaceful havens is based more on romanticized views than realistic assessments of the two environments [4–6]. Furthermore, it has been suggested that certain values which are considered typical of rural areas, such as strong conservative, religious and puritanical views, individualism, traditionalism, familiarism, fatalism, and person-centred relationships, may not beneficially affect the mental health of rural residents [7,8].

Second, it is well recognized that the physical health of rural residents is poor when compared to their metropolitan counterparts [9]; for example, people living in capital cities have greater longevity than those living in other parts of Australia, and deaths from coronary heart disease, asthma and diabetes are higher in rural than in metropolitan areas (Table 1). Many of the factors identified as having a potentially negative impact on physical health may have a similar effect on mental health. These include geographical isolation and problems of access to care, shortage of health care providers and health care services, socioeconomic disadvantage and poor health-related behaviours [9,10]. In addition, physical illnesses, particularly chronic disorders, are often accompanied by significant psychiatric comorbidity; for example, approximately 15% of medical inpatients have an anxiety disorder [11] and one in three have a major depressive disorder [12].

Third, rural life has changed substantially over the past few decades. The traditional characteristics of rural life have been affected by a variety of factors including: globalization, economic restructuring and economic rationalization [13], movement of the younger generation to cities, free-flowing access to information (particularly via the internet), more ready access to urban settings through improved transportation and inward migration of people who commute to urban jobs, and relatively high rates of poverty and unemployment [5,6].

Fourth, many of the studies cited by those claiming urban-rural differences were done many years ago [1]. Methodological changes over the past 20 years have enabled the conduct of new, so-called 'third-generation' studies characterized by improved diagnostic reliability and validity. Studies investigating the prevalence of psychiatric disorders in communities are generally grouped into first-generation or pre-World War II studies, second-generation studies (conducted between World War II and 1980), and third-generation or post-1980, studies [14].

Table 1. *Health of urban and rural residents (source: Australian Institute of Health and Welfare [9])*

	Males							Females						
	1	**2**	**3**	**4**	**5**	**6**	**7**	**1**	**2**	**3**	**4**	**5**	**6**	**7**
Life expectancy (years) 1994–96	75.6	75.2	74.5	74.7	74.7	72.3	71.5	81.2	80.8	80.6	80.8	80.8	78.3	77.4
Death Rates for coronary heart disease (per 100 000 population) 1992–96	205.0	216.7	231.9	225.6	221.9	237.1	232.3	113.0	121.0	128.6	122.1	118.8	135.6	120.8
Death rates for asthma (per 100 000 population aged 5–64 years) 1992–96	1.4	1.5	2.0	1.1	2.1	2.4	2.5	1.5	1.4	2.4	1.5	2.3	3.4	2.9
Death rates for diabetes (per 100 000 population)1992–96	16.8	12.9	16.0	18.0	18.3	30.4	28.4	11.5	10.2	13.0	11.6	13.6	24.0	29.7

1, Metropolitan zone – capital cities; 2, Metropolitan zone – urban centre population > 100 000; 3, Large rural centre – urban centre population 25 000–99 999; 4, Small rural centre – urban centre population 10 000–24,999; 5, Other rural – urban centre population < 10 000; 6, Remote centre – urban centre population > 5 000; 7, Other remote area – urban centre population < 5 000.

Third-generation studies, conducted following the introduction of DSM-III, are characterized by the use of standardized diagnostic interviews, improved survey research design, and computerized data processing.

Finally, and perhaps most importantly, most studies examining rural/urban differences have simply focused on the 'quantity' question – are disorders more or less prevalent in urban than in rural settings. This is a crude and relatively uninteresting question, in which rural or urban are simply treated as a locations, that is, positions identified by grid coordinates; but rural and urban are places, that is, locations, in which social relations are constituted [15]. As place may have broad socio-environmental influences on health, the more interesting question is the 'quality' question – how does place (rural or urban) influence mental health?

Here we review relevant studies, with an emphasis on key third-generation cross-sectional community studies which have compared urban and rural populations, and the three national household surveys conducted over the past two decades. These studies are described and their weaknesses are highlighted. The limitations of these studies point to the need for more sophisticated approaches to the epidemiology of mental disorders; in particular, studies need to go beyond the 'one size fits all' terms rural and urban, which assume location is the key issue, and examine the mix of economic, physical, social, environmental and socio-cultural factors within both rural and urban settings which may be important determinants of mental illness.

Cross-sectional community studies

First-generation studies relied on key informants and agency records to provide information to identify cases. Thus, these studies did not account for untreated cases of disorder. Second-generation studies used direct interviews of community residents and so were concerned with measuring the true prevalence of psychological symptoms or psychopathology in communities. Two different types of interview were used: one approach involved a personal interview by a psychiatrist to generate clinical diagnoses, but with the interview procedures not necessarily made explicit; in the other, standard and explicit data collection procedures were used and the classification of 'caseness' was made by evaluation of protocols compiled from the interview responses and sometimes also ancillary data, such as informants and information from previous records. A variation of this involved dispensing with clinical judgement and using objectively scored measures of psychopathology. These studies lacked content validity as there was little consensus at the time about the signs and symptoms to be elicited, different nomenclatures were used, and in many studies, diagnosis of a named disorder was bypassed for the general concept of caseness [16] and impairment [17]. A number of these studies documented the relatively high rate of certain types of impairment in rural areas, and though confined to these areas, and thus not comparative, they nevertheless provide important data [16,18–20].

Two key second-generation studies have been widely examined and discussed and are of direct relevance to this paper. The Mid-town Manhattan study sampled 110 000 adult residents of a section of mid-town Manhattan [17]; the Stirling county study sampled 20 000 residents of a Canadian rural county [16], populations at the extreme of a commonsense definition of an urban-rural continuum. Both studies relied on non-clinician interviewers recording information on structured interview protocols, which were subsequently rated by a psychiatrist. While the two studies used different screening instruments, both had as their core a portion of the items from the Psychosomatic Scale of the Neuropsychiatric Screening Adjunct [21]. Srole [6] roughly matched the two studies on major demographic characteristics (race, nativity, age, sex and socio-economic class) and found the current prevalence of 'psychiatric caseness' was significantly higher in Stirling county than in mid-town Manhattan. This finding, which is contrary to many studies investigating urban/rural differences, while of interest, must be viewed with caution. Matching on these variables may have washed out any real differences between the two locales. Furthermore, a variety of problematic assumptions were made by Srole, particularly the assumption that the way in which 'caseness' was derived in the two studies was equivalent [22]. There are also difficulties with interpretation of the Manhattan data, given the exceptionally high rates of psychiatric morbidity identified. Nevertheless, it raises the possibility that disorders in rural areas may be more prevalent than is often assumed.

The National Institute of Mental Health (NIMH) epidemiologic catchment area survey (ECA) [23] was the first of the third-generation studies. The study was characterized by its sample size of at least 3500 subjects per site (about 20 000 total), the focus on diagnostic interview Schedule (DIS)-defined DSM-III [24] mental disorders, one-year interview-based longitudinal design to obtain incidence and service use data, the linkage of epidemiologic and health service use data, and the replication of design and method in multiple sites.

Two of the five ECA sites (Durham and St Louis) had sufficient populations to examine rural-urban differences. In the Durham site there were four rural counties contiguous to a small central city; most rural residents were farmers or in local retail or trade services. In the St Louis site, the rural sample was drawn from two rural counties contiguous to the (larger) metropolitan centre. Rural residents in these areas were less likely to be farmers and more likely to commute to the urban area for employment opportunities.

As shown in Table 2, perhaps not surprisingly given the within-rural differences, urban-rural comparisons at these two sites gave results that were not consistent across diagnostic categories [23,25].

Subsequent to publication of the initial findings from the Durham site [23], further analysis using logistic regression was undertaken to examine the effects of urban/rural residence on major depression, controlling for demographic and social characteristics that previous literature indicated are risk factors for major depression (age, sex, race, marital status, education, socio-economic status, stressful life events, mother with small children, availability of confidante) [3]. Current major depression was nearly three times more common in the urban than in the rural communities (OR 2.99; $p < 0.01$). Rural residence decreased the risk of major depression for some but not all demographic subgroups: the risk of major depression was decreased for young rural residents (aged 44 years and younger) compared to their urban aged peers, and rural residence was more protective for young women than for young men.

It should be noted that this study treated depression as a stand-alone disorder, when in fact individuals may have carried other additional high prevalence disorders, for example, substance misuse disorders and anxiety disorders. Given this likely comorbidity, it is important to consider that the predictor set for depression may have been as powerful (or even more powerful) in predicting the additional disorders. A second point at issue is that the authors of the study did not analyse interaction effects but treated the independent variables as main effects. While the authors acknowledge this problem, the fact is that interaction effects may 'trump' the main effects, and be more illuminating. For example, consider the three–way interaction of age, sex, and rurality. Could it not be that the risk for depression might be synergistically increased for young urban males? Understanding of urban-rural differences would therefore be advanced by the investigation of interaction effects. Of course larger sample sizes (in the order of 10 000) would be needed to identify 2- and 3-way interactions involving high-prevalence disorders. Such future investigations would also be facilitated by using continuous (quasi-normally distributed) variables in place of categorical measures.

In considering these findings, in addition to the points made above, the particular features of this sample should be noted. The sample had age and sex distributions characteristic of both North Carolina and the USA generally, but a large proportion of non-white (41% rural, 32% urban) subjects, most of whom were black. Durham county is a major metropolitan centre in an area that contains more than 500 000 people and three major universities and a large industrial park that is the site of the research facilities for a number of major industrial firms. Approximately 24% of the population had at least a college education, and the mean per capita family income was over $20 000, reinforcing that this is not a typical urban setting. By contrast, the four rural counties are most representative of the rural south, and as such are characterized by a higher percentage of blacks and persons of lower educational attainment and socio-economic status than comparable national figures.

A variety of other studies conducted over the past 20 years have investigated the prevalence of psychiatric disorders in rural as opposed to urban communities [26–35]. The findings of several of these studies should

Table 2. Urban/rural differences in prevalence rates: epidemiologic catchment area study (St. Louis and Durham sites) [23]

Generalized anxiety disorder	Increased one year and lifetime prevalence in urban areas (NS)
Obsessive compulsive disorder	No difference urban versus rural one year and lifetime prevalence rates
Alcoholism	One year prevalence higher in urban dwellers in St. Louis, and rural dwellers in Durham (NS)
Bipolar affective disorder	One year prevalence rate of bipolar disorder over two times higher in urban versus rural areas in St. Louis ($p < 0.001$) and four times higher in urban versus rural areas in Durham ($p < 0.05$) (rates adjusted for sex, age and race/ethnicity)
Major depressive episode	One year prevalence rate of major depressive episode less in urban versus rural areas in St. Louis ($p < 0.001$) and two times higher in urban versus rural areas in Durham ($p < 0.05$) (rates adjusted for sex, age, and race/ethnicity)

Total rural n = 2157; urban n = 4768; Durham: rural n = 1946, urban n = 1889; St. Louis: rural n = 211, urban n = 2879; NS, not statistically significant.

be viewed with caution. Few studies have used reliable diagnostic processes to define specific disorders. In addition, urban/rural comparisons have often been made across rather than within studies. This approach, which does not take into account regional, cultural, or methodological variations between studies, is likely to obscure any urban/rural differences which may be present. Very few studies have taken compositional differences between urban and rural areas into account; this is particularly important when investigating those disorders in which there are age/sex differences in prevalence. If urban/rural residence is a risk factor for psychiatric morbidity, that relationship should be observed once compositional differences (e.g. age, sex, socioeconomic status) between urban and rural settings are statistically controlled [3]. Furthermore, reliance on cross-sectional data, unless accompanied by data about migration history, means it is not possible to know if current urban or rural residence precedes or follows the onset of disorder. The impact of psychiatric disorder on location of residence has been inadequately researched. While greater accessibility of services in urban regions might tend to attract individuals suffering psychiatric disorders [36–38], it might equally be hypothesized that more vulnerable or less resourceful individuals gravitate to less competitive rural environments. In addition, it is well recognized that in Western countries there has been an outflow of low-income households, a group at increased risk of mental illness, from the major capital cities to rural areas [39].

Studies which have used reliable diagnostic processes and made within-study urban/rural comparisons are shown in Table 3. No significant urban/rural difference in the rate of depression was found in any of these studies [30,33,34]; one study found alcohol dependence, agoraphobia and panic disorder were more common in rural than urban residents, while antisocial personality disorder was more common in urban dwellers [30].

Lee and colleagues [30] provided no data regarding the composition of the sample, and no examination of possible differences due to age/sex/socioeconomic status and other differences between the rural and urban samples (see Lee *et al.* [40] for methodology). By contrast, the other two studies also investigated possible differences in rates of a variety of known risk factors for anxiety and depression [33,34], which may have confounded any findings with respect to urban/rural differences.

Parikh and colleagues compared socio-demographic characteristics of their urban and rural samples (age, sex, education, household income, marital status, employment) and found the urban group had higher educational achievement, higher employment, higher family income, and a lower rate of being married [33]. When demographic information on those with affective

Table 3. Key third-generation studies assessing urban-rural differences in 'high prevalence' disorders

Investigator	**Study site**	**Definition of rural/urban status**	**Diagnostic process**	**Findings**
Lee *et al.* 1990 [30]	Korea Rural n = 1966 Urban n = 3134	Capital city Seoul, and 'scattered rural locations' throughout the country	DIS, DSM-III	alcohol dependence rural > urban($p < 0.001$) Agoraphobia rural > urban ($p < 0.01$) Panic disorder rural > urban ($p < 0.001$)
Parikh *et al.* 1996 [33]	Canada Rural n = 2295 Urban n = 5821	Population density related criteria	Modified CIDI DSM-III–R (mood disorders only)	No significant difference in prevalence of affective disorder between urban and rural
Romans-Clarkson *et al.* 1990 [34]	New Zealand Women only n = 314 total	Population density related criteria	GHQ-28 screen PSE interview Interview re risk factors	No differences urban v rural in any measures of psychiatric morbidity

DIS, Diagnostic interview schedule [52]; PSE, present state examination [53]; CIDI, computerized international diagnostic instrument [44]; GHQ-28 = general health questionnaire screen [54].

disorders was examined, similar risk factors seemed to operate in both rural and urban settings. Both urban and rural mood disorder respondents were more likely to be poor, unemployed, female and unmarried compared to the rest of the population (all $p < 0.01$).

Romans-Clarkson and colleagues [34] conducted a two-phase study using questionnaires and face-to-face interviews to examine sociodemographic risk factors for psychiatric morbidity in urban and rural women. The researchers used weighted logistic regression to assess simultaneous effects of age, marital status, social class, employment status, and urban/rural residence on total present state examination (PSE) score. Age was associated with PSE caseness for urban but not rural women, but only for women aged 65 years and older; for both urban and rural women high PSE case rates were found in separated women and those who had never been married, and those of lower socio-economic class. Paid employment was associated with a lower case rate for urban women but not for rural women. Factor analysis was used to reduce the data to a manageable number of relatively independent variables. Identified factors were then entered into a regression analysis using the total PSE score as the dependent variable. Three factors (self-related alcohol problems, childhood sexual abuse, social networks) individually explained a significant amount of the variance in total PSE score; the same three factors applied to both the urban and rural data sets.

Subsequently, Romans-Clarkson and colleagues reported a more detailed examination of the association between psychiatric morbidity in women and social interaction in the two geographical locations [41]. Using the Interview Schedule for Social Interaction (ISSI) [42], the researchers examined availability and adequacy of attachment, and availability and adequacy of social integration. Women who described less available and less adequate attachments and social integration showed more psychiatric morbidity. Rural women had higher adequacy of attachment and social integration scores than did urban women, but as noted above they did not have less psychiatric disorders.

Each of the studies described above examined a particular rural and a particular urban setting, each with its own particular social, cultural, economic and demographic characteristics; however, each simply talks of urban/rural differences, assuming each is representative of whatever 'urban' and 'rural' are. None attempted to capture the specific features of the setting (e.g. community in growth/decline, community cohesiveness, community attractiveness, lay systems of beliefs and behaviours, services provided) which might be of particular relevance in determining risk for the development of psychiatric disorder.

In summary, although many studies have been reported, few fulfil basic methodological requirements such as the use of reliable diagnostic procedures to define disorders, designs which enable rural/urban comparisons within the same study, examination of interaction effects, and measures to control for compositional differences. Where the latter have been examined, it seems that more often than not, demographic and social characteristics previously found to be risk factors for depression are more powerful predictors of depression than place of residence.

National household surveys

Three genuine national household surveys have now been completed around the world, and the details of these are outlined in Table 4. These allow more definitive statements about nationwide psychiatric morbidity and also about regional and socio-demographic variation. However, the ability of such surveys to fulfil the latter function (examine regional and socio-demographic variation) is much more limited than is generally acknowledged. A 'one size fits all' construct of urban and rural focusing on location rather than place can only answer the quantity not quality question. Furthermore, the presentation of findings in aggregated de-identified form means any intra-area differences will be averaged out and disparate towns and cities grouped together, so providing little or no information on patterns of illness in either rural or urban areas [43].

The 1990 US national comorbidity survey (NCS) included 8098 subjects aged 15 to 54 years to form a probability sample of 48 contiguous states [44]. Urbanicity was examined at the county level by distinguishing major metropolitan counties (major metropolitan areas), urbanized counties that are not in the major metropolitan areas (other urban areas) and rural counties (rural). The effects of urbanicity at county level were generally not significant. The one exception noted was that residents of major metropolitan counties were more likely than residents of rural counties to have comorbidity in the 12 months before interview. This pattern was thought to reflect a low rate of comorbidity in rural America rather than a high rate in major metropolitan counties.

The 1993 UK Household Survey of the national morbidity survey of Great Britain used a postcode address file sampling frame to identify adults 16 to 64 years old living in all the areas of England, Scotland and Wales except the highlands and islands of Scotland [45]. In total, 9777 subjects were interviewed. High prevalence disorders were assessed using the Revised Clinical Interview Schedule (CIS-R) [46] leading to ICD-10 [47]

Table 4. *National household surveys*

	Total number	Definition of rural/urban status	Diagnostic process
National comorbidity survey – Kessler *et al.*, 1994 [44]	8098 15–54-year-olds	Used large metropolitan statistical areas (MSA), small MSA and Not MSA classification of US Bureau of the Census – major metropolitan areas, other urban areas, rural counties	CIDI/DSM-III–R disorders
National survey of mental health and wellbeing 1997 [55]	10 601 18–99-year-olds	Rural centres (pop. 10 000–100 000) n = 1562 Remote areas (pop. < 10 000) n = 1942 Urban areas (pop. > 100 000) n = 7137	CIDI/ICD-10 disorders
Household Survey of National Morbidity Survey of Great Britain – Paykel *et al.*, 2000 [45]	9777 16–64-year-olds	Interviewer coded the area around the home as urban (n = 6416), semirural (n = 2324) or rural (n = 1008) based on their own judgements	CIS-R/ICD-10 neurotic disorders Drug & alcohol dependence

CIDI, Computerized international diagnostic instrument [44]; CIS-R, revised clinical interview schedule [46].

diagnostic categories, and questions about alcohol and drug misuse and dependence using quantity/frequency questions from the regular national surveys of alcohol and tobacco consumption. Those scoring greater than or equal to 12 on the CIS-R were regarding as suffering from a neurotic disorder while alcohol and drug dependence was defined according to responses to questions on quantity/frequency of use. Higher rates of psychiatric morbidity (CIS-R score ≥ 12), and alcohol dependence and drug dependence, were found in urban compared to rural areas; semirural areas were generally intermediate (Table 5).

Despite including a large sample, the study treated each of the three diagnostic categories as independent of one another. Logistic regressions were run for each diagnostic category, ignoring likely comorbidity. Naturally, an individual may have been positive for one, two or three of the categories. Predictor sets may well have had different power according to the number as well as type of category endorsed.

The authors looked at main effects and also at simple two–way interactions with rurality in predicting diagnostic category, but they failed to look at three-way or more complex interaction terms. Such complex interactions could potentially be more predictive of diagnostic category. For example, a young, poorly educated and unemployed male living in a rural area is likely be at much more risk of a mental disorder than an older financially secure married male who has moved to the country to grow grapes.

The 1997 Australian national survey of mental health and wellbeing surveyed adults aged 18 to 99 years who were identified in a cluster sample of households selected so the result would be representative of the entire Australian population [48]. No urban/rural differences were found for affective disorders, anxiety disorders, alcohol or drug dependence [49]. There was, however, a gender–urbanicity interaction: for males, the rate of mental disorder (sum of anxiety, affective and

Table 5. *National morbidity survey of great britain: prevalence of disorder by urban–rural residence [45]*

	Urban n = 6416	Semi-Rural n = 2324	Rural n = 1,008
Disorder	% (n)	%(n)	%(n)
CIS-$R \geq 12$	16.0 (1024)	12.0 (279)	9.6 (97)
Alcohol dependence	5.5 (354)	3.9 (90)	3.5 (35)
Drug dependence	2.6 (164)	1.6 (37)	0.9 (9)

substance use disorders) was slightly greater for those living in capital cities (17.5% *vs* 17.1%) while for females the rate was greater for those living outside capital cities (18.9% *vs* 17.5%). It is to be hoped that further fine-grained analyses of this comprehensive data set are forthcoming.

Each of these surveys aimed to answer three primary questions: how prevalent are mental disorders; how disabling are these disorders; and which health services are used? Thus it is perhaps not surprising, albeit disappointing, that only one of these studies has published a detailed analysis of possible urban/rural difference [45]. In the UK survey, urban subjects, when compared to rural subjects, were significantly younger, not currently married, of lower social class, non-white, less well-educated, living in flats or non-detached houses – a lower proportion of which were owned outright. Semi-rural subjects tended to be intermediate. The proportion of subjects employed full time was similar in rural and urban areas, but overall employment was higher in rural areas due to more part-time work. Urban residents were more likely to have experienced a stressful life event in the last year, to perceive themselves as lacking in support, and to have a small primary support group.

When these social differences were taken into account, the urban/rural differences in psychiatric morbidity, alcohol and drug dependence were reduced, and those with alcohol and drug dependence were no longer significant. The relationship between psychiatric morbidity (CIS-R ≥ 12) and urban/rural residence was examined by logistic regressions to determine the extent to which it was due to the social differences between urban and rural settings. In a logistic regression using urban/rural residence alone, the effect was highly significant overall with odds ratios (OR) for urban residents compared to rural of 1.63 ($p < 0.001$) and for semirural compared with rural of 1.22 (NS). Pairwise analyses conducted using two independent variables, area of residence and one other social or demographic factor in turn (age, sex, employment status, any life event in the last year, primary support group size, perceived level of social support, tenure of housing, social class, educational level, ethnicity, accommodation type, marital status) revealed the relationship with the area of residence was largely unaffected by any of these. A multiple logistic regression analysis incorporating all the independent variables entered simultaneously, reduced the effect of area of residence but it remained significant ($p < 0.05$). The strongest independent effect was due to occurrence of any life event in the last year (OR 2.50, $p < 0.001$), followed by size of primary support group, sex, marital status, perceived social support and employment status.

Similar analyses were conducted for alcohol and drug dependence. For alcohol there was a significant effect of area of residence analysed alone (OR 1.6, $p < 0.02$ for urban *vs.* rural, 1.06 NS for semirural *vs.* rural). In the multiple logistic regression analysis employing all the independent variables the effect of urban/rural residence was not significant. The highest relationships with alcohol dependence were for sex, age, marital status and life events. Findings for drug dependence were similar. There was a significant effect for area of residence (OR 2.31, $p < 0.05$ for urban versus rural, 1.31 NS for semirural *vs* rural). In the multiple logistic regression employing all independent variables, the effect of area of residence fell below significance. The highest relationships were with age, life events, marital status, unemployment and sex.

In summary, two of the three national household surveys found few differences in prevalence rates between urban and rural residents, while the third (the UK survey) found higher rates of disorder in urban areas. Importantly however, none of the studies were specifically constructed to investigate rural/urban differences. Of note, urban residents in the UK survey were younger, not currently married, of lower social class, less well-educated, more often had experienced a stressful life event and felt less supported. When these factors were taken into account statistically, urban-rural differences remained only for neurotic disorder. However, statistical models are unlikely to be able to unravel and account for the contagion of stressors which may coalesce to produce psychiatric disorder, leaving the question of whether place of residence or sociodemographic factors truly accounted for urban/rural differences unanswered.

Discussion

Contrary to popular belief that urban living is a risk factor for psychiatric disorder, there appears to be limited data to support the popular view that 'high prevalence' disorders are more common in urban residents. Studies examining possible urban/rural differences in prevalence suggest other factors are more powerful than location of residence. These include poverty, unemployment, being female, not being married [33], lower socio-economic class, women who were separated or never married, self-related alcohol problems, history of childhood sexual abuse, poor social networks [34], life event in previous 12 months, size of primary support group, marital status, low perceived social support, employment status, and sex [45].

The failure to demonstrate a difference in prevalence of disorder between urban and rural settings should not be a surprise. The reliance on rural or urban as units of analysis can have the effect of averaging out differences between communities which are likely to be highly variable, and obscure the localization of factors possibly contributing to mental ill health such as poverty, deprivation [43] and a variety of health-promoting and health-damaging behaviours.

Studying the prevalence of disorder in rural versus urban environments is of interest; urban or rural residence is an obvious social characteristic to consider as a risk factor for psychiatric morbidity and assessing the 'quantity' question is an important first step. However, the more important and informative question is what is the nature of any differences or what issues are specific to, or especially important in, the rural setting? One set of variables will most likely relate to place, and in evaluating these, heterogeneity within urban and rural settings must be recognized – one size does not fit all. In addition, individual differences between people need to be taken into account. This interaction will be further compounded by the presence or absence of more specific risk factors such as traumatic life events, substance misuse, stress and significant life changes. These interactions are likely to occur in both rural and urban settings.

Is there a need to further examine urban/rural differences in high prevalence disorders? We believe there is, but that the question asked should be – which factors operative in each environment are likely to be important in the development of psychiatric disorder and to be somewhat unique to that environment? Thus, further studies of prevalence need to go beyond the crude variable of 'rural' or 'urban' and to examine both settings at a more micro level. Rather than simply comparing urban and rural, studies should be directed to identifying particular groups in both settings whose risk of illness is increased. It is likely that the within-group differences will exceed the 'averaged out' differences between a 'one size fits all' view of rural versus urban location.

Studies conducted to date have essentially treated risk factors as main effects. In no case did any one study examine more than two-way interactions. Clinicians are very aware than there are a variety of risk factors that interact synergistically to contribute to the development of disorder(s) in any one individual. Future studies need to more closely mirror the real situation with respect to patients in need of care and take into account a variety of individual- and community-based risk factors. Also, given that comorbidity is the rule not the exception, future studies also need to take into account in their data analyses the fact that a person may meet criteria for more than one diagnosis.

What benefits will flow from such studies? Understanding how rural or urban place contributes to the development of psychiatric morbidity has obvious implications for efforts directed towards prevention and early intervention approaches. While the effect of 'rurality' on prevalence of mental illness is unclear, there is clear evidence that residence in a rural location significantly influences people's behaviour with respect to how they address their needs for health care services [50,51]. Accurate data regarding prevalence and the factors contributing to this are required to inform service delivery, and to identify the groups of people with the greatest need for treatment. Obtaining such data should be a priority for researchers, policy makers and clinicians in terms of both risk factors for mental illness and access to care.

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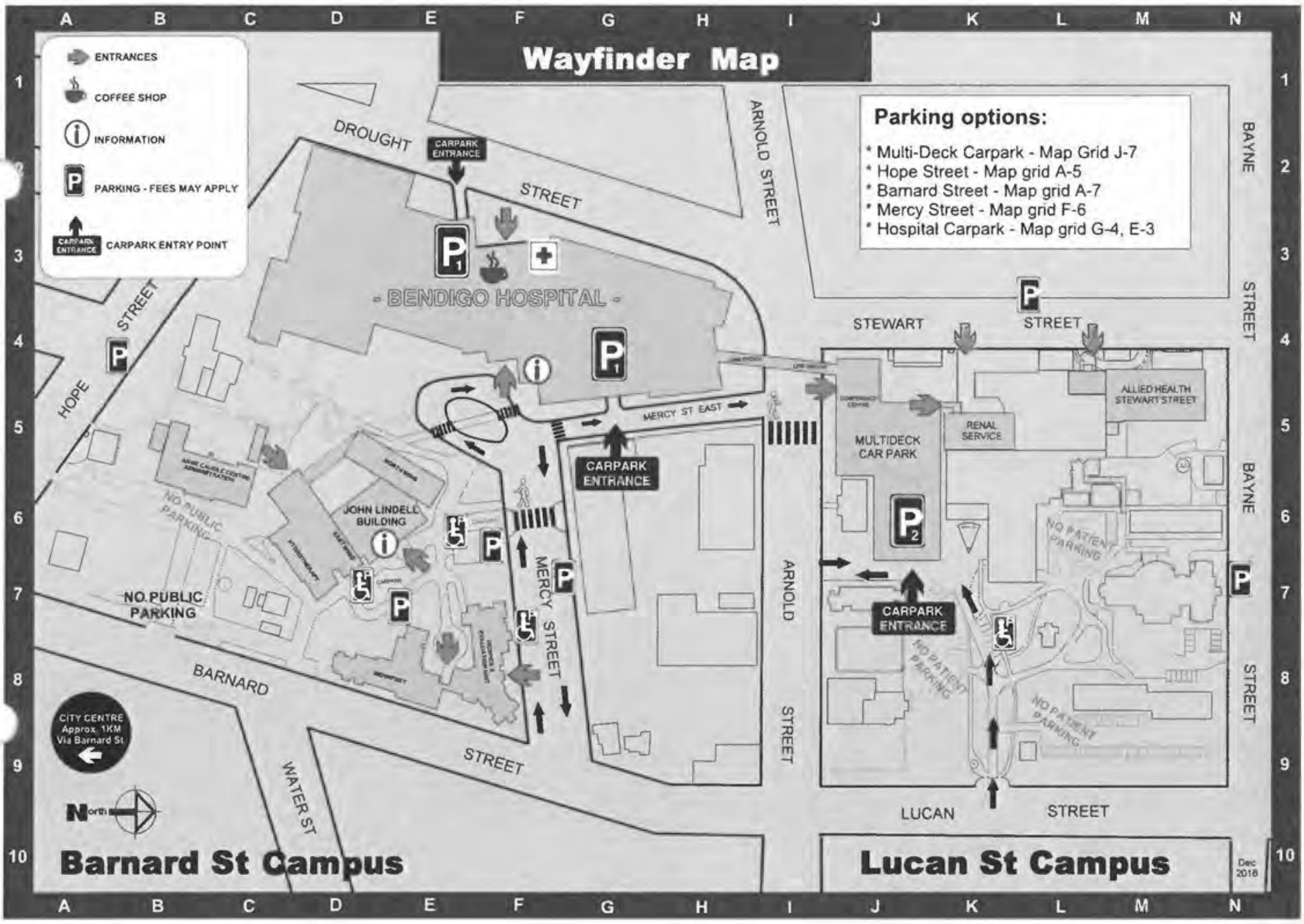

Wayfinder Map

Parking options:

- * Multi-Deck Carpark - Map Grid J-7
- * Hope Street - Map grid A-5
- * Barnard Street - Map grid A-7
- * Mercy Street - Map grid F-6
- * Hospital Carpark - Map grid G-4, E-3

ATTACHMENT RB-22

This is the attachment marked '**RB-22**' referred to in the witness statement of Dr Ravi Subramanya Bhat dated 4 July 2019.

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Suicidal behaviour in Indigenous compared to non-Indigenous males in urban and regional Australia: Prevalence data suggest disparities increase across age groups

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Abstract

Objectives: We compare the prevalence of suicidal thoughts and attempts between Indigenous and non-Indigenous males in urban and regional Australia, and examine the extent to which any disparity between Indigenous and non-Indigenous males varies across age groups.

Methods: We used data from the baseline wave of The Australian Longitudinal Study on Male Health (Ten to Men), a large-scale cohort study of Australian males aged 10–55 years residing in urban and regional areas. Indigenous identification was determined through participants self-reporting as Aboriginal, Torres Strait Islander or both. The survey collected data on suicidal thoughts in the preceding 2 weeks and lifetime suicide attempts.

Results: A total of 432 participants (2.7%) identified as Indigenous and 15,425 as non-Indigenous (97.3%). Indigenous males were twice as likely as non-Indigenous males to report recent suicidal thoughts (17.6% vs 9.4%; odds ratio = 2.1, $p < 0.001$) and more than three times as likely to report a suicide attempt in their lifetime (17.0% vs 5.1%; odds ratio = 3.6; $p < 0.001$). The prevalence of recent suicidal thoughts did not differ between Indigenous and non-Indigenous males in younger age groups, but a significant gap emerged among men aged 30–39 years and was largest among men aged 40–55 years. Similarly, the prevalence of lifetime suicide attempts did not differ between Indigenous and non-Indigenous males in the 14- to 17-years age group, but a disparity emerged in the 18- to 24-years age group and was even larger among males aged 25 years and older.

Conclusion: Our paper presents unique data on suicidal thoughts and attempts among a broad age range of Indigenous and non-Indigenous males. The disparity in the prevalence of suicidal thoughts increased across age groups, which is in contrast to the large disparity between the Indigenous and non-Indigenous suicide rates in younger age groups.

Keywords
Indigenous, Australia, prevalence, suicidal ideation, suicide attempt

Background

High rates of Indigenous suicide is a distressing phenomenon that plagues several postcolonial countries, including Australia, Canada, the United States and New Zealand (Leenaars et al., 2007; McLoughlin et al., 2015). Suicide among Indigenous peoples is a complex socio-cultural, political, biological and psychological phenomenon that needs to be understood in the context of colonisation, loss of land and culture, trans-generational trauma, grief and loss and racism and discrimination (Coupe, 2000; Elias

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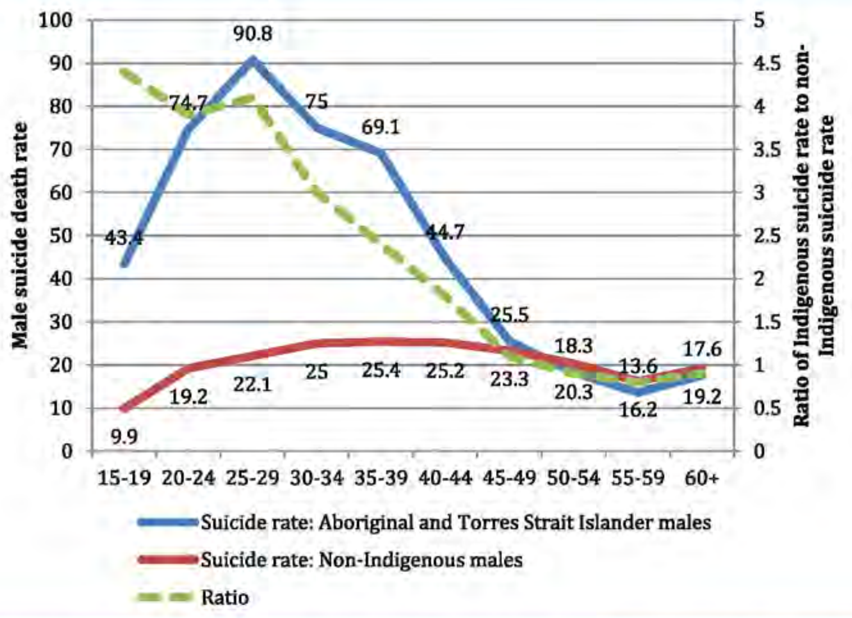

Figure 1. Comparison of age-specific suicide rates of males from five Australian states, by Indigenous identification.

Source: Australian Bureau of Statistics, Aboriginal and Torres Strait Islander Suicide Deaths in New South Wales, Queensland, South Australia, Northern Territory and Western Australia, 2001–2010, www.abs.gov.au/ausstats/abs@.nsf/Products/3309.0~2010~Chapter~Aboriginal+and+Torres+Strait+Islander+suicide+deaths?OpenDocument.

The Australian Bureau of Statistics only presented the above data for these five states as this is where the Indigenous identification in mortality data was considered acceptable.

et al., 2012; Hunter and Harvey, 2002). The higher levels of marginalisation and social disadvantage experienced by Indigenous peoples increases their exposure to mental disorders, substance abuse and a suite of chronically stressful life events, e.g., unemployment, homelessness, incarceration and family breakdown, all of which are well-documented suicide risk factors (Barlow et al., 2012; Cwik et al., 2015; Elliott-Farrelly, 2004; Gracey and King, 2009; Hawton and Van Heeringen, 2009; King et al., 2009).

In Australia, suicide is a leading cause of mortality for Indigenous people, and this is particularly the case for Indigenous males among whom suicide is the second leading cause of death (Australian Bureau of Statistics, 2016a). Indigenous suicide prevention has become a major theme of the Close the Gap Campaign, given that premature mortality from suicide is a major contributor to the life expectancy gap between Indigenous and non-Indigenous Australians (Holland, 2015). The suicide rate for Indigenous males was estimated to be 34.1 per 100,000 in 2014, twice the rate (17.7 per 100,000) for non-Indigenous males (Australian Bureau of Statistics, 2016a). Figure 1 provides a useful visual overview of the disparity between the Indigenous and non-Indigenous suicide rates across age groups, and was the primary motivator behind the concept of this paper. The Indigenous suicide rate is highest among younger males aged 25–29 years at 90.8 per 100,000, compared to 22.1 per 100,000 among their non-Indigenous peers (Australian Bureau of Statistics, 2016c) – a fourfold difference. These figures underscore a striking disparity in suicide rates between Indigenous and non-Indigenous males in younger cohorts; among males aged 15–34 years, the Indigenous suicide rate is approximately four times the non-Indigenous rate, and it remains two-and-a-half to three-and-a-half times the non-Indigenous rate among those aged 35–44 years. Meanwhile, among males aged 45 years and older, there appears to be no or minimal disparity in suicide rates by Indigenous identification.

While there is evidence about the disparity in suicide rates between Indigenous and non-Indigenous males, there is a dearth of data related to suicidal thoughts and attempts among Indigenous men across a broader range of age groups. Regional cross-sectional studies have predominantly been undertaken among youth and have observed a high prevalence of suicidal thoughts and attempts. These studies have used a wide variety of measures and have targeted different population groups making comparisons difficult. For example, a study of male and female Indigenous youth aged 12–26 years who were affiliated with the Victorian Aboriginal Health Service reported a prevalence of 23.3% for suicidal thoughts in the preceding 2 weeks, and 24.4% had attempted suicide in their lifetime, with no statistically significant difference across genders (Luke et al., 2013). The Western Australian Aboriginal Child Health Survey of 12- to 17-year-olds from Perth and rural

Western Australia reported a prevalence of 15.6% (males 11.9%, females 19.5%) for suicidal thoughts and 6.5% (males 4.1%, females 9.0%) for suicide attempts in the 12 months prior to the survey (Zubrick et al., 2005). Additionally, there have been surveys of suicidal thoughts and/or attempts among predominantly male Indigenous offenders in a variety of locations (Butler et al., 2007; Larney et al., 2012; Sawyer et al., 2010; Stathis et al., 2012), although it is difficult to generalise the findings from these studies beyond custody/detention settings.

Notwithstanding these studies, much remains unknown about the prevalence of suicidal thoughts and attempts across a broader age range of Indigenous men in general community settings throughout Australia. This paper contributes to addressing this gap by analysing data collected for the Ten to Men study of the health of boys and men aged 10–55 years from urban and regional Australia, with analyses of differences in suicidal thoughts and attempts between sub-samples of Indigenous and non-Indigenous males. The objectives of our analyses were (1) to compare the prevalence of suicidal thoughts and attempts between Indigenous and non-Indigenous males in the Ten to Men sample and (2) to examine the extent to which any disparity between Indigenous and non-Indigenous males varies across age groups.

Methodology

Data source

We used data from The Australian Longitudinal Study on Male Health (Ten to Men), a large-scale cohort study of Australian males aged 10–55 years. Ten to Men is a longitudinal study and our paper presents analyses of cross-sectional data collected in 2013–2014 for the baseline wave. Full details of the study design and methods are available elsewhere (Currier et al., 2016; Pirkis et al., 2016). In brief, multi-stage stratified cluster sampling was used to recruit Australian boys and men from households in Australian Statistical Geographical Standard (ASGS) major city, inner regional and outer regional areas of Australia. Due to resource limitations and operational considerations, remote and very remote areas were excluded. Because it was not possible to include males from remote areas, it was decided to over-sample males from regional areas. A total of 104,484 households were approached in 2013 and 2014, from which 15,988 Australian males were recruited, resulting in a response fraction of 35% among confirmed in-scope males.

Eligible participants were males aged 10–55 years at the time of recruitment, who were Australian citizens or permanent residents and had a sufficient understanding of English to provide informed consent and to complete the questionnaire. The questionnaire for young men aged 15–17 years and the questionnaire for adults aged 18–55 years were self-administered, while the questionnaire for boys aged 10–14 years was completed using a computer-assisted personal interview. The questionnaires captured information about suicidal thoughts and attempts, as well as other information about physical and mental health, health-related behaviours, social and environmental determinants of health, health literacy and health service use. Copies of the questionnaires are available at the study website www.tentomen.org.au.

The baseline wave of Ten to Men received ethical clearance from the University of Melbourne Human Sciences Human Ethics Sub-Committee (HREC 1237897 and 1237376). Participants aged 18–55 years provided written consent; participants aged 10–17 years provided written assent and a parent/guardian provided written, parental consent.

Measures

The prevalence of recent suicidal thoughts was assessed using Item 9 of the Patient Health Questionnaire-9 (PHQ-9) Brief Depression Severity Measure for adults and the PHQ-9 Modified for Teens (Kroenke et al., 2001; Richardson et al., 2010). Item 9 asks participants how often they had been bothered by '*thoughts you would be better off dead or of hurting yourself in some way*' in the preceding 2 weeks. Participants who responded '*several days*', '*more than half the days*' and '*nearly every day*' were collapsed into one category in a dichotomous variable and compared against those who responded '*not at all*'. This variable has been observed to be associated with a 75%–185% increase in the risk of suicide in a study of veterans in the United States (Louzon et al., 2016). The lifetime prevalence of suicide attempt(s) was assessed by asking participants aged 14 or older whether they had ever tried to kill themselves; participants aged 10–13 years were not asked this question. Both measures of suicidality have previously been used in a survey of Indigenous youth in Australia (Luke et al., 2013).

Indigenous identification was determined through participants self-reporting as Aboriginal, Torres Strait Islander or both. Participants were excluded from our analyses if they refused or did not answer the question ($n = 117$), if they answered that they '*don't know*' ($n = 13$) or if they gave an invalid multiple response ($n = 1$).

Statistical analyses

All analyses were conducted in Stata version 13.0 using survey commands to account for the complex sampling design (Spittal et al., 2016). Sampling weights were also used to account for unequal probability of selection, and these were calculated based on the inverse of the probability of selection at the level of the individual participant (Spittal et al., 2016). Both unweighted and weighted

Table 1. Sample characteristics, by Indigenous identification.

	Aboriginal or Torres Strait Islander (n = 432)	Non-Indigenous (n = 15,425)	
	% (n)[a]	% (n)[a]	p-value[b]
Age (years)			<0.001
10–17	24.0 (103)	12.9 (1971)	
18–24	17.5 (75)	12.5 (1911)	
25–29	12.8 (55)	8.8 (1348)	
30–39	18.2 (78)	23.2 (3564)	
40–55	27.5 (118)	42.7 (6548)	
State			<0.001
ACT	1.2 (5)	1.2 (187)	
NSW	38.2 (165)	27.7 (4275)	
NT	1.9 (8)	0.5 (78)	
QLD	34.5 (149)	20.8 (3204)	
SA	2.1 (9)	5.3 (814)	
TAS	5.3 (23)	1.5 (229)	
VIC	9.0 (39)	31.2 (4811)	
WA	7.9 (34)	11.8 (1821)	
Remoteness			<0.001
Major cities	35.0 (151)	58.4 (8997)	
Inner regional	29.9 (129)	22.5 (3465)	
Outer regional	35.2 (152)	19.2 (2957)	

ACT: Australian Capital Territory; NSW: New South Wales; NT: Northern Territory; QLD: Queensland; SA: South Australia; TAS: Tasmania; VIC: Victoria; WA: Western Australia.

[a] Sample characteristics without adjustment for the complex sampling design.

[b] Chi-square test of difference between Indigenous and non-Indigenous sub-samples across age, state and remoteness categories.

percentages were generated to describe the Indigenous and non-Indigenous sub-samples across age, state and remoteness categories, with chi-square tests used to examine differences between the two sub-samples. Adjusted estimates of the prevalence of suicidal thoughts and attempts within the Indigenous and non-Indigenous sub-samples were generated with 95% confidence intervals, both across all age groups and within age groups. Logistic regression analyses were used to generate the odds of Indigenous males experiencing suicidal thoughts and attempts compared to non-Indigenous males. These analyses were conducted both across all age groups and within age groups; analyses across all age groups adjusted for age and remoteness, while analyses within age groups adjusted for remoteness.

Results

Sample characteristics

The sample size for our analyses was 15,857 men, among whom 432 (2.7%) identified as Aboriginal (n = 379), Torres Strait Islander (n = 27) or both (n = 26); and 15,425 (97.3%) identified as non-Indigenous. The characteristics of the Indigenous and non-Indigenous sub-samples differed significantly across age, state and remoteness categories (see Table 1). Compared to non-Indigenous participants, the Indigenous sub-sample had a higher proportion of younger males, with approximately one-quarter (24.0%) between the ages of 10 and 17 years (cf. 12.9% among non-Indigenous males). There was a lower proportion of Indigenous males than non-Indigenous males from major cities (35.0% vs 58.4%) and a higher proportion from outer regional areas (35.2% vs 19.2%). There was also some variation by state, with higher proportions of Indigenous males than non-Indigenous males from New South Wales (38.2% vs 27.7%) and Queensland (34.5% vs 20.8%), and a considerably lower proportion from Victoria (9.0% vs 31.2%). The majority of participants in both the Indigenous (88.2%) and non-Indigenous (82.4%) sub-samples resided in eastern Australia (Queensland, New South Wales, Victoria, Australian Capital Territory or Tasmania).

Table 2. Two-week prevalence of suicidal thoughts and lifetime prevalence of suicide attempt(s) by Indigenous identification, both across age groups and within age groups.

	Aboriginal or Torres Strait Islander % (95% CI)	Non-Indigenous % (95% CI)	Unadjusted odds ratio[a] (95% CI), p-value	Adjusted odds ratio[b] (95% CI), p-value
Two-week prevalence of suicidal thoughts				
10–17 years	9.11 [4.6, 17.4]	9.0 [6.9, 11.8]	1.0 [0.5, 2.3], $p=0.982$	1.0 [0.4, 2.3], $p=0.994$
18–24 years	10.8 [4.7, 22.9]	11.4 [9.7, 13.5]	0.9 [0.4, 2.3], $p=0.889$	0.9 [0.4, 2.4], $p=0.877$
25–29 years	20.2 [7.8, 43.1]	10.5 [8.6, 12.8]	2.1 [0.7, 6.6], $p=0.182$	2.2 [0.7, 7.1], $p=0.194$
30–39 years	19.3 [10.7, 32.2]	8.3 [7.0, 9.7]	2.6 [1.3, 5.4], $p=0.007$	2.4 [1.2, 4.8], $p=0.014$
40–55 years	28.7 [18.4, 41.8]	9.2 [8.2, 10.3]	4.0 [2.2, 7.3], $p<0.000$	4.1 [2.3, 7.2], $p<0.001$
All ages combined	17.6 [12.9, 23.5]	9.4 [8.7, 10.2]	2.1 [1.4, 3.0], $p<0.001$	2.1 [1.4, 3.0], $p<0.001$
Lifetime prevalence of suicide attempts				
14–17 years[c]	3.4 [0.7, 14.7]	3.6 [2.4, 5.3]	0.9 [0.2, 4.9], $p=0.945$	0.9 [0.2, 4.4], $p=0.862$
18–24 years	14.7 [8.0, 25.6]	6.3 [5.0, 7.9]	2.6 [1.2, 5.3], $p=0.012$	2.5 [1.2, 5.2], $p=0.014$
25–29 years	21.7 [9.9, 41.3]	5.9 [4.2, 8.3]	4.4 [1.6, 11.9], $p=0.004$	4.9 [1.7, 14.3], $p=0.004$
30–39 years	22.0 [12.5, 35.9]	4.8 [4.0, 5.8]	5.5 [2.7, 11.4], $p<0.001$	4.8 [2.3, 10.0], $p<0.001$
40–55 years	18.0 [11.5, 27.2]	5.1 [4.3, 5.9]	4.1 [2.4, 7.2], $p<0.001$	4.1 [2.3, 7.1], $p<0.001$
All ages combined	17.0 [12.7, 22.4]	5.1 [4.6, 5.7]	3.8 [2.6, 5.5], $p<0.001$	3.6 [2.5, 5.2], $p<0.001$

CI: confidence interval.

[a] Binary logistic regression analyses were used to generate the odds of Indigenous males experiencing suicidal thoughts and attempts compared to non-Indigenous males. Reference category is non-Indigenous.

[b] Adjusted for age and remoteness for analysis across all ages combined. Adjusted for remoteness for analysis within age groups.

[c] Boys aged 10–13 years were not asked if they had a history of attempting suicide.

Disparity in the prevalence of recent suicidal thoughts and lifetime attempts

Table 2 shows the disparity in the prevalence of suicidal thoughts and attempts between Indigenous and non-Indigenous males. Indigenous males were twice as likely to report recent suicidal thoughts (17.6% vs 9.4%; odds ratio [OR]=2.1, $p<0.001$) and more than three times as likely to report a suicide attempt in their lifetime (17.0% vs 5.1%; OR=3.6; $p<0.001$), adjusting for age and remoteness.

The pattern of disparity across age groups

Table 2 also shows the pattern of disparity across age groups. The disparity between Indigenous and non-Indigenous males in recent suicidal thoughts trended upwards across age groups. The prevalence of recent suicidal thoughts did not differ between Indigenous and non-Indigenous males in the 10–17 years or 18–24-years age groups. Although the difference wasn't significant, the beginning of a disparity between Indigenous and non-Indigenous males emerged in the 25- to 29-years age group (20.2 vs 10.5%; OR=2.1, $p=0.182$); this age group had the smallest number of Indigenous males ($n=55$), which may have reduced the power to detect differences between these subsamples. There was strong evidence of a difference among those aged 30–39 years (19.3% vs 8.3%; OR=2.6, $p=0.007$), and among those aged 40–55 years (28.7% vs 9.2%; OR=4.0, $p<0.001$).

The lifetime prevalence of suicide attempts did not differ between Indigenous and non-Indigenous males in the 14–17 years age group (3.4% vs 3.6%; OR=0.9, $p=0.862$). However, there was evidence of a disparity in the 18–24 years age group (14.7% vs 6.3%; OR=2.5, $p=0.014$). In the age groups 25–29 years, 30–39 years and 45–50 years, approximately one in five Indigenous males had ever attempted suicide, and they had odds that were 4.4, 5.5 and 4.1 times higher for ever attempted suicide respectively compared to their non-Indigenous counterparts within the same age groups.

Discussion

We found that, in urban and regional Australia, the prevalence of recent suicidal thoughts and having ever attempted suicide was substantially higher among Indigenous males compared to non-Indigenous males. This is extremely concerning, yet the findings from our analyses of the Ten to Men sample are consistent with what is already known about the gap in suicide rates between Indigenous and non-Indigenous males, with suicide rates being twice as high among Indigenous males (Australian Bureau of Statistics, 2016a; De Leo et al., 2011; Snowdon, 2016).

While there was no disparity in the lifetime prevalence of a suicide attempt between Indigenous and non-Indigenous males aged 14–17 years (3.4% vs 3.6%), there was a disconcertingly higher proportion of young Indigenous males aged 18–24 years who had attempted suicide (14.6%) compared to non-Indigenous males (6.3%). This disparity was even larger among males aged 25–29 years. This indicates an immediate rise in the risk of suicide for young Indigenous males as they enter adulthood, which is consistent with the peak in Indigenous suicide rates among males in this age group (see Figure 1). Of further concern, those Indigenous males who have attempted suicide at this young age will be carrying a lifelong suicide risk factor into their adult years, given that a history of attempting suicide has consistently been identified as a predictor of future suicide attempts and deaths (Cavanagh et al., 2003; Hawton and Van Heeringen, 2009; Ribeiro et al., 2016).

There was a noteworthy age pattern in the disparity between Indigenous and non-Indigenous males with respect to the prevalence of recent suicidal thoughts. There was no disparity in younger age groups of males aged 10–24 years, and a non-significant gap among males aged 25–29 years. However, among those aged 30–39 years, there was a marked and statistically significant disparity that was even larger in the 40–55 years age group. A key feature of this disparity was that the prevalence of recent suicidal thoughts increased across age groups among Indigenous males, while it remained relatively flat across age groups among non-Indigenous males. Interestingly, this is consistent with a review of findings from community mental health surveys (Jorm et al., 2012). Across seven studies, Indigenous adults were consistently found to have a higher prevalence of self-reported psychological distress than non-Indigenous adults, while two surveys of adolescents found no similar disparity.

This trend is curiously different from the age pattern for the ratio of the Indigenous suicide rate compared to the non-Indigenous suicide rate, where there is a high level of disparity observed in the younger age groups which then trends towards parity among middle-aged males (see Figure 1). One might have expected to find that the disparity in suicidal thoughts across age groups in our sample would follow this pattern, but it trends in the opposite direction and moves from parity at younger ages to disparity at older ages.

There are a number of aetiological and methodological reasons why these two suicide indicators may not match neatly. First, suicide deaths and suicidal thoughts are related yet still quite different phenomena. While suicidal thoughts may be a necessary antecedent to a suicide death, not all people who have suicidal thoughts will attempt or die by suicide (Ribeiro et al., 2016). Second, the data presented in Figure 1 refer to suicide deaths between 2001 and 2010, which is a considerably different time period to the 2013–2014 sample being studied in this paper. Third, our sample was collected in urban and regional areas, whereas the suicide death data also represent deaths in remote areas. This is relevant given that approximately one in five Indigenous people reside in remote areas and the Indigenous suicide death rate in some remote areas is very high and has a prominent youth profile; e.g., 68% of suicide deaths in the high-suicide Kimberley region between 2005–2014 were under the age of 30 (McHugh et al., 2016). Further to this point, the data in Figure 1 refer to suicide deaths in only five states and territories where Indigenous identification in mortality data was considered to be acceptable: New South Wales, Queensland, South Australia, Northern Territory and Western Australia. However, our sample is under-represented in terms of Indigenous males from the Northern Territory, Western Australia and South Australia (Australian Bureau of Statistics, 2016b), and these states have the highest Indigenous suicide rates (Australian Bureau of Statistics, 2016c). Thus, the data we have presented are primarily representative of Indigenous males from regional and urban areas in eastern Australia and we ought not to generalise beyond this.

Another part of the explanation may lie in the high number of suicide deceased persons whose Indigenous identification is classified as ‘unknown’, which could impede accurate estimates of the Indigenous suicide rate across age groups. An examination of data from the National Coronial Information System (NCIS) revealed that, in older age groups compared to younger age groups, there is a marked increase in the proportion of deaths with an unknown Indigenous status relative to those classified as Indigenous (see Supplementary File 1) (NCIS, 2016). If a percentage of those with unknown Indigenous identification is actually Indigenous people, then we are potentially more severely underestimating the Indigenous suicide rate in older age groups than in younger age groups. However, even if this were the case, it is unlikely that the suicide rate for older Indigenous males would rise to the same heights as the rate for younger Indigenous males.

Notwithstanding these aetiological and methodological considerations, the divergent trends across age groups for suicide deaths and suicidal thoughts raise some pertinent questions. In some ways, the features of the divergent trends we have observed are somewhat similar to ‘*the gender paradox of suicidal behaviour*’ (Canetto and Sakinofsky, 1998); in many countries, females have higher rates of suicidal ideation and behaviour than males, while mortality from suicide is typically lower for females than males. Our observation raises the possibility that a similar paradox exists among Indigenous males in Australia, in that older Indigenous males could have higher rates of suicidal ideation than younger Indigenous males, while mortality from suicide remains higher for younger Indigenous males. Aside from the use of more lethal suicide methods by males, several other hypotheses have been posited to explain the gender paradox, two of which may be relevant to the discussion of our observation (Canetto and Sakinofsky, 1998; Schrijvers et al., 2012).

First, it is posited that the duration of '*the suicidal process*' (i.e. the transition from suicidal thoughts to a suicide plan through to a suicide death), which can vary from many years to a few hours or even minutes, is shorter for men (Schrijvers et al., 2012). This means that, on average, men may have a quicker progression from suicidal thoughts to a suicide death than women, and thus have a shorter period of time for their suicidal thoughts to be detected by a suicide survey/assessment. Following this idea, our observation certainly raises the possibility that the suicidal process is shorter for younger Indigenous males than it is for older Indigenous males. Indigenous males in late adolescence and early adulthood are also going through a life stage where they are susceptible to a range of compounding risk factors for suicidality, e.g., early exposure to alcohol and other substance misuse and higher levels of aggression/violence, risk-taking and impulsivity (Bridge et al., 2006; McLoughlin et al., 2015), all of which may coalesce with suicidal thoughts to contribute to a substantial shortening of the suicidal process. It is also a life stage at which culture-based identity forming structures and social systems (e.g. cultural ceremonies, guidance from Elders) are important, yet these are less available to guide and help moderate Indigenous youth through this period than they once were (Procter, 2005). Importantly, we don't have data on how intense or determined the suicidal thoughts were for the participants. It may be that younger Indigenous males who do have suicidal thoughts tend to experience them in a more intense and resolute way that allows them to progress to a suicide attempt at a more rapid pace.

Second, '*cultural script theory*' posits that women and men will tend to adopt the self-destructive behaviours that are congruent with the gender scripts of their cultures, with attempting suicide ascribed a more feminine quality and killing oneself ascribed a more masculine quality in some cultural settings (Canetto and Sakinofsky, 1998). Without discussing the merits of this as it applies to the gender paradox, it is useful to contemplate that cultural narratives can influence the dynamics and frequency of individual suicides, in that individuals draw upon these cultural meanings in choosing their course of action. In this vein, it is possible that a particular cultural script may be present among some young Indigenous males who attempt or die by suicide, and that this script does not affect older Indigenous males. In the 1980s, Rubinstein undertook research on the newly emerging male youth suicide epidemic in Micronesia (Rubinstein, 1983). His findings suggested that, in one setting, a single suicide case had become a model for successive youth suicides. These youth suicides were typically characterised as spontaneous, unplanned and connected to seemingly minor situational triggers, predominantly relationship conflict with parents or girlfriends. He suggested that some male youth in this setting had developed a greater familiarity with, and acceptance of, the idea of suicide, and in some cases had expressed a sense of inevitability in relation to suicide. It was also noted that the youth suicide epidemic was occurring within the context of rapidly changing socio-cultural and intergenerational dynamics. Rubinstein's work signposted that cultural scripts around suicide may heighten the suicide contagion process and that they can affect, even temporarily, particular age groups. We should definitely be cautious in reasoning about suicide phenomena across unique culture groups; however, several aspects of his description of the youth suicide epidemic in Micronesia echo some features of the literature on Indigenous youth suicide in Australia. In particular, the concepts of suicide contagion and suicide clusters are similarly prominent in the Australian Indigenous suicide literature (Hanssens, 2008; Hunter and Harvey, 2002), and there are some reports raising concerns about the normalisation of suicide and suicidal behaviour in youth in some Indigenous communities (Select Committee on Youth Suicide in the Northern Territory, 2012). Our observation resonates with a previous suggestion that future research should explore the potential '*age cohort*' feature of suicide contagion in Indigenous communities (Hanssens, 2011).

Finally, the data also highlight some potentially positive findings. The prevalence of suicidal thoughts among younger Indigenous males was equivalent to the prevalence of suicidal thoughts among younger non-Indigenous males. That is, there was no gap at younger ages, and this is good news. Notwithstanding the nuances discussed above, it is thus possible that there could be a cohort effect, whereby the younger generation of Indigenous males in urban and regional areas is experiencing less suicidal thoughts than older generations of young Indigenous males. However, given that very high rates of Indigenous youth suicide in some locations continue to be reported, this may be wishful thinking (Campbell et al., 2016). There is another aspect of the findings that could be worth further consideration. If it holds true that older Indigenous males are less likely than younger Indigenous males to act on their suicidal thoughts, there may be value in examining the resilience and protective strategies deployed by older Indigenous males that support them in preventing their suicidal thoughts from translating into suicide attempts, and how these can best be shared with younger Indigenous males.

In any case, these are all queries that our data can only tentatively provoke, but cannot answer. As stated earlier, this paper is based on analyses of cross-sectional data collected for the baseline wave of the Ten to Men cohort study. The longitudinal nature of the Ten to Men study will mean that we may be able to explore this further with future waves of data.

Strengths and weaknesses

Our study has a number of strengths, most notably the large sample size and use of data collected from males in urban and regional settings across Australia. To the best of our knowledge, our analyses are the first to present data on suicidal thoughts and attempts among a nationwide sample of urban and regional Indigenous males in the general community encompassing a broad range of age groups.

Nonetheless, the data used for our analyses were collected for the baseline wave of the Ten to Men cohort study and, as such, were not designed to make these prevalence estimates. While the Ten to Men cohort study attempted to recruit as representative a sample as possible, there were various constraints. Thus, there are some limitations to the generalisability of the findings that should be taken into consideration. First, the Ten to Men study didn't have the resources to go to remote areas and, related to this, there is an under-representation of Indigenous males from the Northern Territory, Western Australia and South Australia. However, the Ten to Men study intentionally over-sampled men from regional areas, which appears to have helped in recruiting a larger sample of Indigenous males; 65.1% of the Indigenous sub-sample were from regional areas compared to 41.7% of the non-Indigenous sub-sample. Additionally, the total proportion of Indigenous males in the sample (2.7%) is roughly equivalent to the proportion of Indigenous males in the general population (3.0%) (Australian Bureau of Statistics, 2016b). Second, the survey was self-administered for males aged 15–55 years (with a computer-assisted personal interview for boys aged 10–14 years) and this could have prevented Indigenous males with poor literacy from taking part in the study. This could be an important source of sampling bias considering that the substantial gap in literacy measures between Indigenous and non-Indigenous people remains a major issue (Ford, 2012), and the prevalence of suicidal thoughts and attempts among less literate Indigenous males could be markedly different.

Third, Indigenous researchers and advocates are calling for a greater focus on the cultural context of suicide and strengths-based research that focuses on cultural resilience and culture-based protective factors (Department of Health and Ageing, 2013), as well as the development and evaluation of self-harm interventions that are led by Aboriginal and Torres Strait Islander communities (Carter et al., 2016). This also includes the evaluation of culturally appropriate interventions that are framed around the holistic concept of social and emotional wellbeing and the promotion of multiple protective factors (e.g. physical activity, employment opportunities, strengthening families and engaging young people in culture), not just screening and clinical treatment (Aboriginal and Torres Strait Islander Suicide Prevention Evaluation Project, 2016; Luke et al., 2013). Our epidemiological analyses of trends in the prevalence of suicidality across age groups are unable to illuminate on the cultural strengths that will be of benefit to upstream Indigenous suicide prevention, although we do present new prevalence data that can inform policy, programming and future research. Finally, the primary variable in our analyses (i.e. Indigenous status) is a dichotomous variable based on an Indigenous identification question. We recognise that while this categorisation has been useful for the objectives of our analyses, neither the Indigenous persons nor the non-Indigenous persons (comprising Caucasian, Asian and other ethnicities) categories represent a homogenous group of people. Moreover, research from Queensland highlights that the concentration of Indigenous suicide deaths varies considerably across different Indigenous communities at different time points, suggesting a degree of '*community risk*' that varies by time and location (Hunter and Harvey, 2002). Further studies in this area are required that disaggregate Indigenous suicide data across a range of socio-demographic, geographical and cultural resilience variables.

Conclusion

Our study of men from urban and regional Australia found a substantial disparity between Indigenous and non-Indigenous males with respect to the prevalence of recent suicidal thoughts and a history of having attempted suicide. There is a clear imperative to devote resources and further research to the area of Indigenous suicide prevention, with a view to increasing the availability of culturally appropriate and holistic suicide prevention supports that target Indigenous males of all ages.

Declaration of Conflicting Interests

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Supplementary materials

The survey data analysed for this manuscript are available on request at the following website: www.tentomen.org.au

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ATTACHMENT RB-23

This is the attachment marked '**RB-23**' referred to in the witness statement of Dr Ravi Subramanya Bhat dated 4 July 2019.

Refugee migration and risk of schizophrenia and other non-affective psychoses: cohort study of 1.3 million people in Sweden

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ABSTRACT

OBJECTIVE

To determine whether refugees are at elevated risk of schizophrenia and other non-affective psychotic disorders, relative to non-refugee migrants from similar regions of origin and the Swedish-born population.

DESIGN

Cohort study of people living in Sweden, born after 1 January 1984 and followed from their 14th birthday or arrival in Sweden, if later, until diagnosis of a non-affective psychotic disorder, emigration, death, or 31 December 2011.

SETTING

Linked Swedish national register data.

PARTICIPANTS

1 347 790 people, including people born in Sweden to two Swedish-born parents (1 191 004; 88.4%), refugees (24 123; 1.8%), and non-refugee migrants (132 663; 9.8%) from four major refugee generating regions: the Middle East and north Africa, sub-Saharan Africa, Asia, and Eastern Europe and Russia.

MAIN OUTCOME MEASURES

Cox regression analysis was used to estimate adjusted hazard ratios for non-affective psychotic disorders by refugee status and region of origin, controlling for age at risk, sex, disposable income, and population density.

RESULTS

3704 cases of non-affective psychotic disorder were identified during 8.9 million person years of follow-up. The crude incidence rate was 38.5 (95% confidence interval 37.2 to 39.9) per 100 000 person years in the Swedish-born population, 80.4 (72.7 to 88.9) per 100 000 person years in non-refugee migrants, and 126.4 (103.1 to 154.8) per 100 000 person years in refugees. Refugees were at increased risk of psychosis compared with both the Swedish-born population (adjusted hazard ratio 2.9, 95% confidence interval 2.3 to 3.6) and non-refugee migrants (1.7, 1.3 to 2.1) after adjustment for confounders. The increased rate in refugees compared with non-refugee migrants was more pronounced in men (likelihood ratio test for interaction χ^2 (df=2) z=13.5; P=0.001) and was present for refugees from all regions except sub-Saharan Africa. Both refugees and non-refugee migrants from sub-Saharan Africa had similarly high rates relative to the Swedish-born population.

CONCLUSIONS

Refugees face an increased risk of schizophrenia and other non-affective psychotic disorders compared with non-refugee migrants from similar regions of origin and the native-born Swedish population. Clinicians and health service planners in refugee receiving countries should be aware of a raised risk of psychosis in addition to other mental and physical health inequalities experienced by refugees.

WHAT IS ALREADY KNOWN ON THIS TOPIC

Immigrant populations are at elevated risk of schizophrenia and other non-affective psychotic disorders

Whether refugees have rates of these disorders over and above those typically observed in non-refugee immigrant groups is unclear

WHAT THIS STUDY ADDS

The incidence rate of a non-affective psychotic disorder was 66% higher among refugees than among non-refugee migrants from similar regions of origin, and nearly three times greater than in the native-born Swedish population

These patterns were apparent for men and women, although they were stronger in men

Refugees from all regions of origin had higher rates of psychotic disorder than non-refugee migrants, except for people from sub-Saharan Africa, for whom rates in both groups were similarly high relative to the Swedish-born population

Clinicians and health service planners should be aware of early signs of psychosis in vulnerable migrant populations, who may benefit from timely and early interventions

Introduction

Schizophrenia and other psychotic disorders lead to lifelong health and social adversities, culminating in a reduction in life expectancy of 10-25 years.[1] Immigrants and their descendants are, on average, 2.5 times more likely to have a psychotic disorder than the majority ethnic group in a given setting,[2,3] although the exact risk varies by ethnicity and setting. For example, in Europe, incidence rates for people of black Caribbean or African descent are approximately five times higher than those for the white European population.[2,4] These marked differences persist after adjustment for age, sex, and socioeconomic position,[5] are maintained in the descendants of first generation migrants,[2] and do not seem to be attributable to higher incidence rates in people's country of origin or selective migration.[6-9] Possible explanations centre on various social determinants of health, including severe or repeated exposure to psychosocial adversities such as trauma, abuse, socioeconomic disadvantage, discrimination, and social isolation. If this is the case, people granted refugee status may be particularly vulnerable to psychosis, given their increased likelihood of having experienced conflict, persecution, violence, or other forms of psychosocial adversity.[10,11]

Although refugees have more mental health problems than their non-refugee counterparts,[11,12] including post-traumatic stress disorder and common mental disorders,[13 14] little is known about the risk of psychosis in refugees. One previous longitudinal study from Denmark observed that refugees were at elevated risk of psychosis compared with the native-born Danish population.[15] However, the risk in refugees was not compared with that in other non-refugee migrants (henceforth referred to as migrants), who are known to be at increased risk,[16] making attribution of this excess directly to a refugee effect impossible. More recently, a Canadian cohort study found that refugees had a modestly increased risk of schizophrenia compared with other migrants,[17] but neither group was at elevated risk compared with an ethnically diverse Canadian-born background population, making this finding difficult to interpret and contrary to a large literature on immigration and psychosis.[2]

Here, we clarify the risk of non-affective psychotic disorders, including schizophrenia, in refugees compared with other migrants and the native-born Swedish population in a national population based cohort of 1.3 million people. Sweden has a total population size of 9.7 million inhabitants, of whom 1.6 million were born abroad. In 2011 refugees constituted 12% of the total immigrant population. Sweden experienced high levels of labour immigration between 1940 and 1970, followed by substantial refugee immigration.[18] On a per capita basis, Sweden grants more refugee applications than any other high income country,[19] which, combined with national linked register data, makes it an excellent setting in which to conduct this research. We hypothesised that refugees would have a higher risk of non-affective psychotic disorders than migrants and that risk for both groups would be elevated compared with the Swedish-born population. We also hypothesised that the risk in refugees compared with migrants would vary by region of origin, given putative differences in the pre-migratory experiences of migrants from different regions and differences in how they might adjust to a new society.

Methods

Study design and population

We established a retrospective cohort of 1 347 790 people born after 1 January 1984, who were born in Sweden to two Swedish-born parents (n=1 191 004; 88.4%) or were refugees (n=24 123; 1.8%) or non-refugee first generation migrants (n=132 663; 9.8%) granted residency in Sweden. To permit valid comparisons between refugees and migrants, we restricted the immigrant sample to people born in geographical regions with at least 1000 refugees in our cohort (see below). We excluded people without an official residence permit in Sweden—that is, undocumented migrants or people with an official asylum decision pending. We followed participants from their 14th birthday, or date of arrival in Sweden if later, until diagnosis of an ICD-10 (international classification of diseases, 10th revision) non-affective psychotic disorder (F20-29), emigration, death, or 31 December 2011, whichever was sooner. We could not include people who immigrated to Sweden before 1 January 1998 (n=53 855), because refugee status was not sufficiently recorded in the Swedish national registers before this date. We also excluded 812 (0.06%) participants with missing data on municipality of residence in Sweden at cohort entry, needed for estimation of urban residency as a covariate (see below). Excluded participants did not differ from immigrants included in the cohort by sex (51.0% (27 471/53 855) versus 50.7% (79 863/157 531) men; χ^2 P=0.21) but had a higher disposable income (11.0% (5924/53 855) versus 5.4% (8533/157 531) were in the highest income quarter; χ^2 P<0.001) and were more likely to come from the former Yugoslavia (32.4% (17 457/53 855) versus 8.4% (13 275/157 531); χ^2 P<0.001) than other regions. Crude incidence rates were similar between excluded (77.7 (95% confidence interval 70.4 to 85.8) per 100 000 person years) and included immigrants (86.6 (79.1 to 94.7) per 100 000 person years).

Data sources

We extracted data from a large, longitudinal database of linked national registers, known as Psychiatry Sweden, which included data on all people officially resident in Sweden after 1 January 1932, linked via a unique personal identity number and anonymised by Statistics Sweden for research purposes. We obtained relevant outcome, exposure, and covariate data from the following registers: the register of the total population to identify cohort participants and obtain basic demographic data (birth date, sex, country of birth); the multi-generation register to link participants to their parents for identification of the native-born Swedish population; the longitudinal integration database for health insurance and labour market studies (LISA) to obtain data on disposable income; the immigration and emigration database (STATIV) to obtain migration and refugee data; the national patient register to obtain outcome data; and the causes of death register for data pertaining to mortality.

Patient involvement

No patients were involved in setting the research question or the outcome measures, nor were they involved in developing plans for design or implementation of the study. No patients were asked to advise on interpretation or writing up of results. However, we will disseminate the results of our research to agencies responsible for the healthcare of refugee and migrant groups in Sweden.

Outcome

Our primary outcome was an ICD-10 clinical diagnosis of non-affective psychotic disorder (F20-29), which included schizophrenia (F20) and all other non-affective psychotic disorders (F21-29). We defined cases as cohort participants with a first recorded diagnosis between 1 January 1998 and 31 December 2011 in the national patient register, which records diagnoses following inpatient and outpatient admissions in Sweden (including privately run public healthcare settings). Inpatient records are complete since 1987, and complete recording from outpatient settings began in 2001. We excluded anyone with a recorded diagnosis of non-affective psychotic disorder made before the age of 14 years (n=156).

Exposures

Our primary exposure was refugee status, defined as refugee, other migrant, or person born in Sweden to two Swedish-born parents, obtained from the STATIV database, which records the reason why a residence permit was granted. Permanent residency for asylum in Sweden is based on the Swedish Migration Agency's definition of refugee status,[18] made in accordance with Swedish law and the UN Refugee Convention, as someone who, "owing to a well-founded fear of being persecuted . . . is unable to, or owing to such fear, is unwilling to avail himself of the protection of that country."[20] All other immigrants granted official residency were classified as migrants. We identified people born in Sweden to two Swedish-born parents (henceforth the "Swedish-born" group) via linkage to the multi-generation register.

As a secondary exposure, we classified people according to region of origin, as defined by country of birth. Although Statistics Sweden records data on specific country of birth, information is released for research purposes according to 13 larger geographical regions to ensure confidentiality. From this variable, we derived a broader region of origin variable for analysis, which included Sweden (Swedish-born only) and four other regions from which at least 1000 refugees in our cohort originated—sub-Saharan Africa, Asia, eastern Europe and Russia, and the Middle East and north Africa (see supplementary table A).

Confounders

We included age at risk and sex as two a priori confounder variables in all analyses. We also included individual disposable income in Sweden and population density at cohort entry as covariates, to adjust for possible differences between refugees, migrants, and the Swedish-born population.

We defined disposable income as annual disposable income, based on total family income from all registered sources, including wages, welfare benefits, other social subsidies, and pensions. Statistics Sweden estimated individual disposable income, weighting total family income according to household size and composition, with younger children given lower weights than older household members. We measured disposable income at the earliest point during follow-up (available in LISA at 16 years old or arrival in Sweden, if later). To account for inflation, we categorised individual disposable income into quarters, relative to all other cohort members assigned a disposable income score in the same year.

We defined urban residency according to the population density of each participant's municipality of residence at cohort entry, expressed as the total population per square kilometre (ppkm^2). Sweden consists of 290 municipalities (median population density 26.3 (interquartile range 12.2-75.7) ppkm^2). For descriptive purposes, we classified participants into three population density categories: 0-26.2 ppkm^2 (very rural areas, below Swedish median), 26.3-260 ppkm^2 (rural and semi-rural areas), and 260.1-4617.2 ppkm^2 (metropolitan, suburban, and urban areas). To adjust more effectively for population density, we used a continuous measure in our analyses, first transformed on to the natural logarithm scale to account for its positive skewed distribution across municipalities.

Statistical analyses

We recorded basic descriptive statistics and crude incidence rates for refugees, migrants, and the Swedish-born group. Next, we fitted Cox proportional hazard models to estimate hazard ratios and 95% confidence intervals according to each exposure variable. Follow-up time was based on the earliest date of entry into the risk period (date of 14th birthday or, for all immigrants older than 14 years on arrival, date of immigration) until exit from the cohort. We modelled age at risk as a time varying covariate, using Lexis expansion to stratify each participant into N observations, taking into account differing ages at risk over the follow-up period (14-16, 17-19, 20-22, 23-25, 26-27; N_{max}=5).

We initially examined the effect of refugee status on risk of non-affective psychotic disorder, after adjustment for age at risk, sex, and their interaction, if statistically significant. In a second adjustment, we added disposable income and population density. We tested whether the relation between refugee status and non-affective disorder differed between men and women by fitting an interaction term between refugee status and sex, with results presented separately for men and women, where appropriate. We repeated these analyses for our secondary exposure variable, region of origin. Next, to determine whether risk of non-affective psychotic disorder in refugees relative to migrants differed by region of origin, we fitted a Cox regression model to a subset of the cohort, excluding the Swedish-born group who did not contribute information to these analyses. Given the small sample of female refugees diagnosed as having psychosis (n=27), we did these analyses for both sexes combined and, separately, for men only. We assessed all statistical interactions by using likelihood ratio tests against a model without the relevant interaction term.

To minimise the possibility that any immigrants diagnosed as having non-affective psychotic disorder may have been prevalent (that is, existing) cases on arrival in Sweden, we did sensitivity analyses on all models, excluding any refugee or non-refugee migrant given a diagnosis within 12 months of immigration. Finally, we checked our main models (via likelihood ratio tests) for departure from proportional hazards. We used Stata v13 to analyse the data.

Results

We identified 3704 cases during more than 8.9 million person years of follow-up (table 1). Median age at first diagnosis in the Swedish-born population was 20.1

Table 1 | Cohort characteristics by migrant status—refugees, non-refugee migrants, and Swedish-born population. Values are numbers (percentages)

	Swedish-born population		Non-refugee migrants		Refugee migrants	
Characteristics	Cases (n=3232)	Person years* (n=8 384 891)	Cases (n=379)	Person years* (n=471 308)	Cases (n=93)	Person years* (n=73 604)
Sex:						
Men	1778 (55.0)	4 310 990 (51.4)	234 (62)	232 118 (49.2)	66 (71)	41 069 (55.8)
Women	1454 (45.0)	4 073 901 (48.6)	145 (38)	239 190 (50.8)	27 (29)	32 535 (44.2)
Birth year:						
1984-86	1279 (39.6)	2 928 401 (34.9)	175 (46)	185 052 (39.3)	35 (38)	23 820 (32.4)
1987-89	1111 (34.4)	2 510 835 (29.9)	107 (28)	125 770 (26.7)	28 (30)	19 093 (25.9)
1990-92	649 (20.1)	1 896 903 (22.6)	74 (20)	91 965 (19.5)	22 (24)	16 837 (22.9)
1993-95	174 (5.4)	903 840 (10.8)	19 (5)	56 237 (11.9)	8 (9)	11 728 (15.9)
1996-97	19 (0.6)	144 911 (1.7)	4 (1)	12 283 (2.6)	0 (0)	2127 (2.9)
Region of origin:						
Sweden	3232 (100.0)	8 345 891 (100.0)	-			
Sub-Saharan Africa	-	-	111 (29)	59 447 (12.6)	31 (33)	18 670 (25.4)
Asia	-	-	66 (17)	105 647 (22.4)	15 (16)	12 929 (17.6)
Eastern Europe	-	-	80 (21)	134 094 (28.5)	7 (8)	6546 (8.9)
Middle East	-	-	122 (32)	172 120 (36.5)	40 (43)	35 459 (48.2)
Income:						
Lowest quarter	1156 (35.8)	2 161 330 (25.8)	264 (70)	339 062 (71.9)	63 (68)	51 953 (70.6)
Second quarter	830 (25.7)	2 185 386 (26.1)	52 (14)	63 153 (13.4)	12 (13)	10 486 (14.2)
Third quarter	679 (21.0)	2 073 841 (24.7)	45 (12)	35 919 (7.6)	13 (14)	6768 (9.2)
Highest quarter	567 (17.5)	1 964 334 (23.4)	18 (5)	33 174 (7.0)	5 (5)	4398 (6.0)
Population density†:						
0-26.2	875 (27.1)	2 303 728 (27.5)	50 (1)	55 129 (11.7)	25 (27)	21 746 (29.5)
26.3-260	1698 (52.5)	4 472 698 (53.3)	168 (44)	216 155 (45.9)	49 (53)	35 031 (47.6)
260.1-4617.2	659 (20.4)	1 608 466 (19.2)	161 (42)	200 024 (42.4)	19 (20)	16 827 (22.9)

*Rounded to nearest integer.

†People per km^2.

(interquartile range 18.3-22.3) years, younger than for refugees (21.0 (19.2-23.7) years; Mann-Whitney P<0.001) and non-refugees (20.9 (18.7-23.6) years; P<0.001), for whom age at first diagnosis was similar (P=0.30). Following arrival in Sweden, time to first diagnosis was shorter for refugees (median 2.8 (0.7-5.6) years) than for migrants (3.9 (1.2-7.0) years; Mann-Whitney P=0.02).

The crude incidence rate of non-affective psychotic disorders was 38.5 (95% confidence interval 37.2 to 39.9) per 100 000 person years in the Swedish-born population, 80.4 (72.7 to 88.9) per 100 000 person years in migrants, and 126.4 (103.1 to 154.8) per 100 000 person years in refugees. This corresponded to an absolute rate difference of 45.9 (19.0 to 72.9) per 100 000 person years in refugees compared with migrants, in addition to an extra 41.9 (33.7 to 50.1) cases per 100 000 person years in migrants compared with the Swedish-born population. Compared with the Swedish-born population, hazard ratios were 2.90 (95% confidence interval 2.31 to 3.64) in refugees and 1.75 (1.51 to 2.02) in migrants, after adjustment for age, sex, their interaction, disposable income, and population density (table 2). Refugees were 1.66 (1.32 to 2.09) times more likely to be diagnosed as having non-affective psychotic disorders than were migrants. These associations were more pronounced in men than women (likelihood ratio test P for interaction=0.001; table 2 and fig 1).

Taking refugees and migrants together, immigrants from all regions of origin had increased rates of disorder relative to the Swedish-born population, after adjustment for age at risk and sex (supplementary table B). Hazard ratios were most pronounced for all immigrants from sub-Saharan Africa (hazard ratio 5.23, 4.32 to 6.34), which was also observed for both men (6.68, 5.33 to 8.37) and women (3.64, 2.68 to 4.94) separately. These patterns persisted after adjustment for disposable income and population density, ranging from 1.41 (1.11 to 1.78) in people from eastern Europe and Russia to 4.10

Table 2 | Risk of non-affective psychoses by migrant status after adjustment for confounders. Values are hazard ratios (95% CIs)

	All		Men		Women	
Category	Model 1	Model 2	Model 1	Model 2	Model 1	Model 2
Swedish-born as reference						
Non-refugee migrant	2.28 (1.99 to 2.62)	1.75 (1.51 to 2.02)	2.61 (2.22 to 3.07)	2.01 (1.70 to 2.38)	1.91 (1.58 to 2.31)	1.44 (1.19 to 1.76)
Refugee migrant	3.61 (2.87 to 4.53)	2.90 (2.31 to 3.64)	4.28 (3.28 to 5.58)	3.49 (2.67 to 4.55)	2.65 (1.80 to 3.92)	2.07 (1.40 to 3.06)
Non-refugee migrant as reference						
Refugee migrant	1.58 (1.26 to 1.99)	1.66 (1.32 to 2.09)	1.64 (1.25 to 2.15)	1.74 (1.32 to 2.28)	1.39 (0.92 to 2.10)	1.43 (0.95 to 2.16)

Model 1 was adjusted for age at risk, sex, and their interaction. Model 2 was also adjusted for disposable income and population density. A likelihood ratio test confirmed statistical interaction between sex and age at risk in model 1 (χ^2 (df=4) 71.5; P<0.001) and model 2 (χ^2 (df=4) 73.0; P<0.001), as well as between sex and refugee status in model 1 (χ^2 (df=2) 11.7; P=0.003) and model 2 (χ^2 (df=2) 13.5; P=0.001). Hazard ratios by refugee status are therefore presented separately for men and women.

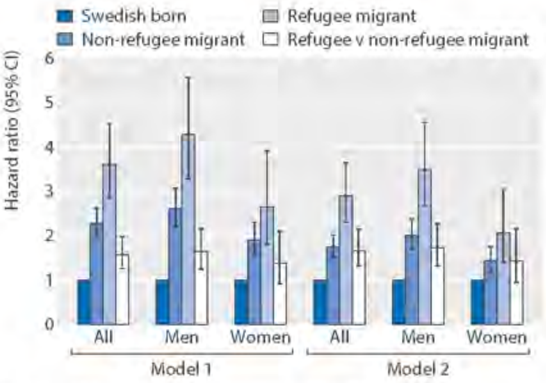

Fig 1 | Hazard ratios for schizophrenia and other non-affective psychotic disorders by refugee status and sex. Model 1 was adjusted for age at risk, sex, and their interaction (where appropriate). Model 2 was additionally adjusted for disposable income and population density. Swedish-born group provides reference category, except for fourth (white) bar in each group, which shows hazard ratio for refugees relative to non-refugee migrants. Error bars represent 95% confidence intervals

(3.38 to 4.98) in people from sub-Saharan Africa, relative to the Swedish-born population.

We next investigated whether the elevated rates of non-affective psychotic disorders in refugees compared with migrants differed by region of origin, excluding the Swedish-born population who did not contribute to these analyses. For men and women combined, we found evidence that the rate of non-affective psychosis in refugees compared with migrants varied by region of origin (table 3; likelihood ratio test P=0.05). This finding was even more pronounced in men (likelihood ratio test P=0.007), such that rates of non-affective psychotic disorder were elevated in refugees compared with migrants from all regions of origin, except sub-Saharan Africa (hazard ratio 0.68, 0.40 to 1.16), after adjustment for age at risk, sex, disposable income, and population density (table 3). Male refugees from eastern Europe and Russia were at greatest risk compared with their migrant counterparts (hazard ratio 2.88, 1.22 to 6.82). In general, the rate of psychotic disorders in refugees relative to migrants became smaller as the crude incidence rate in non-refugees from each region of origin increased (table 3). We made no attempt to examine this effect in women, given insufficient numbers of refugees (n=27).

Sensitivity analyses excluding potentially prevalent cases among immigrants did not appreciably alter estimates of associations for our main exposures (supplementary tables C and D). The assumption of proportional hazards was not violated (P=0.84 and P=0.13 for analyses of refugee status and region of origin, respectively).

Discussion

In this cohort study, we found that refugees granted asylum in a high income setting were, on average, 66% more likely to develop schizophrenia or another non-affective psychotic disorder than non-refugee migrants from the same regions of origin and up to 3.6 times more likely to do so than the Swedish-born population.

Strengths and weaknesses of study

This study has several methodological strengths. It was based on a large, national population based cohort of more than 1.3 million people, followed for more than 8.9 million person years by using linked Swedish register data. This research has not previously been possible owing to a lack of information on the reason for migration in official Swedish registers; one earlier attempt to investigate this question in Sweden could not distinguish between refugees and non-refugees from the same region.[21] Swedish register data are known to be reliable for research purposes,[22,23] and diagnosis of psychotic disorders recorded in the national patient register has good validity and positive

Table 3 | Risk of non-affective psychoses in refugees relative to non-refugees, by region of origin

	All		Men	
Category	Crude incidence rate (95% CI) per 100 000 PYAR	Hazard ratio (95% CI): model 2	Crude incidence rate (95% CI) per 100 000 PYAR	Hazard ratio (95% CI): model 2
Swedish born	38.5 (37.2 to 39.9)		41.2 (39.4 to 43.2)	
Eastern Europe:				
Non-refugees	59.7 (47.9 to 74.3)	1	62.5 (45.9 to 85.2)	1
Refugees	106.9 (51.0 to 224.3)	1.76 (0.81 to 3.82)	184.1 (82.7 to 409.8)	2.88 (1.22 to 6.82)
Asia:				
Non-refugees	62.5 (49.1 to 79.5)	1	67.0 (48.3 to 92.9)	1
Refugees	116.0 (69.9 to 192.4)	1.78 (1.01 to 3.14)	146.1 (83.0 to 257.3)	2.20 (1.13 to 4.25)
Middle East and north Africa:				
Non-refugees	70.9 (59.4 to 84.6)	1	94.4 (75.9 to 117.4)	1
Refugees	112.8 (82.7 to 153.8)	1.56 (1.08 to 2.23)	143.5 (100.3 to 205.2)	1.55 (1.01 to 2.36)
Sub-Saharan Africa:				
Non-refugees	186.7 (155.0 to 224.9)	1	269.0 (215.1 to 336.3)	1
Refugees	166.0 (116.8 to 236.1)	0.81 (0.54 to 1.23)	207.1 (130.5 to 328.8)	0.68 (0.40 to 1.16)

Estimates from model 1 and model 2 were similar; only data from model 2, adjusted for age at risk, sex, their interaction (for both sexes combined), disposable income, and population density, are reported. Likelihood ratio test χ^2 (df=3) and P values, for statistical interaction between refugee status and region of origin were 8.0 and 0.05 for full sample and 12.0 and 0.007 in analysis restricted to men. Given small number of refugee women with outcome (n=27), no attempt was made to inspect risk by region of origin separately for women.
PYAR=person years at-risk.

predictive value.[24-26] This register is highly complete, recording all psychiatric contacts from inpatient settings from 1987 onwards and from outpatient settings since 2001. Although this may have led to slight under-ascertainment from outpatient settings between 1998 and 2000, we have no reason to believe that this would have introduced differential bias by refugee status or region of origin. We cannot exclude the possibility that we underestimated the true incidence of non-affective psychoses in Sweden, particularly for certain groups, such as recent immigrants or refugees, who may have been unfamiliar with the Swedish healthcare system, have faced greater language barriers, or had poor health literacy.[27] If these accessibility factors differed according to sex, the true incidence among migrant and refugee women may have been underestimated in the Swedish patient register, making our hazard ratios conservative.

Sensitivity analyses suggested that our results were not attributable to prevalent cases among refugees and migrants. In our study, migrants and refugees from sub-Saharan Africa were at increased risk of having a psychotic disorder, compared with the Swedish-born group. This finding is consistent with many other European and worldwide studies.[2] Although diagnostic bias has been proposed to explain excess rates of psychotic disorders observed in ethnic minorities,[8] little evidence supports this possibility in general.[28] Studies in which psychiatrists were blinded to participants' ethnicity during the diagnostic process have confirmed rates of psychotic disorders in ethnic minority groups,[29] including people of black Caribbean and black African origin. In Sweden, by law, interpreters have to aid clinical consultations when necessary. Furthermore, any diagnostic biases are less likely to have accounted for observed differences in risk between refugees and migrants from the same regions of origin observed in our study. Refugees are also at elevated risk of post-traumatic stress disorder,[13] which can present with psychotic features; however, our findings are unlikely to be attributable to misdiagnosed cases of this disorder among refugees, as it often presents comorbidly in people exposed to potentially traumatic events and experiences.[30]

We were unable to include immigrants who arrived in Sweden before 1998 in our study, because data on refugee status were unavailable before that year. These groups were more likely to come from the former Yugoslavia, reflecting geopolitical conflicts of the time. This may have reduced our power to detect differences between refugees and other migrants from eastern Europe, but we have no reason to believe their exclusion would have otherwise biased our estimates; the crude incidence in this group was comparable to that for included immigrants, despite their higher post-migratory disposable income. Finally, notwithstanding our large cohort size, the number of cases in refugees was small, which limited our power to detect effects in certain groups, most notably women, for whom risk of non-affective psychotic disorders is, on average, half that of men.[31]

As our study was based on routine register data, information on potentially relevant experiences before migration was unavailable. Such pre-migratory experiences remain an important area for future research. Our cohort included migrants and refugees exposed to various humanitarian crises resulting from conflict (such as Iraq, Iran, Afghanistan, the Balkans, central Africa) as well as famine (such as east Africa). Although it is too early to determine whether people currently seeking refuge in Europe following contemporary humanitarian crises (in Syria, Iraq, Afghanistan, parts of north Africa, Kosovo, Albania) would also be at greater risk of psychotic disorder, we assume that our findings will generalise to these groups for two reasons. Firstly, a degree of geographical overlap exists between the regions we included and those generating current humanitarian crises.[32] Secondly, we presume that exposure to war, persecution, and exposure to other psychosocial adversity would have a universal effect on individual risk of psychosis, independent of other risk factors.

We adjusted for possible differences between refugees, migrants, and the Swedish-born population with regard to age, sex, disposable income, and population density at cohort entry. We did not include other post-migratory markers of potential social disadvantage; such factors may lie on the causal pathway between immigration and risk psychosis, thus making adjustment difficult to interpret. We were unable to examine risk of psychosis in so-called second generation refugees or migrants, because our study population was born after 1984, making their children too young to have entered the risk period for psychosis before the end of our follow-up period in 2011.

Clinical and public health implications of study

Contemporary humanitarian crises in Europe, the Middle East, north Africa, and central Asia have contributed to more displaced people, asylum seekers, and refugees worldwide than at any time since the second world war.[33] The severe social, economic, and health inequalities faced by displaced populations arising from these crises are often compounded by national immigration policies and structural constraints in receiving countries. In turn, exposure to these ongoing adversities seems likely to contribute to the increased risk of post-traumatic stress disorder and common mental disorders among refugees.[11-13] Our data highlight further mental health inequalities facing such groups.[34] Clinicians and service planners in high income settings should be aware of the early signs of psychosis in refugees, for whom median presentation to services after arrival to Sweden was more than a year sooner than for other migrant groups. Just as for the general population, refugees and their families will benefit from timely and early intervention and care, particularly in those exposed to severe psychosocial adversity.

Our findings are consistent with the hypothesis that increased risk of non-affective psychotic disorders among immigrants is due to a higher frequency of exposure to social adversity before migration,[35] including the effects of war, violence, or persecution. Further studies will be needed to confirm this possibility. Violence experienced by children and adults who flee persecution has been linked to worse subsequent mental health in general.[11,36] Intriguingly, our study suggested that risk of psychosis in refugees relative to other migrants varied by region of origin in our data. Although this finding needs to be replicated in larger samples, it suggests that in addition to refugee status, context matters. For example, we observed no differences in risk of psychosis between refugees and non-refugee migrants among immigrants from sub-Saharan Africa, perhaps because both groups had highly increased rates of disorder (more than 165 new cases per 100 000 person years).

One parsimonious explanation for this finding is that a larger proportion of sub-Saharan Africa immigrants will have been exposed to deleterious psychosocial adversities before emigration, irrespective of refugee status. By contrast, pre-migratory psychosocial adversities experienced by refugees from eastern Europe and Russia may differ substantially compared with non-refugee migrants from these countries, thus confining excess risk to refugees from such regions. It is also possible that post-migratory factors, such as discrimination, racism, and social exclusion, may explain the high rates of psychotic disorder in migrants and refugees from sub-Saharan Africa, given the absence of a "refugee effect" in this group. Visible minority status may lead to more post-migratory psychosocial adversity. In general population samples, some evidence suggests that perceived discrimination and ethnic density (proximity to one's own ethnic group) are, respectively, risk and protective factors for psychosis.[37,38] Although we controlled for income and post-migratory urban residency, we were unable to investigate other post-migratory factors, including racism, discrimination, and ethnic density, in the available data; further exploration of such factors presents an important avenue for future research. Other factors, including difficulties in the asylum process, also warrant further investigation. For example, women seeking asylum are less likely to be granted refugee status than men, given greater structural and cultural barriers in the asylum process.[39] In our study, such an effect would have led to a higher proportion of women being classified as migrants, which may have partially explained why differences in incidence between female refugees and non-refugees were less pronounced than for their male counterparts. A recent study by Oram et al has further highlighted high levels of severe mental illness faced by trafficked migrants, who represent another vulnerable group of migrants.[40]

Conclusion

Our study shows that, on average, refugees in a high income setting face substantially elevated rates of schizophrenia and other non-affective psychoses, in addition to the array of other mental, physical, and social inequalities that already disproportionately affect these vulnerable populations. This risk exceeded the well established excess burden of psychosis experienced in immigrant and ethnic minority groups more generally and thus emphasises the need to take the early signs and symptoms of psychosis into account in refugee populations, as part of any clinical mental health service responses to the current global humanitarian crises. More broadly, our findings support the possibility that exposure to psychosocial adversity increases the risk of psychosis.

Contributors: A-CH and CD conceived of the study. A-CH, JK, and CD designed the study and obtained funding. A-CH, CD, and HD acquired the migration data. CD and HD acquired all other cohort data. A-CH, JBK, and HD prepared the data. A-CH, JK, CD, CM, and GL interpreted statistical analyses. HD coordinated the data management, and A-CH wrote the study protocol. A-CH and JBK did the statistical analyses, drafted the data tables, and co-wrote the manuscript. All authors critically revised the paper for important intellectual content and approved the final version. JBK and CD were co-senior authors of the manuscript. A-CH and JBK are the guarantors.

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Competing interests: All authors have completed the ICMJE uniform disclosure form at www.icmje.org/coi_disclosure.pdf (available on request from the corresponding author) and declare: financial support to A-CH, JBK, and CD as described above; no other financial relationships with any organisations that might have an interest in the submitted work in the previous three years; no other relationships or activities that could appear to have influenced the submitted work.

Ethical approval: This research has ethical approval as part of Psychiatry Sweden "Psykisk ohälsa, psykiatrisk sjukdom: förekomst och etiologi," approved by the Stockholm Regional Ethical Review Board (number 2010/1185-31/5).

Data sharing: The statistical code is available from the corresponding author. Under Swedish law and ethical approval, patient level data cannot be made available.

Transparency declaration: The lead authors (the manuscript's guarantors) affirm that the manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned (and, if relevant, registered) have been explained.

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Supplementary tables

Royal Commission into
Victoria's Mental Health System

ATTACHMENT RB-24

This is the attachment marked '**RB-24**' referred to in the witness statement of Dr Ravi Subramanya Bhat dated 4 July 2019.

Why don't younger people from refugee backgrounds call a rural early psychosis service?: an investigation.

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150-250 words

Purpose (stating the main purposes and research question)

Methods

Results

Conclusions

This study was instigated by regional statistics showing that a very small number of the CALD population in the Goulburn Valley were accessing local mental health services. Evidence is clear that trauma experienced during a family's flight from a country of origin has a profound effect on the mental health of children. Even if born in the country of refuge children will suffer mental health difficulty because of their refugee status. In Australia and elsewhere young people from these backgrounds are not utilising mental health services and research on the reasons why this is so remains scarce. Meta-analyses indicate a consistent relationship between durations of untreated psychosis (DUP) and poor mental health prognosis independent of other factors. Possible delay in presentation to mental health services is of major concern for young minds. This paper presents the findings of 4 focus groups held with 32 young people aged 16 - 21 years from refugee backgrounds living in the Shepparton area. A vignette was utilised to begin a semi-formal conversation around perceived barriers to seeking help. Participants first gave pragmatic responses to the scenario. Themes later emerged describing cultural, social and personal barriers to help-seeking amongst young CALD people. The findings suggest most young people would first approach close friendship networks for help with psychosocial problems. Other avenues of assistance would depend on personal experience and context, culture and social situation. The implications of reducing DUP in CALD communities is discussed. Possible methods to disseminate service information is addressed.

Keywords: 4-6 (for indexing purposes)

rural, refugees, mental health, DUP, access, CALD.

Introduction

Trauma has also long been recognised as a strong risk factor for mental illness [1,2,3] and recent research has linked long-term stress with changes to the structure of the brain itself[4,5]. Specific research into the effects of trauma on refugees and their children[6,7,8,9] , indicates a strong correlation with mental illness for that group. Following a history of ongoing trauma in the country from which they have fled, the perils of flight to a safe haven has a strong impact on the mental integrity of both adults and the children they bring[6,10]. It has also been shown for some time that migration alone correlates a higher risk of developing schizophrenia than in a resident population[11,12,13] and this could make the psychological impact of past trauma on younger minds even more complex[1,14,15]. The damage that the combination of stress, conflict and trauma may inflict on the developing brain of a displaced child can only be speculated as specific research is lacking.

A major concern for refugees is delay in seeking assistance, as longer durations of untreated symptoms have been shown to intensify the symptoms as mental illness progresses[4,16,17,18]. Although the epistemology of early onset symptoms is yet to be completely understood, research has shown that longer Durations of Untreated Psychosis (DUP) strongly correlate with more complex and severe presentations and prognoses[16,19]. Although prolonged DUP (>54 weeks) has been correlated with greater deterioration in the pre-morbid phase, a weaker social network, and social withdrawal in native populations[17], data on migrant populations are limited. Although higher attendance rates at local GPs is associated with shorter DUP in young people[20], it has been suggested that social isolation and perhaps preserved coping skills of the sufferer can prolong a hesitation to seek help for mental illness[16, 18].These findings may indicate a greater integration with the local social network and culture is beneficial. It is imperative that mental health services take steps to facilitate a mutual understanding of the needs of new young arrivals who may have a very different perception of mental illness; its implications, consequences and possible treatments[21,22].

This recognition of trauma as a major risk factor for mental illness[1,2] is especially pertinent in Shepparton as refugees reaching Australia, often with their children, are very likely to have been exposed to high levels of trauma before leaving their homeland and on the journey to safety[3,23]. The Hume region receives many young arrivals from such dire circumstances who have survived much suffering, hardship and trauma while journeying to Australia. To find exact numbers of migrants and refugees in the Hume region from troubled states is problematic. The Australian Bureau of

Statistics[24] (ABS) (2006) found there were 59,427 people in the Greater Shepparton area in 2006, nearly 7,000 of whom were born overseas. Taking into account the large family sizes in local cultural groups the Shepparton Ethnic Council[25] estimates that Shepparton is home to approximately 1000 (130 families) Sudanese refugees, mainly from South Sudan; 160 (23 families) of Congolese; 300 to 4000 (300 families) Iraqis, and 1200 (120 families & 350 singles) Afghans, 50% of whom are believed to have arrived by boat and experienced Australian detention centers. These numbers are for residents and do not include those young, single males who pass through while looking for work. When one considers that many itinerant young people may choose to remain on the move precisely because they suffer some form of mental illness, these numbers could be much larger.

However, statistics from Goulburn Valley Health Mental Health Service show that the numbers of young new arrivals that make contact with this service are minimalIt would appear from this investigation that of all patients of any age accessing the Goulburn Valley mental health system from July 2012 to June 2013 ($n=4575$) only nine declared a country of birth as Afghanistan ($n=7$) or Iraq ($n=2$). The other countries mentioned above do not appear. This research project was instigated to educate and support mental health service staff and young clients in ethnic communities who may not yet have confidence in, or knowledge of, the efficacy of a western model of mental health services.

Methods:

The Sample

Selection of participants required negotiation around appropriate vehicles for provision of information considering the ages and cultural backgrounds of the target population and Goodwin's[26] description of ethical qualitative research as a ‘process rather than an outcome’ and a process of ‘thorough negotiation’ when doing research in particular settings’ provided some insight into the selection of sites for the interviews .

The sites from which participants were then sought were two agencies: an organization that provides newly arrived refugees and migrant families with social support and a local high school with a high percentage of students from diverse backgrounds. Information about the research project was disseminated at these sites using flyers written in English.

Volunteers for the project then received further information and consent forms to be considered by their parents/guardians where necessary. Provision of information about the project and the need for consent was negotiated with direct-care workers and school counselors.

Thirty-two self-selected English-speaking volunteers aged between ten and twenty one years from seven countries volunteered to participate. (Table 1).

Table 1: Sample Characteristics *(N=32)*

	Males		**Females**	
Country of Birth	**Age range**		**Age range**	
	10-15	16-21	10-15	16-21
Afghanistan		3	2	5
Iran		3	1	1
Iraq		7		4
Jordon			1	
Sudan			1	1
Syria		1	1	
Turkey				1
Total		**14**	**6**	**12**

The purpose of the groups was to explore how decisions in refugee communities might be made; what social and cultural processes are involved and how information might be transferred between people in community networks[27]. The use of forums is thought to facilitate information which may emerge from more natural discussions which may not be forthcoming in more formal interview styles[27]. Importantly, the participants also have more control in groups as they outnumber the 'experts' in the room providing an ethical advantage to participants from cultural minorities[27]. Focus groups were then utilised to highlight attitudes, priorities and frameworks of understanding of the participants[28] and to engage the young people in a group discussion among peers to expose ideas and experiences that a one-on-one interview may not illustrate[28].

Confidentiality is essential when dealing with both the young and the vulnerable[29] and a strategy was put in place to maintain the privacy of the young people involved. It was explained that identifying details would not be recorded, instead participants would be allotted a number and the facilitator would keep details of only their cultural identification, age and gender. During the conversation they would be referred to by their number so that their names would not be recorded. This was acceptable to all participants without reservation.

As described by Vaughan et al.[30], the age of the participants influenced the size of the groups and the length of the conversations. It was planned to use groups of six or seven participants with conversations lasting about 60 minutes. Four gender specific focus groups, two female and two male, were organized to respect cultural and religious sensibilities of the young participants. The formed groups were homogenous to gender and, in the most part, to age.[30] Groups with females had cultural liaison officers from sample sites present.

For this project, Alexander and Becker's definition of vignettes as "short descriptions of person or a social situation which contain precise references to what are thought to be the most important factors in the decision-making or judgment-making processes of respondents"[31] was influential in the design of the narrative used. A vignette about a young male, called Ishmael, experiencing possible sub-threshold psychotic symptoms became the focal point generating a semi-formal discussion[31, 32]. It was considered that such an objective context would provide a focus to which the facilitator could refer during the conversation and so avoid self-disclosures that might re-traumatise the participants. A copy of the vignette was given to each participant and also read aloud by the facilitator at the start of the session.

With permission from the participants, the conversations around the vignette were audio recorded and later transcribed. Analysis was carried out using a modified version of the framework approach developed by the National Centre for Research in the United Kingdom[26] that requires ordered stages of collection and analysis. Transcriptions of the recorded sessions were examined for perceptions and perspectives of participants that were coded according to the nature of the reference. These coded statements were sorted for thematic trends. Once trends had been identified, alternative meanings and understandings of topics raised were explored. Possible cultural or experiential influences that may have shaped or generated statements were considered. Themes were noted, collated and used to extrapolate hypotheses around perceived obstacles to engagement with local mental health services. The analysis also took into account contextual elements of the participants' statements as expressed and the group-experience of the facilitator.

Ethics approval:

Ethics approval for this project was received from the Goulburn Valley Health Ethics committee. The local education department was approached and the writers were advised formal approval would not be needed from that department as the participants would be asked for opinions only. However, the permission of school principals would be required and was verbally received from McGuire College.

Results

The sessions began quickly once the vignette was read. At first reading most participants accepted Ishmael's problems as 'real' events experienced by a troubled and sad young man. Comments were made which came from a pragmatic understanding of a young male who has failed his exams. This seemed to be a strong feature in the minds of the participants. Perhaps being students it was something immediate and important to their own lives. The exploration of why a young man would socially isolate from his family was complete and generated comments from most young participants. Males and females seemed equally concerned that Ishmael was feeling ‘depressed’ and some discussion of the meaning of this word ensued.

These topics merged quietly into a discussion of the older generations’ views on mental health and the western medical system in general. These conversations highlighted some of the distinctions young people feel mark them as different from older community members. The discussion then moved on to perceived barriers to CALD young people seeking assistance from the mental health services. Some of these barriers were about the resilient nature of migrants and their tolerance to illness, some were cultural and others social. None of these aspects appeared to overly concern the participants, which may indicate the socialised ‘fit’ of these concepts, even within a new cultural context, in the minds of the young people voicing them. Information for, and education of elders was thought to be necessary for elders to better understand the western concept of mental health. Effective methods of delivery of pertinent content concluded the forums.

There was a commonality in both the themes and in the order that they emerged in all the semi-structured focus groups. The main themes are presented here in the order in which the participants raised them.

Normalising Ishmael’s situation

Ishmael’s situation was not conceptualized as ‘illness’, but rather in an attributional style that emphasized cultural consequences ”because he’s failed his exam” (20-year-old Afghan female), and “maybe he was stressed about exams and everything. Too much pressure on his brain” (16-year-old Afghan female) or that “he may be scared” (18 year-old Iraqi female). Male participants made more personal and contextual statements. They looked for reasons such as “he’s being bullied” (19-year-old Iraqi male) or “…he’s sad about, like, living there or something” (16-year-old Irani male) but early on the general consideration was that “he’ll get over it” (16-year-old Iraqi male). Most participants could empathise with a young male who had not met family expectations of success. His reactions were not considered unusual. Most participants decided that they would ‘talk’ to the sufferer, which they also considered the first action likely to be taken by Ishmael’s parents.

"He's depressed"

Ishmael was seen to be a young male experiencing symptoms of low mood brought about by anxiety around failure and its consequences. In this intial conversation a clinical picture of depression was not described by the participants. As 'depression' was often mentioned by participants they were asked for their definition of the word. The general view was of a very low mood that most stated they have experienced themselves when falling short of familial expectations. "You don't want to talk to anyone, you just sitting in your room, do nothing" (16-year-old Afghan female) and "it is when you are under too much stress .... and you just want to be by yourself .... (18-year-old yo Afghan male). A more personal perspective was generally accepted "because I usually do it. Like when I've got too much stress, I just leave everything, just have a chillax" (18-year-old Afghan male). Again 'talking' was suggested with some mention of counselling. For example, in one group a participant said "maybe treat them with special care, like..." (16-year-old Iraqi male) to which another added, "or, like a psychologist or something" (18-year-old Iraqi male).

The family will try to manage the situation

This notion was both culturally and practically accepted; cultural in that it was considered the responsibility of one's family to manage the situation and practical because for many their family was the primary source of support. The family will attempt to contain the situation in order to save 'face' in the community. On the other hand, because mental illness is not understood in a Western sense[22, 34], the symptoms are not seen as a health problem but as difficulties arising in the child's character or circumstances that should be tackled as a family "because you think it will cure itself, you can cure it in that period of time. Two three days it will be gone" (19-year-old Iraqi male). Many males spoke of the way extreme situations were privately handled by family or friends in their country of origin and this appeared to raise expectations that the family was capable of tolerating a complex situation and finding a makeshift resolution to any practical problem that might arise. This masculine identification with traditional idealogy has been noted in other migrant populations in Australia[35].

A perceived lack of understanding of mental illness by community elders

The participants often indicated they felt older community members acted on beliefs about psychiatric symptoms brought from their homelands. This knowledge base was seen to be old fashioned, seldom including a modern understanding of mental illness that participants were learning in schools. Even so, the younger participants themselves used colloquial phrases such as “schizzed out” to describe extreme and/or unpredictable behaviours. Participants told stories of people exhibiting psychotic symptoms in their homelands being treated as social outcasts who were rarely cured – “they wouldn’t say he’s sick, they just say he’s crazy, that’s all” (19-year-old Iraqi male), “they don’t count it as a sickness” (19-year-old Afghan male) and “they gonna think if he’s crazy, there’s no cure for him. Just leave him alone” (19-year-old Iraqi male). Fears expressed by older community members that mental illness is incurable and costly to treat were seen as major hurdles for young people who want to seek help outside the family circle.

Participants suggested this misunderstanding by older community members could be addressed by providing information on how easy it is to present for assistance from the mental health service. They suggested the community be given education on how mental illness is treated in Australia and the need and benefit of early intervention. Participants suggested that apprehension of the cost when accessing mental health serivices, a major factor in their home country, would be a barrier to presentation also should be addressed with education around the Medicare benefits in this country.

Discussion

There is little evidence to establish how mental health services are perceived or accessed by younger new arrivals in rural areas. It appears, however, that young refugees do not utilise Mental Health services in expected numbers[33, 36]. Obstacles to accessing mental health may be cultural, political, psychological or social. One Canadian project[37] found little difference in help-seeking among settled ethnic communities but in Australia it is still unknown whether young refugees are constrained by cultural beliefs of their parents, extended family or cultural group.

Perhaps contact with mental health services in their home country was so harsh as to engender fear that Australia may inflict a similar experience. It could be fear of the same social 'stigma' with which Australian young people[23, 38, 39] and those from eastern cultures[36, 40] would rather not be associated. Or it may be merely a perceived inability to afford medical attention. Research in South Australia has suggested that such obstacles could be overt, others covert[22] making the challenge of a valid diagnostic screening for symptoms in migrant populations problematic over diverse cultural and linguistic origins[41]. Recent western studies have identified the influence of "help-negation", defined as "the refusal to accept or access available helping resources" that is argued to generate from "hopelessness, pessimism and cynicism regarding the efficacy of treatment"[42] and this could possibly add another layer of complexity to help seeking in a new cultural milieu. Cultural obstacles for older migrants have also been identified[43]; however obstacles that might exist for young migrants living in the Hume region are yet to be studied.

The investigators very carefully considered issue of English language proficiency of the young persons and their parents and their capacity to read in their preferred spoken language. The question of translating information into community languages spoken by parents was also considered. However, community consultants to the project revealed that older persons in these communities were commonly illiterate in their own language. They were unlikely to ask for help outside the family to read any translated material that the project provided. In their experience, such older persons preferred to receive information in simple English and they could then ask their English-proficient children to read the information sheet to them. The younger people were usually able to use words and phrases from the parent's preferred language to adequately explain information of a general non-personal nature.

It was decided the project would utilise a vignette's capacity to more closely "approximate real-life decision-making situations[31] among young refugees in a rural context. Vignettes have been discussed as a tool for qualitative research since the 1990's[31, 44]. Case vignettes are an especially helpful way for culturally and linguistically diverse groups to explore perceptions and experiences[32]. More recently Wilks[32] has discussed researchers' increasing use of vignettes generating 'more complex and sophisticated understandings', especially in projects that cross cultural obstacles of language and experience.

The range of themes expressed in conversations in this project did indeed show that cultural constructions play a very important role in the initial reaction of people from refugee families to psychotic symptomatology. The conversations considered how Ishmael's problems might be perceived by the participants' older countrymen and women both in their homelands and now in Australia. An interesting conversation around the way the family of a young person exhibiting Ishmael's symptoms would react brought out many differing views based on personal or vicarious experiences and apparent gender-specific reactions across the cultures represented in the sample.

The facilitator was impressed with the openness with which each topic was approached and discussed. When reflecting on the power of themes generated, one overarching attitude came to mind immediately: the collective belief in concern of parents for the welfare of their children. Over this parental concern was laid cultural and social considerations. At one stage two young males suggested that a major concern for parents would be they might 'lose' their child. That "they gonna be scared" because "he might kill himself" (16-year-old Iraqi male). This natural concern resonated long after the conversation concluded and brought into tight focus the dilemma of the refugee parent.

The writers found that the sessions, both male and female, evolved in similar patterns of thought and conversation. The young participants initially normalised Ishmael's presentation and suggested that their first response would be to talk with him. This explanatory model of illness sprang from the stance that they would themselves talk to peers when they had problems they did not want known to their parents or community elders. Other ideas emerged later but the first intention was to talk to the sufferer. This aspect brought out some differences between the participants and the older relatives who appear to be perceived by the younger people as a separate stratum of the social order.

Adults in the community were considered not to understand the western model of mental illness as did the younger community because education in Australia had changed the way the participants now perceive mental illness. The respect to be shown to the parents of an afflicted relative or friend, especially a family patriarch, was a possible barrier to being able to immediately assist another with new-found knowledge. Before this comment it was as if respectful submission to parents was a given and too obvious to mention. This respect to be accorded to parents could act as a barrier to help-seeking because parents were seen, effectively, as a filter in the pathway to care[45]. This was due both to perception of psychosis held by the elders and their fear of losing control over their child. Both scenarios were thought to dissuade parents from allowing their child to be dealt with by a mental health service which may worsen their problems. The resulting struggle for a young person caught between the paradoxical cultural conceptions of the psychiatric symptomatology and help seeking must be enormous when it involves the suffering of someone to whom they are close.

This is a major consideration in that the participants were mindful that community awareness of “craziness” in a relative brings personal shame on family members and is to be avoided for the sake of other family members’ social standing. “Mostly people don’t spread out (knowledge of their child’s illness) so people won’t say their child is psycho or something” (18-year-old Afghan male) because “like in our community what people say it really matters. Like, it’s a big thing” (18-year-old Afghan male). On the other hand, “if their son’s in danger they wouldn’t worry about (stigma)” (16-year-old Irani male). Participants also mentioned that parents would be concerned about losing their son or daughter to either a dominant medical system, where parental control would be forfeited, or, in the worst case, suicide. Delving further into the role of older family members led one participant to comment that she would help a friend “if they would allow me.... the parents” (17-year-old Iraqi female). An important element of her argument to parents for taking action would be that she would “keep it a secret” from the community, emphasising the social strictures within which families live .

It was generally agreed by participants that information about mental illness was needed to change their community’s perceptions and attitudes towards sufferers. To affect community attitudes and create understanding, all agreed this information should be distributed amongst elders “who usually handle this stuff” (17-year-old Iraqi male). These holders of knowledge were considered to be the ’go to people’ within the communities and had the influence to change attitudes of people who sought their help. The information suggested was very pragmatic and practical. Details an Australian born resident would know easily and take for granted but are unknnown to new arrivals not used to free health care. Participants made it clear that their comunity was still unsrure of the cost and process of getting the help they might need. An important message to their elders would be that "it's no big thing, just call" (16year-old Iraqi male).

To disseminate the necessary information to their community, participants' suggested GVHealth:

- Develop a DVD 'with real people telling real stories' (but not loccal community members) that can be given to elders at the major mosques
- Design a poster with key elements of the message to be put on walls where communities gather (meeting houses, doctors clinics etc.)
- Printed material that can be taken home for English readers (usually sons or daughters) to read, translate and explain in privacy.

Conclusions:

When considering early intervention, the main conclusion from this investigation is that cultural constructions of illness are a strong indicator of precipitate action that might be generated by attenuated psychiatric symptomatology. In this, explanatory models of mental illness held by members of newly arrived communities may differ within families between generations, especially as younger family members come into contact with general mental health promotion information. More discussion is needed to bring various explanatory models into dialogue with western methodology.

Even with new knowledge, cultural tradition will be a major factor in the way a young person may be encouraged or constrained to seek help for themselves or others. As described in this project and others, the apparent first step to help-seeking for the young is with their friends and peers[33, 36, 46, 47]. The participants in this project were confident that new information could be afforded to the elders through culturally congruent paths, i.e. through the holders of knowledge in their community. All participants considered educating the community elders as integral to better access to services by young people. Further conversations with these community leaders could bring mutual understanding about mental illness between younger people, their families and communities and mental health practitioners.

This project suggests that more work is needed to design pathways to assist young people in their quest to navigate the two cultures that affect their everyday lives. The young people in this project have indicated they feel that change needs to begin with the elders of their communities, but how these people with their histories of violence and loss can be engaged in change dialogue is yet to be investigated. The process requires minority cultures to be more fully involved in the design of triage and assessment processes within mental health services. This is especially so in rural areas where cultural beliefs, attitudes and old rivalries may restrict the inclusion of certain members of the local community when dealing with individuals. These cultural elements need further investigation to enable services to assist young people to engage with and educate their peers and elders in the possibilities of western medicine and psychiatry.

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Royal Commission into
Victoria's Mental Health System

ATTACHMENT RB-25

This is the attachment marked '**RB-25**' referred to in the witness statement of Dr Ravi Subramanya Bhat dated 4 July 2019.

Suicide and mental health in rural, remote and metropolitan areas in Australia

Tanya M Caldwell, Anthony F Jorm and Keith B G Dear

ABSTRACT

Objectives: To compare the prevalence of mental health disorders and the use of professional help by area of residence, age and sex; and to determine whether the differences parallel differences in suicide rates.

Design: Retrospective cross-sectional analysis of Australian national mortality data (1997–2000) and the National Survey of Mental Health and Wellbeing (1997), using broad area-of-residence classifications based on the Rural, Remote and Metropolitan Area (RRMA) index.

Main outcome measures: (a) Suicide rates; (b) prevalence of depression, anxiety and substance-use disorders; and (c) use of health professionals for mental health problems — by age, sex and area of residence.

Results: Higher suicide rates were evident for men, particularly young men in rural (40.4 per 100 000; *z*, 3.2) and remote (51.7 per 100 000; *z*, 7.2) populations compared with metropolitan (31.8 per 100 000) populations. Although the proportion of young men reporting mental health disorders did not differ significantly between rural (23.5%; *z*, −0.5) and remote (18.8%; *z*, −1.6) areas compared with metropolitan (25.6%) areas, young men with a mental health disorder from non-metropolitan areas were significantly less likely than those from metropolitan areas to seek professional help for a mental health disorder (11.4% v 25.2%; *z*, −2.2).

Conclusions: There is a need to investigate why young men in non-metropolitan areas, the population with the greatest suicide risk, do and do not engage with mental health services.

MJA 2004; 181: S10–S14

In Australia, suicide rates have consistently been found to be higher in rural than in metropolitan areas.[1] Adolescent and young adult males,[2,3] especially those in rural or remote areas, have particularly high suicide rates.[4–6] Mental health disorders have been described as the strongest risk factor for suicide across all ages[7] and in young people.[8] However, only a small body of literature has specifically focused on how mental health differs by age and sex across rural and metropolitan areas.

Judd et al[9] conducted a literature review on rural psychiatric morbidity and found few differences in the prevalence of mental health disorders among urban and rural residents.[9] The adult component of the 1997 Australian National Survey of Mental Health and Wellbeing (NSMHWB)[10] revealed a slightly increased risk of anxiety disorders in rural centres, but a lower risk of "any mental health disorder" in "other rural" compared with urban areas. However, these differences were not significant after adjusting for a wide array of sociodemographic characteristics. Judd et al[9] commented that variation in subgroups may be missed by such broad analyses and that further analysis of the NSMHWB data was needed.

Betts and Thornicroft[11] noted that mental health services are generally recognised as being less available in rural and remote areas, where access to qualified specialist staff is often very limited. For instance, there are far fewer psychiatrists (by main place of work) for rural and remote populations (3.3 and 1.8 per 100 000, respectively) than for metropolitan populations (14.2 per 100 000).[12] Service use is not independent of provision, ease, and means of access. However, there are few Australian community-based studies looking at service use and mental health that incorporate area of residence in their analyses. In the NSMHWB, residents of rural centres and "other rural" areas were found to be less likely than metropolitan residents to receive help from psychiatrists and psychologists for a mental health problem, findings which persisted after taking a wide range of characteristics into account, including the prevalence of disorders.[13] However, there was no association between participants' area of residence and whether or not they accessed help from any mental health professional or from a general practitioner for a mental health problem.[13]

Higher suicide rates in rural compared with metropolitan areas, despite similar rates of reported mental disorders, suggest that factors other than mental health (including sociodemographic and service-related factors) may also influence suicide rates. For instance, compared with other age groups, young adults, particularly young men, visit GPs infrequently for general healthcare.[14,15] Andrews et al[16] found that men without tertiary education and without family responsibilities were the group least likely to consult a professional for a mental health problem and suggested they may not recognise they have a problem. These investigators argued that mental health literacy programs should specifically target these men.[16]

The aim of our study was to determine, using existing datasets, whether age, sex and area differences in the prevalence of mental disorders and the use of professional help parallel differences in suicide rates.

METHODS

In Australia, deaths are recorded by the state registries of births, deaths and marriages. The Australian Bureau of Statistics (ABS) codes these mortality data according to ICD-10 "X" codes for suicide.[17] Suicide refers to deaths resulting from intentional self-harm (X60–X84), including poisoning; hanging/suffocation; drowning; use of a firearm, explosive material, sharp or blunt objects; motor vehicle crashes; and other or unspecified means.

In our study, we used suicide data collated by the Australian Institute of Health and Welfare over a four-year period (1997–2000). We also analysed data from the NSMHWB to examine

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regional differences in prevalence of mental health disorders and use of professional help for these disorders.

The NSMHWB was designed to establish the prevalence of common mental health disorders and the utilisation and need for mental health services. The survey was carried out by the ABS using trained interviewers. Households were randomly selected using a stratified, multistage area sample. The ABS provided appropriate weights so that an individual's chances of selection, which varied by state, territory and region, did not bias the results.[18] About 13 600 private dwellings were approached between May and August 1997. From each household, one resident aged 18 years or over was randomly selected and interviewed. The response rate was 78% ($n = 10\,641$). The survey did not include homeless people or people living in non-private dwellings such as prisons, hospitals or nursing homes. Comprehensive descriptions of the NSMHWB methods have been previously reported.[18,19]

In the NSMHWB, a modified version of the Composite International Diagnostic Interview was used to assess past-year prevalence rates for substance use, affective and anxiety disorders according to ICD-10 criteria.[20] All respondents were asked about consultations for mental health problems with a wide range of health professionals, including GPs, psychiatrists, psychologists, social workers, welfare workers, drug and alcohol counsellors, nurses, a mental health team or other health professionals.

The Rural, Remote and Metropolitan Area (RRMA) index was included in both the NSMHWB and the ABS mortality data. It is a seven-category classification system based on statistical local areas (Box 1).[21] First, statistical local areas in capital cities and statistical subdivisions containing an urban centre of 100 000 or more people are identified.[22] Then, other statistical local areas are designated an RRMA category based on population numbers and an index of remoteness. The index of remoteness includes a factor relating to the distance from an urban centre (ie, a centre of > 10 000 people) and a population density factor.

The NSMHWB data available to us had been collapsed into three area divisions: metropolitan (RRMA categories 1 and 2), rural centre (RRMA categories 3 and 4) and other rural/remote are (RRMA categories 5, 6 and 7).[19] The suicide data (classified according to the RRMA designation of the usual residence of the deceased) were grouped according to the three NSMHWB area divisions to enable comparison across datasets.

1 Rural, Remote and Metropolitan Area (RRMA) index[1]

Category number	RRMA index categories
1	Capital cities
2	Other metropolitan centres (urban centre population> 100 000)
3	Large rural centres (urban centre population 25 000–99 999)
4	Small rural centres (urban centre population 10 000–24 999)
5	Other rural areas (urban centre population < 10 000)
6	Remote centres (urban centre population > 5000)
7	Other remote areas (urban centre population < 5000)

2 Suicide rates (95% CI) per 100 000 population, by sex, age and RRMA division*

Age (years)	Metropolitan area†	Rural centre‡	z§	Other rural/ remote area¶	z§
Men					
20–29	31.8 (30.1–33.4)	**40.4 (35.5–45.4)**	**3.2**	**51.7 (46.1–57.3)**	**7.2**
30–44	30.4 (29.0–31.7)	**38.0 (34.2–41.8)**	**3.7**	**34.9 (31.4–38.3)**	**2.6**
45–59	20.5 (19.3–21.8)	**29.5 (24.8–32.1)**	**4.0**	**28.3 (25.0–31.6)**	**4.7**
⩾60	22.1 (20.6–23.5)	24.0 (20.5–27.4)	1.0	**27.7 (24.231.1)**	**3.1**
Overall	20.2 (19.6–20.7)	**24.0 (22.625.4)**	**4.9**	**25.7 (24.426.9)**	**7.9**
Women					
20–29	7.2 (6.4–8.0)	8.0 (5.8–10.2)	0.7	7.2 (5.2–9.2)	–0.0
30–44	7.9 (7.2–8.6)	**10.2 (8.212.2)**	**2.1**	7.7 (6.2–9.2)	–0.3
45–59	6.8 (6.1–7.5)	5.5 (3.9–7.1)	–1.4	6.4 (4.9–7.9)	–0.4
⩾60	6.1 (5.4–6.8)	4.8 (3.4–6.2)	–1.5	4.9 (3.5–6.3)	–1.5
Overall	5.6 (5.3–5.9)	5.7 (5.0–6.4)	0.4	5.1 (4.5–5.7)	–1.4

RRMA index = Rural, Remote and Metropolitan Area index.[21]

* **Bold** figures indicate proportions significantly different from those in metropolitan areas ($P < 0.05$).

† Metropolitan area = RRMA categories 1 and 2. ‡ Rural centre = RRMA categories 3 and 4.

¶ Other rural/remote area = RRMA categories 5, 6 and 7.

§ z-score of the difference between RRMA groups and metropolitan areas.

Age-specific suicide rates per 100 000 population were calculated using the ABS estimate of the population age groups living in the different RRMA divisions between 1997 and 2000.

All analysis of the NSMHWB data was conducted using STATA software[23] and applying the weights provided by the ABS. The differences between metropolitan areas and each of the other RRMA divisions were evaluated using z-scores, calculated according to the formula $z = D_{xy} / \sqrt{(S_x^2 + S_y^2)}$, where D_{xy} represents the difference between rates for two RRMA divisions and y (assumed independent), and S_x^2 and S_y^2 are the variances of the suicide rate among people in RRMA divisions x and y, respectively. A z-score greater than 1.96 or less than –1.96 indicates a significant difference ($P < 0.05$).

RESULTS

Suicide

Across almost all age groups, suicide rates for men were higher in rural centres and other rural/remote areas than metropolitan areas ($z > 1.96$), but men aged 20–29 years in non-metropolitan areas had particularly high suicide rates. For women, only those in the 30–44-years age group in rural areas had higher suicide rates than metropolitan women of the same age (Box 2).

Variation in mental health disorders across RRMA divisions

Findings from the analysis of the 1997 NSMHWB data are shown in Boxes 3–6.

Compared with men in metropolitan areas and rural centres, a smaller proportion of men in other rural/remote areas reported substance-use disorders or "any mental health disorder". Apart from this, there were no significant differences in mental health disorders across RRMA divisions for either men or women (Box 3).

While small cell sizes prevented an examination of specific disorders by age, sex and RRMA division, it was possible to make comparisons based on the broader category of people with "any mental health disorder". In rural areas, women aged 30–44 reported higher rates of "any mental health disorder" than their metropolitan counterparts, but otherwise there were no significant differences in the prevalence of mental health disorders between metropolitan areas, rural centres and other rural/remote areas within age groups (Box 4).

3 Proportion of the population (weighted estimates and 95% CIs) with various types of mental health disorder, by sex and RRMA division*

	Metropolitan area† (3151 men, 3986 women)	Rural centre‡ (677 men, 885 women)	z§	Other rural/remote area (877 men, 1065 women)	z§
Affective disorders					
Men	5.4% (4.5%–6.2%)	6.9% (4.9%–9.0%)	1.4	4.1% (2.7%–5.5%)	–1.5
Women	9.3% (8.4%–10.3%)	9.7% (7.7%–11.8%)	0.3	8.4% (6.7%–10.1%)	–0.9
Anxiety disorders					
Men	7.2% (6.2%–8.1%)	8.3% (6.0%–10.6%)	0.9	5.4% (3.8%–7.1%)	–1.7
Women	11.8% (10.7%–12.9%)	14.2% (11.8%–16.7%)	1.8	11.0% (8.9%–13.0%)	–0.7
Substance use disorders					
Men	11.5% (10.2%–12.8%)	11.1% (8.5%–13.6%)	–0.3	**8.6% (6.5%–10.7%)**	**–2.3**
Women	4.4% (3.8%–5.1%)	4.6% (3.2%–6.1%)	0.2	4.1% (2.7%–5.4%)	–0.5
Any mental health disorder					
Men	18.4% (16.8%–19.9%)	18.9% (15.6%–22.1%)	0.3	**15.2% (12.5%–17.8%)**	**–2.1**
Women	19.4% (18.0%–20.7%)	21.2% (18.3%–24.1%)	1.1	16.8% (14.4%–19.2%)	–1.8

RRMA index = Rural, Remote and Metropolitan Area index.[21]

* **Bold** figures indicate proportions significantly different from those in metropolitan areas ($P < 0.05$).

† Metropolitan area = RRMA categories 1 and 2. ‡ Rural centre = RRMA categories 3 and 4.

¶ Other rural/remote area = RRMA categories 5, 6 and 7.

§ z-score of the difference between RRMA groups and metropolitan areas.

4 Proportion of the population (weighted estimates and 95% CIs) with any mental health disorder in the previous year, by sex, age and RRMA division*

Age (years)	Metropolitan area† (3151 men, 3986 women)	Rural centre‡ (677 men, 885 women)	z§	Other rural/remote area (877 men, 1065 women)	z§
Men					
18–29	25.6% (21.9%–29.4%)	23.5% (15.0%–32.0%)	–0.5	18.8% (11.1%–26.5%)	–1.6
30–44	21.0% (14.3%–27.7%)	22.4% (9.0%–35.9%)	0.2	22.1% (12.1%–32.2%)	0.2
45–59	14.8% (11.9%–17.7%)	16.8% (11.0%–22.5%)	0.6	13.0% (8.2%–17.7%)	–0.6
⩾60	7.9% (5.6%–10.1%)	11.3% (5.5%–17.2%)	1.1	5.2% (2.1%–8.4%)	–1.3
Women					
18–29	25.5% (22.3%–28.7%)	25.9% (19.2%–32.7%)	0.1	23.1% (15.8%–30.4%)	–0.6
30–44	21.1% (18.7%–23.4%)	**27.1% (21.6%32.6%)**	**2.0**	20.3% (15.9%–24.7%)	–0.3
45–59	19.3% (16.3%–22.2%)	20.1% (14.2%–26.0%)	0.3	17.8% (13.2%–22.5%)	–0.5
⩾60	9.6% (7.5%–11.8%)	10.0% (5.7%–14.4%)	0.2	6.7% (3.4%–9.9%)	–1.5

RRMA index = Rural, Remote and Metropolitan Area index.[21]

* **Bold** figures indicate proportions significantly different from those in metropolitan areas ($P < 0.05$).

† Metropolitan area = RRMA categories 1 and 2. ‡ Rural centre = RRMA categories 3 and 4.

¶ Other rural/remote area = RRMA categories 5, 6 and 7.

§ z-score of the difference between RRMA groups and metropolitan areas.

Professional help for mental health problems

The proportion of the population who had received professional help for any mental health disorder during the previous year is shown in Box 5. Small cell sizes meant that all rural centres and other rural/remote area categories (ie, RRMA categories 3–7) needed to be combined into one group ("non-metropolitan") for purposes of analysis. A smaller proportion of non-metropolitan than metropolitan young adults (both men and women) had received professional help for a mental health problem.

The proportion of those who met the ICD 10 criteria for any mental health disorder who had received professional help for a mental health disorder during the previous year is shown in Box 6. In non-metropolitan areas, a smaller proportion of young men with any mental health disorder accessed professional help than in metropolitan areas. There was no difference between young women from metropolitan and non-metropolitan areas when only those with a mental health disorder were included in the analysis. Subsequent analyses also indicated that, in non-metropolitan areas, a smaller proportion of young men with any mental health disorder accessed professional help than young women (z, 2.3).

DISCUSSION

Our study confirmed that young men in non-metropolitan areas have higher suicide rates than their metropolitan counterparts. However, while mental health disorders are a leading risk factor for suicide, we did not find that young men in non-metropolitan areas reported higher levels of mental health disorders.

For women, both mental health disorders and suicide rates in the 30–44-years age group were slightly higher in large rural areas compared with metropolitan areas. However, these findings were of borderline statistical significance, and further confirma-

5 Proportion of the population (weighted estimates and 95% CIs) who had received professional help for any mental health disorder during the previous year, by sex, age and RRMA group*

Age (years)	Metropolitan area† (3151 men; 3986 women)	Non-metropolitan area‡ (1554 men; 1950 women)	z§
Men			
18–29	8.1% (5.9%–10.4%)	**3.8% (1.0%–6.5%)**	**–2.4**
30–44	10.9% (8.9%–12.9%)	8.0% (5.7%–10.3%)	–1.9
45–59	8.8% (6.6%–10.9%)	9.9% (6.7%–13.1%)	0.6
⩾60	4.5% (2.8%–6.3%)	3.8% (1.7%–5.9%)	–0.5
Overall	8.5% (7.5%–9.6%)	**6.7% (5.4%8.0%)**	**2.1**
Women			
18–29	15.8% (13.2%–18.4%)	**9.5% (6.3%12.7%)**	**3.0**
30–44	16.1% (14.0%–18.2%)	18.1% (15.0%–21.3%)	1.1
45–59	15.6% (13.0%–18.3%)	14.3% (11.0%–17.6%)	–0.6
⩾60	7.6% (5.6%–9.7%)	5.2% (3.1%–7.4%)	–1.6
Overall	14.1% (12.9%–15.3%)	12.4% (10.8%–13.9%)	–1.8

RRMA index = Rural, Remote and Metropolitan Area index.[21]

* **Bold** figures indicate proportions significantly different from those in metropolitan areas ($P < 0.05$).

† Metropolitan area = RRMA categories 1 and 2.

‡ Non-metropolitan area = RRMA categories 3, 4, 5, 6 and 7.

§ z-score of the difference between RRMA groups and metropolitan areas.

tion is needed before conclusions can be drawn. Overall, for women, there were few differences in rates of suicide and mental health disorders across RRMA divisions.

Our results show that only a small proportion (11%) of 18–29-year-old men with mental health disorders in non-metropolitan areas had accessed professional help. Young men (the group with the highest suicide rates) had less contact with health professionals for a mental health problem than both metropolitan young men and non-metropolitan young women with any mental health disorder.

Our study has many of the shortcomings evident when attempting to investigate aspects of rural health. Although the higher proportion of Indigenous people in rural and remote areas may be an important factor affecting suicide rates, it was not possible to identify Indigenous status in the data we used. The NSMHWB data file did not specify Indigenous status, and suicide rates among Indigenous people were not available for all Australian states. The NSMHWB data reported here did not include adolescents (aged < 18 years), so our analysis cannot explore this population. While this study discusses trends and suggests possibilities, it cannot directly evaluate cause and effect, because the data were cross-sectional. Furthermore, the RRMA classification does not allow for diversity within statistical local areas and combines the concepts of distance and population density.[22] We acknowledge and emphasise that there is considerable variability within and across regions of Australia. It is also important to note that the NSMHWB data reflect self-reported symptoms/disorders and that young men, particularly those in non-metropolitan areas, may have been less likely to report, recognise or be concerned about symptoms than their metropolitan counterparts.

The small number of participants surveyed in non-metropolitan areas has several implications. First, rural and remote RRMA categories needed to be collapsed when reporting service-use patterns from the NSMHWB dataset, so we were unable to compare rural and remote areas. Second, a range of subgroups, specific services, patterns of use and characteristics could not be examined. Third, four years of suicide data (1997–2000) from the ABS needed to be combined to enable a breakdown by age and sex, whereas the NSMHWB was conducted over a single year (1997). Finally, the small sample sizes in rural and remote areas may have meant that some significant differences between groups were not found (eg, in the proportion of mental health disorders among young men in rural and remote areas compared with metropolitan areas).

We were unable to investigate the reasons why professional help is or is not used. Tudiver and Talbot[24] argued that men do not seek general healthcare for a range of reasons, including a tendency to use indirect sources of help; the perception that seeking help will show their vulnerability; fear and denial; difficulty relinquishing control; and systematic barriers. Another study indicated that knowledge about depression and its treatments was greater among women and younger people.[25] Mental health literacy may be a particular problem for young men in rural areas, who may be less likely to recognise or report symptoms of distress or know what can be done to help.

Some researchers have argued that a high proportion of suicides among patients with psychiatric disorders may be preventable through appropriate service-system responses.[26,27] While improving suicide prevention strategies for people already in contact with professional help is vitally important, mental health policy and services also need to better incorporate people who currently have little contact with the healthcare system.

6 Proportion (weighted estimates and 95% CIs) of those meeting the ICD-10 criteria for any mental health disorder who received professional help during the previous year, by sex, age and RRMA group*

Age (years)	Metropolitan area† (602 men; 823 women)	Non-metropolitan area‡ (264 men; 386 women)	z§
Men			
18–29	25.2% (18.1%–32.3%)	**11.4% (1.1%–21.7%)**	**–2.2**
30–44	34.0% (27.3%–40.7%)	27.3% (19.1%–35.6%)	–1.2
45–59	35.8% (25.9%–45.8%)	41.3% (27.9%–54.7%)	0.6
⩾60	26.9% (14.1%–39.7%)	24.4% (8.4%–40.4%)	–0.2
Overall	30.6% (26.4%–34.7%)	26.2% (20.5%–31.9%)	–1.2
Women			
18–29	37.3% (30.6%–44.0%)	27.9% (17.8%–38.0%)	–1.5
30–44	49.7% (43.5%–55.9%)	50.1% (41.7%–58.5%)	0.1
45–59	53.5% (45.1%–61.9%)	53.7% (43.1%–64.3%)	0.0
⩾60	39.5% (27.8%–51.2%)	41.0% (24.2%–57.8%)	0.1
Overall	45.4% (41.6%–49.3%)	44.3% (38.9%–49.7%)	–0.3

RRMA index = Rural, Remote and Metropolitan Area index.[21]

* **Bold** figures indicate proportions significantly different from those in metropolitan areas ($P < 0.05$).

† Metropolitan area = RRMA categories 1 and 2.

‡ Non-metropolitan area = RRMA categories 3, 4, 5, 6 and 7.

§ z-score of the difference between RRMA groups and metropolitan areas.

Overall, a wide range of factors, including those relating to being male, together with a fundamental lack of services, may help to explain why young men, particularly those in rural areas, do not access professional help.

Given that mental health problems are a major risk factor for suicide, a better understanding of the reasons behind young rural men's use and non-use of services is of considerable importance. Increasing service use by and for these men, even to a small degree, might reduce their suicide rates.

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COMPETING INTERESTS

None identified.

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ATTACHMENT RB-26

This is the attachment marked '**RB-26**' referred to in the witness statement of Dr Ravi Subramanya Bhat dated 4 July 2019.

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Original communication

Ten years of suicide mortality in Australia: Socio-economic and psychiatric factors in Queensland

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ABSTRACT

Background: With the exception of the United States, in recent years suicide rates have been declining in most western countries. Notoriously, suicide rates fluctuate – especially in males – in response to a range of socio-political and environmental factors, some of them difficult to identify. Our aim was to obtain an updated profile of main commonalities in suicide cases of Queensland residents between 2002 and 2011 to inform prevention strategies.

Methods: Data were obtained from the Queensland Suicide Register (QSR), including police and toxicology reports, post-mortem autopsy and Coroner's findings. Data are crosschecked with records from the National Coronial Information System. Age-standardised rates (ASR) of suicide, Poisson regression and Chi^2 tests are presented.

Results: A total of 5752 suicides by Queensland residents was registered between 2002 and 2011; 76.9% by males and 23.1% by females. The average ASR was 14.3 per 100,000, with a significant decrease between 2002 and 2011. Rates declined significantly in males, not in females. On average, rates were 3.41-times higher in males. ASR for Aboriginal and Torres Strait Islander peoples was significantly higher than for other Australians. Overall, male suicide rates were particularly high in remote areas, as well as in the most disadvantaged ones. One third of suicide cases presented history of previous suicidal behaviour, and half a detected and treated mental disorder. Hanging was the most common method.

Conclusions: Suicide rates have declined in Queensland, Australia. It is problematic to say if this was due to suicide prevention programs or other factors.

1. Introduction

The recent World Health Organization's report on suicide (*Preventing Suicide: A Global Imperative*) has indicated that, globally, during the period 2000–2012 suicide figures have declined by 9%: from 883,000 to 804,000.[1] With the notable exception of the United States, most western countries have witnessed remarkable declines in suicide rates. The reasons for these changes are unknown, even if they are generally attributed to improvements in health conditions and quality of life of individuals.[1]

The WHO report also highlights the fact that, in order to develop suitable suicide prevention programs for a community or country, a deeper understanding of the existing data is required. Governments are then compelled to improve data quality in order to measure the effectiveness of their interventions.[1]

The Queensland Suicide Register (QSR) is a comprehensive suicide database that runs since 1990 and is managed by the Australian Institute for Suicide Research and Prevention (AISRAP). The QSR includes a wide range of high-quality data on all suicides by Queensland residents.

Aim of the current paper is to analyse the most recent information in order to inform suicide prevention planning in Queensland, and possibly Australia. Analyses of suicide trends by age and gender and in vulnerable populations, such as Aboriginal and Torres Strait Islander peoples, are presented. In addition, suicide methods, and socio-demographic and psychiatric characteristics of people who died by suicide in the ten years between 2002 and 2011 are explored.

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2. Methods

2.1. The Queensland Suicide Register

Information sources of the QSR include police report of death to a Coroner (Form 1), post-mortem autopsy report, toxicology report and Coroner's findings, including narrative of circumstances of death (who the deceased person was, and how, when and where the person died). Documents are crosschecked with records from the National Coronial Information System (NCIS). The QSR scrutinises all cases of possible suicide to determine the level of probability that the death was due to suicide. Following a decision tree described elsewhere,[2] cases are classified into three different levels: 1) beyond reasonable doubt; 2) probable; and, 3) possible.

For the present analyses, only cases falling into the categories of Beyond Reasonable Doubt and Probable were included.

The QSR procedures are approved by the Griffith University Human Research Ethics Committee (CSR/02/10/HREC).

2.2. Definition of variables

2.2.1. Remoteness

The Accessibility/Remoteness Index of Australia (ARIA+) is the standard Australian Bureau of Statistics (ABS) endorsed measure of remoteness, and forms the basis for the ABS "Remoteness Structure" component of the Australian Statistical Geography Standard (ASGS).[3] It is a continuous index with values ranging from 0 (high accessibility) to 15 (high remoteness). The index is based on road distance measurements from over 12,000 populated localities to the nearest Service Centres in five-size categories, based on population size.[4]

Each area in Queensland corresponds to one of five categories of remoteness: Major Cities, Inner Regional, Outer Regional, Remote, and Very Remote. In this article, Metropolitan areas are those categorised as Major Cities; Regional areas are those categorised as Inner Regional and Outer Regional; and, Remote areas are those categorised as Remote and Very Remote.

2.2.2. Socio-Economic Indexes for Areas (SEIFA)

Socio-Economic Indexes for Areas (SEIFA) were developed by the ABS to rank areas in Australia according to relative socio-economic advantage and disadvantage. The indexes are based on information from five-yearly Censuses. SEIFA 2011 is based on 2011 Census data, and consists of four indexes, each focussing on a different aspect of socio-economic advantage and disadvantage and being a summary of a different subset of Census variables.[5] SEIFA 2011 is released according to the Australian Statistical Geography Standard (ASGS).

The Index of Relative Socio-Economic Disadvantage (IRSD) summarises variables that indicate relative disadvantage. It ranks areas on a continuum from most disadvantaged to least disadvantaged. A low score on this index indicates a high proportion of relatively disadvantaged people in an area. However, an area with a very high score does not automatically imply a large proportion of relatively advantaged people, as there are no variables in the index to indicate this.

The Index of Relative Socio-Economic Advantage and Disadvantage (IRSAD) summarises variables that indicate either relative advantage or disadvantage. This index ranks areas on a continuum from most disadvantaged to most advantaged. An area with a high score on this index has a relatively high incidence of advantage and a relatively low incidence of disadvantage.

The Index of Economic Resources (IER) summarises variables relating to the financial aspects of relative socioeconomic advantage and disadvantage. These include indicators of high and low income, as well as variables that correlate with high or low wealth. Areas with higher scores have relatively greater access to economic resources than areas with lower scores.

The Index of Education and Occupation (IEO) summarises variables relating to the educational and occupational aspects of relative socio-economic advantage and disadvantage. This index focuses on the skills of the people in an area, both formal qualifications and skills required to perform different occupations. A low score indicates that an area has a high proportion of people without qualifications, without jobs, and/or with low-skilled jobs. A high score indicates many people with high qualifications and/or highly skilled jobs.

For ease of interpretation, quantiles are used for the current analysis rather than index scores, as recommended by ABS. *The indexes are assigned to areas, not to individuals*. They indicate the collective socio-economic characteristics of the people living in an area.[5]

2.3. Population data

The following population data were used in order to calculate rates or make relevant comparisons.

Population numbers by gender and age – Estimated Resident Population (ERP) by Region, Age & Sex, 2001 to 2013.[6] *Remoteness* – The 2011 Census of Population and Housing.[7] *Socio-Economic Indexes for Areas (SEIFA)* – Queensland Regional Database.[8] *Aboriginal and Torres Strait Islander peoples* – Estimates and Projections, Aboriginal and Torres Strait Islander Australians, 2001 to 2026 from the ABS.[9] *Employment status* – 2011 Census of Population and Housing Time Series Profile.[10]

2.4. Statistical analysis

Age-standardised suicide rates (ASR) were calculated using the direct method and the Australian population of 2001 as the standard. The rate ratios (RR) were calculated using the ASR of all of Queensland as the denominator, providing an indication of the regional mortality rate relative to the all-of-Queensland rate. Confidence intervals are shown for the calculated ASRs and RRs. Poisson regression analyses were performed to determine any significant linear trends in suicide rates by gender, age group and Indigenous background. Incidence Rate Ratios (iRR), with 95% confidence intervals (95% CI), are presented. Chi^2 were calculated compare groups and Chi^2_{trend} to measure change in prevalence in time. The analysis was performed with IBM SPSS version 22.0.

3. Results

3.1. Suicide incidence and rates by gender and age

A total of 5752 suicides by Queensland residents was registered between 2002 and 2011 (as 'beyond reasonable doubt' or 'probable'); 4422 were males (76.9%) and 1330 females (23.1%). The average yearly incidence was 575 suicides, with 442 males and 133 females (Fig. 1a). The average ASR was 14.3 per 100,000 persons, with a significant decrease from 16 in 2002 to 13.5 in 2011 (iRR = 0.985, 95%CI: 0.976–0.994, $p = 0.001$) (Fig. 1b). The male ASR declined significantly from 25.5 in 2002 to 19.5 in 2011 (average 22.3; iRR = 0.98 95%CI: 0.97–0.99, $p < 0.001$). The female ASR was relatively stable, with a non-significant increase from 6.8 in 2002 to 7.2 in 2011 (average 6.5; iRR = 1.01 95%CI: 0.99–1.03, $p = 0.149$). The male ASR was significantly higher than the female ASR during the reported period, being on average of 3.41 times higher (95%CI: 3.21–3.62).

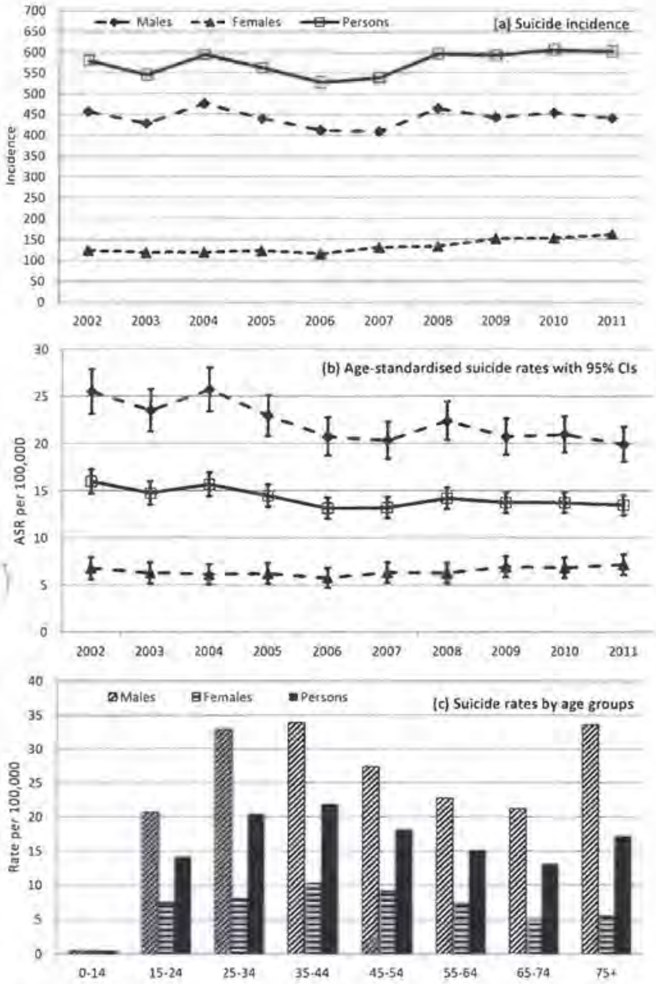

Fig. 1. Suicide incidence, ASR per 100,000 and rates by age groups in 2002–2011.

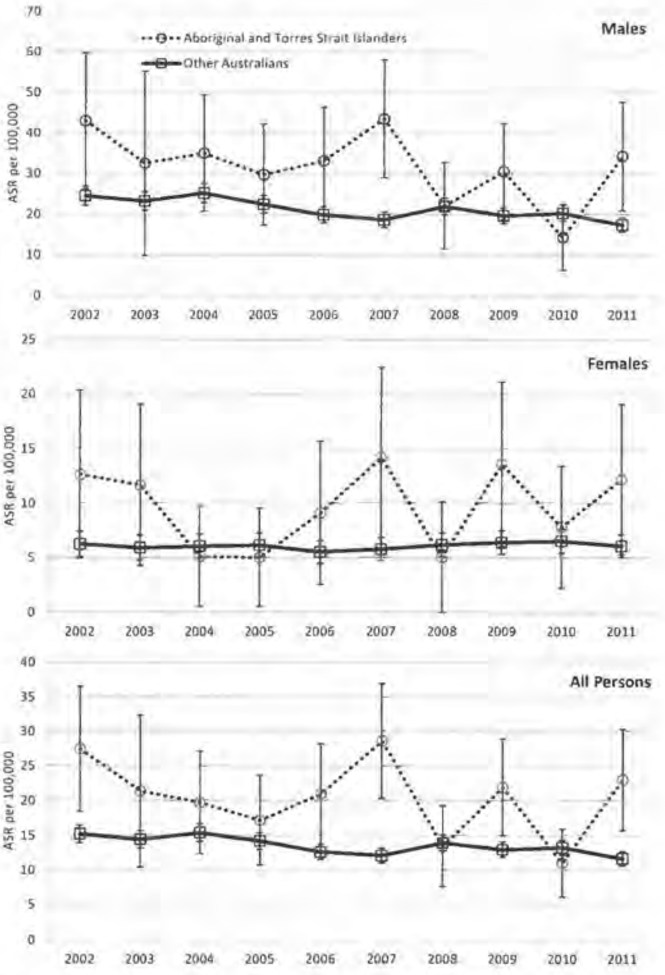

Fig. 2. ASR of Aboriginal and Torres Strait Islander peoples and other Australians by gender.

Suicide rates for all persons, males and females were highest in the age group 35–44 years (Fig. 1c). Suicide rates in the age group below 15 years were the smallest, at 0.5 per 100,000 on average for both genders, fluctuating between 0 and 1.2 per 100,000 during 2002–2011. Poisson regression models showed a significant decline in suicide rates for males in the age groups 15–24 years (iRR = 0.96 95%CI: 0.93–0.99, $p = 0.003$), 25–34 years (iRR = 0.95 95%CI: 0.93–0.98, $p < 0.001$), 35–44 years (iRR = 0.97 95%CI: 0.95–0.99, $p = 0.006$) and 65–74 years (iRR = 0.96 95%CI: 0.92–0.99, $p = 0.028$) and for females in the age group 25–34 years (iRR = 0.94 95%CI: 0.90–0.98, $p = 0.005$). The only group showing a significant increase was that of females aged 45–54 years (iRR = 1.06 95%CI: 1.01–1.10, $p = 0.011$).

3.2. *Aboriginal and Torres Strait Islander peoples*

Between 2002 and 2011, 341 Aboriginal and Torres Strait Islander suicides (5.9%) and 5292 other Australian suicides were identified in Queensland, while ethnicity was unknown for 119 suicide cases (2.1%). It is important to note that the unknown category increased over time, being the highest in 2011 (8.5%) and the lowest in 2003, when there were no unknown cases. Unknown cases were excluded from this analysis.

For 2002–2011, the ASR for Aboriginal and Torres Strait Islander peoples was significantly higher than for other Australians (20.5 vs 13.3 per 100,000; iRR = 1.54, 95% CI: 1.38–1.72) (Fig. 2). Males had 1.49-times higher rates (95%CI: 1.31–1.70) and females 1.6-times higher rates (95%CI: 1.29–1.98) than other Australians. The suicide trends of Aboriginal and Torres Strait Islander peoples showed a non-significant decline for males (iRR = 0.97, 95%CI: 0.93–1.02, $p = 0.238$) and a relatively stable trend for females.

For Aboriginal and Torres Strait Islander males, suicide rates were highest in the age group 25–34 years (72.1 per 100,000), followed by 15–24 year olds (53.9) and 35–44 year olds (49.1). For other Australian males in Queensland, suicide rates were highest in 35–44 years (32.6 per 100,000), followed by males aged over 75 years (32.8) and 25–34 years (30.40). Similarly to males, Aboriginal and Torres Strait Islander females were generally younger when they died by suicide, with the highest rates in the age group 15–24 years (26.8) followed by 25–34 years (15.7) and 35–44 years (14.8). There were no Aboriginal or Torres Strait Islander female suicides in age groups over the age of 55 years, while for other Australian females suicide peaked in the age group 35–44 years (9.8), followed by 45–54 (9.0) and 55–64 years (7.4). Suicide rates were significantly higher in Aboriginal and Torres Strait Islander peoples in age groups below 45 years, while, in age groups over 45 years, suicide rates for other Australians were higher.

3.3. *Suicide rates by remoteness and SEIFA*

ASRs for 2009–2011 were calculated for metropolitan, regional and remote areas of Queensland using ARIA+ 2011 categories. For both genders, ASRs increased with remoteness - for males 18.6, 23.9 and 33.6 per 100,000 and for females 6.8, 7.4 and 12.0 per 100,000. Suicide rates in remote areas were significantly higher compared to the Qld average for both genders (males - RR = 1.63 95%CI: 1.26–2.12; females - RR = 1.72 95%CI: 1.08–2.72) and, for males, the regional rate was also significantly higher (RR = 1.16 95%CI: 1.05–1.29).

Fig. 3 presents ASRs by SEIFA indexes divided into quartiles (1 presents the most disadvantaged and 4 the most advantaged areas) in 2009–2011. All indexes showed the highest suicide rates in the most disadvantaged areas and the lowest in the most advantaged areas for both gender. Differences were more pronounced for males (Fig. 3).

3.4. Suicide methods

ASRs for the four most frequent suicide methods are presented in Fig. 4. All other methods are merged together into one category. Hanging was the most frequently used suicide method, representing 45.1% of all suicides; it was significantly more frequent in males than females (47.9% vs 35.8%; $Chi^2 = 61.29$ df = 1, $p < 0.001$). Average ASR of hanging for males was 10.58 per 100,000 and 2.34 for females. The latter showed a significant increase in the choice of this method (iRR = 1.04, 95%CI: 1.01–1.07, p = 0.015) during the study period (Fig. 4). Drug poisoning was the second most frequent suicide method overall, used by 16.3% people who died by suicide; while it was the second most frequent for females, it was the third for males. It was used significantly more often by females than males (33.3% vs 11.2%; $Chi^2 = 364.75$ df = 1 $p < 0.001$). The third most frequent suicide method was poisoning with carbon monoxide (CO), mainly from motor vehicle exhaust. It represented 11.4% of all cases, being the second most frequent method for males (12.4% vs 8.1%; $Chi^2 = 18.37$ df = 1 $p < 0.001$). However, ASR showed a significant decline for CO poisoning in both genders (for males iRR = 0.88, 95%CI: 0.86–0.92, $p < 0.001$; for females iRR = 0.88, 95% CI: 0.82–0.94, $p < 0.001$). The fourth most prevalent suicide method was firearms and explosives, used by 8.9% of persons who died by suicide. Also this method was significantly more frequently used by males (10.8% vs 2.6%; $Chi^2 = 84.28$ df = 1 $p < 0.001$). However, its use declined significantly (only for males) during 2002–2011 (iRR = 0.97, 95%CI: 0.95–1.00, p = 0.027). The most frequent other method was jumping from height (3.4%), followed closely by suffocation by plastic bag (2.6%), being hit by a moving object (2.5%), drowning (2.3%) and cutting/piercing (2.2%).

3.5. Marital and employment status

The analysis by marital status includes people aged 15 years and over; cases with 'unknown' marital status were excluded (15.3%: 15.2% for males and 16.1% for females). For both genders, people were most frequently married (41.4%: males 40.4%, and females 45%), followed by never married (30.7%: males 31.5%, and females 28%). Of the remaining sample of people who died by suicide, 15.1% were separated (males 15.9%, and females 12.5%), 8.8% we divorced (males 8.5%, and females 9.7%) and 3.9% widowed (male 3.7%, and females 4.8%).

The analysis by employment status includes people aged 15 years and over. Cases with 'unknown' status were excluded from the analysis (15.8%: 14.7% for males and 19.7% for females). In the 2011 Census of Population and Housing, employment information was not stated in 6% of persons. Suicide rates were by far the highest in unemployed persons of both genders (for males 161.1 per 100,000 and for females 61.6). Rates were the lowest in employed people (for males 16.6 per 100,000 and for females 3.7), followed closely by people out of the work force (for males 20.2 per 100,000 and for females 7.3).

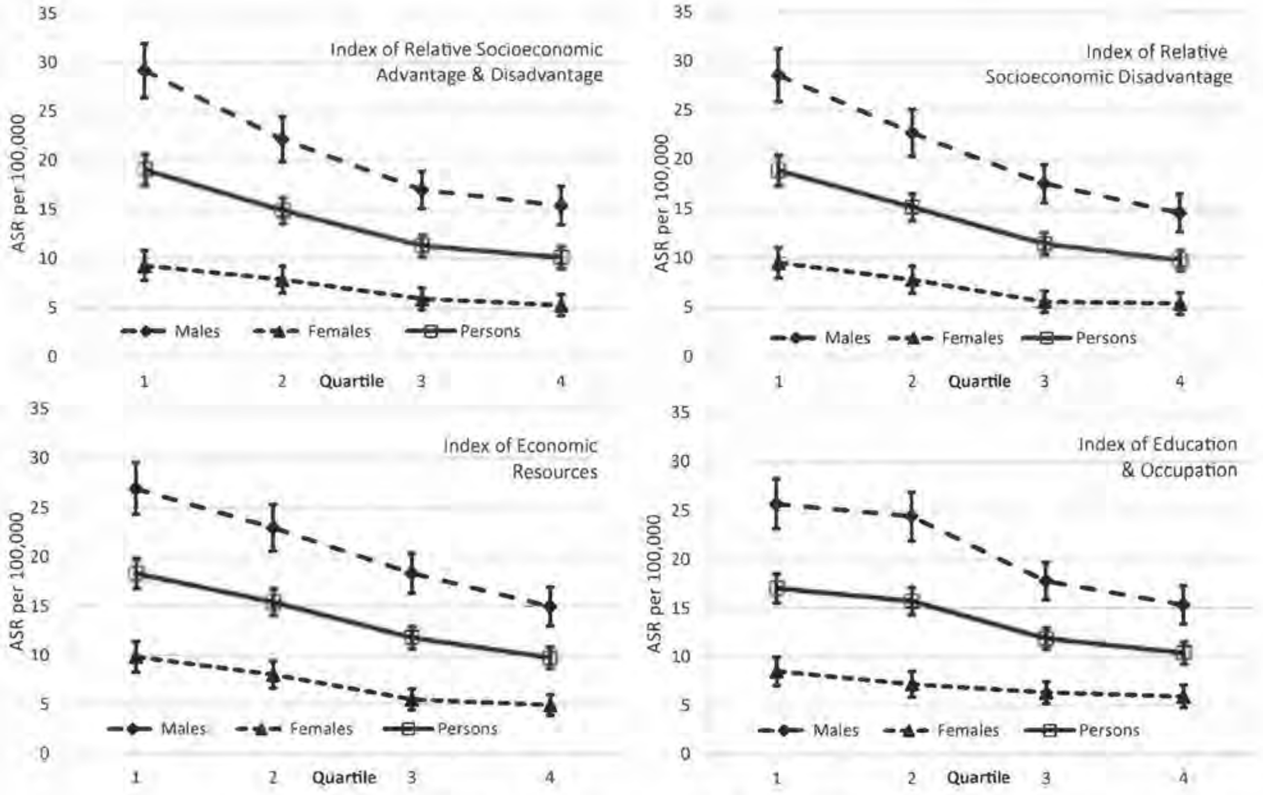

Fig. 3. ASR and RR by SEIFA indexes in quartiles for QLD in 2009–2011.

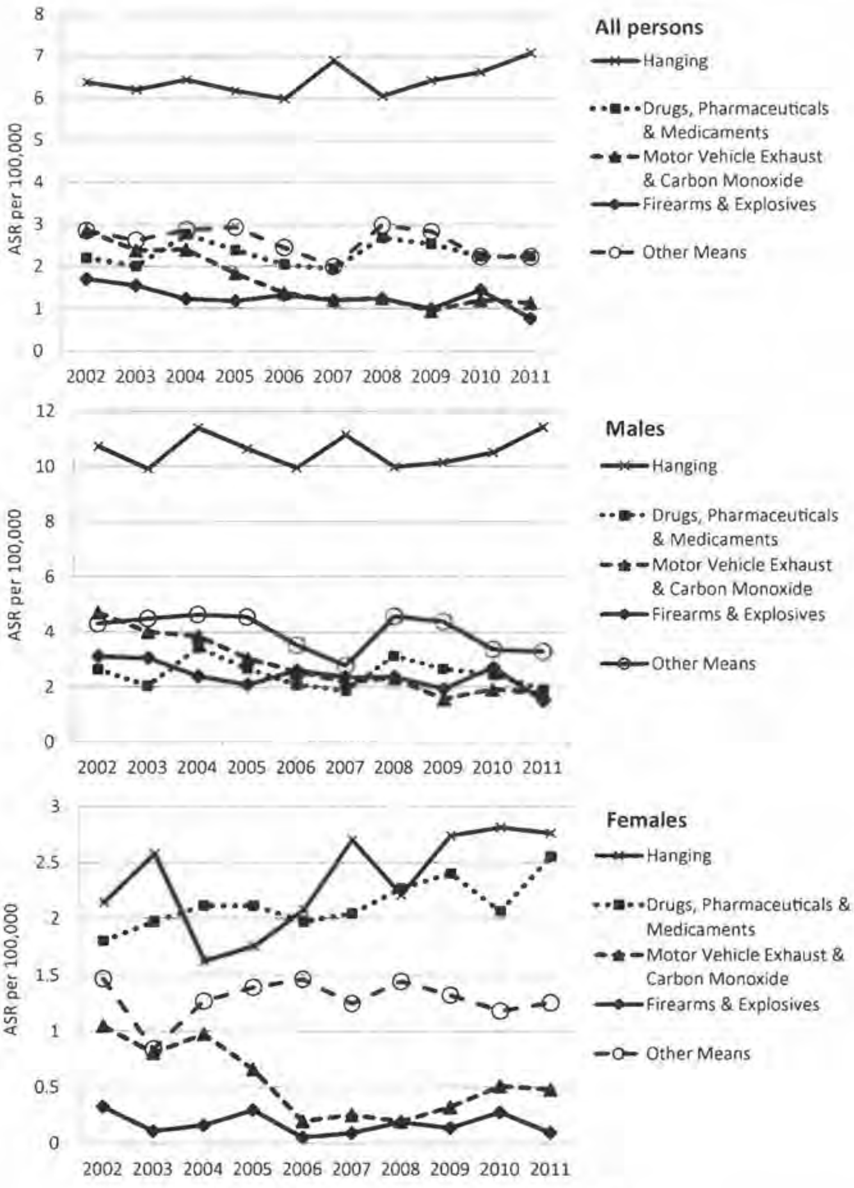

Fig. 4. ASR of suicide methods for QLD in 2002–2011.

3.6. *Psychiatric disorders and treatment*

In total, 49.2% of all suicide cases had information that the deceased suffered from at least one psychiatric disorder (Fig. 5a), and this was significantly more frequent in females than in males (63.6% vs 44.9%; $\text{Chi}^2 = 143.26$ df = 1 $p < 0.001$). Prevalence of psychiatric disorders increased significantly for both genders between 2002 and 2011 (Fig. 5a; males $Chi^2_{trend} = 9.38$, df = 1, $p = 0.002$; females $Chi^2_{trend} = 6.02$, $p = 0.014$).

Unipolar depression was the most frequent diagnosis (34.7%), and was significantly more prevalent in females than males (45.8% vs 31.4%; $\text{Chi}^2 = 91.11$, df = 1, $p < 0.001$). It was followed by psychotic disorders (6.8%), without significant difference by gender (7.6% vs 6.5%). Substance use disorders (5.4%), anxiety disorders (4.9%), bipolar depression (4.5%) and personality disorders (1.4%) were all significantly more prevalent in females.

Fig. 5b presents the prevalence of psychiatric treatment during lifetime and Fig. 5c in the three months prior to suicide. Overall 49% of people who died by suicide received psychiatric treatment and 27.4% had a consultation with a health professional with regards to their mental health condition in the three months prior to suicide. Females were treated more frequently (62.0% vs 45.6%; $\text{Chi}^2 = 116.44$, df = 1, $p < 0.001$) and also had a consultation more often in their last three months (35.3% vs 25%; $\text{Chi}^2 = 54.19$, df = 1, $p < 0.001$).

Evidence of untreated psychiatric condition was reported in one-fourth (26.6%) of cases, being significantly more frequent in males (27.7% vs 22.9%; $\text{Chi}^2 = 91.11$, df = 1, $p < 0.001$). This phenomenon also showed a significant upward trend for males ($Chi^2_{trend} = 50.59$, df = 1, $p < 0.001$).

One-third (31.2%) of people who died by suicide had a history of previous suicide attempt(s). This was significantly more frequent in females (44.4% vs 27.3%; $\text{Chi}^2 = 139.22$, df = 1, $p < 0.001$).

3.7. *Life events*

In the QSR, relationship problems are divided into two main categories: conflict and separation. Relationship conflict was recorded in 12.7% of cases, without differences by gender (males 12.9%, females 11.9%). Relationship separation is present more

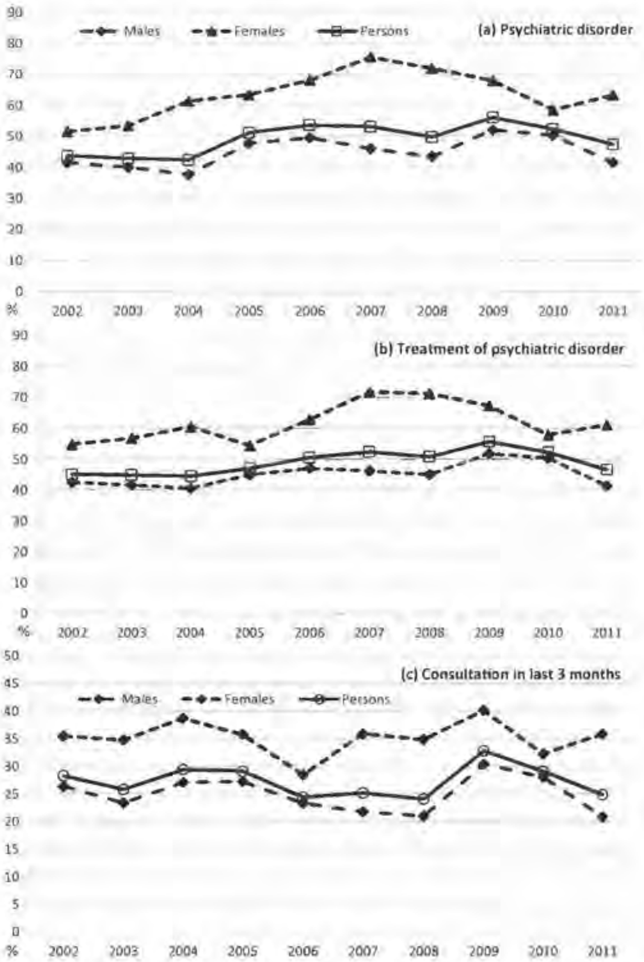

Fig. 5. Prevalence of psychiatric disorders, psychiatric treatment, and a consultation with a professional about a psychiatric condition in last 3 months in suicide cases by gender (2002–2011).

frequently than conflict (22.6%), and is significantly more frequent in males (23.9% vs 18.1%; $\text{Chi}^2 = 18.68$, df = 1, p < 0.001). Conflict with other family members was recorded in 8.1% of cases, more frequently in females than males (11.4% vs 8.1%; $\text{Chi}^2 = 24.28$, df = 1, p < 0.001). Other interpersonal conflicts occurred in 4.4% of cases (males 4.4%, females 4.2%).

Financial problems constituted the most frequent socio-economic event (12.7% of suicides cases), being significantly more frequent in males (13.5% vs 9.8%; $\text{Chi}^2 = 33.08$, df = 1, p < 0.001). This was followed by pending legal matters (8.9%), being significantly more frequent in males too (10.1% vs 5.0%; $\text{Chi}^2 = 12.65$, df = 1, p < 0.001), and recent or pending unemployment (7.4%), again more frequent in males (8% vs 5.2%; $\text{Chi}^2 = 12.00$ df = 1 p = 0.001). Work- and school-related problems were reported in 6.9% of cases, without differences by gender.

Recent bereavement was reported in 10.4% of people who died by suicide without significant differences by gender (males 10.9%, and females 11.6%). Child custody dispute was recorded in 3.5% of cases, without significant gender differences (males 3.2%, females 4.3%). Childhood trauma (2.0%) and sexual abuse (1.6%) were both significantly more frequent in females than males who died by suicide.

3.8. Physical health

Physical illnesses were reported in 34.9% of cases; they were significantly more frequent in females than males (39.3% vs 33.5%; $\text{Chi}^2 = 14.97$, df = 1, p < 0.001). Both genders had significant upward trend of prevalence during 2002–2011 (males: $Chi^2_{trend} = 64.49$, df = 1, p < 0.001; females: $Chi^2_{trend} = 35.76$, df = 1, p < 0.001).

4. Discussion

Some limitations may hinder the accuracy of results based on QSR. First of all, Form 1 is completed by a member of the Queensland Police Service immediately or soon after the body is found, following an interview with the deceased's next-of-kin. Form 1 was not specifically designed for suicide research but to rule out suspicious circumstances. In addition, when investigating possible suicides, some information that might be relevant for a better understanding of that person's death can go unrecorded if the investigating officer does not systematically enquire about it. However, when facing a possible suicide, police officers usually do not omit asking for history of previous attempts and presence of a psychiatric condition, which they consider the strongest elements in support of suicide as cause of death. Obviously, accuracy of data may also be hindered by the informant's lack of knowledge of particular aspect of the deceased's life (e.g., presence of medical o psychiatric diagnosis, precipitating life events). In addition, current paper focuses on 10-year time period which enables to measure potential cyclical nature of suicide trend.

A total of 5752 suicides by Queensland residents was registered in 2002–2011. The average age-standardised suicide mortality rate was 14.3 per 100,000 persons, with a significant decrease from 16 in 2002 to 13.5 in 2011. The male ASR was 3.41-times higher than the female ASR. While male rates showed a significant decline (from 25.5 in 2002 to 19.5 in 2011), female rates were relatively stable. For both genders the age group with the highest rates was the 35–44 years old. This decline is in parallel with what has been happening in most western countries.[1] The decrease in rates has been more pronounced during the first five years of the study period (2002–2006); in the second half trends appear essentially static. Whether or not it is legitimate to correlate this good news to the efforts made by federal and state governments and the NGOs operating in the area of suicide prevention is hard to say. However, suicide in males has attracted many initiatives in the country, mostly targeting open talking and help-seeking behaviour. Some positive influence is probably to be attributed to the marked increase of male immigrants from countries with relatively low ra of suicide. This aspect has received attention on a separate study.[illegible] Nevertheless, WHO report highlighted that relevant interventions would include mental health policies, policies to reduce harmful use of alcohol, access to health care, restricting access to means, responsible media reporting and raising awareness about mental health, substance use disorders and suicide.[1]

Suicide continues to be significantly more frequent in Aboriginal and Torres Strait Islander peoples, the rates of which are 50% higher than those of other Australians in Queensland. In addition, suicide rates in Indigenous Australians peak in the first part of life – in contrast to most other Australians – and are very low or close to zero over the age of 45 years.[11] Particularly high rates are still reported in males aged 15–34 years. Despite increased knowledge about suicide risk factors in Indigenous people, it remains unclear if the higher suicide rates in Aboriginal and Torres Strait Islander peoples are related to cultural, social, political or environmental factors. Regardless, the very meaning of suicide does indeed differ from culture to culture.[12] There is still no clear understanding how Australian Indigenous people define, describe or understand mental health problems; what language they use for them or how they would correlate with Western concepts and diagnoses.[13] It has been hypothesised that Indigenous Australians have a unique understanding of mental illness in terms of the presentation of symptoms and responses to Western treatments.[14]

Suicide rates in remote areas were significantly higher compared to the Qld average for both genders and, for males, the regional rate was also significantly higher. Similar results have been presented earlier, particular risk groups in rural and remote areas are young males, farmers and Indigenous, contextual and lifestyle factors increasing the suicide risk include impact of natural disasters, limited access to services, higher alcohol consumption.[15] However, analysis by Socio-Economic Indexes for Areas (SEIFA) has not been presented in earlier studies; results showed the highest suicide rates in the most disadvantaged areas and the lowest in the most advantaged areas.

Hanging was the most frequently used suicide method (45.1%), followed by drug (16.3%) and carbon monoxide poisoning (11.4%) and firearms (8.9%). In 2002–2011, hanging showed a significant increase in ASRs for females; and CO poisoning showed a significant decline for both genders. Once the method of choice of Australian males,[16] firearm use continues its decline appearing today especially chosen by older adults, possibly indicating a generational pattern of familiarity with firearms, and probably the consequence of a stricter legislation on firearm use.[17] Restricting access to means has been proven one of the most effective prevention methods[1] and this strategy should be put in place wherever is possible. Unfortunately, hanging is the most difficult to control of all methods. In Australia, starting with the second half of the '80s, hanging has dramatically increased in frequency.[16]

Confirming the previous aggregate-level positive correlations between suicide rate and unemployment rate in Australia,[18] unemployed people were at highest risk of suicide: 161.1 per 100,000 for males, and 61.6 for females. Unfortunately, marital status by Australian Household Censuses is not directly comparable to the QSR as the Census has two categories – Registered Marital Status and Social Marital Status[19]; these two cannot be directly linked.[20] However, the QSR has one category for marital status, which includes a shared category of married/*de facto*. Nevertheless, separated males and females are at a particularly high risk of suicide: there were 17.6% of separated males who died by suicide in 2009–2011 compared to 3.1% in the total population according to the 2011 Census.[19] The corresponding figures for females were 12.6% and 3.5%, respectively. This is consistent with a previous analysis showing that suicide risk is highest in separated males.[21]

Previous psychological autopsy studies have shown that up to 90% of people who die by suicide had diagnosable psychiatric disorders.[22] However, more recent studies indicate that this might be somewhat of an overestimate.[23] Information from the QSR shows that almost one-half of people who died by suicide had at least one diagnosed psychiatric disorder (49.2%) and a similar proportion was reported to have had psychiatric treatment and one-quarter (27.4%) a consultation with a health professional concerning own mental health condition in the three months prior to suicide. Prevalence of psychiatric disorders was significantly higher in females than in males (63.6% vs 44.9%). In contrast, evidence of an untreated psychiatric condition was significantly more frequent in males (27.7% vs 22.9%). This might reflect general help-seeking patterns, as males are known not to seek help for mental health problems.[24] The proportion of diagnosed psychiatric disorders in people who died by suicide showed increase for both genders. This might be indicative of some improvements in help-seeking behaviours; however, it also raises questions about the treatment received.

Previous suicide attempt has been considered the strongest suicide risk factor.[1,25] One-third (31.2%) of people who died by suicide had a history of previous suicide attempt(s). This is similar to the proportion recorded in a more detailed psychological autopsy investigation in Queensland and NSW.[23]

Life events can be important triggers for suicide[26]; childhood sexual abuse, for example, can increase the risk of suicide throughout life.[27] Relationship problems were the most frequently recorded life event, with relationship separation reported in 22.6% of people who died by suicide. Socio-economic problems are considered of particular importance as they can cause harmful substance use, financial stress and relationship/family problems, which in turn could lead to psychiatric disorders and suicidal behaviours.[1] Financial problems were recorded in 12.7% of suicides cases, followed by pending legal matters (8.9%), recent or pending unemployment (7.4%), and work- and school-related problems (6.9%). Recent bereavement was reported in 10.4% of people who died by suicide, and child custody dispute was recorded in 3.5%.

5. Conclusions

In parallel with what has been happening in most western countries, suicide rates have been significantly declining, particularly in males, in Queensland too. Whether or not it is legitimate to correlate this good news to the efforts made by federal and state governments and the NGOs operating in the area of suicide prevention is hard to say. Decline in Aborigines and Torres Strait Islander people did not reach statistical significance and suicides in this group remain significantly higher.

Apart from the expected presence of mental disorders in those who died by suicide, unemployment was overwhelmingly present. All the SEIFA indexes point at the importance of socio-economic disadvantage, poor resources, poor education and poor occupation as areas of risk on which action is urgently needed. Relationship separation represents another important risk factor for suicide, especially in males. Interventions are possible and urgent also in this area. Recent bereavement is present in one out of ten individuals who die by suicide. Australia is internationally at the forefront of initiatives aimed at supporting bereaved persons, particularly when the loss was due to suicide. The concept of connectedness is central to the recent WHO report on suicide[1] and certainly much can be done to avoid discrimination and isolation, increase resilience and sense of community belongingness, especially in areas where resources are limited.[29] Narrowing the prevention strategy to controlling mental disorders or confining it uniquely to the health sector would not be sufficient to substantially reduce suicide. As no single approach can significantly impact suicide trends,[1] positive outcomes can only derive by adding to the health sector the joint and coordinated action of other key-sectors, such as education, employment, social welfare, and the judiciary. This would make the reduction of suicide rates a reachable target and create legitimate expectations for it.

Conflict of interest

None.

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Ethical approval

None.

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Royal Commission into
Victoria's Mental Health System

ATTACHMENT RB-27

This is the attachment marked '**RB-27**' referred to in the witness statement of Dr Ravi Subramanya Bhat dated 4 July 2019.

Victoria's low availability of public psychiatric beds and the impact on patients, carers and staff

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For decades, governments in high-income countries have made savings by moving long-term responsibilities for severe mental illness (SMI) to unpaid informal carers. As governments closed beds in standalone mental hospitals, financial and emotional burdens were shifted to the families of people with SMI. While community teams offer first-line treatment by visiting patients at home, carers often do the bulk of the work, spending an average of 5–6 hours per day supporting a relative with SMI, saving governments the cost of providing comparable care and accommodation (Yesufu-Udechuku et al., 2015). These daily demands increase the stress on families with deleterious effects on carers' health, wellbeing, occupational status and finances (Yesufu-Udechuku et al., 2015).

The process of bed closures and burden shifting is well advanced in Australia, where governments have closed most non-acute beds in mental hospitals to fund smaller numbers of acute beds in general hospitals. More recently, Australian governments have begun restricting acute beds, and reducing lengths of stay (Allison and Bastiampillai, 2015; Allison et al., 2017). As public beds reduced, private sector beds became a growth area with an average increase of 9% annually, reaching 11 beds per 100,000 population (Australian Institute of Health and Welfare, 2014–2015: https://mhsa.aihw.gov.au/resources/facilities/beds/). Private beds cater for patients with disorders such as depression who cannot access the public system, but families on low incomes and people with SMI are usually not admitted to private beds. After these shifts, Australia has relatively few beds left (39 public and private hospital-based psychiatric beds per 100,000 population).

Australia ranks 26th of the 35 Organisation for Economic Cooperation and Development (OECD) countries for total hospital-based psychiatric bed numbers (OECD average of 71 beds per 100 000 population: OECD Health Statistics, 2015: http://stats.oecd.org/#). There is wide variation within the OECD with some European countries such as France (87 beds per 100,000 population) and Germany (127 beds per 100,000 population) having far greater inpatient capacity than Australia, and other European countries such as the United Kingdom (46 beds per 100,000 population) and Italy (10 beds per 100,000 population) (Tyrer et al., 2017).

Within Australia, state governments have also adopted widely different polices with the two largest states, Victoria and NSW providing a stark contrast. Victoria spends the least per capita on mental health services (AUD197 versus the Australian average of AUD$219 per capita; AIHW, 2014–2015). Victoria also has far lower numbers of publicly funded hospital-based psychiatric beds for people with SMI (22 beds per 100,000 population) than NSW (36 beds per 100,000 population). The Australian average is 29 public beds per 100,000 population. The World Health Organization (WHO) reports that high-income countries have an average of 42 hospital-based psychiatric beds per 100,000 population, and European countries have an average of 45 beds per 100,000 population (http://apps.who.int/iris/bitstream/10665/178879/1/9789241565011_eng.pdf).

Staff working on the psychiatric wards in Victoria's underfunded mental health system can experience high levels of stress from managerial pressure for early patient discharge, increasing proportions of involuntary patients and disrupted environments. They must also deal with the systemic challenges of inadequate clinical governance, poor quality and safety monitoring, wide variations in clinical practice and the risks of serious harm to psychiatric inpatients (Newton et al., 2017). Average mental health emergency department (ED) waiting times in Victoria's public hospitals are well in excess of the 4-hour target, due to the complexity of mental health assessments, and low availability of public psychiatric beds, increasing the pressure on ED staff.

What has been the impact of these system-wide problems on carers? Carers Victoria recently submitted a response to the proposed Victorian Mental Health Plan addressing the issue (www.carersvictoria.org.au/publications/policy-submissions#Section2). Their response was based on feedback from the many carers for people with SMI who identified problems with the public mental health system, and published reports on the effects of psychiatric bed shortages in Australia (Allison and Bastiampillai, 2015; Allison et al., 2017). Carers Victoria stated, '*If a person in need is unable to access an acute bed, severe emotional or at times physical harm to them and their carer or family is a potential or high risk and can affect the wider community*' (p. 7). While Carers Victoria noted the efforts of community-based services to compensate for low acute bed numbers, they specifically recommended that the '*(Victorian) Government substantially increases investment in acute beds and coincides this with follow up programs to support people at high risk of readmissions*' (p. 4).

The Royal Australian and New Zealand College of Psychiatrists should join Carers Victoria in advocating for safe minimum numbers of psychiatric beds for people with SMI. This advocacy needs to be evidence-based with studies of the effects of interstate differences in the bed mix especially between Victoria and NSW, international comparisons with other high-income countries, including a broad sample of Western European countries as well as Italy, a systematic review of the research literature, and the opinions of clinical psychiatrists. Psychiatrists should be able to refer a patient in need for timely acute admission when their carer is distressed by a relative's symptoms, risk profile and behaviour at home. This does not seem to be the case in jurisdictions around Australia.

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See Commentary by Allison et al (2017) 51: 191–192.

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Royal Commission into
Victoria's Mental Health System

ATTACHMENT RB-28

This is the attachment marked '**RB-28**' referred to in the witness statement of Dr Ravi Subramanya Bhat dated 4 July 2019.

ADULT Mental Health Quarterly KPI Report - 2017-18 Q4

Inpatient - FY17-18 Q4		Inpatient Local access	Bed Occ. (excl leave)	Trim avg LOS <=35 days	Long stay patient bed occ. >35 days	28 day Re-adm rate (lagged)	Secl per 1000 Occ. beddays	% Multiple secl. episodes	Pre-adm. Contact Rate, In Area Clients	Pre-adm. Contact Rate, In Area Ongoing	Post-discharge follow up Rate	% Valid HoNOS compliant	% From ED to MH bed within 8 hrs
Alfred Health	Inner South East (The Alfred)	73 %	95 %	11.4	13 %	14 %	3.4	2 %	66 %	88 %	88 %	64 %	72 %
Austin Health	North East (Austin)	64 %	83 %	6.8	12 %	10 %	7.5	1 %	47 %	61 %	90 %	81 %	90 %
Eastern Health	Central East (Box Hill)	70 %	99 %	10.9	9 %	11 %	15.1	4 %	61 %	93 %	97 %	61 %	61 %
	Outer East (Maroondah)	69 %	98 %	8.3	8 %	14 %	11.4	1 %	58 %	91 %	89 %	77 %	71 %
	TOTAL	69 %	98 %	9.0	9 %	13 %	12.6	2 %	59 %	91 %	91 %	72 %	69 %
Melbourne Health	Inner West (RMH)	81 %	83 %	9.0	4 %	13 %	15.5	1 %	70 %	92 %	97 %	19 %	37 %
	Mid West (Sunshine)	91 %	96 %	9.9	4 %	11 %	13.8	3 %	66 %	95 %	92 %	98 %	23 %
	North West (Broadmeadows)	74 %	97 %	10.0	12 %	21 %	6.8	2 %	78 %	92 %	92 %	88 %	
	Northern	54 %	95 %	10.2	7 %	13 %	15.4	2 %	61 %	88 %	81 %	38 %	45 %
	TOTAL (excl ORYGEN)	72 %	93 %	9.8	7 %	14 %	13.4	2 %	67 %	92 %	89 %	56 %	38 %
	ORYGEN Youth Health	93 %	93 %	8.8	8 %		15.5	2 %	80 %	78 %	93 %	85 %	
Monash Health	Casey	77 %	120 %	9.5	9 %	13 %	5.1	1 %	44 %	75 %	90 %	98 %	29 %
	Dandenong	72 %	99 %	9.6	10 %	14 %	13.3	2 %	60 %	86 %	95 %	49 %	45 %
	Middle South (Monash Adult)	35 %	97 %	11.3	5 %	15 %	7.7	3 %	58 %	83 %	92 %	29 %	39 %
	TOTAL	65 %	103 %	10.0	8 %	14 %	9.5	2 %	53 %	82 %	93 %	59 %	36 %
Peninsula Health	Peninsula	82 %	92 %	7.2	2 %	15 %	0.7	0 %	54 %	81 %	92 %	96 %	80 %
St Vincent's Hospital	Inner East (St Vincent's)	61 %	82 %	9.2	15 %	18 %	7.9	4 %	69 %	95 %	88 %	82 %	83 %
Mercy Health	South West (Werribee)	82 %	94 %	11.4	20 %	15 %	15.4	5 %	67 %	68 %	84 %	76 %	41 %
TOTAL METRO	(Excl ORYGEN)	71 %	95 %	9.5	10 %	14 %	10.3	2 %	61 %	83 %	90 %	68 %	52 %
TOTAL STATEWIDE	(Excl ORYGEN)	76 %	94 %	9.4	10 %	14 %	10.9	2 %	61 %	84 %	89 %	72 %	59 %

Data Source: CMI/ODS as at 11/07/2018, and VEMD as at 01/07/2018. Blank results indicate KPI result is not applicable in this instance. N/A = not available.

ADULT Mental Health Quarterly KPI Report - 2017-18 Q4

Inpatient - FY17-18 Q4		Inpatient Local access	Bed Occ. (excl leave)	Trim avg LOS <=35 days	Long stay patient bed occ. >35 days	28 day Re-adm rate (lagged)	Secl per 1000 Occ. beddays	% Multiple secl. episodes	Pre-adm. Contact Rate, In Area Clients	Pre-adm. Contact Rate, In Area Ongoing	Post-discharge follow up Rate	% Valid HoNOS compliant	% From ED to MH bed within 8 hrs
Ballarat Health	Grampians	91 %	84 %	11.6	8 %	10 %	20.6	3 %	82 %	94 %	98 %	91 %	75 %
Barwon Health	Barwon	91 %	98 %	8.0	10 %	15 %	31.5	5 %	62 %	88 %	98 %	80 %	78 %
Bendigo Health	Loddon/Southern Mallee	93 %	86 %	8.1	6 %	17 %	6.9	1 %	55 %	87 %	76 %	71 %	96 %
Goulburn Valley Health	Goulburn & Southern	85 %	94 %	9.5	11 %	14 %	6.3	5 %	75 %	91 %	92 %	81 %	92 %
Latrobe Regional	Gippsland	92 %	95 %	9.4	5 %	13 %	1.2	0 %	62 %	87 %	83 %	94 %	81 %
Mildura Base Hospital	Northern Mallee	92 %	71 %	6.6	9 %	11 %	15.4	3 %	66 %	88 %	84 %	75 %	100 %
Albury Wodonga Health	North East & Border	89 %	87 %	10.7	11 %	9 %	16.1	6 %	57 %	80 %	70 %	91 %	78 %
South West Health	South West Health Care	87 %	103 %	10.9	15 %	13 %	5.3	1 %	63 %	79 %	90 %	82 %	94 %
TOTAL RURAL		91 %	90 %	9.1	8 %	13 %	12.9	3 %	63 %	87 %	86 %	83 %	86 %
TOTAL STATEWIDE	(Excl ORYGEN)	76 %	94 %	9.4	10 %	14 %	10.9	2 %	61 %	84 %	89 %	72 %	59 %

Data Source: CMI/ODS as at 11/07/2018, and VEMD as at 01/07/2018. Blank results indicate KPI result is not applicable in this instance. N/A = not available.

ADULT Mental Health Quarterly KPI Report - 2017-18 Q4

Community - FY17-18 Q4		New case rate	Case re-referral rate (lagged)	Avg length of case (days)	Avg Treat. Days	% Comm. Cases with Client on CTO	% Valid HoNOS compliant	Mean HoNOS at comm. case start	% Clients with sig. improv. case end	% Self Rating Measures Completed	Chg in Mean # of Clin Signif HoNOS items
Alfred Health	Inner South East (The Alfred)	26 %	23 %	241.9	10.5	29 %	43 %	13.4	49 %	0 %	1.3
Austin Health	North East (Austin)	44 %	30 %	102.0	7.0	10 %	80 %	14.4	56 %	1 %	1.4
Eastern Health	Central East (Box Hill)	25 %	19 %	272.8	10.4	23 %	72 %	11.9	44 %	2 %	0.9
	Outer East (Maroondah)	28 %	23 %	217.1	7.9	22 %	69 %	15.1	53 %	2 %	1.4
	TOTAL	27 %	21 %	236.5	8.9	22 %	70 %	14.0	50 %	2 %	2.2
Melbourne Health	Inner West (RMH)	26 %	25 %	141.2	6.5	15 %	27 %	16.0	100 %	0 %	
	Mid West (Sunshine)	27 %	25 %	188.8	6.8	16 %	84 %	12.0	49 %	0 %	1.2
	North West (Broadmeadows)	24 %	30 %	241.0	9.3	19 %	68 %	11.4	44 %	4 %	1.1
	Northern	25 %	26 %	269.1	10.2	18 %	53 %	12.8	56 %	3 %	1.5
	TOTAL (excl ORYGEN)	25 %	27 %	215.0	8.2	17 %	61 %	12.3	49 %	2 %	3.8
	ORYGEN Youth Health	28 %	21 %	214.7	7.7	6 %	32 %	15.7	68 %	1 %	2.5
Monash Health	Casey	48 %	20 %	104.9	4.8	16 %	58 %	11.8	60 %	4 %	2.0
	Dandenong	31 %	28 %	238.1	8.1	26 %	80 %	13.8	50 %	6 %	0.9
	Middle South (Monash Adult)	29 %	24 %	290.6	7.9	22 %	90 %	12.6	54 %	6 %	1.5
	TOTAL	38 %	23 %	176.5	6.9	21 %	73 %	12.5	55 %	5 %	4.3
Peninsula Health	Peninsula	42 %	28 %	140.3	7.4	12 %	76 %	14.5	39 %	2 %	1.0
St Vincent's Hospital	Inner East (St Vincent's)	24 %	23 %	319.4	11.2	13 %	52 %	12.3	29 %	10 %	0.6
Mercy Health	South West (Werribee)	84 %	23 %	37.3	6.3	12 %	24 %	11.8	66 %	8 %	1.9
TOTAL METRO	(Excl ORYGEN)	35 %	25 %	164.1	8.3	17 %	64 %	13.1	48 %	4 %	1.2
TOTAL STATEWIDE	(Excl ORYGEN)	32 %	24 %	180.5	7.7	15 %	61 %	13.3	52 %	7 %	1.4

Data Source: CMI/ODS as at 11/07/2018, and VEMD as at 01/07/2018. Blank results indicate KPI result is not applicable in this instance. N/A = not available.

ADULT Mental Health Quarterly KPI Report - 2017-18 Q4

Community - FY17-18 Q4		New case rate	Case re-referral rate (lagged)	Avg length of case (days)	Avg Treat. Days	% Comm. Cases with Client on CTO	% Valid HoNOS compliant	Mean HoNOS at comm. case start	% Clients with sig. improv. case end	% Self Rating Measures Completed	Chg in Mean # of Clin Signif HoNOS items
Ballarat Health	Grampians	20 %	15 %	313.2	6.5	11 %	30 %	12.6	60 %	11 %	1.7
Barwon Health	Barwon	15 %	19 %	284.8	6.4	10 %	48 %	13.0	64 %	29 %	2.0
Bendigo Health	Loddon/Southern Mallee	30 %	22 %	157.7	6.9	9 %	55 %	14.0	61 %	7 %	2.1
Goulburn Valley Health	Goulburn & Southern	42 %	28 %	99.2	7.3	10 %	20 %	15.1	63 %	9 %	2.5
Latrobe Regional	Gippsland	25 %	23 %	177.3	8.7	8 %	92 %	15.0	49 %	3 %	1.4
Mildura Base Hospital	Northern Mallee	29 %	18 %	192.5	9.8	8 %	74 %	12.1	73 %	12 %	2.3
Albury Wodonga Health	North East & Border	27 %	25 %	200.3	4.3	7 %	49 %	14.6	66 %	16 %	1.9
South West Health	South West Health Care	17 %	8 %	484.6	5.2	6 %	57 %	11.5	71 %	21 %	2.1
TOTAL RURAL		24 %	21 %	227.2	6.7	9 %	55 %	13.7	60 %	14 %	1.9
TOTAL STATEWIDE	(Excl ORYGEN)	32 %	24 %	180.5	7.7	15 %	61 %	13.3	52 %	7 %	1.4

Data Source: CMI/ODS as at 11/07/2018, and VEMD as at 01/07/2018. Blank results indicate KPI result is not applicable in this instance. N/A = not available.

ADULT Mental Health Quarterly KPI Report - 2017-18 Q4

Inpatient - Year to Date (FY17-18 Q1-4)		Inpatient Local access	Bed Occ. (excl leave)	Trim avg LOS <=35 days	Long stay patient bed occ. >35 days	28 day Re-adm rate (lagged)	Secl per 1000 Occ. beddays	% Multiple secl. episodes	Pre-adm. Contact Rate, In Area Clients	Pre-adm. Contact Rate, In Area Ongoing	Post-discharge follow up Rate	% Valid HoNOS compliant	% From ED to MH bed within 8 hrs
Alfred Health	Inner South East (The Alfred)	72 %	98 %	10.7	17 %	14 %	5.7	2 %	65 %	89 %	87 %	64 %	77 %
Austin Health	North East (Austin)	67 %	82 %	6.7	11 %	11 %	2.9	0 %	52 %	66 %	89 %	76 %	89 %
Eastern Health	Central East (Box Hill)	60 %	98 %	10.8	8 %	14 %	14.3	3 %	66 %	92 %	91 %	56 %	59 %
	Outer East (Maroondah)	73 %	99 %	8.1	11 %	15 %	7.0	1 %	57 %	91 %	91 %	77 %	68 %
	TOTAL	69 %	99 %	8.9	10 %	15 %	9.3	2 %	59 %	91 %	91 %	71 %	66 %
Melbourne Health	Inner West (RMH)	78 %	84 %	8.3	4 %	12 %	21.6	4 %	67 %	92 %	95 %	4 %	34 %
	Mid West (Sunshine)	92 %	96 %	9.4	7 %	14 %	19.6	4 %	64 %	90 %	91 %	97 %	26 %
	North West (Broadmeadows)	75 %	97 %	10.7	10 %	18 %	6.8	2 %	84 %	94 %	93 %	86 %	
	Northern	56 %	97 %	10.1	9 %	15 %	9.3	2 %	70 %	92 %	85 %	39 %	41 %
	TOTAL (excl ORYGEN)	73 %	94 %	9.6	8 %	15 %	13.5	3 %	69 %	92 %	90 %	53 %	35 %
	ORYGEN Youth Health	91 %	93 %	8.4	5 %		13.0	3 %	78 %	82 %	91 %	83 %	
Monash Health	Casey	81 %	109 %	8.7	10 %	15 %	10.2	2 %	50 %	80 %	89 %	97 %	29 %
	Dandenong	73 %	99 %	10.0	9 %	14 %	12.1	3 %	55 %	86 %	90 %	67 %	42 %
	Middle South (Monash Adult)	36 %	99 %	11.1	7 %	14 %	7.7	2 %	64 %	83 %	94 %	55 %	33 %
	TOTAL	67 %	101 %	9.9	9 %	14 %	10.4	2 %	54 %	83 %	91 %	72 %	34 %
Peninsula Health	Peninsula	84 %	93 %	6.6	3 %	15 %	2.4	1 %	56 %	86 %	89 %	97 %	68 %
St Vincent's Hospital	Inner East (St Vincent's)	61 %	87 %	9.9	18 %	13 %	9.8	3 %	66 %	90 %	85 %	76 %	74 %
Mercy Health	South West (Werribee)	82 %	93 %	10.9	15 %	14 %	11.8	3 %	66 %	69 %	79 %	52 %	36 %
TOTAL METRO	(Excl ORYGEN)	72 %	95 %	9.3	11 %	14 %	9.8	2 %	62 %	84 %	89 %	67 %	49 %
TOTAL STATEWIDE	(Excl ORYGEN)	77 %	94 %	9.1	10 %	14 %	10.3	2 %	61 %	85 %	88 %	71 %	56 %

Data Source: CMI/ODS as at 11/07/2018, and VEMD as at 01/07/2018. Blank results indicate KPI result is not applicable in this instance. N/A = not available.

ADULT Mental Health Quarterly KPI Report - 2017-18 Q4

Inpatient - Year to Date (FY17-18 Q1-4)		Inpatient Local access	Bed Occ. (excl leave)	Trim avg LOS <=35 days	Long stay patient bed occ. >35 days	28 day Re-adm rate (lagged)	Secl per 1000 Occ. beddays	% Multiple secl. episodes	Pre-adm. Contact Rate, In Area Clients	Pre-adm. Contact Rate, In Area Ongoing	Post-discharge follow up Rate	% Valid HoNOS compliant	% From ED to MH bed within 8 hrs
Ballarat Health	Grampians	93 %	83 %	10.7	9 %	9 %	18.6	5 %	73 %	91 %	94 %	91 %	81 %
Barwon Health	Barwon	93 %	86 %	7.2	8 %	13 %	31.2	4 %	58 %	84 %	96 %	76 %	85 %
Bendigo Health	Loddon/Southern Mallee	93 %	87 %	8.5	8 %	17 %	7.6	1 %	59 %	86 %	82 %	76 %	81 %
Goulburn Valley Health	Goulburn & Southern	83 %	90 %	8.4	8 %	13 %	6.3	1 %	66 %	89 %	87 %	86 %	88 %
Latrobe Regional	Gippsland	92 %	94 %	8.5	6 %	15 %	1.4	0 %	56 %	92 %	82 %	93 %	78 %
Mildura Base Hospital	Northern Mallee	94 %	72 %	6.2	7 %	12 %	15.7	2 %	61 %	89 %	84 %	77 %	94 %
Albury Wodonga Health	North East & Border	94 %	84 %	11.1	11 %	8 %	10.7	4 %	60 %	80 %	82 %	89 %	81 %
South West Health	South West Health Care	93 %	106 %	10.6	12 %	14 %	6.2	2 %	70 %	89 %	95 %	83 %	84 %
TOTAL RURAL		92 %	88 %	8.6	8 %	13 %	12.0	2 %	61 %	87 %	87 %	84 %	82 %
TOTAL STATEWIDE	(Excl ORYGEN)	77 %	94 %	9.1	10 %	14 %	10.3	2 %	61 %	85 %	88 %	71 %	56 %

VICTORIA

Data Source: CMI/ODS as at 11/07/2018, and VEMD as at 01/07/2018. Blank results indicate KPI result is not applicable in this instance. N/A = not available.

ADULT Mental Health Quarterly KPI Report - 2017-18 Q4

Community - Year to Date (FY17-18 Q1-4)		New case rate	Case re-referral rate (lagged)	Avg length of case (days)	Avg Treat. Days	% Comm. Cases with Client on CTO	% Valid HoNOS compliant	Mean HoNOS at comm. case start	% Clients with sig. improv. case end	% Self Rating Measures Completed	Chg in Mean # of Clin Signif HoNOS items
Alfred Health	Inner South East (The Alfred)	26 %	24 %	270.7	10.4	28 %	51 %	14.1	55 %	0 %	1.2
Austin Health	North East (Austin)	49 %	32 %	96.9	7.4	10 %	83 %	14.6	61 %	2 %	1.5
Eastern Health	Central East (Box Hill)	27 %	22 %	233.5	9.8	23 %	70 %	11.8	41 %	3 %	1.0
	Outer East (Maroondah)	28 %	25 %	210.0	8.3	21 %	73 %	15.5	48 %	2 %	1.2
	TOTAL	28 %	24 %	219.0	8.9	22 %	72 %	14.2	46 %	2 %	2.2
Melbourne Health	Inner West (RMH)	26 %	25 %	190.6	6.8	15 %	7 %	15.7	100 %	0 %	
	Mid West (Sunshine)	30 %	25 %	187.2	6.6	17 %	85 %	12.6	49 %	0 %	1.2
	North West (Broadmeadows)	26 %	25 %	218.7	8.5	20 %	65 %	11.8	51 %	4 %	1.2
	Northern	25 %	23 %	316.0	9.3	18 %	51 %	12.6	49 %	3 %	1.2
	TOTAL (excl ORYGEN)	27 %	25 %	231.2	7.8	17 %	58 %	12.4	50 %	2 %	3.6
	ORYGEN Youth Health	30 %	22 %	221.0	7.3	6 %	40 %	15.1	65 %	2 %	2.2
Monash Health	Casey	49 %	22 %	77.2	5.0	17 %	66 %	11.6	57 %	3 %	1.7
	Dandenong	32 %	26 %	215.0	7.3	27 %	82 %	13.5	51 %	6 %	1.3
	Middle South (Monash Adult)	30 %	25 %	238.3	8.3	20 %	90 %	12.9	59 %	7 %	1.6
	TOTAL	39 %	24 %	149.9	6.8	21 %	77 %	12.5	56 %	5 %	4.7
Peninsula Health	Peninsula	43 %	28 %	123.7	7.6	12 %	78 %	14.5	40 %	2 %	1.1
St Vincent's Hospital	Inner East (St Vincent's)	31 %	25 %	187.6	11.2	11 %	67 %	12.7	29 %	13 %	0.7
Mercy Health	South West (Werribee)	71 %	31 %	161.3	6.3	16 %	17 %	12.2	69 %	4 %	2.2
TOTAL METRO	(Excl ORYGEN)	36 %	27 %	175.7	8.2	18 %	65 %	13.2	49 %	4 %	1.3
TOTAL STATEWIDE	(Excl ORYGEN)	33 %	25 %	190.8	7.7	15 %	63 %	13.3	52 %	8 %	1.5

Data Source: CMI/ODS as at 11/07/2018, and VEMD as at 01/07/2018. Blank results indicate KPI result is not applicable in this instance. N/A = not available.

ADULT Mental Health Quarterly KPI Report - 2017-18 Q4

Community - Year to Date (FY17-18 Q1-4)		New case rate	Case re-referral rate (lagged)	Avg length of case (days)	Avg Treat. Days	% Comm. Cases with Client on CTO	% Valid HoNOS compliant	Mean HoNOS at comm. case start	% Clients with sig. improv. case end	% Self Rating Measures Completed	Chg in Mean # of Clin Signif HoNOS items
Ballarat Health	Grampians	20 %	14 %	366.5	6.3	10 %	37 %	13.1	64 %	11 %	2.1
Barwon Health	Barwon	18 %	15 %	365.6	6.8	9 %	52 %	12.5	58 %	34 %	1.8
Bendigo Health	Loddon/Southern Mallee	35 %	21 %	136.1	7.3	10 %	58 %	13.4	56 %	11 %	1.8
Goulburn Valley Health	Goulburn & Southern	49 %	27 %	87.6	7.9	11 %	35 %	13.2	62 %	13 %	2.1
Latrobe Regional	Gippsland	25 %	21 %	314.9	8.4	8 %	89 %	14.7	54 %	4 %	1.6
Mildura Base Hospital	Northern Mallee	32 %	19 %	125.0	8.3	7 %	76 %	13.3	74 %	8 %	2.6
Albury Wodonga Health	North East & Border	30 %	20 %	187.9	5.0	8 %	56 %	14.3	66 %	19 %	2.2
South West Health	South West Health Care	20 %	11 %	355.7	5.2	6 %	55 %	11.3	74 %	19 %	2.3
TOTAL RURAL		27 %	19 %	235.3	6.8	9 %	59 %	13.4	61 %	16 %	1.9
TOTAL STATEWIDE	(Excl ORYGEN)	33 %	25 %	190.8	7.7	15 %	63 %	13.3	52 %	8 %	1.5

Data Source: CMI/ODS as at 11/07/2018, and VEMD as at 01/07/2018. Blank results indicate KPI result is not applicable in this instance. N/A = not available.

ADULT Mental Health Quarterly KPI Report - 2017-18 Q4

Definitions

Setting	KPI	Description	Target	Comments
Inpatient	Inpatient Local access	Percentage of separations from inpatient units for residents of the AMHS's catchment. Includes only separations where client was discharged home / to a residential service. Excludes same day stays.		No specified benchmark – reflection of a service's ability to meet the inpatient mental health needs of people within its catchment.
	Bed Occ. (excl leave)	Total number of occupied bed hours (excl leave) in inpatient units divided by total number of funded bed hours.		Underpinning data supports the statewide bed availability query system.
	Trim avg LOS <=35 days	The average length of stay (days) of discharges from inpatient units, excluding same day stays & excluding discharges with length of stay greater than 35 days.		Shorter lengths of stay can be associated with higher readmission rates. Note this KPI is based on the episode start & end dates (as opposed to individual admission events within an episode).
	Long stay patient bed occ. >35 days	Admission hours for "long stay" admissions in inpatient units, as a proportion of funded bed hours. Excludes the first 35 days (840 hours) of admission.		(For ADULT - Can reflect SECU capacity constraints).
	28 day Re-adm rate (lagged)	Number of discharges from an inpatient unit where the client was readmitted (planned or unplanned) to any inpatient unit within 28 days of discharge, compared to the total number of discharges. Lagged by one month. EXCLUDES a)discharges where client was transfered to another inpatient unit, b)same day stays, c)overnight ECT admissions (where ECT occured on the day of separation), d)re-admissions to the following specialty inpatient units: Mother/Baby, Eating Disorder, PICU and Neuropsychiatry.	14.0 %	Can reflect quality of care, effectiveness of discharge planning, level of support post discharge, and other factors.
	Secl per 1000 Occ. beddays	The number of ended seclusion episodes divided by occupied beddays multiplied by 1000. Occupied beddays excludes leave and same day stays. Excludes units that do not have a seclusion room. (NB. Beddays calculated in minutes & converted to days)	15.0	Policy emphasis is on reducing use of seclusion where possible. Defined according to proposed national definition.
	% Multiple secl. episodes	Percentage of separations with a multiple seclusion episodes during the episode. Seclusion events are recorded here against the team where the client was originally admitted, even though the seclusions may have occured in different units. Excludes units that do not have a seclusion room (i.e. Forensicare Bass, Daintree & Jardine)	3.0 %	While an initial need for seclusion can sometimes be unforeseen, close management can sometimes avoid repeated episodes.
	Pre-adm. Contact Rate, In Area Clients	Percentage of admissions to inpatient unit(s) for which a community ambulatory service contact was recorded in the seven days immediately preceding the day of admission. Excludes same day stays. Transfers from another hospital and out of area admissions are excluded.	60.0 %	Reflects service responsiveness and a planned approach to admission, rather than a crisis response. NOTE: Data collection from Oct'11 to Jun'12 was affected by protected industrial action.
	Pre-adm. Contact Rate, In Area Ongoing	Percentage of admissions to inpatient unit(s) for which a community ambulatory service contact was recorded in the seven days immediately preceding the day of admission. Excludes same day stays. Transfers from another hospital and out of area admissions are excluded. Clients must have had an open community episode open within the 7 days preceeding the admission.	60.0 %	Reflects service responsiveness and a planned approach to admission, rather than a crisis response. NOTE: Data collection from Oct'11 to Jun'12 was affected by protected industrial action.
	Post-discharge follow up Rate	Percentage of non-sameday inpatient separations where client was discharged to private residence / accomodation, for which a contact was recorded in the seven days immediately after discharge (does not include contact made on the day of discharge). When a client is sent on leave & then discharged whilst on leave, contact must occur within the 7 days since the client was on leave. Lagged by 7 days.	75.0 %	Indicator of effective discharge management. NOTE: Data collection from Oct'11 to Jun'12 was affected by protected industrial action.

Data Source: CMI/ODS as at 11/07/2018, and VEMD as at 01/07/2018. Blank results indicate KPI result is not applicable in this instance. N/A = not available.

ADULT Mental Health Quarterly KPI Report - 2017-18 Q4

Setting	KPI	Description	Target	Comments
Inpatient	% Valid HoNOS compliant	Participation rate in HoNOS (HoNOSCA/HNSADL/HoNOS65) outcome measurement scales (number of valid HoNOS collection events / total number of outcome collection occasions that should be recorded for in-scope service settings). Excludes instances where the HoNOS score entered was invalid (more than 2 times rated as 9). Calculated from Jan'09 onwards only.	85.0 %	Commitment to adoption of outcome measurement part of National Mental Health Strategy, and National Action Plan. Barwon data calculated differently as they do not use tasks in the CMI. NOTE: Data collection from Oct'11 to Jun'12 was affected by protected industrial action.
	% From ED to MH bed within 8 hrs	Percentage of emergency department presentations departing to a mental health bed within 8 hours of arrival.	80.0 %	Mental health bed access indicator, although affected by local admission practices, such as direct admissions. Activity in all non-specialty EDs is included. Client Groups based on client age at date of presentation (CYMHS <18 yrs, ADULT 18-64yrs, AGED 65+yrs, Unknown ages excluded). EDs without on-site acute MH beds for the appropriate age group are mapped to their responsible AMHS.
Community	New case rate	Number of new community cases opened in the period, as a percentage of number of community cases open at any time during the period.		No specified benchmark set.
	Case re-referral rate (lagged)	Percentage of cases closed during the reporting period where the client involved has a new case opened within six months of case closure. Lagged by six months.		No specified benchmark set. Excludes cases that were opened on the same day or the day after the previous case closure, assuming they are data errors.
	Avg length of case (days)	The average length of case (days) for all community cases that were closed during the reporting period.		No specified benchmark set.
	Avg Treat. Days	The number of distinct days with a contact, for each client with an open community case during the reporting period divided by the number of clients with an open community case during the reporting period. Cases must have been open for more than 91 days.. All reportable contacts are included.		NOTE: Data collection from Oct'11 to Jun'12 was affected by protected industrial action.
	% Comm. Cases with Client on CTO	Percentage of Clients with an open community case during the reporting period, who were concurrently on a CTO (Community Treatment Order) during the reporting period.		From 1/7/2014 the data reflects the new compulsory orders under the MH Act 2014.
	% Valid HoNOS compliant	Participation rate in HoNOS (HoNOSCA/HNSADL/HoNOS65) outcome measurement scales (number of valid HoNOS collection events / total number of outcome collection occasions that should be recorded for in-scope service settings). Excludes instances where the HoNOS score entered was invalid (more than 2 itmes rated as 9). Calculated from Jan'09 onwards only.	85.0 %	Commitment to adoption of outcome measurement part of National Mental Health Strategy, and National Action Plan. Barwon data calculated differently as they do not use tasks in the CMI. NOTE: Data collection from Oct'11 to Jun'12 was affected by protected industrial action.
	Mean HoNOS at comm. case start	The average HoNOS total score (HoNOSCA/HNSADL/HoNOS65) collected on case commencement, excluding invalid scores.		Contextual measure of symptom severity at case commencement. Dates determined from HoNOS completion date. NOTE: Data collection from Oct'11 to Jun'12 was affected by protected industrial action.
	% Clients with sig. improv. case end	Percentage of completed cases with a significant positive change calculation on HoNOS collected on case start and case end. (Total number of cases with a Significant change score >.5 / The total number of completed case in-scope service setting).		Method aims to focus more on clinically significant change as opposed to overall change. NOTE: Data collection from Oct'11 to Jun'12 was affected by protected industrial action.
	% Self Rating Measures Completed	Consumer Completion Rate of the relevant self-rating measures (Basis 32 or SDQ's where appropriate), in a community setting.		A measure of engagement with family/carer. Barwon data calculated differently as they do not use tasks in the CMI. NOTE: Data collection from Oct'11 to Jun'12 was affected by protected industrial action.
	Chg in Mean # of Clin Signif HoNOS items	The difference between the mean number of clinically significant HoNOS (HoNOSCA/HNSADL/HoNOS65) scales at community case end and the mean number of clinically significant HoNOS scales at community case start. Includes all ended community cases with a valid HoNOS score at start & end. Excludes HoNOSCA Qns 14 & 15, and HoNOSADL & HoNOS65 Qns 11 & 12.		Alternative measure of symptom severity reduction based only on split of each HoNOS item into clinically significant (2,3,4) or not clinically significant (0,1), rather than the sum of each scaled measure. Barwon data calculated differently as they do not use tasks in the CMI. NOTE: Data collection from Oct'11 to Jun'12 was affected by protected industrial action.

Data Source: CMI/ODS as at 11/07/2018, and VEMD as at 01/07/2018. Blank results indicate KPI result is not applicable in this instance. N/A = not available.

Royal Commission into
Victoria's Mental Health System

ATTACHMENT RB-29

This is the attachment marked '**RB-29**' referred to in the witness statement of Dr Ravi Subramanya Bhat dated 4 July 2019.

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RESEARCH ARTICLE **Open Access**

No longer *'flying blind'*: how access has changed emergency mental health care in rural and remote emergency departments, a qualitative study

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Abstract

Background: Mental health presentations are considered to be a difficult aspect of emergency care. Although emergency department (ED) staff is qualified to provide emergency mental health care, for some, such presentations pose a challenge to their training, confidence, and time. Providing access to relevant and responsive specialist mental health care can influence care and management for these patients. The Mental Health Emergency Care-Rural Access Program (MHEC-RAP) is a telepsychiatry program that was established to improve access to specialist emergency mental health care across rural and remote western NSW, Australia.

Method: This study uses interviews with ED providers to understand their experience of managing emergency mental health patients and their use of MHEC-RAP. The lens of access was applied to assess program impact and inform continuing program development.

Results: With MHEC-RAP, these ED providers are no longer 'flying blind'. They are also more confident to manage and care for emergency mental health patients locally. For these providers, access to specialists who are able to conduct assessments and provide relevant and responsive advice for emergency mental health presentations was valued. Assessing the fit between the consumer and service as a requirement for the development, evaluation, and ongoing management of the service should result in decisions about design and delivery that achieve improved access to care and meet the needs of their consumers. The experience of these providers prior to MHEC-RAP is consistent with that reported in other rural and remote populations suggesting that MHEC-RAP could address limitations in access to specialist care and change the provision of emergency mental health care elsewhere.

Conclusion: MHEC-RAP has not only provided access to specialist mental health care for local ED providers, but it has changed their practice and perspective. MHEC-RAP could be adapted for implementation elsewhere. Provider experience confirms that the program is accessible and offers insights to those considering how to establish an emergency telepyschiatry service in other settings.

Keywords: Access, Mental health, Emergency care, Telehealth, Rural and Remote, Australia, Qualitative study

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Background

There is a consistently reported gap between the need for mental health services and actual mental health service use, not only in Australia but overseas [1-5]. Although there is little difference in the prevalence of mental health problems across urban and rural populations in Australia, rural and remote communities have poorer access to and lower use of specialist mental health services [6,7]. This makes the provision of emergency mental health care problematic and is associated with poorer mental health outcomes, such as higher Kessler Psychological Distress Scale scores and higher suicide rates [8-10].

Emergency Departments (EDs) and General Practitioners (GPs) are common providers of mental health care in rural communities [11-16]. Although GPs and ED staff are qualified to provide this care, responding to emergency mental health presentations (patients with acute acerbations of their condition, in crisis, or endangering themselves, others, or their reputation) pose diagnostic and management challenges for local providers who may lack specific mental health training, confidence, or time for emergency mental health presentations. In some communities, the facility may not be adequately equipped for the safe assessment and monitoring of these patients whose needs differ from those with physical ailments [15,17-22].

In Australia, the National Strategic Framework for Rural and Remote Health, along with the National Mental Health Plan and complementary State Action Plans all aim to improve access to care [23-27]. In line with national and state policies, the Mental Health Emergency Care-Rural Access Program (MHEC-RAP) was established in the Western NSW and Far West Local Health Districts (WNSW/FWLHD) of NSW to improve access to specialist emergency mental health care, safety and service coordination, and patient outcomes [27-29].

MHEC-RAP has been operating since 2008. It was not the first, nor the only, telepsychiatry service to be developed and used in Australia [30,31]. But it was the first to provide 24-hour access to a dedicated, regionally-based team of mental health specialists offering timely information and support, emergency telephone triage, and video assessment for all providers, patients, and residents needing urgent mental health care in rural and remote communities. The MHEC-RAP evaluation has already reported findings from earlier studies that demonstrate use of the program by those in need and examined clinical service activity from the area EDs [32,33]. This was the first evaluation to use a time and motion study method to assess program efficiency and to present a translatable program model for transferability [34,35].

One aim of MHEC-RAP is to improve access. Providing access to relevant and responsive specialist mental health care can have significant implications for the patient, their family, local providers, emergency services, and the local health service. The aim of this study was to examine the impact of MHEC-RAP on providing access to specialist care through the experience of local providers and was guided by six concepts of access (accessibility, availability, acceptability, affordability, adequacy, and awareness) [36].

Methods

This part of the MHEC-RAP evaluation was approved by the Greater Western Human Research Ethics Committee and adheres to the National Statement on the Conduct of Human Research by the Australian National Health and Medical Research Council, Project Number: HREC/13/GWAHS/9.

Study design

This study applied a qualitative method to interpret the experience of the local ED providers and examine the impact of MHEC-RAP on the provision of access to specialist emergency mental health care. The analysis was guided by six concepts of access [36]. Their experiences can be used to inform further program development, implementation, and transferability.

Semi-structured interviews were conducted with providers of emergency mental health care from communities across the WNSW/FWLHD. Interviews would be conducted with consenting participants until there was a saturation of findings. Saturation was determined to be achieved when no new or differing information was revealed across the interviews. Participants were asked about providing emergency mental health care, the resources available to them, the positive experiences, as well as the challenges and other considerations of providing this care in rural and remote western NSW.

The questions were developed in consideration of the theory of access but allowed for open response from each provider to share their experience and perception of emergency mental health care and MHEC-RAP [36]. Initially, broad questions were used to explore their experience which later transitioned to focus on MHEC-RAP after the program was mentioned in the interview. If it was not mentioned, the provider was directly asked about their knowledge and experience of the program. This question design, and the bracketing of previous knowledge, enabled ES to conduct interviews that informed current understanding of experience and perception of emergency mental health care and the impact of MHEC-RAP on access.

The program

MHEC-RAP was developed to improve access to mental health specialists for anyone needing emergency mental health care or assistance in the WNSW/FWLHD. Combined, these health districts serve approximately 300,000 residents living across 445,000 km^2 of regional, remote, and very remote countryside [37]. Providing care from one program for this population is challenging because this area is similar in size to Germany or the state of Montana (Figure 1). MHEC-RAP employs telehealth technologies and a freecall number to provide timely information and clinical services from a dedicated team of mental health specialists. Further detail of the program model and structure is available in a previous publication [35].

Recruitment

Rural and remote providers, specifically ED staff (managers and nurses) and GPs, were invited to participate. They were purposely chosen because the video assessment equipment used to connect with MHEC-RAP is located in the hospital EDs and for many rural or remote communities, the local GPs also work in the local hospital.

Based on the patterns of use of MHEC-RAP clinical services in 2011, 18 communities from the 48 with hospital facilities across the region were identified for recruitment [32]. Communities with high use received 50 or more MHEC-RAP clinical services that year, medium use was 10–49 services, and low use was below 10. Six communities were identified from each of the remoteness structure categories; remote and very remote communities were combined for this. All GPs from the identified communities were invited for participation along with four ED staff from each hospital via their hospital manager; 169 providers in total. The invitation included an information letter as well as consent and withdrawal forms and a pre-addressed and stamped return envelope. All participants were informed of the purpose of the interview in the invitation letter and this was again reviewed on the day of the interview. No incentives were provided to eliminate any possible coercion to participate. The recruitment strategy acknowledged that there could be a high drop-out rate because some invitations could be lost, misplaced, or ignored thereby justifying the large recruitment population and resulting in a convenience sample of the population. All those invited were free to withdraw their participation without prejudice prior to the interview.

Thirteen consenting responses were received from seven communities across the region. Respondents were male and female, of rural and urban background, and served as a provider for varying lengths of time. All 13 consenting respondents were approached for an interview (an 8% response rate); 12 were ED staff and one was a GP, no additional GPs responded. No identifiable information, such as community, was reported to maintain participant confidentiality; though the participants were free to disclose their participation to others.

Data collection

Twelve of the consenting participants from six of the identified communities were interviewed; one respondent withdrew. ES conducted all 12 interviews in September and October 2013. All but two interviews were conducted

Figure 1 Map of NSW divided by Local Health District - FarWest LHD and Western NSW LHD identified.

face-to-face; telephone interviews were arranged for those who were unable to attend their face-to-face interview due to unplanned commitments on the day. The interviews were commonly conducted in the health service setting; one interview was in a private home and another in a public venue as requested by those participants. Each interview was digitally recorded for transcription and analysis. All interviews were private and the recordings were no longer than one hour. Notes were also recorded after each interview. All participants were available by telephone for subsequent contact to clarify any query to their response as needed.

Analysis

Each interview was transcribed by ES within two days and initial analyses begun immediately; this helped to determine saturation of findings. Although the response rate was low and the researchers were permitted to extend the invitation for participation to other communities, this was not considered necessary with a saturation of findings. ES conducted all data analyses; the transcripts and resulting analyses were reviewed and discussed with SK and DL to confirm usefulness, rigour, and quality of findings. Coding and analysis were conducted using paper-based methods and NVivo [38]. For reporting purposes, locations were given a number associated with its remoteness category and the number of participant interviews conducted. Participant responses were identified by their community number and assigned a letter (A, B, C) which was determined by the order of the interviews as they were conducted. For instance, the third participant interviewed in community 3 would be identified as 3C (Table 1).

The analysis presented here examined the provider experience of MHEC-RAP. It was structured using a theoretically concept-driven content analysis that aligned to the six concepts of access. Access is about providing the right care, from the right provider, at the right time, and in the right place. Penchansky and Thomas define 'access' as the degree of fit between the consumer and the service [36]. Their theory of access incorporates and addresses five specific concepts of fit; accessibility, availability, acceptability, affordability, and adequacy (Table 2).

The theory was modified with the inclusion of a sixth concept – awareness. Awareness was identified as an important concept of access from interviews during the initial study of MHEC-RAP. In these interviews providers and patients spoke about how such a program is needed and could be useful, but that they did not know anything about it. They did not know that the program existed, what it did, why and how they would use it, and how to share this information with others who would benefit from the program. Informal conversations with colleagues and other health providers confirmed the importance of awareness to making a health service useful and effective. Consumers could better use services if they were simply aware of them in the first place.

ES was part of the initial study of MHEC-RAP in 2008 [39]. To understand the impact of MHEC-RAP on access and the experience of local providers five years later, ES applied Husserl's approach to bracket her "beliefs, preconceptions, and prejudices" about the program and its influence on access to be open to the current experience [40-43]. Bracketing is putting one's preconceptions aside to limit the influence of foreknowledge on the data collection, analysis, and interpretation.

'Awareness' is the missing concept of access and is more than knowing that a service exists, it includes identifying that the service is needed, knowing who the service is for, what it does, when the service is available, where and how to access it, why the service would be used, how to use it, and maintaining that knowledge. Others have also considered 'awareness' when applying the theory of access [44]. Although each concept is an individual consideration of fit between the service and the consumer, they are inter-connected and naturally overlap. All six concepts should be considered when applying the theory of access to the development or evaluation of health services and other programs more generally. Analysis and the reporting of the results of this study were structured to align with all six concepts.

Table 1 Characteristics of each community and those interviewed

Community	Interviews		Remoteness category*	Level of use of MHEC-RAP**
	N = 12	Provider		(High/Medium/Low)
1	3	ED/GP	Inner Regional	High
2	1	ED	Inner Regional	High
3	3	ED	Outer Regional	Medium
4	1	ED	Outer Regional	High
5	3	ED	Remote	Low
6	1	ED	Remote	Medium

*as determined by the Australian Standard Geographical Classification.

**actual use of MHEC-RAP clinical services from the ED in 2011; High ≥ 50 clinical services, Medium = 10-49, Low < 10.

Table 2 The concepts of access

Concept of access	Definition	Concept components and examples
Accessibility*	Location	An accessible service is within reasonable proximity to the consumer in terms of time and distance.
Availability*	Supply and demand	An available service has sufficient services and resources to meet the volume and needs of the consumers and communities served.
Acceptability*	Consumer perception	An acceptable service responds to the attitude of the provider and the consumer regarding characteristics of the service and social or cultural concerns. For instance, a patient's willingness to see a female doctor may determine whether a service is acceptable or not.
Affordability*	Financial and incidental costs	Affordable services examine the direct costs for both the service provider and the consumer.
Adequacy* (Accommodation)	Organisation	An adequate service is well organised to accept clients, and clients are able to use the services. Considerations of adequacy include hours of operation (afterhour services), referral or appointment systems, and facility structures (wheelchair access).
Awareness**	Communication and information	A service maintains awareness through effective communication and information strategies with relevant users (clinicians, patients, the broader community), including consideration of context and health literacy.

*The five concepts of access identified by Penchansky and Thomas [36]. Penchansky, R. and J. W. Thomas. "The Concept of Access: Definition and Relationship to Consumer Satisfaction." *Medical Care* **19**(2): 127–140.

**Awareness, a sixth concept that may influence access.

A before and after category was also applied to help determine effect and impact of the program.

Results

The general accounts of providing emergency mental health care in rural and remote EDs varied. Some providers had positive experiences - when patients received timely and appropriate care, but everyone had negative experiences - dealing with patients who were variously abusive, sedated and involuntarily admitted to hospital (scheduled), absconding, or threatening harm, with no one to help. Mental health presentations were considered to be a difficult aspect of emergency care challenging their training and causing stress and disruption.

> *We're just so focused on people that are bleeding and coughing and everything else ... there's just not a lot of training [for mental health]. -6A*

> *If [mental health is] not managed well, [it] can be devastating for the whole department and other patients and a whole lot of other things 'cause they do tend to disrupt [the whole department]. -5B*

Residing and working in a rural or remote community also influenced their experience of providing emergency mental health care. This was true for those who were born or raised locally and those who were new in town. Some reflected on knowing their regular patients and their different relationships within the broader community (nurse, friend, relative). Those who had worked in metropolitan hospitals reflected on the differing access to care and resources. Everyone spoke about the limited resources available to them for managing mental health emergencies. Limitations ranged from the layout of the ED to the availability of local mental health workers, other hospital staff, or even the police for assistance when needed. In the end, everyone wanted to do the best that they could for their patients.

> *This being a small rural town, we know the majority of them and we can have a really good relationship with them and they feel secure by coming here and talk to us because they know who we are, they know our role, they know that we are here to help them, and the majority of them are very accepting of the service that we provide for them because we have a really good rapport with them. -3C*

> *The design of our ED makes it even worse than it is, we're just not designed for a lot of things, it's not just mental health, but mental health's so difficult. -2A*

> *I called the local mental health care team who couldn't do anything because it was Friday afternoon and none of them work on the weekend. -1B*

MHEC-RAP was introduced to provide access to specialist emergency mental health care. The local providers' experience of MHEC-RAP has been interrogated using six concepts of access and identifies a change in practice.

Accessibility

MHEC-RAP had changed accessibility because local providers were now able to access a mental health specialist for immediate assistance, by telephone or video link, no matter which community in western NSW they were from. They did not have to send the patient to another facility or wait for a specialist to arrive to get assistance or have a patient assessed.

> *They're there, there's video conferencing, you can talk to them, they're there 24-hours a day. -4A*

> *It makes such a difference being able to have somebody on the other end of the phone. -5B*

> *The nearest mental health is actually based in [a town over an hour's drive away]. ... When somebody comes in, they're reviewed, they're assessed, they're immediately talking to MHEC-RAP. -6A*

Availability

MHEC-RAP was valued as a resource with specialist knowledge available to respond to the needs of local providers and ease the demands placed upon them during emergency mental health presentations. For some of the staff, MHEC-RAP was not only about getting specialist help for their patients, but about responding to their personal need for support in clinical decision making. There were some incidents when a request for assistance from MHEC-RAP was met with delay, but it was acknowledged that MHEC-RAP usually responds in a timely fashion.

> *For us, having someone to just talk to, having someone that you can say 'look, I've got this situation, what do you suggest, how do you think I should handle it'. ...I'm quite happy with what [MHEC-RAP are] doing, you know, they're giving me what I need. –3B*

> *We can still ring [MHEC-RAP], get advice over the phone, put the person over in front of the tv camera, they can still do a face-to-face interview. ... because they're busy, it's difficult when they're not available and so sometimes that's a bit frustrating, that you're trying to get on to them. But on the whole I really like them. I think they're a really good service. So it saved our bacon a few times. -1A*

Acceptability

Although *"it doesn't solve everything" -5C*, MHEC-RAP was acceptable to these providers. It was helpful and supportive, a constant and easy resource. A few commented about being generally uncomfortable with mental health and that for them, MHEC-RAP provided trained specialists to help with these emergencies. MHEC-RAP also improved their confidence to provide mental health care locally, and the hours associated with an emergency presentation, both waiting for and managing care, were reduced. With MHEC-RAP, providers were able to get their patients seen in a timely manner thereby reducing the possible anxiety, aggression, or absconding as well as helping to provide responsive care. Providers felt supported in their decisions and management of patients, and patients were seen to receive appropriate care and to have better outcomes.

> *If we can get them MHEC-RAPped and they have someone to talk to, then they'll find they go home with a plan. ...I love it because I really, I don't like dealing with [mental health] and I'd rather them talking to someone that's gonna help them. -3A*

> *Before MHEC-RAP there was, patients used to sit in emergency departments for much much longer with no definitive care. -1A*

> *[MHEC-RAP has] basically reduced the crisis. ...They come in and instead of sort of waiting for our doctors to come and da-da-da, we can actually get the process happening straight away and everything just calms down. Everything's just alleviated and we can get the right treatment for them rather than managing them and waiting for our doctors to turn up. -3B*

MHEC-RAP was also acceptable because ED providers could leave the patient with the MHEC-RAP specialist over the video link, if appropriate, allowing for privacy and permitting the local staff to continue providing care to others. A MHEC-RAP video assessment was considered for use for almost every mental health presentation except those particularly violent or under the influence of substances. Even patients who were having auditory hallucinations had no problem using MHEC-RAP. There were a couple accounts of patients who did not want to be assessed by MHEC-RAP because they were uncomfortable with the technology or had a preferred psychiatrist, but MHEC-RAP was still able to provide assistance to the local provider for those patients. For a few providers, MHEC-RAP became their standard practice for emergency mental health presentations; some EDs were even told by the local doctors to have a patient seen by MHEC-RAP before they became involved.

> *I can leave them in the room and then they can either talk to [MHEC-RAP] over the phone or ... have a chat to them via the tele[vision] and I just think that's brilliant. -3B*

> *Especially the drug-induced psychosis type people that come in and they just want to bash the wall or hit people or bite and hit and screaming, ... they're not in any shape to talk to anybody so we don't usually use [MHEC-RAP] for that. -1C*

> *Everyone that's acutely unwell from the mental health perspective ... are reviewed by MHEC-RAP. -6A*

Nonetheless, there were reservations expressed about the program. One provider felt that it should not become a replacement for local specialist care because there is a need for local face-to-face care. A note of caution was expressed if the MHEC-RAP clinicians appeared to not fully understand the local context or situation, and concern was raised when the advice given was dissonant to local clinical judgement. However, if local providers were concerned, they felt comfortable enough to talk with MHEC-RAP about it.

> *[MHEC-RAP] is only as good as the person behind the telephone and sometimes, I've been lucky enough, they've been fairly good, but there's always the one that doesn't realise the severity of the situation at the time. -2A*

> *I suppose even though [MHEC-RAP have] done the assessment and they've got the documentation, can make you worry about somebody when they've been discharged and you don't think that they're right to go on their own. -1A*

The providers also felt MHEC-RAP was acceptable for their patients. Through MHEC-RAP, patients were getting the specialist help they needed. It was felt that patients could speak openly with MHEC-RAP and not feel stigmatised using the program. They were also able to maintain a level of privacy in their crisis by speaking with someone external because *"In a small country town ... there's no chance to be anonymous." -1A.*

> *They might not want to speak to me face-to-face, but they're happy to speak to a complete stranger sometimes and discuss with them their own personal issues. -4A*

> *We always give the patient the [freecall] number to take away as well in case they want to ring away from the hospital. -3A*

Affordability

There were no direct costs borne by the providers to contact MHEC-RAP for help, and it was known to be free for the patients too, yet affordability of the program was discussed as providers identified other costs. MHEC-RAP was perceived to save the cost of unnecessary transportations of patients out of their community to another hospital thereby changing the previous culture of 'schedule and transport' to 'assess and transport as needed'. The transportation of patients was significant for everyone because of variables of distance, time, and workforce implications.

> *The only cost to us [is] transport, we have to call in people to transport and plus it's the cost for us to transport by ambulance. I mean that's $7900 just to drive them to [the nearest mental health inpatient unit], might be even a lot more than that. That's where it comes to cost the system here. MHEC-RAP has reduced that. ...so MHEC-RAP's actually saved us money, a lot of money in transport fees. -4A*

> *It does save money over a period of time because there are a number of times where we probably would have scheduled and sent somebody off, [with MHEC-RAP], they've assessed them and we could put that off for a period of time or assess whether it's urgent that they go or not. -5B*

Although it was recognised that it may be necessary and appropriate to transport the patient for their safety and wellbeing, the financial cost for the patient and their family was also a consideration. Financial savings were believed to extend to the patient and their family when the patient was able to be cared for locally; specifically in respect to the expense for the patient's return trip home or travel costs for the family to visit them in hospital.

> *The most negativity is transport back. Because we ship them off there, but they can't get back, so a lot of family,*

> *including the patient, say 'oh I can't go there'. ...[They] do not wish to be voluntary patients. Family say 'look they can't go, we can't get them back here'. -4A*

> *Sometimes with that MHEC-RAP service they can deem that the person doesn't need to be scheduled, they're happy for them to go home ... so it is a useful service in that way, not everybody obviously gets scheduled, but everybody gets, can get help through that service. -5B*

Adequacy

Emergencies are unpredictable and the 24-hour structure of the program responded to deeply felt inadequacies of local specialist access, particularly afterhours and on weekends.

> *[MHEC-RAP] is a fantastic service because we got quite a large mental health population and we didn't have anything afterhours Monday to Friday ... Having [MHEC-RAP] now 7 days-a-week, 24 hours-a-day is brilliant. -5B*

There were some aspects of MHEC-RAP that came under scrutiny; such as the video equipment used for clinical assessments and the layout of the local facilities. While the structure of the hospital ED is difficult to change, MHEC-RAP may respond to suggestions to modify the model of the video equipment to better meet local needs and concerns. For instance, large wall mounted systems could be exchanged with portable desktop devices bringing MHEC-RAP to the patient and possibly addressing local facility flaws.

> *We've got a little lounge room at the back of ED [where the MHEC-RAP video is located], unfortunately, it's not private, can't shut the door ... so it's not as confidential as it could be and that's a flaw in the design of our emergency department. -1A*

> *Probably the biggest drawback is that [our MHEC-RAP system is] a fixed wall system ... I think that it would be nice, as I said, occasionally if it were truly portable. -5B*

Awareness

Only one provider had not heard of or used MHEC-RAP. Everyone else was aware and had some experience with the program. A few providers even identified it as part of their role to teach others locally about this resource, such as when, why, and how to use it.

> *[The staff here] all know about it. ...it's more word of mouth. [MHEC-RAP hasn't] changed much at all, they haven't changed numbers, they do the same hours, the whole lot. -4A*

> *I do a lot of orientation for the hospital, so I do make sure that they know about [MHEC-RAP] and the doctors, that's part of our orientation with the doctors, you know even the locums that come in, that they know it's there as well. -5B*

Reporting specific details of the program was fuzzy, such as where the service was located, but knowing this sort of detail is inconsequential. The providers who used the program were informed about its purpose and function. Some used MHEC-RAP infrequently while for others it became a routine part of their practice. The variation in their knowledge, understanding, and use of MHEC-RAP demonstrated local adaptation and flexibility of the model to meet need and complement existing systems.

> *It depends, depends on the triage when they come through the door as to how we manage it. ... Monday to Friday, during office hours, if we've got someone presenting to the emergency department with a mental health problem our first thing to do is to ring the community mental health team ... it's harder on the weekends and out of hours when we don't have that, but we do have MHEC-RAP. -1A*

> *If it's a mental health presentation, we do MHEC-RAP. -6A*

> *It helps when you do know about it, once you've used the MHEC-RAP a couple of times, you become, you know it does become your best friend afterhours especially ... when you strike somebody who's provided really sensible advice and so we use it a lot. -5B*

Before and after

Before MHEC-RAP, providers felt alone, unsupported, and lacked confidence when dealing with emergency mental health presentations. They were mindful of long waiting times for assessments and concerned when patients were simply being medicated, involuntarily admitted to hospital, and unnecessarily transferred out of community which incurred costs of money, time, emotion, and human resources. Since MHEC-RAP, not all difficulties have been resolved, but access to specialist mental health care has changed the provision of such care locally. Many providers are using MHEC-RAP for every mental health presentation so that patients can get the right care with the assistance of a specialist. Some patients receive care plans that help direct local care and may reduce re-presentations. Providers also have access to much needed afterhour support. With MHEC-RAP, local providers have greater support and confidence to care for mental health patients.

> *[MHEC-RAP will] actually guide us on what treatment what path to go down, whether it's medication to give, that the patient's right to go home, that they can be followed up by community mental health...or whether the patient needs scheduling and transferring. ... I would think [MHEC-RAP] would have to reduce the level of re-presentation for someone who gets seen and treated [because] a care plan is started so that they go home. And it can make a difference, absolutely. -1A*

> *MHEC-RAP's made a big difference to the management of mental health problems to a point because you're not then trying to do it by yourself ... [MHEC-RAP] is providing a degree of reassurance. ... Prior to [MHEC-RAP] you kind of felt like you were flying blind....despite the fact that we [see] a lot of [mental health]. ... I think MHEC-RAP has changed the face of mental health in the bush. Reasonably in as much as it just gives us that afterhours support and so that helps significantly. I think it's not the answer to everything and it doesn't always work, and you can't always put them in front of the camera and all that sort of thing, but it certainly helps significantly. -5B*

Discussion and conclusions

Mental health emergencies are difficult to manage and required a different approach to patients presenting with physical ailments. Some local providers were not confident in their training and reluctant to provide care for such emergencies. Having access to MHEC-RAP who are able to conduct assessments, provide relevant and responsive information and advice on appropriate management and care of an emergency mental health presentation was invaluable. With MHEC-RAP, the local ED providers were no longer *'flying blind'*.

MHEC-RAP was considered useful because there was a specialist on the other end of the telephone line who could help at any time of day. The program offered support and feedback to ED staff, while providing access to specialist assessment for their patients. MHEC-RAP not only enabled access to specialist emergency mental health care for these local providers, it changed their clinical practice and perspective. These providers reported a greater level of confidence to manage and care for mental health patients locally because of MHEC-RAP. They also felt that patient outcomes were improved, that fewer patients were being transferred for specialist mental health care, and that there were fewer representations of mental health patients in crisis. Initial studies support this, but further research is necessary to determine such outcomes [32,33].

Access is the degree of fit between the consumer and the service, and activity data from the evaluation showed that MHEC-RAP was well used by the ED providers, offering further evidence of access through use [33]. Understanding the experience of the program users through the lens of access, MHEC-RAP is able to identify modifications to ensure its services continue to be relevant and responsive to the needs of their consumers. For example, scheduling regular visits to communities across the region to promote the program and discuss local issues that impact on use of the service, as well as offering education sessions over the video link to remote local providers on a more frequent basis would support dialogue between MHEC-RAP and end users of the service. This would benefit access by raising awareness of the program and providing MHEC-RAP with feedback to further refine program delivery to ensure its acceptability and adequacy at the community level.

The experiences of these ED providers align with those reported by other providers in rural and remote communities [15,17-19,21,22,45-47]. Their access, use, and experience of MHEC-RAP suggest that the program could be implemented to address limitations in access to specialist care for emergency mental health presentations in other rural or remote communities.

The number of provider participants is small yet similar to other rural and remote research, however this may be considered to be a limitation as more participants would naturally provide more information. Still, this group of participants provided rich and useful information regarding their experience of emergency mental health care and their access to and use of MHEC-RAP with no new or differing information revealed over the course of the interviews. Personal participant details, such as age and time in place and occupation, were not directly collected. This may be considered a limitation in the data collection confining the degree of interpretation of the data and the detail of the participants reported. However, this and other analyses have yielded relevant interpretations that can inform program development and implementation.

For other areas considering the establishment of an emergency telepsychiatry service, assessing the fit between the consumer and service as a requirement for the development, evaluation, and ongoing management of the service would result in decisions about design and delivery that achieve improved access to care. While MHEC-RAP offers a practical and transferable model, assuring its sustainability also requires investigations into other potential impacts of the program, such as analysing patterns in patient transportations and cost-effectiveness. Additional research is also required to examine the experience of people with mental health conditions and their family and carers to determine the impact and 'fit' of MHEC-RAP with the broader community.

This study reports the change in practice through the experience of access to MHEC-RAP. Analysing provider experience through the lens of access confirms that the program is accessible and offers insights for those considering how to establish an emergency telepyschiatry service in other settings. MHEC-RAP has *"changed the face of mental health in the bush"* and it could transform the provision of emergency mental health care for providers and communities elsewhere.

Abbreviations

ED: Emergency departments; GP: General practitioners; MHEC-RAP: Mental health emergency care-rural access program; WNSW/FWLHD: Western NSW and far west local health districts.

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

ES contributed to the study concept and design; conducted data collection, analysis, and interpretation; and drafted the manuscript. SK contributed to the interpretation of data and critically revised the manuscript. DL contributed to the study design and the interpretation of data, and critically revised the manuscript. All authors read and approved the final manuscript.

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ATTACHMENT RB-30

This is the attachment marked '**RB-30**' referred to in the witness statement of Dr Ravi Subramanya Bhat dated 4 July 2019.

Academic Health Center Management of Chronic Diseases through Knowledge Networks: Project ECHO

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Abstract

The authors describe an innovative academic health center (AHC)-led program of health care delivery and clinical education for the management of complex, common, and chronic diseases in underserved areas, using hepatitis C virus (HCV) as a model. The program, based at the University of New Mexico School of Medicine, represents a paradigm shift in thinking and funding for the threefold mission of AHCs, moving from traditional fee-for-service models to public health funding of knowledge networks. This program, Project Extension for Community Health care Outcomes (ECHO), involves a partnership of academic medicine, public health offices, corrections departments, and rural community clinics dedicated to providing best practices and protocol-driven health care in rural areas. Telemedicine and Internet connections enable specialists in the program to comanage patients with complex diseases, using case-based knowledge networks and learning loops. Project ECHO partners (nurse practitioners, primary care physicians, physician assistants, and pharmacists) present HCV-positive patients during weekly two-hour telemedicine clinics using a standardized, case-based format that includes discussion of history, physical examination, test results, treatment complications, and psychiatric, medical, and substance abuse issues. In these case-based learning clinics, partners rapidly gain deep domain expertise in HCV as they collaborate with university specialists in hepatology, infectious disease, psychiatry, and substance abuse in comanaging their patients. Systematic monitoring of treatment outcomes is an integral aspect of the project. The authors believe this methodology will be generalizable to other complex and chronic conditions in a wide variety of underserved areas to improve disease outcomes, and it offers an opportunity for AHCs to enhance and expand their traditional mission of teaching, patient care, and research.

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Healthy People 2010 for the first time identified the elimination of health disparities as a national health goal of the United States.[1] Rural, uninsured, and underserved populations represent three of the most significant sectors of inequality in the U.S. health care system. This inequality is especially prominent in the treatment of chronic, common, and complex diseases that disproportionately contribute to the overall morbidity and mortality in this country.[2] A central contributor to health disparities in underserved areas is a shortage of health care providers with the specialty expertise required to manage chronic disorders, such as diabetes, hepatitis C virus (HCV), cardiovascular disease, and depression, optimally.[3] In this article we describe the rationale for an innovative telemedicine program based in an academic health center (AHC) designed to improve patient care by developing and supporting the competence of primary care providers in underserved areas to manage complex disorders. This competence is developed through access to AHC specialists using a unique process of case-based learning known as knowledge networks. These networks integrate the strengths and resources of academically diverse partners in the modern health care sector in a model that is widely applicable for managing diverse national public health challenges. In the University of New Mexico's Project Extension for Community Health care Outcomes (Project ECHO), we use the treatment of HCV, a complex, chronic condition, as a model for managing other common and complex conditions, such as diabetes, cardiovascular diseases, mental health disorders, and HIV.

New Mexico as a Medically Underserved Area

New Mexico is the fifth-largest state in the country with a predominantly rural and frontier population of 1.83 million people, over half of whom are members of racial and ethnic minorities.[4] The population in many rural parts of the state is widely dispersed, making the availability of specialty care economically nonviable. Forty percent of patients in New Mexico are Hispanic, an ethnic group that has high rates of HCV infection nationally.[4,5] It is conservatively estimated that 32,000 New Mexicans are infected with HCV, and the state leads the nation in deaths from chronic liver disease and cirrhosis.[6]

The poverty rate in New Mexico is 17.7% compared with 11.7% nationally. New Mexico also has one of the highest rates of uninsured citizens in the United States. According to 2002 data, 21.3% of New Mexicans lack health insurance, considerably more than the 15.2% national average. Thirty-two percent of Hispanic adults and 29.4% of American Indians in New Mexico lack health care coverage.[7] Uninsured rural inhabitants often receive their primary health care from federally qualified health centers

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that are paid to provide indigent care through a cost-reimbursement mechanism. Access to infectious disease specialists, gastroenterologists, or hematologists trained in HCV management is extremely limited for both insured and uninsured rural patients in New Mexico. Most of these specialists are concentrated in the one AHC that serves the entire state, the University of New Mexico Health Sciences Center. Although pharmaceutical companies have offered antiviral therapy to indigent patients through patient-assistance programs in rural and frontier areas, lack of primary care expertise in the treatment of HCV and scarce specialty resources have limited patients' ability to take advantage of such programs.

Compounding the obstacles of a predominantly rural population with a high rate of uninsured citizens is a shortage of health care providers. Thirty-two of the 33 counties in New Mexico are listed as medically underserved areas, and 14 of these counties are designated as locations of health professional shortage. Only 20% of New Mexico physicians practice in rural or frontier areas.[7]

HCV: A National Public Health Problem

HCV qualifies as a pandemic, with perhaps 200 million HCV-infected persons worldwide and three million persons chronically infected in the United States alone. Twenty percent of those infected with HCV will develop cirrhosis over the course of two decades, and 4% of these individuals will progress to liver cancer annually. Statistical projections for 2010 through 2019 indicate there may be as many as 193,000 deaths attributed to HCV in the United States, with a total of 1.83 million life-years lost to the disease. The estimated total cost of advanced liver disease due to HCV is $11 billion in direct medical care costs and nearly $54 billion in societal costs due to premature disability and death.[8] Current treatments combining pegylated interferon and ribavirin result in a sustained viral response for 45% to 71% of patients. Effective treatment leads to improvement of liver disease and, in many instances, reversal of cirrhosis.[9] One of the major obstacles to patients receiving treatment for HCV has been the serious and complex side effects of antiviral therapy (e.g., anemia, neutropenia, depression) and the coexistence of psychiatric and substance abuse disorders.[10,11] The complexity of disease management and lack of access to trained specialists, who are typically available only in urban centers, have been substantial limitations to the provision of care to a largely rural population.

HCV is also endemic in the national prison population, and its treatment in prisoners is somewhat controversial.[12] Despite a lack of universal testing in prisons, to date, 1,978 prisoners have tested positive for HCV in the state of New Mexico, and it is expected that 2,400 of the 6,000 prisoners in New Mexico will eventually be diagnosed with HCV. Before the New Mexico Department of Corrections became a partner in Project ECHO, not a single prisoner had been treated for HCV. Project ECHO has offered at least a partial solution to the difficulties in obtaining appropriate and timely treatment for HCV-infected prisoners in New Mexico.

HCV in New Mexico and Project ECHO

We chose HCV as the exemplar in Project ECHO because it exhibits the six characteristics we have identified that make a disease amenable to treatment using knowledge networks:

1. The disease is common.
2. The disease has complex management.
3. Treatment for the disease is evolving.
4. The disease has high societal impact.
5. There are serious outcomes of failing to treat the disease.
6. Improved outcomes can be obtained with disease management.

Common diseases such as HCV, cardiovascular disease, and mental health disorders account for the majority of morbidity and mortality in the United States.[13,14] Improving outcomes for these diseases can thus have a disproportionately great impact on quality and quantity of life in this country.

These common conditions are also complicated to manage, and effective treatment usually requires a combination of education, lifestyle modification, and medication regimens beyond the training, time, resources, or experience of most primary care providers.[15] Often, multidisciplinary teams with expertise in specific areas are necessary to competently treat these conditions. The treatment of these diseases is rapidly evolving, with new research constantly dictating changes in disease management, making it nearly impossible for a primary care provider to keep up with the latest developments in one, much less a multitude of, chronic health problems.

These diseases have high societal impact, including loss of productivity at work, early disability and retirement, absenteeism, and excessive use of health care resources, including hospitalizations and pharmaceutical costs. Seventy-five percent of the world's annual medical expenditures of $1 trillion can be attributed to chronic diseases.[16] Failing to treat these conditions early and adequately results in increased morbidity and mortality, as these conditions are the leading causes of death in the world. For example, the Global Burden of Disease Study estimates that in 2020, the five leading causes of death worldwide will be ischemic heart disease, unipolar major depression, traffic accidents, cerebrovascular disease, and chronic obstructive pulmonary disease.[17] Through the use of state-of-the-art technology and best practices for the management of such diseases, substantially improved outcomes in quality of life, cost-effectiveness of care, and survival can be achieved.[18,19]

Project ECHO addresses the aforementioned six core characteristics of diseases amenable to treatment via knowledge networks through four major avenues. The first of these avenues is the use of telemedicine to maximize scarce specialty health care resources. The Institute of Medicine's definition of telemedicine is one of the most widely accepted: "the use of electronic information and communication technologies to provide and support health care when distance separates the participants."[20] The broadness of this definition is particularly applicable to Project ECHO, which incorporates several modalities of distance learning, including audio and video teleconferencing, Internet-based assessment tools, best practices, online presentations, and telephone, fax, and e-mail communications. What renders the use of telemedicine in Project ECHO innovative and relatively unique is that learning technology is geared toward ensuring providers are as well informed as possible, rather than telemedicine's traditional focus exclusively on treating the patient. Thus, in contrast to forms of telemedicine that are direct treatment modalities, the use of information technologies in Project ECHO facilitates and supports the provision of care.[21] It is this shift in the fulcrum of telemedicine that gives power and scope to the program's learning loops and knowledge networks.

The second avenue to treating diseases through knowledge networks is the use of a disease-management model combined with the employment of best practices. The third avenue is case-based learning with longitudinal comanagement of patients by primary care providers and specialists from the University of New Mexico Health Sciences Center and the New Mexico State Health Department. The fourth is the coordination of Project ECHO through a centralized Health Insurance Portability and Accountability Act (HIPAA)-compliant database that allows outcomes to be monitored for continuous quality assurance and improvement.

The primary goal of Project ECHO is to demonstrate how a partnership of academic medicine, public health, corrections, and community health centers can foster the capacity of rural physician partners to provide safe and effective treatment for HCV infection in any population, consistent with the accepted standard of care. Current Project ECHO partners include University of New Mexico Health Sciences Center Department of Internal Medicine, eight prisons in the New Mexico Corrections Department, the Indian Health Service hospitals in Santa Fe, the New Mexico State Health Department, federally qualified health centers (Health Centers of Northern New Mexico—two clinics), Presbyterian Medical Services, First Choice Clinics (three clinics), Hidalgo Medical Services, La Casa Family Health, Ben Archer Clinics, La Clínica De Familia), and other health care providers (Pojoaque Primary Care, El Pueblo Community Health, and Memorial Medical Center Family Practice Residency program.) Such a partnership is uniquely suited to address the barriers to treating HCV in medically underserved populations through the use of interactive audio and video clinics called knowledge networks. A secondary goal of Project ECHO is to use the treatment of HCV as a pilot to demonstrate the capacity of an AHC-led partnership that could use public health funding to manage any number of complex diseases in underserved rural and urban populations.

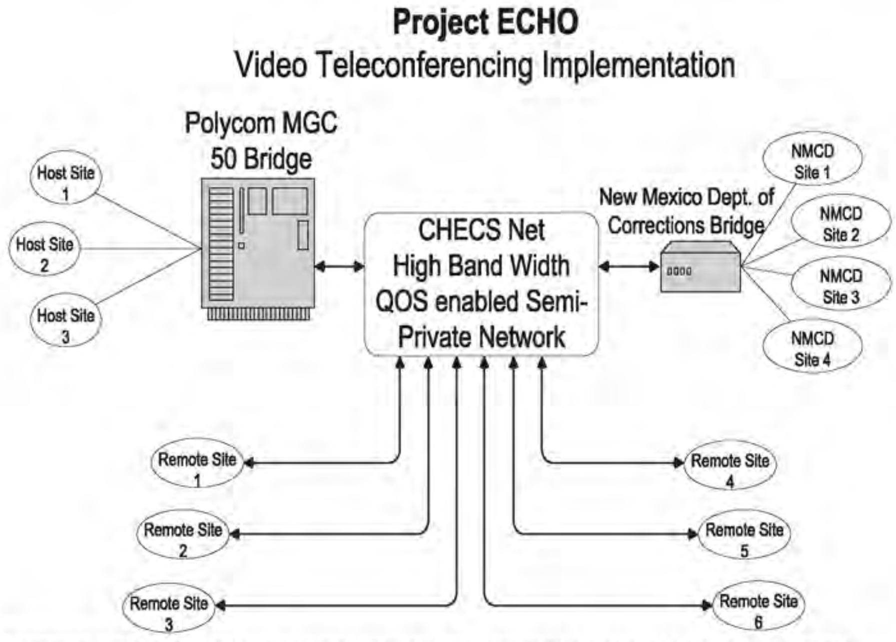

Figure 1 Project ECHO video teleconferencing implementation. Project ECHO is based at the University of New Mexico, Albuquerque, NM, and was implemented in June 2003.

Operation of Project ECHO

Operationally, project partners are recruited through statewide health care conferences, presentations, and partner contacts. Once a partner joins the network, members of the HCV team visit the site to conduct a one-day hands-on training workshop. State-of-the-art technology for data sharing and collaboration and audio/video teleconferencing is essential to Project ECHO's mission of reaching out to underserved rural clinics and prison populations. The current videoconferencing network structure is illustrated in Figure 1. Telemedicine experts assist partners with installation of the *HCV Care Manager*, a specifically designed software program developed by the Liver Research Institute, Denver, Colorado, in collaboration with Project ECHO (Figure 2). Partners then spend one to two days at the University of New Mexico Hepatitis C clinic shadowing the core Project ECHO team to experience the dynamics of an HCV clinic.

After completing this initial orientation and training, partners—who currently include pharmacists, nurse practitioners, primary care physicians, and physician assistants—begin presenting HCV-positive patients during weekly two-hour telemedicine clinics using a standardized, case-based format that includes discussion of treatment complications and psychiatric, medical, and substance abuse issues. During these clinics, partners collaborate with specialists from gastroenterology, infectious disease, psychiatry, substance abuse, and pharmacology, as well as with other network providers in learning loops.

Learning loops are case-based educational experiences in which community providers learn through three main routes: (1) longitudinal comanagement of patients with specialists, (2) other primary care providers on the network via shared case-management decision making, and (3) short didactic presentations on relevant topics, such as vaccination for hepatitis A and B and diagnosis of depression. These learning loops create deep domain knowledge about the area

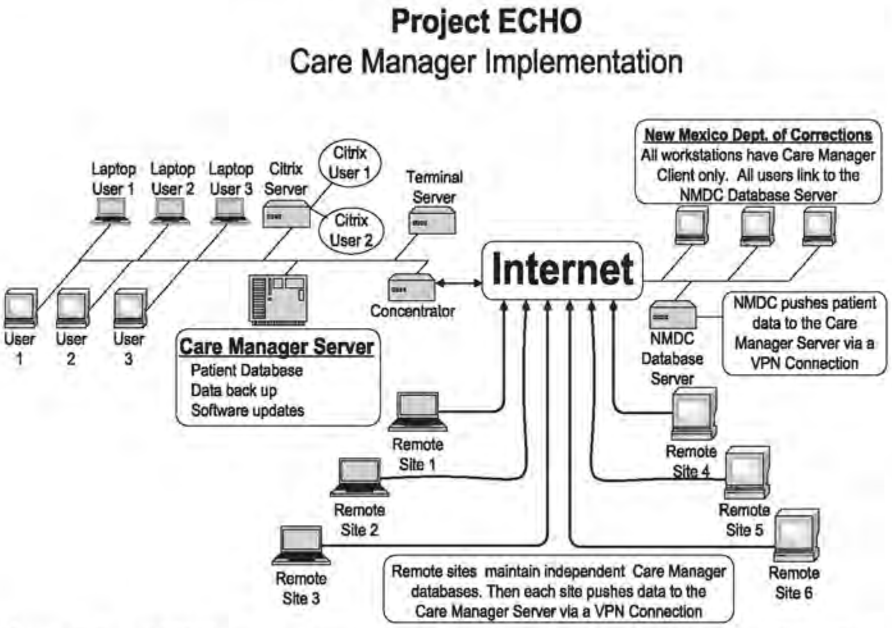

Figure 2 Project ECHO care manager implementation. Project ECHO is based at the University of New Mexico, Albuquerque, NM, and was implemented in June 2003.

in question—here HCV—among rural providers, enabling them to provide the highest-quality treatment for their patients. Ethical and legal issues, such as licensing and credentialing, related to the comanagement of patients through the use of telemedicine have been major obstacles to wider utilization of telehealth.[22] Project ECHO specialists only collaborate with health care providers within the state of New Mexico and so do not confront issues with practicing in other states. Further, the novel use of telemedicine in Project ECHO means that academic specialists serve as consultants to other health care professionals, who remain the primary providers of care for underserved patients.

Benefits of Project ECHO for Providers

Health care providers in underserved areas face a number of unique professional difficulties, including personal isolation and professional stagnation, excessive workload, and lack of access to consultation and continuing medical education (CME). These problems have led to accelerated burnout and rapid turnover, which prevent the development of longitudinal patient–physician relationships and continuity of care among underserved populations.[23] One of the primary benefits of a partnership with an AHC is the potential to improve the recruitment and retention of physicians and other health care providers with personal or professional investments in rural medicine by helping to alleviate the aforementioned stresses.

Project ECHO addresses many of the problems encountered by rural and corrections health care providers. Participants in the network are offered free CME credits. Providers who manage 20 patients through a year of antiviral therapy are eligible to obtain certification demonstrating their expertise in the area of HCV treatment. Participation in weekly telemedicine clinics reduces peer isolation and fosters professional development. Project ECHO strives to restore the balance of education and clinical work that characterizes residency training by using case-based, patient-centered learning that has been shown to be far more effective in building essential clinical knowledge and skills than traditional lecture- or conference-based didactic CME.[24,25] Similar efforts in other rural areas have shown high rates of provider satisfaction.[26]

One of the most important barriers confronting a primary care provider attempting to manage complex diseases like hepatitis C, HIV, or diabetes is the exponential growth of scientific information, which has generated an unprecedented knowledge gap for health professionals. The knowledge networks of Project ECHO deliver patient-specific knowledge on demand, thus bridging this gap to deliver the highest quality of patient care (Figure 3).[27] Indeed, every health care professional practices in an "underserved area" of knowledge outside his or her own expertise and, thus, could benefit from participation in knowledge networks.[28]

Preliminary data from provider satisfaction surveys indicate that many of these goals are being achieved. Twenty-nine providers completed a questionnaire covering their participation during the period August 2004 to June 2005. Ninety-six percent reported enhanced knowledge about management and treatment of HCV patients, and 92% believed they had obtained competence in caring for HCV patients. Reinforcing the target outcomes of Project ECHO to reduce rural provider isolation and to enhance access to specialty services, 84% cited access to expertise in behavioral and mental health care resources as helpful in caring for HCV patients. Seventy-one percent mentioned collegial discussion with peers as a major benefit of participation. Twenty-nine providers completed a survey at the 2006 annual Project ECHO meeting regarding the benefits they received from participation in the network. On a five-point Likert scale (1 = strongly disagree, 5 = strongly agree), the average response to the statement "I have access to Project ECHO specialists and their expertise whenever needed" was 4.8. The practical importance of an integrated approach to health care was shown in the average response of 4.5 given to the statement, "Collaboration among agencies is a benefit to my clinic." Finally, survey respondents were invited to qualitatively describe their reasons for participation in Project ECHO. The single most important reason mentioned was, "To provide appropriate care for hepatitis C patients at their primary care location and to access subspecialty service for patients who would not otherwise have that service."

Benefits of Project ECHO for Patients

Numerous studies have shown that specialist treatment of complex, chronic conditions, such as HIV, diabetes, and

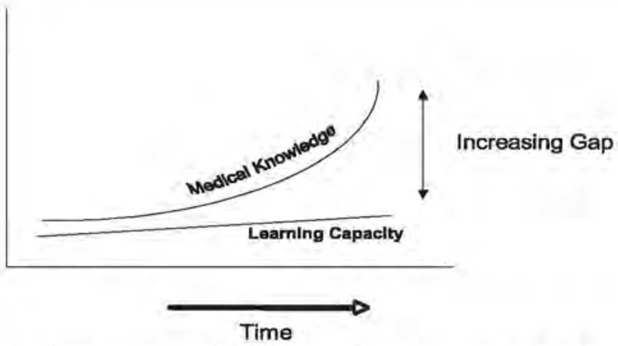

Figure 3 The role of expanding knowledge in caring for underserved populations.

depression, is superior to that of primary care providers, chiefly because of domain knowledge and experience.[18,29,30] The Project ECHO model enables primary care providers, in collaboration with specialists, to develop a similar level of treatment competence in a chosen content area. This increased competence reduces medical errors (e.g., failure to vaccinate HCV-positive patients for hepatitis A and B), avoids unnecessary testing (e.g., the HCV RIBA assay), reduces the morbidity and mortality of untreated disease (e.g., cirrhosis and hepatocellular cancer), mitigates the cost of future interventions (e.g., liver transplantation), and may reduce treatment-related complications (e.g., anemia and depression). The project does not supplant but supplements the traditional strengths of the primary care physician–patient relationship. The model empowers primary providers to offer safer and more comprehensive care for complicated disorders that previously would have been managed through specialty referral, with the resulting long wait times, increased cost, and fragmentation of care.

Since the first Project ECHO HCV telemedicine clinic was held in June of 2003, 137 clinics have been conducted, with a total of 1,234 case presentations of patients enrolled in the HCV disease-management program. In 2005 alone there were 1,581 patient visits for HCV disease management at Project ECHO partner sites. Currently, there are 173 patients on interferon and ribavirin treatment for HCV in New Mexico via Project ECHO. This number is substantial given that most large university HCV programs typically have approximately 50 patients on treatment at one time, given the complexities of the treatment process. In addition, 2,683 hours of CME credit have been issued and 390 hours of on-site staff and provider training have been offered during the last two years at no cost to participants. Through indigent drug-replacement programs, pharmaceutical firms have donated more than three million dollars of no-cost pharmaceuticals for patients in Project ECHO.

We believe that the successes of Project ECHO thus far include significantly improved outcomes in patient care. The numbers of case presentations and teleconference hours represent substantial progress in the treatment of HCV in New Mexico, precisely because participants are providing high-quality and accessible care to hundreds of HCV-positive patients who would otherwise not receive treatment. Our initial goals were to construct a network enabling two major populations—those in the criminal justice system and those in underserved rural and urban areas—to receive state-of-the-art HCV medical management with antiviral therapy, and, concomitant with this outreach, to demonstrate the efficacy of telemedicine for the treatment of chronic disease in a variety of underserved areas. We feel that conducting near-weekly teleconferences with each of these groups in a three-year time period and obtaining free pharmaceutical, laboratory, medical, and behavioral health care for patients enrolled in Project ECHO are evidence of having accomplished our target goals. The teleconference model has been so successful that the Project ECHO team recently instituted separate clinics for HIV–HCV coinfection and substance abuse disorders. On July 1, 2006, additional Project ECHO clinics have started for substance abuse disorders, rheumatology consultation, gestational diabetes, and management of mental health disorders throughout New Mexico. Future patient-care goals are to expand access to these diverse specialty networks to any provider in New Mexico wishing to participate.

Barriers to Project ECHO

Project ECHO incorporates many of the principles, practices, and policies recommended by the Agency for Health care Research and Quality (AHRQ) and other government panels and professional organizations to meet the challenges of 21st-century health care delivery, particularly the problem of health disparities.[31]

The single greatest barrier to the success of Project ECHO was obtaining funding and constructing infrastructure to treat this prevalent and serious infectious disease in one of the most underserved and impoverished states in the country. Without treatment, 8,000 patients in New Mexico will develop cirrhosis, eventuating in several thousand deaths.[6]

Acquiring stable funding and infrastructure to provide disease management for HCV infection and other complex conditions can only be achieved through the collaboration of public health, government, academic, and private sectors in the United States. AHCs, with their triple mission of research, education, and clinical care, are the ideal and perhaps only entity with the technical sophistication, administrative experience, and professional ethos to lead such a collaborative initiative. The most effective interventions to improve health care delivery to rural areas are those that support the education of primary care physicians, increase the flow of providers to rural areas, strengthen and support rural health care institutions with the latest clinical research, and integrate rural health care into larger regional systems.[32,33] Endeavors like Project ECHO have the potential to help achieve the above objectives in almost any setting, including the rural United States or the developing world.[23]

Project ECHO was set up initially on a federal grant from the AHRQ. We subsequently proposed a public health model to operate Project ECHO, and we received key funding from the New Mexico State Legislature to address this health care disparity and achieve continuity of specialty care for the uninsured. Another indication of the success of Project ECHO and its collaborative model has been the acquisition of stable and recurring funding from pharmaceutical companies and the University of New Mexico. In March 2006, the New Mexico State Legislature provided permanent recurring funding for the project.

Project ECHO and the Mission of AHCs

Integral to the value of this paradigm shift in the treatment of chronic, complex diseases is the enabling of AHCs to fulfill their historic threefold mission of clinical care, education, and research, as well as honor an increasingly recognized obligation to protect and improve public health.[34,35] We have already outlined the potential clinical and public health implications of knowledge networks, but they also have significance for education and research.

Psychiatry, family medicine, and internal medicine residents as well as medical students regularly participate in HCV clinics, seeing firsthand the benefits of telemedicine and knowledge networks. They participate in discussions, review cases with faculty, and learn about detailed disease management.

Collaborations such as Project ECHO are ideal venues for the pursuit of clinical research in the fields of epidemiology, health care delivery, best practices, evidence-based medicine, and health care cost-effectiveness, the results of which have real-world applicability.

Knowledge networks offer AHCs a unique opportunity to assume leadership in partnerships with a focused synergy on major public health problems, thus continuing to justify and warrant traditional state and federal mechanisms of funding and support as well as attracting new community, industry, and managed care resources.[36]

Evaluation

Like all innovations, a knowledge network must be constantly evaluated and improved in response to feedback. We survey participants regarding their experience and have incorporated feedback into the timing and length of sessions, case presentation format, disease-management protocols, procedures for accessing indigent care, pharmaceutical drug-replacement programs, efficacy and ease of use of technology, and content of short didactic presentations. Other survey instruments are used to assess the efficacy of knowledge networks and learning loops. A biannual meeting of all providers serves to share best practices among rural sites. Over time, as outcomes become available, we will compare them with alternate care models to assess further the function of the Project ECHO model.

We hope the methodology of Project ECHO can be generalized to many common, complex, and chronic conditions in a wide variety of underserved and developing areas to effectively improve disease outcomes. This project can be a model for the interaction of AHCs with the diverse communities they serve, providing educational, research, and clinical expertise to primary care providers in locations distant from the AHC in both geography and resources.

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ATTACHMENT RB-31

This is the attachment marked '**RB-31**' referred to in the witness statement of Dr Ravi Subramanya Bhat dated 4 July 2019.

The Impact of Project ECHO on Participant and Patient Outcomes: A Systematic Review

Carrol Zhou, MD, Allison Crawford, MD, Eva Serhal, MBA, Paul Kurdyak, MD, PhD, and Sanjeev Sockalingam, MD, MHPE

Abstract

Purpose
Project Extension for Community Healthcare Outcomes (ECHO) uses tele-education to bridge knowledge gaps between specialists at academic health centers and primary care providers from remote areas. It has been implemented to address multiple medical conditions. The authors examined evidence of the impact of all Project ECHO programs on participant and patient outcomes.

Method
The authors searched PubMed, MEDLINE, EMBASE, PsycINFO, and ProQuest from January 2000 to August 2015 and the reference lists of identified reviews. Included studies were limited to those published in English, peer-reviewed articles or indexed abstracts, and those that primarily focused on Project ECHO. Editorials, commentaries, gray literature, and non-peer-reviewed articles were excluded. The authors used Moore's evaluation framework to organize study outcomes for quality assessment.

Results
The authors identified 39 studies describing Project ECHO's involvement in addressing 17 medical conditions. Evaluations of Project ECHO programs generally were limited to outcomes from Levels 1 (number of participants) to 4 (providers' competence) of Moore's framework (n = 22 studies, with some containing data from multiple levels). Studies also suggested that Project ECHO changed provider behavior (n = 1), changed patient outcomes (n = 6), and can be cost-effective (n = 2).

Conclusions
Project ECHO is an effective and potentially cost-saving model that increases participant knowledge and patient access to health care in remote locations, but further research examining its efficacy is needed. Identifying and addressing potential barriers to Project ECHO's implementation will support the dissemination of this model as an education and practice improvement initiative.

Common, complex, and often co-occurring chronic illnesses, such as major depression and ischemic heart disease, are fast becoming the leading causes of death worldwide.[1] In North America, primary care providers (PCPs) are at the forefront of caring for these patients and are typically the point of referral to subspecialist consultation. However, specialists are often affiliated with tertiary care or academic health centers located in urban settings[2]; access to specialist care for patients and primary care physicians in rural areas can be a challenge. Moreover, rapidly evolving evidence for best practices in the management of these conditions outpaces PCPs' ability to remain current. One potential mechanism for increasing the capacity of PCPs to manage these complex and chronic conditions is through the use of education to increase and maintain their competence in specialty areas.

Project Extension for Community Healthcare Outcomes (Project ECHO), a program developed in 2003 to help PCPs in rural New Mexico manage the hepatitis C virus (HCV), is one such innovative solution. Project ECHO's virtual hub-and-spoke educational model harnesses telemedicine to facilitate rural PCPs' learning and supervision by experts at academic health centers, thus increasing their ability to manage complex medical cases. The goals of Project ECHO are to use tele-education to provide access to scarce health care resources; to share best practices and reduce variation in care; to develop specialty expertise in PCPs, allowing them to practice within the full scope of their role; and to improve and monitor patient outcomes.[3]

Project ECHO participants, including clinicians, pharmacists, and nurse practitioners, initially receive one day of training from the HCV treatment team at the University of New Mexico School of Medicine. They then participate in weekly two-hour teleconference sessions, which consist of a combination of didactic lectures and anonymized case presentations of patients managed by the remote sites to facilitate learning. Community health care providers become familiar with managing patients with complex health needs. Arora and colleagues[4] termed these learning opportunities "learning loops," which facilitate PCPs' learning through three main methods:

1. Co-management of patients with specialists;
2. Learning during sessions from other community-based PCPs, who practice in similar settings with comparable barriers to accessing care; and
3. Learning from didactic presentations geared towards specific issues that arise during the telehealth clinic.

The effectiveness of the initial HCV Project ECHO program was evaluated. Patients treated by community-based PCPs trained under the ECHO model had the same health outcomes—specifically, comparable sustained virological response ("cure") rates—as those treated at large academic health centers.[3,5] Since this seminal work, Project ECHO has attracted attention both from members of the scientific community and

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from government agencies, and efforts have been made to adopt this model for a variety of other medical conditions including rheumatology, dermatology, musculoskeletal disease, asthma, chronic pain, palliative care, inflammatory bowel disease, women's health, complex regional pain syndrome, dementia, diabetes, epilepsy, hypertension, liver disease, mental health, and transgender care.[6–20]

Amidst the global proliferation of Project ECHO programs, literature describing program development and related provider and patient outcomes has emerged. However, to date, no systematic review has summarized Project ECHO program results. The purpose of this systematic review was to examine the evidence from all Project ECHO models. We evaluated Project ECHO outcomes in terms of the impact on participant and patient outcomes and cost-effectiveness.

Method

Data sources and identification of studies

We performed a broad search of the English-language literature included in five electronic databases: PubMed, MEDLINE, EMBASE, PsycINFO, and ProQuest. The keywords used in our search were "Project ECHO" and "Project Extension for Community Healthcare Outcomes." We limited our search to literature published from January 2000 to August 2015 as the initial HCV pilot program was launched in 2003. Two authors (C.Z., S.S.) independently reviewed each of the identified abstracts to remove duplicates. Additional studies were identified through searches of the reference lists of the identified review articles related to Project ECHO.

Study inclusion and exclusion criteria

We selected studies for this review using the following inclusion criteria:

1. English-language source;
2. Peer-reviewed journal article or indexed abstract;
3. Published from January 2000 to August 2015; and
4. Primary focus on Project ECHO.

We included both qualitative and quantitative research. Studies were excluded if they were editorials or commentaries because of their subjective nature, non-peer-reviewed articles, or gray literature. We included studies that used the same data pool so long as they analyzed it for different outcomes (i.e., cost-effectiveness vs. patient outcome comparisons). All other duplicate studies were removed. The systematic utilization of these inclusion and exclusion criteria resulted in no disputes between the authors regarding study selection.

Data extraction and classification

This study followed the PRISMA guidelines for conducting a systematic review. Using our search criteria, we initially identified 387 articles and abstracts. Two additional articles were identified through reference list searches. Two authors (C.Z., S.S.) independently reviewed each abstract and removed duplicate articles. After this review, a total of 39 original studies met the inclusion criteria and were included for full-text review (see Figure 1).

Data were extracted by a single researcher (C.Z.). Data extraction categories included location of Project ECHO sites, type of education technology, instructional methods, frequency of sessions, chronic disease focus, and a brief summary of the findings.

We also aimed to assess the fidelity of each replication of the original HCV program. Our assessment criteria were:

- Initial training on Project ECHO model received by participants prior to the learning sessions;
- The duration of each teleconference learning session (two hours);
- The use of a combination of didactic material and case presentations at each session; and
- The frequency of sessions (weekly).

Projects that adhered to all four criteria were rated "high" in fidelity to the original model. Those that adhered to two to three criteria were rated "mid" in fidelity. Those that adhered to less than two and/or did not include enough descriptive data for assessment were rated as "low/insufficient information."

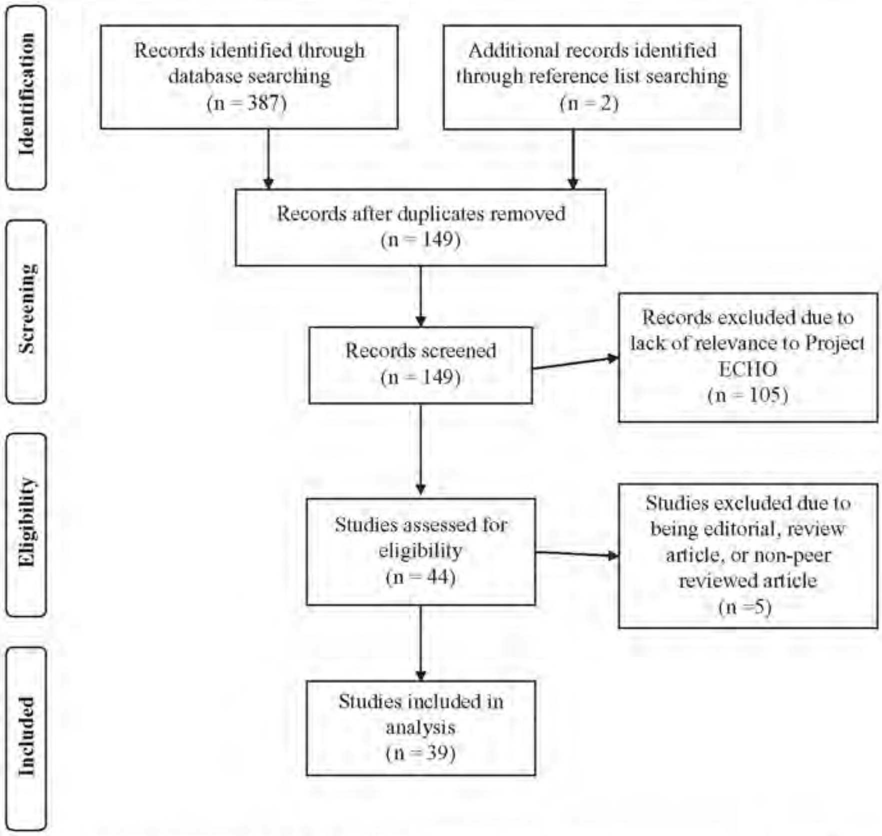

Figure 1 Literature search and study selection process for a systematic review of the literature, published between January 2000 and August 2015, on the participant and patient outcomes of Project Extension for Community Healthcare Outcomes (ECHO) programs. The study followed the PRISMA guidelines for conducting a systematic review.

Quality assessment

We assigned each of the 39 included studies to a level of evidence in Moore's continuing medical education (CME) evaluation framework (see Table 1).[21] Moore's framework is an ideal tool to assess current evidence from Project ECHO studies because it was developed to assess the impact of CME programs by focusing on the target outcomes of CME events with the goal of iteratively modifying the design of the event to achieve the intended results. Moore's framework organizes outcome categories into seven levels, from Level 1 studies that simply describe the number of health care professionals who participated in the CME activity to Level 7 studies that describe the impact of the CME event on the health outcomes of a community.

We discussed the methodology and limitations of the included studies according to each level of Moore's evaluation framework. We first discussed our findings pertaining to the motivating factors and barriers to participation in Project ECHO programs. We also described the studies that did not fit into any level of Moore's framework, such as learning theories behind Project ECHO and the cost–benefit analysis of Project ECHO. Efforts were made to synthesize the available evidence to comment on the clinical effectiveness, feasibility, and meaningfulness of the program.

We calculated descriptive statistics for all extracted data and summarize them and the quality assessment data in the text below and in Appendix 1.

Results

We included 39 studies in this review.[3–5,7,9–20,22–44] Study characteristics and target populations are described first, followed by a description of study outcomes using Moore's evaluation framework (see Appendix 1).

Location

Project ECHO had 462 local programs in New Mexico, 13 national programs in the United States, and 5 international programs.[45]

Twenty-two studies contained Project ECHO models where the hubs (academic health centers) and spokes (remote locations) were located in the same U.S. state, most often New Mexico.[3–5,7,9,11,14,16,17,25–27,29,31–33,35–37,39,40,42] Eight studies described a Project ECHO model with a central hub but multiple spokes from different states.[10,13,18–20,28,34,41] Three recently developed programs in inflammatory bowel disease and transgender medicine employed a decentralized hub of subspecialists across multiple U.S. states.[13,15]

Target population

Thirty studies included civilian populations living in remote areas.[3–5,7,9,11,12,14,16,17,20,22–40] Seven studies focused on veterans.[10,13,15,19,34,41,42] Other special populations studied included indigenous Americans,[3–5,18,22] prison inmates,[3–5,18,25] and long-term care facility residents.[9,26] A recent epilepsy initiative was the first Project ECHO program to include pediatric patients.[20]

Fidelity of subsequent Project ECHO programs to the original HCV Project ECHO program

We assessed 30 studies for their fidelity to the original model. Two met our criteria for high fidelity,[23,36] 11 had midlevel fidelity,[7,15,16,18,25,27,29,35,38,39,42] and 17 were deemed to have low fidelity or contained insufficient information for assessment.[9–11,13,14,17,19,20,26,28,30–33,37,40,41]

Project ECHO program outcomes and quality assessment

Of the 39 included studies, 28 reported at least one outcome from Moore's evaluation framework.[3,5,7,9,10,12–19,22–24,26–28,32,33,35,37–42]

Level 1: Number of participants. Twelve studies reported the number of Project ECHO participants, which ranged from 9 to 710.[7,9,13,17–19,22,24,33,35,39,41] The median number of participants was 38, and the interquartile range was 65.

Level 2: Health care providers' satisfaction. Thirteen studies contained data from surveys and/or semistructured interviews with PCPs involved in Project ECHO.[4,10,12,15–17,19,23,24,27,28,35,37] In all 13 studies, participants indicated a high level of satisfaction with the educational program.

There may have been selection bias in these studies, as PCPs who completed the surveys presumably had at least a baseline interest in Project ECHO because they joined the program on a volunteer basis.[12,24] Another limitation of these studies was the small number of survey respondents.[12,24] The number of participants ranged from 8 to 83 (median of 27).

Level 3: Changes in health care providers' knowledge. Four studies assessed Project ECHO's impact

Table 1

Overview of Moore's Evaluation Framework for Continuing Medical Education (CME),[21] Used to Assess Quality in a Systematic Review of the Literature on the Outcomes of Project Extension for Community Healthcare Outcomes Programs

CME framework	Level	Description
Participation	1	The number of health care professionals who participated in the CME activity or program
Satisfaction	2	The degree to which the expectations of the participants about the setting and delivery of the CME activity or program were met
Learning	3	The degree to which participants could demonstrate that they know what the CME activity or program intended them to know (includes both declarative and procedural knowledge)
Competence	4	The degree to which participants could show in an educational setting how to do what the CME activity or program intended them to be able to do (includes perceived self-efficacy/self-confidence)
Performance	5	The degree to which participants could do what the CME activity or program intended them to be able to do in their practices
Patient health	6	The degree to which the health status of patients improved due to changes in the practice behavior of participants
Community health	7	The degree to which the health status of a community of patients changed due to changes in the practice behavior of participants

on PCPs' knowledge with a pre-/posttest comparison.[14,17,23,38] One study used multiple-choice questions to test PCPs' knowledge of treatment-resistant hypertension and showed a significant increase in knowledge after Project ECHO participation.[17] Other studies comparing self-reported level of knowledge before and after Project ECHO participation found similar results.[14,23,38]

Whereas multiple-choice questions are objective measures of declarative knowledge, self-reported survey responses may lack validity. Specifically, participants may be unwilling to disclose at baseline a lack of knowledge on a particular topic. Second, knowing that a program aims to increase knowledge, participants may overrate the extent of their knowledge increase after the program. Both scenarios could have produced bias that influenced the study results.[46]

Level 4: Health care providers' competence. Eight studies focused on PCPs' competence after participating in Project ECHO.[7,10,14,16,17,23,27,28] These studies used survey rating scales and semistructured interviews to measure the change in participants' confidence. Seven reported an increase in self-confidence.[7,10,16,17,23,27,28] The eighth study found no significant difference in participants' confidence when comparing a pre–post Project ECHO self-efficacy survey, despite participants reporting a significant increase in their knowledge and skills.[14] The authors attributed the negative results to participants' inflated self-efficacy ratings at baseline due to their failure to appreciate their knowledge gaps in pain and headache management.

These self-reported surveys had the same potential biases as those previously discussed for the Level 3 studies.[46] It is also unclear whether self-reported confidence is a good measure of clinical competence.

Level 5: Health care providers' performance. One study assessed participants' performance.[13] Frank et al[13] longitudinally evaluated the Specialty Care Access Network (SCAN)-ECHO program for pain management to find the association between Project ECHO consultation and (1) the delivery of different types of outpatient care and (2) medication initiation. The authors found that an ECHO pain management consultation was associated with increased use of only physical medicine services (not mental health, substance disorder, or pain medicine services) and initiation of nonopioid medications among patients with chronic noncancer pain. Limitations included a lack of control group.

Level 6: Patient health. Seven studies measured the change in patients' health status after Project ECHO implementation.[3,5,26,32,39,40,42] These studies focused on three diseases: HCV, dementia/behavioral issues, and diabetes.

Two studies contained results from the original HCV program.[3,5] A prospective cohort study found that HCV-positive patients treated by Project ECHO PCPs had similar sustained viral response rates as patients treated by specialists.[3] The other study found no significant difference in the number of serious adverse events between both groups.[5] Two other studies replicating the HCV program showed similar results.[39,40]

Two studies focused on the Project ECHO-AGE program, which targeted long-term care residents with dementia and behavioral issues.[26,32] In one study, Catic et al[26] followed the outcomes of 44 long-term care residents who were patients of Project ECHO-AGE PCPs. When the ECHO recommendations were followed, 74% of patients improved, compared with 20% of patients when the recommendations were not followed because of provider judgment or family resistance. Limitations of this study included low statistical power. Gordon et al[32] subsequently conducted a matched cohort study (Project ECHO-AGE patients vs. patients from a non–Project ECHO consultation service) using the same patient population and found that participating nursing homes reported significantly lower restraint levels than those in the control group.

Watts et al[42] showed that, following Project ECHO training, the mean hemoglobin A1c values of patients in a diabetes clinic significantly decreased from 10.2 to 8.4 ($P < .001$) over five months. This decrease was not explained by system-wide improvements, as two clinics of non–Project ECHO PCPs saw a 4% to 15% increase in the percentage of patients with A1c values over 9 during the same period.[42] Limitations of this study and the original HCV study included the lack of randomization in the study design, resulting in an inability to account for confounding factors.[5,42]

Level 7: Community health. We found no studies with Level 7 outcomes.

Additional outcomes: Cost–benefit analysis. Two studies looked at the financial benefits of Project ECHO.[19,43] One discussed the cost-effectiveness of the original HCV program.[43] The authors found that Project ECHO increased quality-adjusted life expectancy by 3.8 (standard deviation 1.4) years per patient. The mean savings from Project ECHO compared with conventional treatment were $1,352 per person or $352,872 for 261 patients. Project ECHO cost an average of $8,300 (standard deviation $7,800) per quality-adjusted life year gained, which was well below the standard U.S. willingness-to-pay threshold of $50,000 per quality-adjusted life year gained. The study deemed the HCV Project ECHO program cost-effective. A second study on the SCAN-ECHO model for chronic liver disease showed that patients saved an average of 187 travel miles per person, for a total of 28,597 miles saved.[19]

Motivating factors and barriers to Project ECHO participation

Some studies qualitatively analyzed motivating factors for Project ECHO participation using surveys or focus groups.[28,41] The most common motivating factors were to increase one's knowledge base, apply new knowledge to future patients, save patients traveling time, and increase collaboration with specialists. Other reasons for participating included obtaining CME credits, decreasing health care and patient costs, preventing professional isolation, sharing new knowledge with colleagues, and trying something new.[41] The main barrier to participation was lack of time.[28,41] Less important barriers included not receiving CME credit, lack of a financial incentive, and the inability to access the videoconferencing technology.[41]

Discussion

On the basis of our knowledge and review of the literature, we believe that this is the first systematic review of the published literature on Project

ECHO programs and their outcomes. Our review showed that evaluations of Project ECHO programs predominantly have been limited to Levels 1 to 4 of Moore's framework. Preliminary data from seven studies suggest that Project ECHO can change PCPs' behavior and patient outcomes.[3,5,26,32,39,40,42] Moreover, emerging data from the HCV Project ECHO program indicate that this model is potentially cost-effective and can save patients the burden and cost of traveling to receive specialist care.[19,43]

Research also suggests that Project ECHO's effectiveness as a CME program may be explained by several learning theories, specifically social cognitive theory, situated learning theory, and communities of practice.[44] Social cognitive theory proposes that, for effective learning to occur, individuals must believe the benefits of performing the new behavior, have confidence in their own ability to perform it, and be positively reinforced to change.[47] Situated learning theory postulates that effective teaching requires interesting and manageable tasks that motivate learners to extend their current skills and knowledge to perform the idealized version of the task.[48] Communities of practice are founded on the premise that learning is more effective when one participates as part of a group of learners.[49,50] Although we propose that these learning theories explain the study outcomes observed in our review, further research is needed to clearly elucidate the salient learning mechanisms and factors responsible for the observed Project ECHO outcomes.

The use of a teleconference-based model contributes to the potential cost-effectiveness and accessibility of Project ECHO because it saves the need for patients to travel long distances for specialist care and takes advantage of existing technology. However, the limited evidence available on the cost-effectiveness of Project ECHO focused only on the initial HCV program and cannot be generalized to other medical conditions. This lack of generalizability exists because other factors, such as the specific illness and the complexity of the patient's condition, also could influence the cost-effectiveness of an intervention. A recent Cochrane Review could not draw definitive conclusions on the cost-effectiveness of telemedicine,[51] but it is important to distinguish telemedicine from Project ECHO. In most telemedicine models, specialists from academic health centers personally manage patients and provide direct care using teleconferencing technology. In contrast, Project ECHO uses an indirect care model and the co-management of patients—specialists support and collaborate with PCPs working in remote locations to manage complex patients. In the Project ECHO model, specialists spending one hour collaborating with PCPs can potentially lead to better management of hundreds of patients.

Other care models are being developed as novel ways to improve patient outcomes, such as collaborative or integrated care approaches that engage interprofessional teams made up of a specialist, a primary care physician who retains overall clinical responsibility for the patient, and a case manager who follows up with the patient and assesses her or his adherence to the prescribed treatments.[52] Collaborative care models have been shown to produce better patient outcomes than routine care under a PCP.[52] However, these outcomes have not been compared with those from Project ECHO. Also separating collaborative care models from Project ECHO programs is the fact that collaborative care does not specifically target patients living in remote geographical settings, as Project ECHO does.

Project ECHO has shown great promise for improving the management of common chronic illnesses within primary care. As a result, government agencies and other funders have increased the resources dedicated to Project ECHO programs and extended its scope of practice to additional diseases. In 2003, Project ECHO was first implemented to address HCV—a complex yet common disease with a large societal burden. Since then, its effects on the management of less common conditions have been studied, including complex regional pain syndrome,[35] transgender medicine,[15] and pediatric epilepsy.[20] The expansion of the scope of Project ECHO may reflect the ability of teleconference technology to bring current medical knowledge to any geographical location.

Limitations

This review has several limitations. First, we used an inclusive approach to Project ECHO research, irrespective of study quality. For example, studies assessing outcomes from Levels 2 and 3 of Moore's framework included a small number of survey respondents[24,41] and contained self-selection bias.[24,30] Second, studies comparing Project ECHO patient outcomes with those of subspecialist care alone have been limited to HCV, and few have looked beyond Level 5 outcomes. This is problematic, given that 17 of the studies contained low/insufficient information to assess fidelity to the original HCV program. As such, the effects of the original Project ECHO program on patient health outcomes cannot be generalized to many subsequent programs. Next, although studies often state that they are implementing "evidence-based" treatment methods, little verification has been done to ensure that this is the case for those Project ECHO programs without studies that yield outcomes at the higher levels of Moore's framework. Further, although we included 39 studies in our review, none used a randomized controlled trial methodology. These limitations are reflective of the current state of Project ECHO research. Despite the growth of Project ECHO's application in addressing HCV and its expansion to other medical conditions, quality studies are lacking. The existing research often includes heterogeneous methodologies that make it difficult to compare studies. Finally, our review consisted of searches of the PubMed, MEDLINE, EMBASE, PsycINFO, and ProQuest databases and could be subject to limitations related to publication bias.

Irrespective of these limitations, Project ECHO is being implemented widely and has shown promise addressing a critically important issue affecting the equity of health care delivery, and an overview of the available literature to synthesize the current evidence supporting its implementation is timely and useful.

Future research directions and challenges

Although we included 39 studies related to Project ECHO in this review, more research that addresses outcomes from Moore's Level 5 (health care providers' performance) and higher is needed to substantiate the claim that Project ECHO is an effective educational innovation. Research focusing on process measures (i.e., provider adherence to protocols, treatment algorithms, and care pathways) is needed to evaluate Project ECHO as a clinical innovation. Randomized controlled trials or additional trial methodologies are needed to further compare the patient and participant outcomes of Project ECHO programs. More studies are also needed to analyze the cost-effectiveness of Project ECHO.

Key barriers still exist to widespread Project ECHO implementation, including a lack of time and financial incentives for health care providers.[27,41,53] Whether the Project ECHO model can be replicated with fidelity to ensure consistent quality learning is another important consideration that has not been addressed in the current literature. By overcoming these barriers and integrating Project ECHO into health systems planning, we can minimize the duplication of services and ensure that this model is delivered where it is most needed and most impactful.

Conclusions

In this review, we found preliminary evidence that Project ECHO is an effective and potentially cost-saving model that increases participant knowledge and patient accessibility to quality health care in remote locations, through improving the capacity of PCPs to manage more complex health conditions. Studies suggest that Project ECHO can narrow knowledge gaps to support the provision of evidence-based care in remote communities and increase self-efficacy in participants' ability to provide up-to-date health care to more individuals in remote areas. As Project ECHO expands to address more medical conditions, further research examining its efficacy is needed to support its widespread use as an education and practice improvement initiative.

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Appendix 1

Characteristics of 39 Studies Included in a Systematic Review of the Literature on the Outcomes of Project Extension for Community Healthcare Outcomes (ECHO) Programs, 2000–2015

Title and reference list number	First author, year	Population studied	Disease focus	Type of conferencing	Schedule	Study design	Conclusions[a]	Level of Moore's framework	No. of participants/ patients	Fidelity to original Project ECHO model
Project ECHO: Linking university specialists with rural and prison-based clinicians to improve care for people with chronic hepatitis C in New Mexico[4]	Arora, 2007	Civilian (prison inmates, Aboriginals)	HCV	Video and telephone	Weekly	Introduction to ECHO project	Project ECHO provides best practices and protocol-driven health care for managing hepatitis C infection among socially isolated populations. Other states and local governments should consider developing telemedicine programs modeled on Project ECHO to improve and extend hepatitis C care.	None	None	N/A (original project)
Project ECHO: The prison peer education project[25]	Boyle, 2014	Civilian (prison inmates)	Pain and addictions	Video	Weekly	Introduction to ECHO project	Project ECHO (Extension for Community Healthcare Outcomes) has a history of success in training primary clinicians in the management of complex conditions using multipoint video teleconferencing and case consultation, together with measurement of outcomes for patients and clinicians.	None	None	Mid
Project ECHO: A novel model for clinical pharmacists in a multidisciplinary telehealth care network for rural and underserved communities[11]	Deming, 2013	Civilian	HCV	Video	Weekly	Introduction to ECHO project	As health care delivery evolves, so do the roles of clinical pharmacists, and involvement in ECHO affords new opportunities to enhance patient care with clinical outreach to rural and underserved communities.	None	None	Low/insufficient information
Project Extension for Community Healthcare Outcomes (ECHO) expands access to hepatitis C treatment for underserved populations[29]	Deming, 2013	Civilian	HCV	Video	Weekly	Introduction to ECHO project	The ECHO model is an effective way to treat HCV in rural and underserved communities and expands access to treatment. By implementing the ECHO model, more patients with HCV can be treated, thereby preventing an enormous burden of illness and death.	None	None	Mid

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Title and reference list number	First author, year	Population studied	Disease focus	Type of conferencing	Schedule	Study design	Conclusions[a]	Level of Moore's framework	No. of participants/ patients	Fidelity to original Project ECHO model
High hopes: A chronic pain/opioid stewardship Project ECHO in Ontario?[30]	Dubin, 2014	Civilian	Chronic pain and opioid stewardship	Unspecified	Unspecified	Introduction to ECHO project	An Ontario-based interprofessional team assembled by Drs. Dubin and Andrea Furlan attended the ECHO replication orientation session in Albuquerque (August 2013). As part of a wider chronic pain strategy, we are working with the Ministry of Health of Ontario to deliver an ECHO chronic pain/opioid stewardship demonstration project to isolated PCPs, using existing telemedicine videoconferencing infrastructure. Discussion of the replication process and early results from this initiative will be presented. If successful, an ECHO model may be highly appropriate in other Canadian provinces and applicable to other disease states.	None	None	Low/insufficient information
When worlds collide: Co-stewardship of chronic pain, addiction, and mental health using the ECHO model[31]	Duhigg, 2014	Civilian	Chronic pain, addiction, mental health	Unspecified	Unspecified	Introduction to ECHO project	Project ECHO eliminates the geographic divide by connecting primary care providers with specialists to deliver evidence-based care to patients where they live. The ECHO approach can mean that PCPs embrace these complex patients with confidence, and maintain the crucial supportive patient-primary care physician relationship.	None	None	Low/insufficient information

(*Appendix continues*)

Appendix 1

(Continued)

Title and reference list number	First author, year	Population studied	Disease focus	Type of conferencing	Schedule	Study design	Conclusions[a]	Level of Moore's framework	No. of participants/patients	Fidelity to original Project ECHO model
The VA's specialty care transformational initiatives to improve access and delivery of specialty care[34]	Ho, 2013	Veteran	15 specialties (unspecified in abstract)	Video	Unspecified	Participation data	Office of Specialty Care Transformation launched four initiatives to improve access and delivery of specialty care to veterans. These initiatives include: (1) Innovations in consult management (EConsults), (2) Specialty Care Access Network-Extension for Community Healthcare Outcomes (SCAN-ECHO), (3) Specialty Care Mini-Residency Program (SC-MRP), and (4) Specialty Care Neighborhood Team (SCNT).	None	None	N/A
Project ECHO: Replicating a novel model to enhance access to hepatitis C care in a community health center[36]	Khatri, 2013	Civilian	HCV	Video	Weekly	Participation data	As health care systems begin to deliver more efficient, integrated care, models like Project ECHO are needed to fundamentally change the current standard of specialist and primary care interaction. A strong, vibrant primary care infrastructure using technology and team-based approach to care, as emphasized in Project ECHO, must be at the heart of any new and innovative health care delivery model.	None	872 patients	High

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Title and reference list number	First author, year	Population studied	Disease focus	Type of conferencing	Schedule	Study design	Conclusions[a]	Level of Moore's framework	No. of participants/ patients	Fidelity to original Project ECHO model
Evaluating the role of key learning theories in ECHO: A telehealth educational program for primary care providers[44]	Socolovsky, 2013	Civilian	None	Video	Biweekly	Direct content analysis of semistructured interviews	We found evidence that the key principles of social cognitive theory, situated learning theory, and community of practice theory indeed form the basis of the ECHO model. This finding supports the contention that ECHO's success depends upon implementation of established learning theories. Although our curriculum was faithful to the key principles of each learning theory, we identified new ways to enhance their implementation, especially with respect to learner motivation and optimizing the experience of case-based discussions and peer-to-peer interactions. We expect that results from this study will encourage others to utilize the key principles of established learning theories as they develop ECHO curricula to train community-based PCPs on the management of complex, chronic diseases.	None	None	N/A
Cost-effectiveness of hepatitis C treatment by primary care providers supported by the Extension for Community Healthcare Outcomes (ECHO) model[45]	Wong, 2013	Civilian	HCV	Video	Biweekly	Cost–benefit analysis	ECHO-facilitated HCV treatment is not only effective but also cost-effective, suggesting that ECHO provides resource efficient care access for underserved communities. Confirmation of these results in additional studies and in other diseases is needed and warranted.	None	261 patients	N/A

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Title and reference list number	First author, year	Population studied	Disease focus	Type of conferencing	Schedule	Study design	Conclusions[a]	Level of Moore's framework	No. of participants/ patients	Fidelity to original Project ECHO model
Child youth epilepsy (CYE) teleECHO: Innovative tele-mentoring clinic for child & youth epilepsy care[20]	Yamada, 2014	Civilian (pediatric)	Child youth epilepsy	Video	Unspecified	Introduction to ECHO project	The ECHO model has been successfully replicated with 39 teleECHO hubs operating in 22 states and ECHO programs in six countries including the United States. These new efforts will help determine the broader applicability of the model. The CYE teleECHO team is looking for participants across the United States and all over the world to improve child youth epilepsy care.	None	None	Low/insufficient information
Project ECHO: Improving asthma care in New Mexico with telehealth technology[33]	Harkins, 2011	Civilian	Asthma	Video	Biweekly	Participation data	Project ECHO is an effective way to help rural providers improve the care of their asthmatics.	1	200 participants	Low/insufficient information
The educational impact of the Specialty Care Access Network–Extension of Community Healthcare Outcomes program[41]	Salgia, 2014	Veteran	Chronic liver disease	Video	Biweekly	Survey	In conclusion, our study is unique in its focus on the educational impact of a distance learning case-based and didactic program for clinical care. Important findings of our study on the VHA SCAN-ECHO program in liver disease include a better understanding of factors that motivate and limit participation in the program, the value of the case-based versus didactic sessions, and the unexpected finding that providers have shared the knowledge they gained with their colleagues. Sustainability of this and similar programs requires that future efforts are focused on providing resources and protected time toward the providers committed to distance learning.	1	24 participants	Low/insufficient information

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Title and reference list number	First author, year	Population studied	Disease focus	Type of conferencing	Schedule	Study design	Conclusions[a]	Level of Moore's framework	No. of participants/ patients	Fidelity to original Project ECHO model
Project ECHO: A model for complex, chronic care in the Pacific Northwest region of the United States[18]	Scott, 2012	Civilian (Aboriginals)	HCV, chronic pain, integrated addictions/ psychiatry, and HIV/AIDS	Video	Weekly	Participation data	The pilot project was successful, as judged by the number of patients co-managed and providers who attended. At the end of June 2012, the project had provided 23 different video conference clinics for hepatitis C, with 263 participating clinicians representing a total of 399 patients. Of this total, 167 patients had started antiviral therapy for hepatitis C, including 50 with newly approved protease inhibitors. The pilot project has expanded to include chronic pain, HIV/AIDS, and addiction and psychiatric problems.	1	399 participants, 167 patients	Mid
Implementation of the first Department of Veterans Affairs Specialty Care Access Network–Extension for Community Healthcare Outcomes (SCAN-ECHO) program for chronic liver disease[19]	Su, 2012	Veteran	Chronic liver disease	Video	Unspecified	Survey and participation data	In summary, we demonstrated the feasibility of implementing this innovative model of care for patients with chronic liver disease within the VA health system. In our preliminary assessment, this appears to be a highly effective method to decrease veteran travel and increase provider competency.	1 and 2	83 participants, 153 patients	Low/insufficient information

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Title and reference list number	First author, year	Population studied	Disease focus	Type of conferencing	Schedule	Study design	Conclusions[a]	Level of Moore's framework	No. of participants/patients	Fidelity to original Project ECHO model
Expanding access to hepatitis C virus treatment—Extension for Community Healthcare Outcomes (ECHO) project: Disruptive innovation in specialty care[24]	Arora, 2010	Civilian (Aboriginals)	HCV	Video	Weekly	Review with survey data	In this article, we demonstrate that using the ECHO model, HCV care delivered by PCPs in rural areas and prisons can be as safe and effective as that provided by specialists at an AMC. Community providers become progressively more independent over time while remaining well-informed about best evidence, protocol changes, and the latest research findings through the clinics and their didactic sessions. Because community providers and academic specialists can adapt the model to an increasingly broad and diverse range of chronic health issues, ECHO has significant potential for replication and expansion.	1 and 2	17, 25, 23, 36, 38, 52 participants	N/A (original project)
Academic health center management of chronic diseases through knowledge networks: Project ECHO[22]	Arora, 2007	Civilian (Aboriginals)	HCV	Video	Biweekly	Review with survey data	We hope the methodology of Project ECHO can be generalized to many common, complex, and chronic conditions in a wide variety of underserved and developing areas to effectively improve disease outcomes. This project can be a model for the interaction of AHCs with the diverse communities they serve, providing educational, research, and clinical expertise to primary care providers in locations distant from the AHC in both geography and resources.	1 and 2	29 participants	N/A (original project)

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Title and reference list number	First author, year	Population studied	Disease focus	Type of conferencing	Schedule	Study design	Conclusions[a]	Level of Moore's framework	No. of participants/patients	Fidelity to original Project ECHO model
Innovative telementoring for pain management: Project ECHO Pain[35]	Katzman, 2014	Civilian	Pain management	Video	Weekly	Survey, pre vs. post, self-reported change in confidence, and participation data	Project ECHO Pain is a successful continuing professional development program. The telementoring model closes the large knowledge gap in pain education seen in primary care and other settings. Expertise is delivered by implementing effective, evidence-based, and work-based education for diverse health professionals. Project ECHO Pain serves as a model for interprofessional collaborative practice.	1 and 3	710 participants for CME surveys, 9 subject focus groups	Mid
Expanding access in rheumatology specialty care in New Mexico via an innovative community outreach program[7]	Bankhurst, 2012	Civilian	Rheumatology	Video	Weekly	Survey and participation data	Since the induction of the program, 18 Centers of Excellence for rheumatology have been established throughout New Mexico. To date, there have been 99 clinics held, with 1,265 attendees, and 644 patient case presentations. Project ECHO's TeleECHO rheumatology clinic is an innovative approach that brings greater access for all patients in New Mexico.	1 and 4	23, 25, 38, 52 participants	Mid

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Title and reference list number	First author, year	Population studied	Disease focus	Type of conferencing	Schedule	Study design	Conclusions[a]	Level of Moore's framework	No. of participants/ patients	Fidelity to original Project ECHO model
Evaluation of a telementoring intervention for pain management in the Veterans Health Administration[13]	Frank, 2015	Veteran	Chronic pain	Video	Weekly and biweekly, variable	Longitudinal observational study	With telementoring in pain management, the VHA's SCAN-ECHO-PM program aims to address a critical need for both primary care providers and patients by extending pain management expertise to the front lines of primary care. This is of particular importance for the nearly 40% of veterans who live in rural areas and who may have limited access to face-to-face specialty consultation. This evaluation of the initial implementation of this program identified increases in guideline concordant pain care following SCAN-ECHO-PM consultation. Additional studies are needed to identify and address facility-level barriers to both the uptake of SCAN-ECHO-PM and to implementation of guideline concordant pain care system-wide in the VHA.	1 and 5	159 participants	Low/insufficient information
ECHO-AGE: A video-consultation program to bring geriatric expertise to long-term care[9]	Catic, 2013	Civilian (long-term care residents)	Dementia and behavioral issues	Video	Biweekly	Survey and clinical data	Applying an established model of care to an isolated, vulnerable population, ECHO-AGE successfully utilizes tele-computing technologies to provide expert consultation to community providers. Surveys indicate improved geriatrics knowledge and possibly patient outcomes at minimal cost. If financial feasibility is proven, widespread dissemination is anticipated.	1	47 patients	Low/insufficient information

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Title and reference list number	First author, year	Population studied	Disease focus	Type of conferencing	Schedule	Study design	Conclusions[a]	Level of Moore's framework	No. of participants/patients	Fidelity to original Project ECHO model
Expanding primary care capacity to treat hepatitis C virus infection through an evidence-based care model—Arizona and Utah, 2012–2014[39]	Mitruka, 2014	Civilian	HCV	Video	Weekly	Participation data and longitudinal observational study	Collaborations with specialists will help primary care providers to begin to incorporate new treatments for HCV infection and will be an important measure for improving access and reducing barriers to treatment. The results of this evaluation demonstrate Project ECHO as a model that can enhance primary care provider capacity to treat HCV infection among underserved populations, including the use of newly approved medications.	1 and 6	90 ECHO participants, 280 patients	Mid
ECHO: An innovative campus–community partnership for managing resistant hypertension in an urban underserved area[17]	Masi, 2012	Civilian	Treatment-resistant hypertension	Unspecified	Unspecified	Pre–post knowledge test, survey, and participation data	By creating a community of learners using videoconference technology, the ECHO model increased hypertension management knowledge and self-efficacy among PCPs in an urban underserved area. The case-based, interactive discussions created learning opportunities for all participants, not just for those who presented cases. Videoconferencing is a convenient way to enhance interaction between community health center providers and university-based specialists, thereby increasing the likelihood that uninsured and underinsured patients will receive state-of-the-art care for complex, chronic diseases.	1, 2, 3, and 4	12 participants	Low/insufficient information

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Title and reference list number	First author, year	Population studied	Disease focus	Type of conferencing	Schedule	Study design	Conclusions[a]	Level of Moore's framework	No. of participants/patients	Fidelity to original Project ECHO model
ECHO Ontario Chronic Pain & Opioid Stewardship: Providing access and building capacity for primary care providers in underserviced, rural, and remote communities[12]	Dubin, 2015	Civilian	Chronic pain and opioid stewardship	Video	Weekly	Survey and focus group	The ECHO model is a promising approach for health care system improvement that is attracting attention from many jurisdictions. ECHO's strength lies in its simplicity, adaptability, and use of existing telemedicine infrastructure to increase both access and capacity of PCPs in underserviced, rural, and remote communities.	2	38 patients	High
Making connections: Using telehealth to improve the diagnosis and treatment of complex regional pain syndrome, an underrecognized neuroinflammatory disorder[38]	Katzman, 2013	Civilian	Complex regional pain syndrome (CRPS)	Video	Weekly	Review with survey data	Because CRPS is such a complex disease and early diagnosis can be difficult to ascertain, it is critical that dissemination of knowledge to primary and specialty health care teams and collaborative opportunities between CRPS experts are increased. Patient organizations can help patients gain information about their disease as well as connect these patients to centers of excellence in treatment and sponsor clinical research activities. Telehealth technologies can be utilized to improve knowledge networks and connect clinicians across wide geographic distances in a timely and patient-centered platform. By connecting CRPS experts to a collaborative telehealth network, it is possible that clinical research opportunities may be cultivated.	2	Unspecified	Mid

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Title and reference list number	First author, year	Population studied	Disease focus	Type of conferencing	Schedule	Study design	Conclusions[a]	Level of Moore's framework	No. of participants/ patients	Fidelity to original Project ECHO model
Dementia care training for primary care providers: Project ECHO[37]	Knoefel, 2015	Civilian	Dementia and behavioral issues	Video	Biweekly	Participation data	The Project ECHO model has proven to be an effective tool for dementia care education and training in the state of New Mexico. The next phase, certification of Centers of Excellence in Dementia Care, is in the planning stages.	2	43 patients	Low/insufficient information
Teleconsultation and training of VHA providers on transgender care: Implementation of a multisite hub system[15]	Kauth, 2015	Veteran	Transgender care	Video and telephone	Weekly	Survey, pre vs. post self-reported change in confidence, and participation data	Results from the first group of participating teams in this three-year pilot program suggest that a program of training and case-based teleconsultation using videoconferencing is an effective strategy for training interdisciplinary teams of VA providers to treat transgender veterans.	2	13 patients	Mid
VHA's comprehensive women's health SCAN-ECHO program: Lessons learned[28]	Cordasko, 2014	Civilian	Women's health	Video	Weekly	Survey, semistructured interviews, field notes	VA's SCAN-ECHO program is a promising modality for building and maintaining PCP knowledge on women's health topics, with attendees indicating that it influences their patient care. However, PCPs receiving time protected from clinical responsibilities is essential for robust and consistent participation. Further, narrowing in on a consistent women's health area, such as gynecology, although sacrificing the program's comprehensiveness, may facilitate PCPs having active case-based questions for the sessions.	2 and 4	65 participants, 58 survey respondents	Low/insufficient information

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Title and reference list number	First author, year	Population studied	Disease focus	Type of conferencing	Schedule	Study design	Conclusions[a]	Level of Moore's framework	No. of participants/patients	Fidelity to original Project ECHO model
Air Force Diabetes Centre of Excellence Project ECHO: Successful telemedicine with a global reach[10]	Davis, 2015	Civilian	Diabetes	Unspecified	Unspecified	Survey and participation data	Given the limited number of AFMS endocrinologists and routine provider turnover, our implementation of the ECHO model improves the providers' knowledge and confidence by delivering both live diabetes education and case discussion to a growing global network.	2 and 4	9 specialists, unspecified participants	Low/insufficient information
Project ECHO: Bringing palliative care consultation to rural New Mexico through a novel telemedicine format[16]	Marr, 2012	Civilian	Palliative care	Unspecified	Biweekly	Survey	The palliative medicine ECHO clinic at the University of New Mexico has demonstrated a new model for training rural primary care providers in care for patients at end of life.	2 and 4	Unspecified	Mid
Partnering urban academic medical centers and rural primary care clinicians to provide complex chronic disease care[23]	Arora, 2011	Civilian (Aboriginals)	HCV	Video	Weekly	Review with survey data	Project ECHO is just such a model. It creates partnerships between primary care providers in rural and underserved areas and specialty care providers at academic medical centers that allow for the sharing of new knowledge in real time. These partnerships exponentially boost the health care system's ability to deliver specialty care to people who otherwise would lack access. Thus, Project ECHO uses technology and existing resources to magnify the capacities of the health care workforce, build a bridge across health care settings, and truly provide health care without walls.	2, 3, and 4	34, 89, 72 participants	N/A

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Title and reference list number	First author, year	Population studied	Disease focus	Type of conferencing	Schedule	Study design	Conclusions[a]	Level of Moore's framework	No. of participants/ patients	Fidelity to original Project ECHO model
Building capacity to reduce disparities in diabetes: Training community health workers using an integrated distance learning model[27]	Colleran, 2012	Civilian	Diabetes	Video and telephone	Weekly	Survey	Community health worker participation in the Project ECHO diabetes training program resulted in significant increases in knowledge, confidence, and attitudes in providing care to patients with diabetes. Studies are ongoing to determine whether the training has a positive impact on patient outcomes.	2 and 4	23 participants	Mid
UNM ECHO pain and headache program[14]	Katzman, 2012	Civilian	Pain and headache	Video	Weekly	Survey, pre vs. post self-reported change in provider confidence	The retrospective analysis indicated that the information and skills learned during the TeleECHO clinic allowed the PCCs to uncover gaps in headache knowledge.	3 and 4	Unspecified	Low/insufficient information
Project ECHO (Extension for Community Healthcare Outcomes): Knowledge networks expand access to hepatitis C (HCV) treatment with pegylated interferon and ribavirin in rural areas and prisons. Care is as effective as a university HCV clinic[3]	Arora, 2009	Civilian (Aboriginals and prison inmates)	HCV	Video	Biweekly	Prospective cohort and survey data	ECHO-based HCV treatment for rural patients and prisoners is as effective as a university HCV clinic.	6	340 patients	N/A

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Title and reference list number	First author, year	Population studied	Disease focus	Type of conferencing	Schedule	Study design	Conclusions[†]	Level of Moore's framework	No. of participants/patients	Fidelity to original Project ECHO model
Outcomes of treatment for hepatitis C virus infection by primary care providers[5]	Arora, 2011	Civilian (Aboriginals)	HCV	Video	Weekly	Prospective cohort	In conclusion, we have shown that treating a complex disease such as HCV using the ECHO model has similar effectiveness as treatment at an AMC. ECHO represents a needed change in conventional paradigms of AMCs and specialist care being available only in urban areas. ECHO has potential for replication in the United States and abroad as community providers and academic specialists partner to respond to an increasingly diverse range of chronic health issues.	6	407 patients	N/A
ECHO-AGE: An innovative model of geriatric care for long-term care residents with dementia and behavioral issues[26]	Catic, 2014	Civilian (long-term care residents)	Dementia and behavioral issues	Video	Biweekly	Clinical comparison of patients who followed recommendations from ECHO-AGE vs. those who did not	The results suggest that a case-based video consultation program can be successful in improving the care of elders with dementia- and/or delirium-related behavioral issues by linking specialists with long-term care providers.	6	45 patients	Low/insufficient information
Project ECHO-AGE and nursing home quality of care[32]	Gordon, 2015	Civilian	Dementia and behavioral issues	Video	Biweekly	Matched cohort study	Project ECHO-AGE may reduce rates of physical restraint usage among long-term NH residents. Larger samples and patient-level data might be helpful in further clarifying Project ECHO-AGE's impact on quality of care.	6	33 patients	Low/insufficient information

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Title and reference list number	First author, year	Population studied	Disease focus	Type of conferencing	Schedule	Study design	Conclusions[a]	Level of Moore's framework	No. of participants/patients	Fidelity to original Project ECHO model
Synchronous cohorts: A novel variation to the Project ECHO approach to hepatitis C treatment[40]	Moore, 2013	Civilian	HCV	Video	Weekly	Participation data and longitudinal observational study	The Synchronous Cohort approach to teleconferencing with primary care providers offered multiple advantages: (1) Simultaneous treatment milestones and adverse event management, enhancing the learning experience for which the ECHO model is known to be effective; (2) Coordination of laboratory results; (3) Focused work-ups and patient education based on synchronous treatment initiation; (4) Less intrusive impact on the busy primary care focused clinics; (5) Treatment outcomes as good as or better than those reported from specialty practices.	6	42 patients	Low/insufficient information
Improved glycemic control in veterans with poorly controlled diabetes mellitus using a Specialty Care Access Network–Extension for Community Healthcare Outcomes model at primary care clinics[42]	Watts, 2016	Veteran	Poorly controlled diabetes	Video	Weekly	Retrospective chart review	Using the SCAN-ECHO model, PCPs can deliver effective care for high-risk diabetes patients in improving glycemic control. This model can be used to provide care to diabetes patients in remote and distant sites. Future research may use the findings of this quality improvement project from SCAN-ECHO diabetes mini-clinics to proceed with a randomized-controlled study of usual care versus mini-clinics run by PCPs for high-risk diabetes patients.	6	39 patients	Mid

Abbreviations: HCV indicates hepatitis C virus; PCP, primary care provider; VA, Department of Veterans Affairs; VHA, Veterans Health Administration; SCAN-ECHO, Specialty Care Access Network–Extension for Community Healthcare Outcomes; AMC, academic medical center; AHC, academic health center; CME, continuing medical education; PM, pain management; AFMS, Air Force Medical Service; UNM, University of New Mexico; PCC, primary care clinician; NH, nursing home.

[a] Data reported in this column are direct quotations from the included studies.

ATTACHMENT RB-32

This is the attachment marked '**RB-32**' referred to in the witness statement of Dr Ravi Subramanya Bhat dated 4 July 2019.

Developing the Agile Implementation Playbook for Integrating Evidence-Based Health Care Services Into Clinical Practice

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Abstract

Problem

Despite the more than $32 billion the National Institutes of Health has invested annually, evidence-based health care services are not reliably implemented, sustained, or distributed in health care delivery organizations, resulting in suboptimal care and patient harm. New organizational approaches and frameworks that reflect the complex nature of health care systems are needed to achieve this goal.

Approach

To guide the implementation of evidence-based health care services at their institution, the authors used a number of behavioral theories and frameworks to develop the Agile Implementation (AI) Playbook, which was finalized in 2015. The AI Playbook leverages these theories in an integrated approach to selecting an evidence-based health care service to meet a specific opportunity, rapidly implementing the service, evaluating its fidelity and impact, and sustaining and scaling up the service across health care delivery organizations. The AI Playbook includes an interconnected eight-step cycle: (1) identify opportunities; (2) identify evidence-based health care services; (3) develop evaluation and termination plans; (4) assemble a team to develop a minimally viable service; (5) perform implementation sprints; (6) monitor implementation performance; (7) monitor whole system performance; and (8) develop a minimally standardized operating procedure.

Outcomes

The AI Playbook has helped to improve care and clinical outcomes for intensive care unit survivors and is being used to train clinicians and scientists in AI to be quality improvement advisors.

Next Steps

The authors plan to continue disseminating the details of the AI Playbook and illustrating how health care delivery organizations can successfully leverage it.

Problem

Despite the more than $32 billion the National Institutes of Health has invested annually, incorporating evidence-based health care services into clinical practice remains an inefficient process.[1] Furthermore, once evidence-based services are implemented, they may not be sustained, adapted, or distributed across health care delivery organizations.[1] As a consequence, a majority of patients receive care that is not based on existing evidence from the literature.[2]

To provide consistently high-value, evidence-based health care services, organizations must use methods that reflect the complex and interconnected nature of today's health care delivery systems. In this article, we describe the Agile Implementation (AI) Playbook, a model developed by the Center for Health Innovation and Implementation Science at Indiana University School of Medicine. This model provides a reproducible and scalable process to rapidly localize, implement, and sustain evidence-based health care services.

Approach

In September 2007, one of us (M.A.B.) assembled an interdisciplinary team of clinicians, implementation scientists, and health care administrators to develop a process to select and implement evidence-based health care services, evaluate the fidelity and impact of those services, and ensure their sustainability and scalability across health care delivery organizations. Over several years and more than 40 implementation projects at the Indiana University Health System and Eskenazi Health, an urban safety-net health care system, the team iteratively developed and refined what would ultimately become the AI Playbook, which was finalized in 2015. The team used multiple theories and frameworks, described below, to develop the AI Playbook.

Theories and frameworks informing the development of the AI Playbook

Complexity theory. A complex adaptive system is an open, dynamic network of semiautonomous individuals who are interdependent and connected in multiple nonlinear ways (see Figure 1). Such a network has the ability to adapt to new states in response to its evolving environment by learning from prior experiences.[3,4] From this perspective, member diversity and culture, member interactions, the surrounding environment, previous history, and changing and learning

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processes all make health care delivery organizations unique.[5] As such, the capability of these organizations to adapt to constant internal and external changes depends on the characteristics of the individual members (e.g., skills, adaptability, and attitudes), as well as on the local organizational structures and environment.[3,5]

Behavioral economics. Behavioral economics recognizes that individuals' behavior is not only driven by their interactions with internal and external stressors but also by their personal attributes, such as emotion, attention, and skills, and by their relational attributes, such as empathy, trust, and history. There are opportunities to leverage these human tendencies in information processing and decision making by modifying the social and physical environment.[6]

Sources of variation theory. Mapping the delivery of a typical health care service reveals three sources of variation in the clinical care provided: (1) the

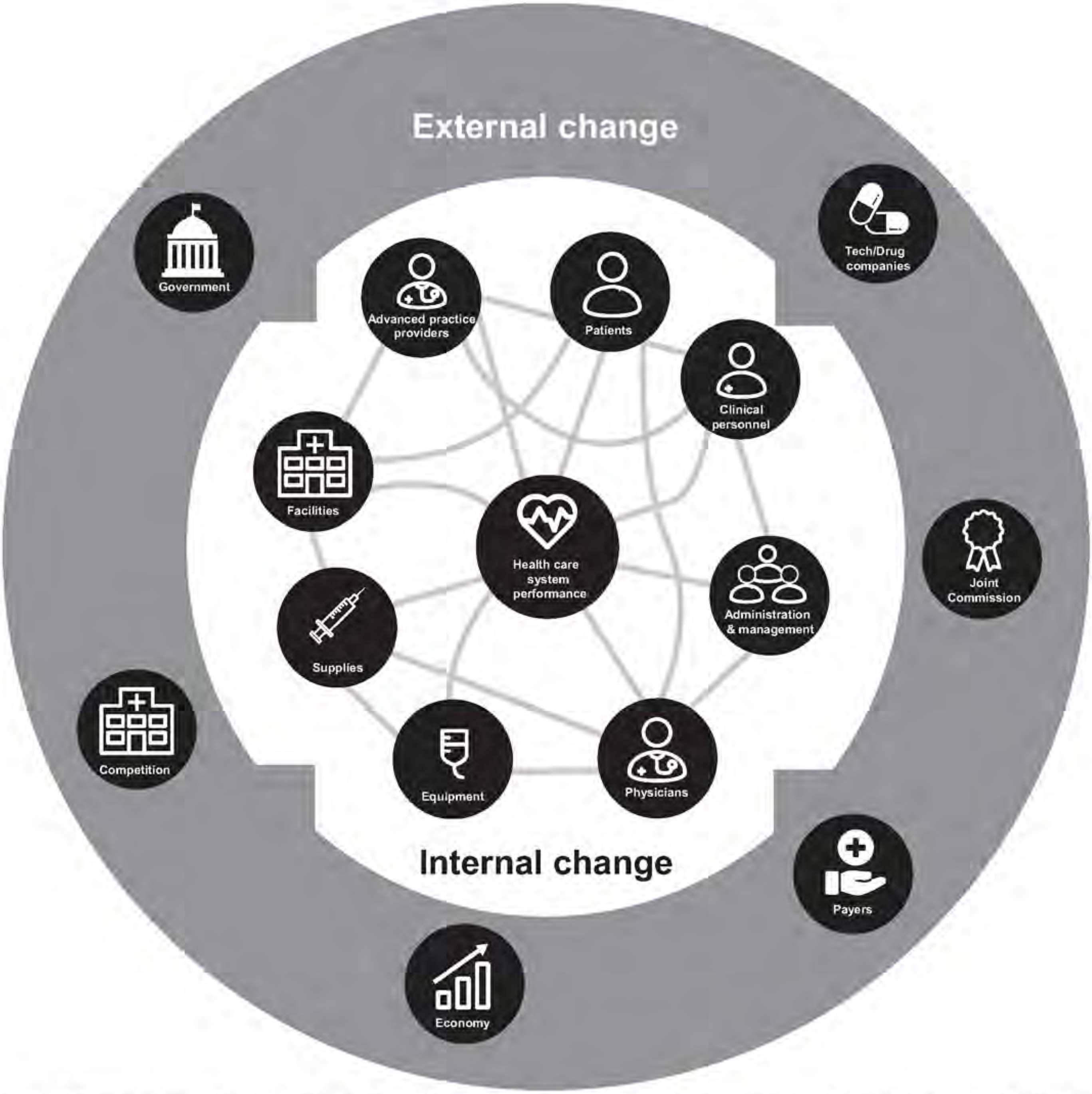

Figure 1 Diagram of a complex adaptive system. The health care delivery system is a complex adaptive system, where individuals are interdependent and connected in multiple nonlinear ways to each other and the unique characteristics of the system itself. Members of such a system experience constant changes that can be internal (e.g., patients, administration, equipment, etc.) or external (e.g., payers, the economy, independent accreditation agencies, etc.). The capability of the system to adapt to these changes depends on the characteristics of the individuals as well as on the system's organizational structure and environment.

clinical decision, which often involves multiple providers and is a function of the decision makers' clinical knowledge and experience as well as currently accepted or emerging practices; (2) the process of translating the clinical decision into patient care; and (3) the patient's response to the health care service provided (see Figure 2).[7] Understanding these sources of variation is crucial to implementing effective and sustainable evidence-based health care services.

Five factors framework. Chaudoir and colleagues' framework depicts five macro-to-micro nested factors that influence the implementation of innovations.[8] At the most macro level is an external, sociocultural, structure-level factor representing the broader context or community in which an organization is nested. Next is an organizational-level factor, followed by a provider-level factor, a patient-level factor, and finally a health-related innovation-level factor that characterizes the innovation itself.

Implications of these theories and frameworks. Across these theories, the common message is that health care delivery organizations are complex, adaptive, and sociotechnical. Implementing changes requires an approach that attends to: (1) variation that is both temporal (across process steps) and hierarchical (across levels of analysis); (2) the human element and human-to-human or human-to-technology interfaces; and (3) the way organizations function in and adapt to the broader sociocultural, legal-political, and organizational-regulatory environments.

The AI Playbook

The AI Playbook is a model for carrying out an interconnected, eight-step, AI cycle (see Figure 3), facilitated by a trained AI agent. This agent may be someone either internal (e.g., clinician or administrator) or external to the organization, but she or he should know how to identify an appropriate evidence-based solution and be able to facilitate changes at both the organizational level (zooming out) and the individual level (zooming in). The steps of the AI process are rooted in the theories and frameworks described above, in that they take into consideration the uniqueness of each health system (complexity theory) and recognize that variation in clinical decisions, translation into patient care, and patient responses (sources of variation theory) will influence the outcomes of a selected solution. The AI Playbook is designed to leverage aspects of behavioral economics and the sociocultural and multilevel factors described in the five factors framework to guide interactions and evaluations to encourage individuals to act in ways that enable the success and sustainability of the selected solution. Below we describe the eight steps in the AI Playbook.

Step 1: Identify opportunities. The AI agent proactively works with leadership and clinical providers to identify opportunities for locally implementing new evidence-based health care services. High demand for addressing an identified opportunity—gauged by the amount of time, personnel, and financial resources executive leadership and frontline clinical providers are willing to invest—is required to proceed.

Step 2: Identify evidence-based health care services. The AI agent conducts a systematic search to identify evidence-based health care services that address the selected opportunity and promote the quadruple aim (high-quality, accessible, cost-efficient, and patient-centered care). When identifying potential solutions, we recommend employing a critical appraisal, such as the grading process used by the U.S. Preventive Services Task Force, to determine the quality and strength of the evidence supporting a service. If there are no evidence-based services that address the selected opportunity and promote the quadruple aim, the AI agent either confirms with leadership their willingness to develop new evidence-based services or returns to Step 1.

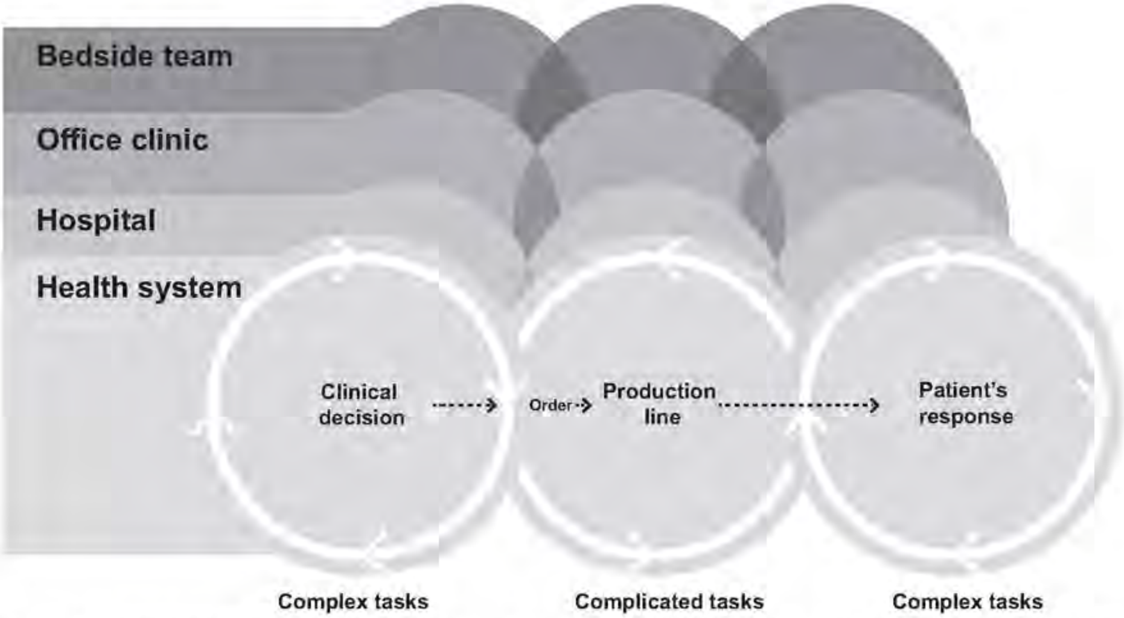

Figure 2 Diagram of the sources of variation theory. There are three sources of variation in clinical care. At each level of an organization, there is variation in the clinical decision, the process of translating the clinical decision into patient care (the production line), and the patient's response to the health care services provided.

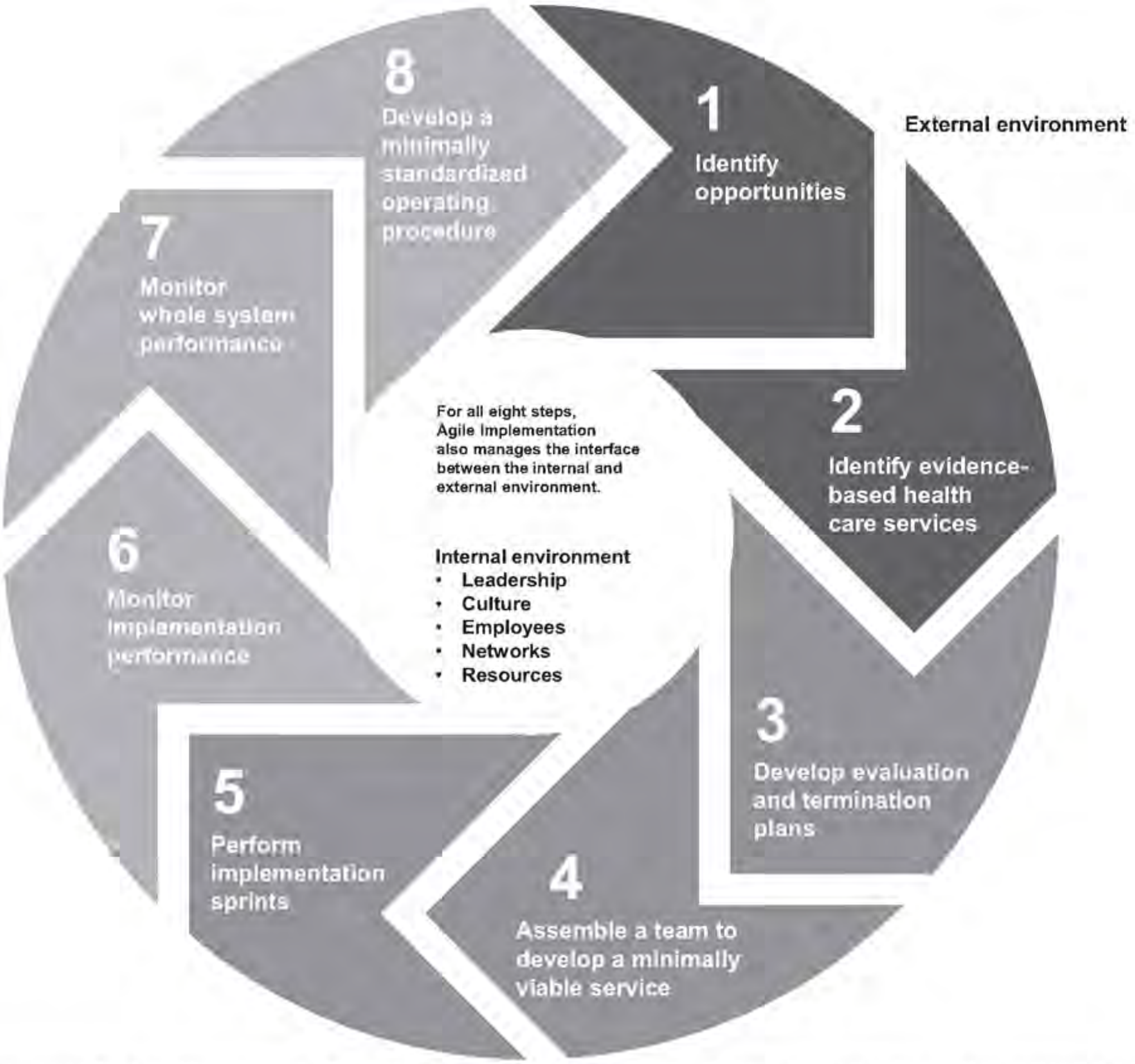

Figure 3 Diagram of the Agile Implementation Playbook. This model has eight interconnected steps for identifying and implementing an evidence-based health care service to address a designated opportunity. These steps attend to the complex nature of health care delivery organizations and acknowledge the uniqueness of the individuals and organizations involved.

Step 3: Develop evaluation and termination plans. The AI agent works with organizational leadership to develop an evaluation protocol and selects the appropriate measures for the organization, the care delivery service type, and the implementation goals. They also set milestones and indicators of success. The evaluation plan must identify the criteria for de-implementing the planned service as early as possible if it is deemed a failure as well as who will lead the de-implementation.

Step 4: Assemble a team to develop a minimally viable service. The AI agent works with leadership to build a diverse, local, interdisciplinary implementation team to convert the selected evidence-based service(s) into a minimally viable service by adapting the content and delivery process to the local setting. A minimally viable service reflects the critical aspects of the solution that must be retained to stay true to the original evidence-based process or method. This step takes into consideration the unique characteristics of the local health care delivery system and its individuals in their surrounding environment. The minimally viable service is iteratively revised in subsequent steps.

Step 5: Perform implementation sprints. The AI agent facilitates self-contained sprint cycles, or units of focused work, to assess the proper process for adapting the selected service to the local setting and to evaluate the service's outcomes via the plan developed in Step 3. Sprints result in lessons learned that can be applied to subsequent redesign-and-sprint iterations.

Step 6: Monitor implementation performance. The AI agent and the implementation team develop feedback loops to monitor the fidelity and performance of the selected service. They reflect on what they are learning, gauge impact while acknowledging any conflict and tension, detect emerging problems, identify and prioritize solutions to those problems, and adjust the implementation process and sprints accordingly.

Step 7: Monitor whole system performance. The AI agent and implementation team monitor the impact of the selected service on the overall quality and financial performance of the entire organization to detect any unintended or adverse consequences as well as any emergent opportunities that can be leveraged for additional benefit.

Step 8: Develop a minimally standardized operating procedure. If the implementation of the selected service is determined to be meeting internal demands and goals, the AI agent and implementation team develop a minimally standardized operating procedure manual. This manual describes the basic attributes of the solution that are required to maintain fidelity to the final service and that should be incorporated when implemented in other settings. It is updated on a regular basis and helps promote the successful service to other departments within the same organization and across organizations.

Outcomes

In 2010, Eskenazi Health enlisted the Center for Health Innovation and Implementation Science to reduce the vulnerability of intensive care unit (ICU) survivors through the development of a critical care recovery center. Stakeholders indicated that there was demand for this improvement (Step 1) by citing the growing trend of hospitals that care for critically ill patients being responsible for their care for a period of time after their initial recovery and/or hospital discharge. Additionally, administrators saw high-quality post-ICU care as a marketable attribute for the facility. After selecting a collaborative care model as the viable evidence-based service (Step 2), the Center for Health Innovation and Implementation Science and selected leadership identified appropriate indicators for success (Step 3), including improved physical and cognitive symptoms in patients, reduced inappropriate post-ICU health encounters, and lower cost.

Adapting the solution to the local setting (Step 4) involved specifying minimum care components, such as early assessment of functionality, patient and caregiver education, and longitudinal monitoring of patient outcomes. Multiple sprints (Step 5) were used to translate the evidence-based protocols of the collaborative care model into protocols to meet the cognitive, functional, and psychological needs of ICU survivors and family caregivers. During one sprint, high no-show rates to the first post-ICU follow-up appointment at the critical care recovery center signaled a need to add a direct referral from the ICU for 90 days after discharge and to set up a pre-clinic phone call with patients and family caregivers to promote the value of the recovery center.

To monitor the critical care recovery center's performance (Step 6), the team distributed quarterly dashboards with data on several measures (e.g., percent receiving antidepressants, number of primary care or specialty visits, etc.) and evaluated changes in patients' cognitive, functional, and behavioral-psychological symptoms at multiple time points. To assess the impact on the health system (Step 7), the team tracked overall readmissions, emergency department use, and a variety of costs related to care utilization.

Early results demonstrated improvements in cognitive, functional, and behavioral measures and a reduction in acute health care utilization.[9] The critical care recovery center is currently in its seventh year of operation. The development of a minimally standardized operating procedure (Step 8) allowed the service to be adapted for home-based ICU survivors and trauma survivors involved in two National Institutes of Health-funded clinical trials currently underway.

In addition to improving care for ICU survivors, the AI Playbook has been used to implement solutions to improve dementia care and reduce health care-associated infections. In addition, as part of the Great Lakes Practice Transformation Network (www.glptn.org), a multistate effort to improve the quality and reliability of the ambulatory care provided within a set area funded by the Centers for Medicare and Medicaid Services' Transforming Clinical Practice Initiative, the Center for Health Innovation and Implementation Science has trained more than 50 quality improvement advisors in AI to guide the transformation of 2,100 practices and implement resources adapted to the unique characteristics of each. A formal evaluation of the impact of this work by an independent organization has been contracted and is expected by the end of 2019.

The AI Playbook can address issues arising from all types of variation within a health care system, and it acknowledges both internal and external forces and accommodates the unique characteristics of each system and its environment. Rooting the AI Playbook in grounded theories and frameworks is supported by evidence that interventions with a theoretical basis are more effective than those without, especially when combinations of theories are used, like in the AI approach.[10] However, the final version of the AI Playbook is also a function of practical experience; it incorporates lessons learned during its development and use, including the importance of confirming demand for a service (Step 1) and relying on previously proven, evidence-based solutions (Step 2) instead of attempting to develop a solution from scratch. Finally, the AI Playbook emphasizes instituting a termination plan (Step 3) for unsuccessful solutions to solicit buy-in from administrators and ensure that resource waste will be minimal.

Next Steps

To improve the implementation of evidence-based health care services, we intend to continue disseminating the details of the AI Playbook and illustrating how health care delivery organizations can successfully leverage it. Doing so will require educating staff and administrators about both the AI process to facilitate mastery of the underlying theories and frameworks and the ability to identify and adapt appropriate evidence-based solutions to local settings.

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ATTACHMENT RB-33

This is the attachment marked '**RB-33**' referred to in the witness statement of Dr Ravi Subramanya Bhat dated 4 July 2019.

Co-production: putting principles into practice in mental health contexts

Co-production: putting principles into practice in mental health contexts

Launched in February at The University of Melbourne by international thought leader on servicer user perspectives Mary O'Hagan (http://www.maryohagan.com/about-mary.php), *Co-production: putting principles into practice in mental health contexts* is an open-access resource (https://recoverylibrary.unimelb.edu.au/__data/assets/pdf_file/0010/2659969/Coproduction_putting-principles-into-practice.pdf)
developed to support consumer-led initiatives in Victoria.

The resource is the culmination of three-years' collaboration between three co-authors: CPN consumer academic Cath Roper (https://www.findanexpert.unimelb.edu.au/display/person6844), independent consumer consultant and peer supporter Flick Grey (https://www.themhs.org/pages/flick-grey.html), and senior project officer Emma Cadogan from Victoria's Department of Health & Human Services (https://www2.health.vic.gov.au/mental-health). It provides practical advice for developing the culture and mind sets from which co-production can occur and includes five case studies that embody co-production principles in mental health.

Co-production is a term in frequent use in public service discourse, and the concept gained wider currency in the Victorian mental health sector when Victoria's 10-year mental health plan (https://www2.health.vic.gov.au/mental-health/priorities-and-transformation/mental-health-plan) named co-production as one of five approaches critical to improving mental health services. But alongside its increase in profile, the authors observed a "lack [of] robust conceptual or practical foundations" when consumers, clinicians, health service and other agency staff sought to co-produce together.

"That's why we felt it was important to develop this resource", says Cath Roper. "We could see that the mental health sector needed support in learning how to adopt co-production principles and practices. Because at best, there is a very uneven understanding of what co-production is, and how it is different from 'business as usual' approaches".

(Above; from left): Flick Grey, Cath Roper and Emma Cadogan at the February launch of *Co-production: Putting principles into practice in mental health contexts*

In the mental health context, co-production extends far beyond traditional consumer participation models of 'collaboration' and 'participation' after an agenda has been set. Instead, it involves consumers from the very beginning: seeking their expertise in the process of framing problems, setting priorities, designing solutions and evaluating their effectiveness. Co-production seeks to create a culture where all types of expertise are valued equally, and recognises that the quality of services is improved by the input of the people who use them.

One of the key drivers for the development of this resource was the recognition that, although a number of co-production resources exist, few speak to the co-production challenges that are specific to mental health. "There are unique considerations about power in the mental health context, not least because of the separate legislative system in place", says Cath. In partnerships between consumer and non-consumer partners, there are likely to be considerable power differentials and "some of the partners … might have been exposed to quite extreme forms of trauma, oppression or marginalisation". The resource outlines affirmative action approaches for equalising power so that consumers can exert influence, including "tools to help map out power" and suggestions for how to shift power in the direction of those with less influence.

Another key principle of co-production is that consumer leadership and capacity is developed through co-production processes. Cath identifies another driver for the resource as "a passion" that she and Flick Grey share for "reposition[ing] consumers from always being learners to being leaders, and to articulate the conditions that might best support that" as another motivating factor.

"This is a resource for everyone", says Cath, who says that the authors hope it will influence approaches to mental health work, policy development and consumer participation across grass roots organisations, government and academia. "But we'd like to see them used to inform any kind of collaborative work when there are a range of partners, with disparate sets of experiences, particularly around experiences of influence and power".

"We hope that the resource results in greater investment in consumer leadership and the incorporation of consumer thinking and expertise in project development across all settings and levels".

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05 Apr 2018

(https://twitter.com/intent/tweet?text=Co-
production:+putting+principles+into+practice+in+mental+health+contexts++https://healthsciences.unimelb.edu.au/departments/
us/centre-for-psychiatric-nursing/news-and-events/test)

(https://www.facebook.com/sharer/sharer.php?
u=https://healthsciences.unimelb.edu.au/departments/nursing/about-us/centre-for-psychiatric-
nursing/news-and-events/test)

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production:+putting+principles+into+practice+in+mental+health+contexts&url=https://healthsciences.unimelb.edu.au/departm
us/centre-for-psychiatric-nursing/news-and-events/test)

ATTACHMENT RB-34

This is the attachment marked '**RB-34**' referred to in the witness statement of Dr Ravi Subramanya Bhat dated 4 July 2019.

Outcomes of a unique Residential Rehabilitation Program from Rural Australia

Vivek H Phutane[1,2], Ravi S Bhat[1,2], David Cahill[3], Pamela Ewert[1], William Brown[1]

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BACKGROUND

- Goulburn Valley did not have a Community Care Unit
- In 2000,

GVAMHS Wellways Australia Limited (MI Fellowship)

↓

Specialist Residential Rehabilitation Program (SRRP)

- **What is unique about SRRP?**

❖ Focus is on recovery and not the long term accommodation (Maximum duration of stay is 2 years)

❖ Partnership: meetings at clinical and operational level

❖ Shared responsibility of participants' care by both Wellways Australia Limited (MI Fellowship) and GVAMHS staff

- SRRP is staffed 24/7 by Wellways Australia Limited (MI Fellowship) staff, who plan and work with participants in achieving their goals

- GVAMHS multidisciplinary staff provide clinical input

❖ Individual participant plan (IPP) prepared by participant, SRRP key worker and GVAMHS case manager

- SRRP staffing:

❖ For 10 units, 7.58 FTE Wellways Australia Limited (MI Fellowship) staff, including 1 FTE program coordinator

OBJECTIVE

- To assess the characteristics and outcomes of participants stayed at SRRP

METHODS

➢ Inclusion criteria: Participants with SRRP stay ≥ 90 days and those participants who stayed from 02/05/2001 to 31/12/2013

➢ 2 years pre SRRP group, during SRRP and 2 years post We did retrospective analysis of routinely collected data by GVAMHS & Wellways Australia Limited (MI Fellowship) from RAPID, Camberwell assessment of needs and Individual participant plans.

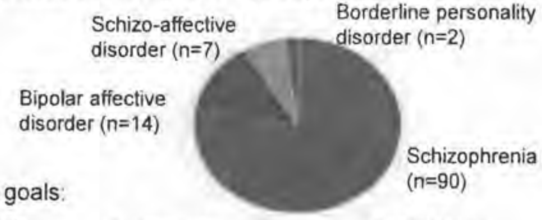
RESULTS

- Total number of participants admitted ≥ 90 ays between 2001 – 2013 = 90
- Total number of participant stays ≥ 90 days at SRRP = 113

Table 1: Sample characteristics

Variables	Values
Total SRRP participant stays assessed n	113
Mean age, years (SD)	34.2 (10.1)
Gender, males (%)	67 (65%)
Median duration of stay at SRRP, days	275
Substance abuse comorbidity	62 (60%)
Use of Mental Health Act at SRRP entry, n (%)	57 (55%)

Fig 1: Diagnoses of participants ≥ 90 days:



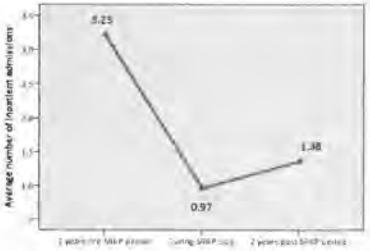
Participant goals:

❑ Employment
❑ Housing
❑ Education
❑ Intimate relationships
❑ Family relationships
❑ Driving
❑ Improve dietary habits
❑ Budgeting
❑ Medication compliance
❑ Physical health Management
❑ Alcohol & drug support
❑ Improve social skills
❑ Independent living skills
❑ Regular physical exercise
❑ Childcare
❑ Sexual health
❑ Linking with GPs
❑ Referral to specialist
❑ Anger management
❑ Telephone skills
❑ Safety of self & others

Table 2: Participant goals

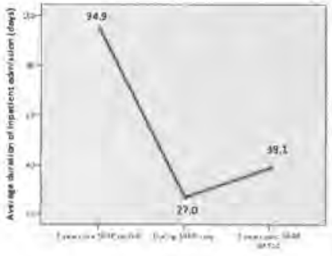
Average number of goals,. Mean (SD)	Values
At SRRP entry	9.8 (3.0)
Achieved at SRRP exit	8.5 (3.8)
Completion rate of selected goals at exit from SRRP (%)	
Housing	90%
Education	69%
Employment	65%
Intimate relationship	57%

Fig 1: Number of inpatient admissions



One way ANOVA: Wilks' lamda = 0.77; F=15.18; $p<0.001$; $\eta^2=0.23$ equivalent to Cohen's d effect size of 0.7

Fig 2: Duration of inpatient admissions



One way ANOVA: Wilks' lamda = 0.69; F=23.09; $p<0.001$; $\eta^2=0.31$ equivalent to Cohen's d effect size of 0.9

CONCLUSION

- ✓ SRRP is unique & only such a program in Victoria and in Australia
- ✓ This partnership model of service delivery is effective in reducing number and duration of inpatient admissions for people with severe mental illness
- ✓ Majority of participants achieved their individual goals at the time of exit from SRRP
- ✓ We believe that the marriage of two perspectives, the clinical and the social community welfare, is central to the success this program

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ATTACHMENT RB-35

This is the attachment marked '**RB-35**' referred to in the witness statement of Dr Ravi Subramanya Bhat dated 4 July 2019.

Discussion Paper

Beyond Survival: The Case for Investing in Young Children Globally

G. Huebner, N. Boothby, J. L. Aber, G. L. Darmstadt, A. Diaz, A. S. Masten, H. Yoshikawa, I. Redlener, A. Emmel, M. Pitt, L. Arnold, B. Barber, B. Berman, R. Blum, M. Canavera, J. Eckerle, N. A. Fox, J. L. Gibbons, S. W. Hargarten, C. Landers, C. A. Nelson III, S. D. Pollak, V. Rauh, M. Samson, F. Ssewamala, N. St Clair, L. Stark, R. Waldman, M. Wessells, S. L. Wilson, and C. H. Zeanah

June 16, 2016

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Beyond Survival: The Case for Investing in Young Children Globally

G. Huebner, N. Boothby, J. L. Aber, G. Darmstadt, A. Diaz, A. S. Masten, H. Yoshikawa, I. Redlener, A. Emmel, M. Pitt, L. Arnold, B. Barber, B. Berman, R. Blum, M. Canavera, J. Eckerle, N. A. Fox, J. L. Gibbons, S. W. Hargarten, C. Landers, C. A. Nelson III, S. D. Pollack, V. Rauh, M. Samson, F. Ssewamala, N. St Clair, L. Stark, R. Waldman, M. Wessells, S. L. Wilson, and C. H. Zeanah

EXECUTIVE SUMMARY

Investing in young children[1] globally is a primary means of achieving sustainable human, social, and economic development, all of which are vital to ensuring international peace and security. Strategic investments in children have been recognized by the world's leaders in their recent adoption of the Sustainable Development Goals, which aim to further peace, end global poverty, and ensure that all human beings can fulfill their potential in dignity (United Nations, 2015). For the first time, early childhood development is acknowledged as a critical part of the global development agenda. Although child development is explicitly referenced under the new education goal, it is naturally linked to other goals—reducing poverty, improving health and nutrition, promoting equality for girls and women, and reducing violence (United Nations, 2015). Indeed, coordinated, evidence-based investments must be made across sectors to ensure that more and more children not only survive but also thrive.

This paper is a call to action, informed by science from multiple disciplines. We hope it will help to close the gap between what is known and what is done to support the development of children globally and, in turn, sustainable progress for communities and nations.

The cost of inaction is enormous (IOM/NRC, 2014). Currently, an estimated 5.9 million children die before their fifth birthday (UNICEF, 2016); 159 million children under age 5 are stunted (UNICEF, 2015); at least 200 million children fail to reach their developmental potential each year (Grantham-McGregor et al., 2007); and 1 billion children experience violence annually (Hillis et al., 2016). As a result, countries lose up to about 30 percent in adult productivity every year (Grantham-McGregor et al., 2007). Meanwhile, return on investments during the prenatal and early childhood years average between 7 and 10 percent greater than investments made at older ages (Carneiro and Heckman, 2003). Although there are other opportunities to enhance human development, cost-effective strategic investments made during children's early years can mitigate the deleterious effects of poverty, social inequality, and discrimination, ultimately resulting in long-lasting gains that reap benefits for children and youth, families, communities, and nations (Carneiro and Heckman, 2003).

Over the course of the last two decades, this knowledge has begun to infiltrate U.S. domestic policy and programs (IOM, 2000). Yet, investing in young children's

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[1] The UN defines the early childhood period as beginning prenatally through age 8.

developmental potential has been a more difficult proposition to sell in some U.S. foreign assistance policy and program circles. The science is clear—and globally applicable—and successful programs have been piloted and brought to scale, both within the United States and internationally. Early investment in young children's development appears to trigger a multiplier effect, with positive outcomes ricocheting across multiple sectors over the long term. Nevertheless, the compelling case for investment continues to be lost in translation.

The U.S. government spends more than $30 billion on foreign assistance[2] and has been at the front line of cutting-edge investments in development for decades. Still, many policies and programs—not to mention the funding to support them—have not kept up with the science that underscores the critical importance of investing early and holistically to ensure healthy and productive lives and communities.

Currently, U.S. government foreign assistance remains fragmented, with little focus on or cross-sectoral funding for holistic child development and with limited mechanisms in place to ensure effective coordination across sectors. Without a proactive effort to integrate programs for young children, harmonize implementation, and synchronize the measurement of results, program and outcome siloes are created, and an important opportunity to maximize results for children is lost. Young children's needs and risks are multidimensional. Tackling one issue at a time, divorced from a more complex reality, is ultimately a disservice to time- and resource-strapped vulnerable families. Young children require integrated support, including health, nutrition, education, care, and protection. The science explains why. By turning attention and resources toward coordinated investments and delivery platforms, it is possible to close the gap between what is known and what is done to support young children globally.

BEYOND SURVIVAL: EXPANDING THE VISION

Evidence-based, results-oriented, coordinated, and effectively monitored international development assistance works. The success of the "child survival revolution" is an important example. In the past two decades alone, child deaths have fallen dramatically, from 12 million in 1990 to 5.9 million in 2015 (UNICEF, 2016). This significant progress is largely due to strategic investments, high-impact interventions, and tools for child survival, notably new vaccines and improved health care practices. Shared targets and coordinated interventions on the part of global public and private partners have ensured that the momentum is maintained.

The success of the child survival revolution is inextricably linked to the focused attention and dedicated funding it has rightfully received for decades from the global development community and donors, including the U.S. government. In 2014, total global development assistance for maternal, newborn, and child health (MNCH) was approximately $9.6 billion, around $1 billion less than the amount provided for HIV/AIDS. Of this total, $3.0 billion was allocated to maternal health. The other $6.6 billion focused on child health activities. Since 1990, the U.S. government has

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[2] According to ForeignAssistance.gov, $33.9 billion is planned in foreign aid in fiscal year 2017. The website offers a breakdown of expenditures by sector and country.

consistently served as the largest source of development assistance for global health. Across MNCH sources, the United States was the origin of 20.8 percent of all MNCH funding in 2014, 72.1 percent of which was channeled through U.S. bilateral aid agencies. Other channels in receipt of substantial U.S. government support for MNCH were UN agencies (8.8 percent, or $177 million), nongovernmental organizations and foundations (7.4 percent, or $148 million), and Gavi, the vaccine alliance (8.9 percent, or $179 million) (IHME, 2014).

Despite this sustained investment and hard-earned progress in reducing preventable childhood deaths, approximately 200 million children under age 5 survive, but fail to thrive. This figure represents 30 times the number of children who die before they reach their fifth birthday and is a population requiring urgent attention (Grantham-McGregor, 2007). Spending early childhood in the midst of extreme poverty and experiencing significant deprivation, violence, and/or neglect results in devastating consequences throughout the life cycle and profound repercussions for society. These 200 million children live below the poverty line and/or are stunted. They attend school for fewer years—or not at all. They are disproportionately affected by violence and are more likely to be exploited. All these factors limit their future ability to live healthy and productive lives, obtain gainful employment, and contribute to their communities and families, perpetuating a multigenerational cycle of poverty. As a result, countries where these 200 million children live have an estimated 30 percent loss in adult productivity and are prone to instability and conflict (Grantham-McGregor, 2007).

If we are serious about eradicating poverty and fostering equity, we must aim higher. Ensuring survival is a crucial first step, of course, but this should be our minimum standard for success. The campaign to save lives will be incomplete if the future prospects of those who survive remain constrained by factors that, with the right attention and focus, could be effectively addressed (Shonkoff et al., 2012). Indeed, improving outcomes for those who survive the scourge of childhood deprivation and illness should be seen as a compelling priority from the standpoint of human rights, sustainable economic and social development, and global security.

The fact is, children develop holistically. As whole human beings, we do not first survive physically and then develop intellectually, socially, and emotionally. The processes of growth and development are by nature interrelated, interdependent, and mutually reinforcing. Yet, international assistance for children in developing countries is rarely holistic. As a foreign assistance community committed to achieving sustainable human, social, and economic development and international security, we have separated children according to the category of their vulnerability and intervened in line with sectoral predispositions, legislative mandates, and associated funding streams. Yet, this segregated, fragmented approach to sustainable development does not offer the greatest return on investment.

Established and emerging science continues to demonstrate that to promote "*child thrival*" successfully, investments and services must be coordinated and integrated where possible, concurrently addressing the health, nutrition, development, education, and protection needs of children, beginning prenatally and, better yet, during the preconception period.[3] This knowledge can inform innovative strategies to address

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[3] For instance, the National Scientific Council on the Developing Child is a multidisciplinary, multiuniversity collaboration committed to closing the gap between what we know and what we do to promote successful learning,

child survival and well-being across domains, leading to improved outcomes for children over the long term as they venture into adulthood in ways that did not exist even 10 years ago (Shonkoff et al., 2012). Focusing on integrated investments and interventions for children ages 0-8 aims to create a *multiplier effect*, building a solid foundation to support long-term development and scaffolding for opportunities across domains.

Child survival can no longer be a sufficient goal. A moral and economic imperative exists to build on the successes of the last two decades and achieve a future for the world's children that envisions healthy and productive lives beyond survival.

FROM NEURONS TO NATIONS: BUILDING THE ARCHITECTURE FOR THE FUTURE

Frederick Douglass, an African American social reformer and statesman is said to have written, "It is easier to build strong children than to repair broken men." This statement not only sounds good; it is biologically true and sensible from an economic perspective as well.

Major advances in neuroscience, molecular biology, genomics, psychology, sociology, and other fields have helped us to understand the significance of early experiences on lifelong health and development. To analyze what science tells us about this critical period, the National Academies' Board on Children, Youth, and Families[4] established the Committee on Integrating the Science of Early Childhood Development in 1997. The committee was charged with reviewing what is known about the nature of early development and the role of early experiences and to discuss the implications of this knowledge base for policy, practice, and further research.

From Neurons to Neighborhoods is the product of this two-and-a-half-year project during which a top-tier scientific committee analyzed and evaluated the extensive, multidisciplinary, and complex science of early human development (IOM, 2000). The committee examined how early experiences affect all aspects of development, from the neural circuitry of the growing brain, to the expanding network of a young person's social relationships, to the enduring and changing values of the society in which caregivers raise children. The committee addressed the critical need to use knowledge about early childhood to maximize the nation's human capital and to nurture, protect, and ensure the health and holistic well-being of all children.

The committee's work was the beginning of a sustained and concerted effort to bridge the gap between what is known and what is done to promote sound physical and mental health and successful learning for all young children in the United States. Following the impactful *From Neurons to Neighborhoods* consensus study, the National Scientific Council on the Developing Child was formed to generate, analyze, and integrate scientific knowledge to educate policy makers, civic leaders, and the general

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adaptive behavior, and sound physical and mental health for all young children. Established in 2003, the council translates science to build public will that transcends political partisanship and recognizes the complementary responsibilities of family, community, workplace, and government to promote child well-being. See http://developingchild.harvard.edu/science/national-scientific-council-on-the-developing-child/. The Forum on Investing in Young Children Globally was launched in 2014. The forum is a 3-year effort that aims to integrate knowledge with action in regions around the world to inform evidenced-based, strategic investments in young children. See http://www.nationalacademies.org/hmd/activities/children/investingyoungchildrenglobally.aspx.

[4] See http://sites.nationalacademies.org/DBASSE/BCYF/index.htm.

public about the rapidly growing science of early childhood development and its underlying neurobiology.

Part of this effort has centered on building awareness on how early experiences affect the development of brain architecture, which provides the foundation for all future learning, behavior, and health. "Just as a weak foundation compromises the quality and strength of a house, adverse experiences early in life can impair brain architecture, with negative effects lasting into adulthood" (National Scientific Council on the Developing Child, 2007). Neural connections are made at a significant speed in a child's early years, and the quality of these connections is affected by the child's environment, including nutrition, interaction with caregivers (National Scientific Council on the Developing Child, 2004), and exposure to adversity, or toxic stress (National Scientific Council on the Developing Child, 2005/2014).

As one commentator put it simply: "Childhood is not Las Vegas. What happens in childhood does not stay in childhood" (Eloundou-Enyegue, 2014). The experiences children have in their early lives—and the environments in which they have them—exert a lifelong impact. These experiences shape the developing brain architecture and influence how and what genes are expressed over time. This dynamic process affects whether children grow up to be healthy, productive members of society (National Scientific Council on the Developing Child, 2010b). This is not to suggest that compromised beginnings cannot be turned around. Indeed, children's resilience is a powerful reality, achieved when protective factors—particularly a stable and committed relationship with a supportive parent, caregiver, or other adult—outweigh other risks (Masten, 2014; Center on the Developing Child at Harvard University, 2015). The neurobiology of brain development clearly shows that it is easier, more efficient, and more cost-effective to build strong beginnings than it is to facilitate repairs later in life, when brain architecture is less malleable (see Figure 1).

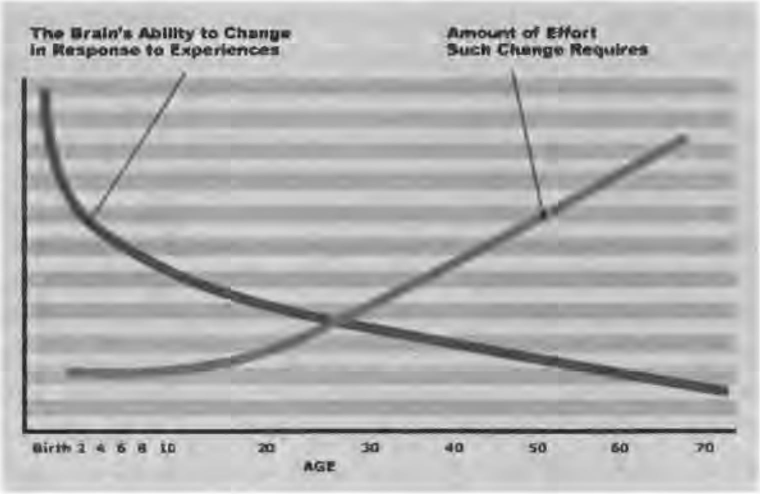

FIGURE 1: The ability to change brains decreases over time.
SOURCE: Center on the Developing Child at Harvard University (n.d).

In addition to the important advances made in better understanding the neurobiological elements of early childhood, James J. Heckman, a Nobel Laureate in Economics, has shown that rates of return on investments made during the prenatal and early childhood years average between 7 and 10 percent greater than investments made at older ages (see Figure 2) (Carneiro and Heckman, 2003; Heckman, 2008). Heckman's cutting-edge work with a consortium of economists, psychologists, statisticians, and neuroscientists shows that early childhood development directly influences economic, health, and social outcomes for individuals and society. His work has demonstrated how adverse early environments create deficits in skills and abilities that drive down productivity and increase social costs—thereby adding to financial deficits borne by the public (Heckman, undated).

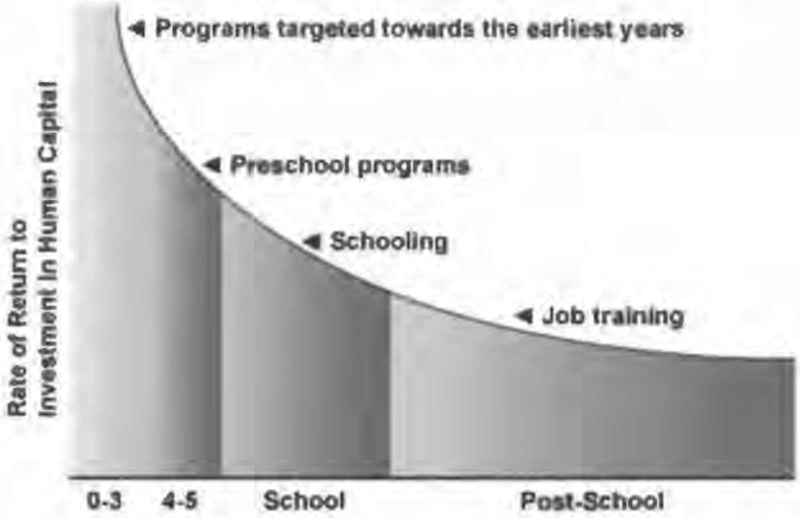

FIGURE 2: Rate of return on investment
SOURCE: Heckman (2008).

As a result of this growing knowledge, over the past two decades we have seen a nationwide groundswell of interest in the critical early years. "In many ways, the 1990s represented an awakening of federal action on child care and early childhood issues that had been slow to evolve in the earlier decades. Emerging evidence and important state and legislative action laid the groundwork for many of the policy issues and debates we see today" (Lombardi et al., 2016). There is now widespread recognition in the United States that what happens during the early childhood period can either contribute to children's healthy development or set the stage for problems in school and throughout life, taking a long-term economic toll on individuals, families, communities, and even the nation. Bipartisan legislation supporting early childhood policies and programs has been passed in dozens of states, and nearly every state has some kind of early childhood agenda (Center on the Developing Child at Harvard University, 2014). Following on progress made under previous administrations (Lombardi et al., 2016), President Obama noted the science of early childhood in several of his State of the Union addresses, making a clear connection between strategic investments in young people and the progress of our nation (Center on the Developing Child at Harvard University, 2014). The president's budget for fiscal year 2017 prioritizes early investments in children, including $1.2 billion to expand early intervention and preschool programs, $9.6 billion for Head Start, and $15 billion in new funding over the next 10 years to extend and expand evidence-based, voluntary home visiting programs, which enable nurses, social workers, and other professionals to support new and expectant parents (U.S. Office of Management and Budget, 2016).

Unfortunately, these connections have not been emphasized or prioritized in U.S. foreign policy or assistance programs (U.S. Department of State, 2015; U.S. Office of Management and Budget, 2016).[5] Nevertheless, the science that has informed U.S. domestic policies and programs is now being examined at a global level. Of note, the National Academy of Sciences—established by an Act of Congress in 1863 and charged with providing independent, objective advice to the nation on matters related to science and technology—established a Forum on Investing in Young Children Globally in 2014.[6] The forum, a collaboration between the Board on Global Health and the Board on Children, Youth, and Families, aims to integrate knowledge with action in regions around the world to inform evidenced-based, strategic investments in young children. Its main objectives are to explore global integrated science of healthy child development through age 8; share models of program implementation at scale and financing across social protection, education, health, and nutrition in various country settings; promote global dialogue on investing in young children; and catalyze opportunities for intersectoral coordination at local, national, and global levels. Just as the National Academy of Science's *From Neurons to Neighborhoods* considered the connection between investments in young children and the ability of American children, families, and communities to prosper, the organization is now dedicated to ensuring that decision makers around the world use the best science and evidence for investing to optimize the well-being of children and their lifelong potential—*from neurons to nations*,[7] so to speak.

The convergence of the biological, developmental, and economic sciences continues to remind us that the clock is always ticking and the cost of inaction continues to rise as time passes (Center on the Developing Child at Harvard University, 2014). Despite the fundamental principles of biology and human development—or, human

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[5] The Quadrennial Diplomacy and Development Review provides a blueprint for advancing America's interests in global security, inclusive economic growth, climate change, accountable governance, and freedom for all. As a joint effort of the Department of State and the U.S. Agency for International Development, the review identifies major global and operational trends that constitute threats or opportunities and delineates priorities and reforms to ensure our civilian institutions are in the strongest position to shape and respond to a rapidly changing world.

[6] See http://www.nationalacademies.org/hmd/activities/children/investingyoungchildrenglobally.aspx.

[7] Jack Shonkoff (Harvard Graduate School of Education; Harvard Medical School; Harvard School of Public Health), Charles A. Nelson (Harvard School of Public Health), and Holly Schindler (Harvard Graduate School of Education) taught an undergraduate course titled "From Neurons to Nations: The Science of Early Childhood Development and the Foundations of a Successful Society." See http://isites.harvard.edu/course/colgsas-81179.

capital formation (Heckman, 2007)—the critical importance of timely and integrated early intervention is often overlooked in our international development and child policies and programs. It is time that our programs, policies, and investments more closely correspond with the established science. It is the best and most cost-effective means to ensure that children, families, communities, and nations catch up with their developmental potential.

RECOGNIZING THE MULTIDIMENSIONALITY OF CHILDREN'S WELL-BEING

Investments in child health and well-being are a cornerstone for productive adulthood and robust communities and societies. Promoting healthy and holistic child development is an investment in a country's future workforce and ability to thrive economically. Ensuring that all children, including the most vulnerable living at the margins of society, have the best first chance in life is a tried-and-true means to stabilize individuals, communities, and societies over the long term.

Risk factors affecting healthy child development are complex and manifold, including undernutrition, toxic stress, and lack of access to life-saving vaccines, nurturing care, protection, and opportunities to learn (Evans et al., 2013; Wachs and Rahman, 2013). U.S. international assistance programs have typically focused on single risks or categories of vulnerability—for example, responding to the devastating impacts of HIV/AIDS or malaria, natural disasters or human conflict, exposure to violence, exploitation, or human rights violations such as child marriage. These diverse efforts to support and protect children have produced substantial benefits, though the diffused approach has also resulted in fragmented responses. Siloed interventions lead to siloed outcomes. By focusing on only a single element of the burden of risks, the effect on outcomes is diminished (Singer, 2014). Science has shown that coordinated, multifaceted, and evidence-based action can help ensure that children in adversity benefit fully from policies and services and achieve better outcomes over the long term (Boothby et al., 2012).

Co-locating and integrating services where possible; maximizing home visiting programs to address issues related to health, nutrition, and parent-child interactions; and creating effective referral mechanisms to close gaps between sectoral interventions and providers go a long way in ensuring that vulnerable children and families have the support they need to succeed. Table 1 summarizes elements of a holistic package of services for young children and their caregivers. While many programs focus on particular intervention or sectoral areas, noting the interlinkages within and across sectors is critical to ensuring children's well-being across domains.

TABLE 1 Elements of a Holistic Package for Young Children and Their Caregivers[8]

Maternal, Newborn and Child Health	Nutrition
• Reproductive health and family planning • Maternal education • Antenatal visits • Skilled assistance during childbirth • Immediate and exclusive breastfeeding for 6 months • Complementary and responsive feeding • Immunizations • Deworming • Regular check-ins with health care providers • Growth monitoring and promotion • Timely diagnosis and treatment of disease • Screening for developmental delays and disabilities • Access to safe water, sanitation, and hygiene/handwashing	• Counseling on adequate diet and appropriate nutrition during pregnancy • Iron-folic acid for pregnant mothers • Complementary feeding • Optimal feeding practices, including responsive feeding and stimulation • Micronutrient supplementation and fortification • Therapeutic zinc supplementation for diarrhea
Early Childhood Care and Education	**Protection from Violence and Neglect**
• Opportunities for play, learning, education, and interaction with responsive adults in safe environments • Child-centered spaces in the community • Equitable access to quality preprimary education, including for children with developmental delays and disabilities and children from marginalized groups • Continuity with quality primary education • Parenting skills and caregiver support, focusing on early stimulation, growth, and development	• Education related to positive parenting, safe discipline, and the effects of violence on child health and development • Household economic strengthening coupled with building of parenting skills; promotion of gender equality to prevent violence against women and girls • Reduced access to and use of alcohol, illegal drugs, and weapons • Legal protections that prevent and respond to violent and neglectful behavior • Services for victims and perpetrators • Social norms and behavior change

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[8] This chart draws from similar depictions that present key interventions by sector and/or age, including "Figure 1: 25 Key Interventions for Young Children and Their Families" in Denboba et al. (2014), p. 3.

Caregiver Support	**Safety Net**
• Parental leave • Quality and affordable child care • Parenting skills and caregiver support • Prevention and treatment of maternal depression • Referral mechanisms for support services	• Birth registration • Social service, child welfare, and protection systems, including effective case management • Household economic strengthening • Prevention of family-child separation and support for family-based alternative care

Maternal, Newborn, and Child Health

Science challenges the fundamental nature of programmatic stovepipes. For instance, there is growing international consensus within the public health community that early development is part of overall child health and is necessary for future prosperity. As far as long-term child outcomes are concerned, a narrow focus on child survival is insufficient. Maternal, newborn, and child health programs must also promote children's developmental potential.

In 2013, Dr. Margaret Chan, director general of the World Health Organization (WHO), emphasized three areas critical for healthy child development: (1) stable, responsive, and nurturing caregiving with opportunities to learn; (2) safe and supportive physical environments; and (3) appropriate nutrition (Chan, 2013). Indeed, many of the strategies that support child development are the same as those that prevent morbidity and mortality (Engle et al., 2011; Jensen et al., 2015). Such interventions enhance and are absolutely consistent with the child survival agenda.

Primary and community health workers may be the first and only service providers to have contact with children during the first few years of life (Engle et al., 2013). Services targeting women and young children—family planning, prenatal care, safe birth practices, neonatal survival strategies, breastfeeding support, growth-monitoring, immunizations—allow opportunities for introducing behaviors and practices that encourage healthy child development. As the WHO director general has stated, "The health sector therefore has a unique responsibility, because it has the greatest reach to children and their families during pregnancy, birth, and early childhood. The evidence is compelling to expand the child survival agenda to encompass child development" (Chan, 2013).

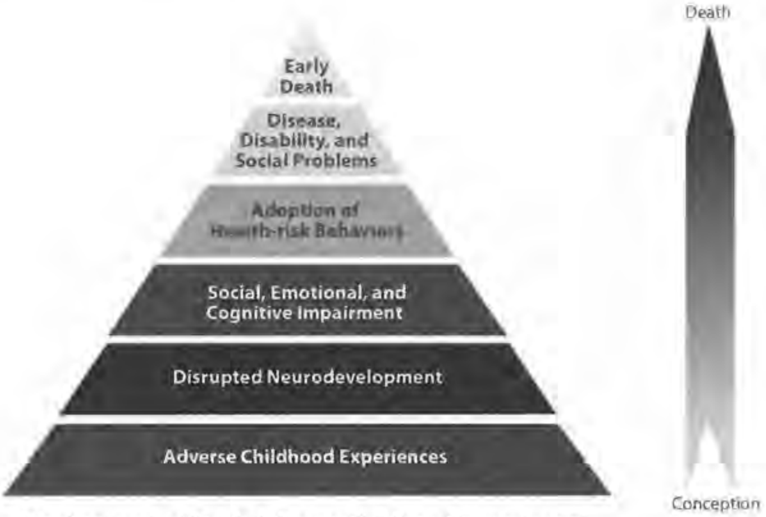
Indeed, strategies to prevent mortality in the first month of life—deaths that account for about half of all deaths in children under 5 years—are significant not only for survival but also for human capacity. "Failure to improve birth outcomes by 2035 will result in an estimated 116 million deaths, 99 million survivors with disability or lost development potential, and millions of adults at increased risk of non-communicable diseases after low birth weight. In the post-2015 era, improvements in child survival, development, and human capital depend on ensuring a healthy start for every newborn baby—the citizens and workforce of the future" (Lawn et al., 2014, p. 9938).

Foundations for healthy child development include many of the best practices that support child survival, including planned pregnancy and skilled assistance during childbirth; exclusive breastfeeding in the first six months of life followed by appropriate complementary and responsive feeding; timely diagnosis and treatment of infections and diseases; and preventive interventions, including vaccinations and regular check-ins with health care providers (Table 1). Nevertheless, these health practices, though critical for every child's well-being, are insufficient on their own and must be reinforced with informed action across sectors (Chan, 2013).

Recognizing the need to equip health care workers with skills to promote holistic and healthy child development, UNICEF and WHO together created Care for Child Development, a landmark intervention that was originally developed in the late 1990s as part of the regular child health visits as specified in the WHO/UNICEF strategy of Integrated Management of Childhood Illnesses (UNICEF and WHO, 2012). Since then, other initiatives have sought to integrate child survival, primary care, and child development, including Accelerated Childhood Survival and Development, Infant Young Child Feeding, and Maternal and Newborn Health Care. The Care for Child Development intervention provides information and recommendations for cognitive stimulation and social support to young children through sensitive and responsive caregiver-child interactions. It also guides health workers and other counselors as they help families build stronger relationships with their children and solve problems in caring for their children at home. These basic care-giving skills contribute to the survival, as well as the healthy growth and development, of young children (Elder et al., 2014).

Efforts to strengthen the capacities of vulnerable families to meet their children's health and developmental needs in the midst of poverty or serious threat suggest two pathways. The first requires improved access to and utilization of preventive health services and treatment. The second requires bolstering children's protective factors and capacity for resilience. Both involve supporting parents' and caregivers' ability to respond appropriately to children facing deprivation or distress. "The biology of adversity and resilience demonstrates that significant stressors, beginning in utero and continuing throughout the early years, can lead to early demise or produce long-lasting impacts on brain architecture and function" (Shonkoff et al., 2012).

The effects of early adversity on long-term health have been shown through the Adverse Childhood Experiences (ACE) Study, one of the largest investigations ever conducted to assess associations between childhood adversity and later-life health and well-being (CDC and Kaiser Permanente, 1998). The study is a collaboration between the Centers for Disease Control and Prevention and Kaiser Permanente's Health Appraisal Clinic in San Diego. The ACE Study's findings suggest that certain experiences are major risk factors for the leading causes of illness and death as well as poor quality of life (see Figure 3). Though the study has focused on the United States, it is critical to understanding how some of the worst health and social problems can arise as a consequence of adverse childhood experiences. Realizing these connections is likely to improve efforts toward prevention and recovery, including doubling up efforts to strengthen children's protective factors. Children who manage, and even do well, in the face of serious hardship typically have developed an array of adaptive capabilities embedded in neurobiological function, behavioral skills, relationships, and cultural or community connections. Resilience is the result of a combination of protective factors, which can be enhanced through strategic investments, including building the capabilities of caregivers and strengthening the communities that together form the environment of relationships essential to children's lifelong learning, health, and behavior (Center on the Study of the Developing Child at Harvard University, 2015; National Scientific Council on the Developing Child, 2015).



Mechanism by Which Adverse Childhood Experiences Influence Health and Well-being Throughout the Lifespan

FIGURE 3: Adverse childhood experiences influence health and well-being throughout the lifespan
SOURCE: CDC and Kaiser Permanente (1998).

Nutrition

Good nutrition is fundamental to child health and well-being, beginning with a mother's nutritional status before and during pregnancy (UNICEF, 2013). Proper nutrition is a key element in combating child mortality and morbidity: approximately 45 percent of all deaths of children under the age of 5 in low-income countries are attributable to undernutrition (WHO, 2016). Beyond its role in ensuring survival, the association between nutrition in early life and long-term health has been of interest for decades (Bhutta, 2013). The biological and epidemiological linkages between various types of undernutrition (stunting, wasting, and micronutrient deficiencies) and impaired cognitive development in the early years is well established (Black and Dewey, 2014). Nutrition plays a key role in healthy child development, particularly in the early years as neurodevelopmental building blocks are being formed and nutritional needs are high (Ramkrishnan et al., 2011). The effect of poor nutrition on young children, particularly between ages 0–8, and most acutely during the 1,000-day period from conception to age 2 years, can be devastating and enduring, having serious implications for health, behavioral and cognitive development, future reproductive health, and future workforce productivity.

Poor nutrition can lead to stunting, a condition that is defined as height for age below the fifth percentile on a reference growth curve. Stunting is used as a measure of nutritional status and serves as an important indicator for chronic undernutrition. Factors contributing to stunting include poor maternal health and nutrition before, during, and after pregnancy, as well as inadequate infant feeding practices, particularly during the 1,000 days from conception through a child's second birthday (WHO, 1997). Stunting early in life seriously affects brain functioning and can cause permanent cognitive impairment. As a result, it has been associated with consequences that threaten equity throughout the life cycle, including diminished health, poor school performance and early termination, and reduced work capacity and future earning potential (Hoddinot et al., 2013). Malnutrition adds staggering health costs for already financially burdened countries.

Early stunting has been used as an indicator, along with poverty, to estimate the number of children who are at risk for not reaching their developmental potential. Currently, nearly one in four children under age 5 worldwide is stunted. This massive burden poses serious threats to individual and community capacity for health, stability, and productivity. The vast majority of the 159 million children under age 5 who are stunted live in Asia and Africa (UNICEF, 2015). The good news is that global stunting prevalence has declined from nearly 40 percent in 1990 to 24 percent in 2014.

Nearly 20 years of research has demonstrated that nutrition programs that are combined with health, water and sanitation, and child development interventions—emphasizing stimulating and responsive parenting—achieve greater immediate and long-term effects (Black and Dewey, 2014). A groundbreaking randomized controlled trial in Jamaica revealed that stunted children who received targeted nutrition interventions alongside support for parents had better outcomes than children receiving only nutrition interventions. A 20-year follow-up shows that the stunted Jamaican toddlers who received 2 years of psychosocial stimulation had higher IQs and experienced reduced anxiety and depression and less violence. Strikingly, their future earnings were 50 percent greater than the nonstimulated stunted group. In fact, their earnings were comparable to a nonstunted sample, indicating that the stimulation intervention enabled them to catch up to their well-nourished peers (Grantham-McGregor et al., 1997 and 2007; Gertler et al., 2014).

In 2014, more than 80 leading researchers from multiple disciplines consolidated the existing evidence to advance knowledge concerning an integrated approach to improving both nutrition and early childhood development. The resulting collection of 20 articles provides a portrayal of the current state of the science linking brain development, psychology, nutrition, and growth, reviewing the impact and lessons learned from integrated interventions to improve outcomes across these domains (Black and Dewey, 2014). It is essential that current policies and programs take this learning into consideration and that funding is used to support evidence-based programming rather than unintegrated program siloes that sever children's needs into separate and uncoordinated services.

Early Childhood Care and Education

Young children's growth and development are profoundly shaped by nurturing care and opportunities for play, learning, education, and interaction with responsive adults—whether these occur at home, in out-of-home caregiving environments, such as child care centers, or in formal or informal child-centered spaces and educational settings in the community (Britto et al., 2013; Ginsburg, 2007). These early interactions lay the groundwork for developmental potential, including physical, cognitive, social, and emotional growth. Skills required for schooling, employment, and family life build cumulatively on these dimensions of developmental potential. Indeed, nurturing early childhood care and education are fundamental to quality basic education and serve as a foundation for equity (Irwin et al., 2007).

Significant disparities in early learning experiences for low-income children can set the stage for achievement gaps that persist through years of school and lead to a lifetime of missed opportunities, inequities, and even health challenges. Increasing access to quality early childhood care and education is considered an effective "equalizer" (Irwin et al., 2007). Research from developing countries shows that early childhood development programs lead to higher levels of primary school enrollment and educational performance, which in turn positively affect employment opportunities later in life. On the contrary, children who start school late and lack the necessary skills to be able to learn constructively are more likely to fall behind or drop out completely, often perpetuating intergenerational cycles of poverty (Engle et al., 2011). Studies show that the returns on investments in early childhood care and education are highest among poorer children, for whom these programs may serve as a stepping stone out of poverty or exclusion (Heckman, 2006).

Despite the proven benefits of early childhood care and education programs, access and attendance remain very low in many developing countries, particularly for children from marginalized populations, including children with disabilities. Attendance in early learning programs among children ages 3 and 4 is less than 50 percent in the majority of countries with available data (UNICEF, 2016). Low attendance is related to limited access—a direct result of the lack of prioritization placed on early childhood programs—and associated minimal funding.

Inadequate attention to the foundational early childhood period has affected global efforts to achieve basic targets in education. Fortunately, the previous lack of focus on early childhood development has been addressed in the post-2015 global development agenda. Target 4.2 of the United Nations' Sustainable Development Goals, announced in September 2015, states that, by 2030, "all girls and boys have access to quality early childhood development, care and pre-primary education so that they are ready for primary education" (United Nations, 2015). The challenges involved in achieving universal access to early childhood development programs are enormous, particularly given ingrained patterns of underinvestment in this area.

The economic science is clear and compelling: investments in learning and development during the early years result in greater cost savings than investments made later in the life cycle (Heckman, 2008). According to the World Bank, high-income countries spend an estimated 1.6 percent of their gross domestic product (GDP) on family services and preschool for children aged 0–6 years and 0.43 percent of GDP on preschools alone. By comparison, low-income countries tend to spend far less than 0.1 percent on preschools (Engle et al., 2011). Yet, even in resource-rich countries, developmental vulnerability increases as socioeconomic status decreases (Irwin et al., 2007). Increasing preschool enrollment rates to 25 percent could yield an estimated $10.6 billion through higher educational achievement, and a 50 percent increase could generate $33.7 billion (Engle et al., 2011). Such investments in preprimary environments yield even greater dividends when coupled with community-based health and nutrition programs and parenting support. Unless governments—including bilateral agencies—allocate increased resources to quality early childhood care and education programs, and, in particular, target children in the lowest economic quintile, economic disparities will continue and widen.

Protection from Violence and Neglect

Over the last few decades, knowledge has accumulated about how normative child development can be significantly derailed by exposure to violence and neglect, particularly when such exposure is repeated or chronic (Center on the Developing Child at Harvard University, 2016). Science shows that early exposure to maltreatment can disrupt healthy development and have lifelong consequences (Cicchetti and Toth, 2016; Pollak, 2015). Research also shows that violence against women and children often co-occur and share common risk factors (Patel, 2011). Women who experience violence from their partners are more prone to depression and less likely to earn a living or provide consistent and nurturing care for their children (National Resource Center on Domestic Violence, 2002). Fortunately, effective strategies to prevent violence against women and children are becoming more fully understood and utilized (WHO, 2010; Bernard van Leer Foundation, 2011; KNOW Violence, undated).

Child maltreatment includes experiencing violent discipline, witnessing intimate partner violence, and being neglected by caregivers (Hillis et al., 2015). Caregivers' failure to provide sufficient and adequate nutrition, clothing, shelter, sleep, or medical care and to ensure that the child's surroundings and activities are responsive, nurturing, and safe all constitute forms of neglect toward a child, leading to more severe deprivations over time. Research has demonstrated that healthy child development can be derailed not only as the result of physical or sexual abuse but also by the lack of sufficient quality experiences, nurturing, and opportunities to learn, particularly in the early years (Cicchetti, 2013). Despite neglect being, by far, the most prevalent form of child maltreatment, it receives far less public attention than physical or sexual abuse (Center on the Developing Child at Harvard University, 2012).

When caregiver or other adult responses to children are violent, erratic, inappropriate, or simply absent, developing brain circuits can be disrupted, affecting how children learn, solve problems, and relate to others (Center on the Developing Child at Harvard University, 2012). Such experiences, particularly in the sensitive period of early childhood, can lead to lasting physical, mental, and emotional harm with long-term effects. Affected children are more likely to suffer from attachment disorders, regressive or aggressive behavior, depression, and anxiety. Child maltreatment and other adverse experiences can affect immediate and long-term health, cognitive function, and socioemotional well-being (Margolin and Elana, 2004; National Scientific

Council on the Developing Child, 2010a). Violence and neglect often cycle through generations, negatively affecting individual and collective opportunities for productivity and health over many years.

A first step in preventing violence and neglect is better understanding their magnitude, nature, and consequences. The CDC's Violence against Children Surveys measure physical, emotional, and sexual violence against girls and boys. The surveys' data have been released in eight countries, with data collection ongoing in several more (CDC, undated). In early 2016, the CDC released a groundbreaking report estimating the global burden of violence against children throughout the world. The study combines data from 38 reports spanning nearly 100 countries to calculate the number of children affected by violence in the past year. Conservative estimates of the data show that a minimum of 50 percent of children in Asia, Africa, and North America experienced serious forms of violence and that more than half of all children in the world—1 billion children ages 2–17 years—are victims of violence, subjected to regular physical punishment by their caregivers (Hillis et al., 2015). An estimated 275 million children witness domestic violence every year. Often, intimate partner violence tends to co-occur with the direct victimization of children (UNICEF, 2014b). Further exposure is detailed in a statistical analysis of violence against children released by UNICEF in 2014, shedding light on the prevalence of different forms of violence against children, with global figures and data from 190 countries (UNICEF, 2014b). Where relevant, data are disaggregated by age and sex to provide insights into risk and protective factors.

The prevalence of violence experienced by children ages 0–8 is difficult to assess because much of the violence occurs within the privacy of individual homes, child care centers, and residential institutions, and thus is often hidden from public view. Caregivers committing violence against children are unlikely to self-report or seek help, particularly where violent discipline is a cultural norm or a social taboo. In lower-income countries, social services are minimal and underresourced, often ill-equipped to assess or effectively respond to violence against children. In addition, existing data-collection mechanisms lack age-appropriate diagnostic tools for children under 15 years of age (Bernard van Leer Foundation, 2012). Nevertheless, data show that the first year is the most dangerous period in a child's life with respect to the risk to survival not only from neonatal causes but also from violence, abuse, and neglect (Da Silva e Paula et al., 2013).

The economic costs associated with neglect of and violence against children can be broadly divided into two categories: direct and indirect. The direct costs are more immediate and easier to measure, including (1) health care costs associated with treatment of physical injuries and psychological and behavioral problems; (2) social welfare costs incurred for monitoring, preventing, and responding to neglect of and violence against children; and (3) criminal justice costs associated with ensuring that perpetrators are punished and that victims are protected. Indirect costs may be less obvious, but loom much larger. These include significant losses in future productivity arising from the negative and often irreversible impact that childhood neglect and violence have on child development and well-being. Adults who experienced violence and/or neglect in childhood have lower levels of education, more limited opportunities for employment, lower earnings, and fewer assets. The adverse experiences in early childhood significantly reduce human capital formation, with serious repercussions for individuals, families, and societies as a whole (Santos Pais, 2015; Berens and Nelson, 2015).

Studies of costs associated with violence against children reference the proportion of gross national income/gross domestic product potentially lost due to expenditure on response, prevention, and productivity losses. Estimates vary depending on the types of violence studied and how comprehensively the direct and indirect costs are assessed. Even when these assumptions are taken into consideration, the lowest estimates at national, regional, or global levels indicate that costs range between 2 and 10 percent of GDP, representing a significant cost to national and global economies (Fearon and Hoeffler, 2014). One study estimates that the global economic impacts and costs resulting from the consequences of physical, psychological, and sexual violence against children can be as high as $7 trillion. This massive cost is higher than the investment required to prevent much of that violence (Pereznieto et al., 2014).

We can take steps to protect the world's children from violence and neglect. Data show that the following strategies are effective in preventing both: teaching positive parenting skills; economically empowering households; reducing violence and neglect through protective policies; improving health, child protection, and support services; changing the social norms that support violence; and teaching children social, emotional, and life skills. These strategies are based on CDC's core package THRIVES (Hillis, 2015) and similar guidance from UNICEF and WHO (UNICEF, 2014a) and are in support of the United Nations' 2030 Sustainable Development Goal to "end all forms of violence against children" (Hillis et al., 2016).

Violence prevention and response interventions have typically focused on school-aged children through programs in schools and communities. More can be done to empower actors across multiple sectors who provide services targeting young children and their families to play a key role in preventing maltreatment and neglect in children's early and most formative years. Nevertheless, although the evidence clearly shows that "prevention pays," current levels of spending on preventive and responsive actions in relation to violence against and neglect of children remain very low (Pereznieto et al., 2014).

FAMILIES ON THE FRONT LINES: SUPPORTING CAREGIVERS

To truly eradicate poverty and foster equity and to seriously put children at the heart of the global development agenda, we must recognize and support the critical role that families—which are, by nature, broadly defined—play in promoting children's health, development, education, and protection. Services delivered to children—whether primary health and nutrition care, early childhood care and development, education, or protection—do not work in a vacuum. They are most effective when they consider the vital role of family in children's lives and well-being. Without the consistent, nurturing and protective care of parents and caregivers, children's well-being suffers across domains.

Empowering Women, Supporting Children

Women's and children's rights have been bifurcated by advocates and policy makers for decades, but in many ways they are indivisible in the real lives of many women and children. This is not to suggest that the promotion of women's empowerment and children's rights are entirely interchangeable. Whether seen as separate or complementary causes, it is important that children are not left out of the equation as workplace and economic productivity or women's empowerment and well-being are promoted.

The link between a mother's education, health, nutrition, psychosocial wellness, safety, and socioeconomic status and her children's well-being is inextricable. Maternal, newborn, and child health programs are therefore often co-located. Yet, beyond the health sector, a gap begins to emerge between that which is done to promote women's empowerment and that which is done to support children.

For instance, quality and affordable child care is a critical part of advancing women's full participation in economic, political, and civic life, yet it is often missing from policy discourse and program implementation. As any working parent can attest, quality child care is a critical link between efforts to promote employment opportunities and holistic child well-being, particularly for poor working families (Heymann, 2006). Pursuing fundamentally separate agendas for women and children can be a disservice to both.

Indeed, labor policies that either facilitate or hinder working adults' ability to balance work and caregiving responsibilities have a particularly large impact on women *and* children. Paid maternity—or, more preferably—parental leave is a key first step, though caregiving does not end at infancy. Finding affordable and quality child care that meets the needs of children and working parents remains difficult worldwide, particularly in low-income countries. Huge gaps in access persist, quality is often substandard, and laws and policies to regulate care are often nonexistent or unenforced (Clinton Foundation and Gates Foundation, 2015).

As a result, the number of young children who are left without adult care while their parents work long hours outside of the home continues to grow. This situation negatively affects the health, development, and safety of these children, impacting their future potential as well as the ability of working parents to be fully productive. According to results from UNICEF's Multiple Indicator Cluster Surveys, more than 17 percent of children under age 5 are left home alone or in the care of another child under the age of 10 (UNICEF, 2012). Poor families are more likely to leave a child in inadequate care than wealthier families, and children from the poorest families are two times less likely to attend an organized early childhood care and education program than the richest families (UNICEF, 2012).

The Safety Net

Improving workplace policies and child care opportunities is important but insufficient, especially for the poorest families who work as part of the informal economy where workplace policies are essentially irrelevant. When vulnerable parents and families are unable to cope on their own, broader systems of support are often necessary. Social protection systems are central to reducing poverty and can have a direct and positive impact on poor families by improving access to better health, more schooling, economic assistance, and skills building. Effective and well-functioning social service and child welfare systems are vital to a nation's social and economic progress and are as important to global development programs as are strong health systems. Yet, in most low-income countries, these systems are understaffed and underresourced. The human resource constraint is critical. With proper investments and training, social service workers are able to help ensure that effective prevention and support services are available to the most vulnerable populations. Social service providers work to register births, connect families with essential services, prevent family-child separation, support alternative care, reunite families, provide critical psychosocial support, and link vulnerable families and parents with social protection schemes and economic strengthening activities (Global Social Service Workforce Alliance, 2015).

Globally, researchers, policy makers, and program implementers have increasingly recognized that family strengthening for the poorest families is key to effective responses to ensure healthy and holistic child development and protection. Economic assistance is a core aspect of a family-strengthening approach. Household economic-strengthening interventions target the family as the beneficiary and include interventions that focus on increasing access to household savings, credit, income generation, and employment opportunities. For example, conditional cash-transfer programs provide money to poor families to target poverty and increase family capital contingent on caretakers engaging in certain target behaviors, such as sending children to school, taking them for health clinic visits, and ensuring vitamin supplements and nutritious food. There is promising evidence regarding the benefits of conditional cash-transfer programs for families with young children (Elder et al., 2014). A review of nearly 50 published or publicly available randomized controlled trial research studies on household economic-strengthening interventions confirmed mostly positive effects on children's outcomes, including improved nutrition status and increased enrollment in education (Chaffin and Mortensen Ellis, 2015). The review also illustrated how conditional cash transfers can have secondary and longer-term positive impacts on children beyond those stipulated in the conditions of the cash transfer, including reduced sexual activity in adolescence and lower levels of psychological distress. Still, implementation of cash transfer programs—whether conditional or unconditional—varies considerably, and mixed results from some programs require further consideration (Chaffin and Mortensen Ellis, 2015). Research has helped to identify a combination of interventions that effectively lift vulnerable households out of poverty and improve caregiving environments, resulting in positive and measurable outcomes for children across domains.

The Ultimate Breakdown: Children Living Outside of Family Care

When vulnerable parents and families do not have the resources to meet basic needs, the risk of child neglect and separation from the birth family increases. Extreme poverty and inadequate access to basic services have led to millions of children living outside of family care—in institutions, on the street, trafficked, or separated from their families as a result of conflict, disaster, forced labor, or disability (Maholmes et al., 2012). These children have largely fallen off the world's statistical maps (Clay et al., 2011). For instance, there is currently no global data on the numbers of children living in institutions. Estimates range from 2 to 8 million, but the actual number of orphanages or residential institutions and the number of children living in them are unknown. Many institutions are unregistered, and underreporting is widespread. No international monitoring frameworks exist, and many countries do not routinely collect or monitor data on institutionalized children (Berens and Nelson, 2015).

The fact is, we measure what we care about, and we care about what we measure. Given the inextricable links among data, advocacy, and strategic action—not to mention the extraordinarily negative effects of spending early childhood without the nurturing and protective care of a permanent caregiver—this kind of invisibility has real-life repercussions for the world's most vulnerable children.

Strengthening families must be a global priority if we are serious about promoting children's well-being from survival to *thrival*. With inadequate investments in families, it will be impossible to reduce child morbidity and mortality, improve educational outcomes, and protect children from violence, exploitation, and abuse. Yet, despite the critical role families play in children's lives, they receive short shrift in global development policies and programs. The one passing reference to "families" in the United Nation's new sustainable development goals is a case in point (United Nations, 2015). It has been said that family is like oxygen—taken for granted until it is gone. Children do not fare well without at least one stable and committed relationship with a supportive parent, caregiver, or other adult. We cannot truly support children without investing in these relationships (Richter and Naicker, 2013).

PROTECTING THE FUTURE THROUGH STRATEGIC INVESTMENT

As global scientific and development communities continue to learn more about what works to promote children's optimal health, development, and protection, there is growing recognition of the need to finance successful programs beyond the pilot stage and take them to scale at the national level. A funding gap to support comprehensive early childhood programs has existed for some time. Given the strong evidence base and "proof of concept," it is time to close it (IOM/NRC, 2015).

Improving investments in coordinated programs for children ages 0–8 requires harmonization across funding streams and sectoral siloes. Child development is multidimensional and therefore requires multisectoral investments. As a promising example, the World Bank has been increasing support for integrated early childhood programs in recent years. Between 2001 and 2013, it invested $3.3 billion in early childhood programs through health, education, and social protection programs targeting pregnant women, young children, and their families. The World Bank has also invested substantially in research and impact evaluations concerning programs for children ages 0–8, focusing on early childhood nutrition, health, and development and expanding the evidence base on effective, quality, and scalable interventions (World Bank, 2014; Denboba et al., 2014). In April 2016, the World Bank and UNICEF jointly launched a global alliance on early childhood development (Kim, 2016). Prioritization of early childhood development is also occurring on the U.S. domestic front, with U.S. tax dollars allocated to early childhood programs through the Departments of Education and Health and Human Services (U.S. Office of Management and Budget, 2016).

Nevertheless, similar levels of attention and prioritization have yet to be seen in the realm of U.S. government foreign assistance programs. Indeed, U.S. international assistance to children is substantial and channeled through offices in multiple U.S. government departments and agencies—the Departments of Agriculture, Defense, Health and Human Services, Labor, and State; the U.S. Agency for International Development (USAID); and the Peace Corps (U.S. Government, 2014). Yet, to date, limited funds have been set aside for early childhood development per se.

Public Law 109-95, titled the *Assistance for Orphans and Other Vulnerable Children in Developing Countries Act of 2005,* was signed into law to promote a comprehensive, coordinated, and effective response on the part of the U.S. government to the world's most vulnerable children (U.S. Congress, 2005). It calls for an interagency strategy and a whole-of-government monitoring and evaluation system. The act also establishes a special advisor, currently based at the USAID, but the position comes with no oversight or funding authority.

In 2012, in accordance with Public Law 109-95, the U.S. government released the *Action Plan on Children in Adversity*, the first whole-of-government strategic guidance for U.S. international assistance programs (U.S. Government, 2012). The plan is grounded in evidence that shows that a promising future belongs to those nations that invest wisely in their children, while failure to do so undermines social and economic progress. It states that child development is a cornerstone for all development and therefore central to U. S. development and diplomatic efforts. The action plan seeks to achieve three principal objectives: (1) Build strong beginnings; (2) Put family care first; and (3) Protect children from violence, exploitation, abuse, and neglect. Multiple offices within 11 U.S. government departments and agencies agreed to specific actions to implement the plan.

No dedicated funding was appropriated to implement the plan until fiscal year 2015. Since then, appropriations' report language has suggested that approximately $10 million per year be directed toward its implementation. Annual reports to Congress suggest that multiple U.S. government offices contribute broadly to the plan's objectives, though details related to inputs and outcomes are slim. One of the action plan's strengths is its focus on measurable results, specifically achieving significant reductions in the number of children not meeting age-appropriate growth and developmental milestones; children living outside of family care; and children who experience violence or exploitation. Despite these laudable goals, it would appear that few U.S. government programs are tracking these outcomes (U.S. Government, 2014).

U.S. government appropriations continue to provide robust support for important global health, nutrition, and education programs (Kaiser Family Foundation, undated), though none of the corresponding funding directives includes language to support investments specifically in early childhood development. The one exception is the President's Emergency Plan for AIDS Relief (PEPFAR), which has a 10 percent set-aside for Orphans and Vulnerable Children's (OVC) Programming, which has historically promoted integrated programs for children affected by HIV and AIDS. In 2016, House report language recommended that PEPFAR integrate the action plan's "Strong Beginnings" objective into programs for the prevention of mother-to-child transmission of HIV. In addition, Senate report language directed that up to $20 million of OVC program funds be used for children living outside of family care (U.S. Congress, 2015b).

The lack of explicit reference to the importance of integrated and coordinated cross-sectoral investments in early childhood development in funding directives and strategies for the U.S. government's foreign assistance portfolio has meant that such activities are not prioritized or do not occur at all. Despite significant investments in maternal, newborn, and child health and nutrition programs and the synergies that exist between such investments and child development outcomes, the USAID's Bureau for Global Health, which is home to maternal and child health and nutrition programs, currently does not track funding, programming, or outcomes related to early childhood development (U.S. Government, 2014). Nor has early childhood development been included in the USAID's education strategy (USAID, 2011). In a more hopeful vein, the USAID's nutrition strategy recognizes the important linkages between appropriate nutrition and the holistic growth, health, and development of young children (USAID, 2014). A similar lack of prioritization exists within other U.S. government international assistance programs. For example, the Centers for Disease Control and Prevention, which does significant work to prevent child morbidity and mortality, has received no appropriations to continue its important work conducting Violence against Children Surveys or to implement its corresponding program, THRIVES. The Eunice Kennedy Shriver National Institute of Child Health and Human Development supports important research related to child health and development, but there is currently no established feedback loop to ensure that science is informing U.S. government international programs and policies. Of note, the Department of State has no office, ambassador, or other high-level appointee to represent global children's issues.[9]

As a result, those attempting to deliver integrated programs for young children at the country level are left to stitch together a patchwork quilt of funding from separate and uncoordinated donor sources. This has serious implications for programmers who are committed to providing comprehensive services to the most vulnerable households and families. It also creates complications for those attempting to measure and assess the overall impact of U.S. government international assistance to young children.

A CONCLUDING CALL TO ACTION

With its significant investments in international development, the technical expertise and research capabilities embedded within key agencies, and diplomatic outreach, the U.S. government is well positioned to lead and mobilize around a sensible and strategic global agenda for young children. Child development is, after all, one of the world's greatest challenges in scope, scale, and impact. The persistent lack of attention to child development in policies and programs threatens the socioeconomic fabric of nations. The failure to invest in the developmental potential of children locks families, communities, and nations into poverty and threatens global security. Evidence from across disciplines—from neuroscience to biological and developmental science to economic science—has clearly demonstrated that investing in young children's holistic

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[9] The State Department's Special Advisor for Children's Issues oversees intercountry abduction and adoption only.

well-being is a proven pathway out of poverty and into promise. It is past time to take that road.

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Royal Commission into
Victoria's Mental Health System

ATTACHMENT RB-36

This is the attachment marked '**RB-36**' referred to in the witness statement of Dr Ravi Subramanya Bhat dated 4 July 2019.

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Tulane Early Childhood Collaborative - TECC

The Tulane Early Childhood Collaborative program provides consultation to pediatric primary care providers to promote mental health in children under 6.

Our goal: Promoting early childhood and family well-being by supporting pediatric primary care providers to identify risk factors early, promote family well-being, and address early mental health problems.

Who we are: We are pediatric mental health providers: child psychiatrists, pediatrician-child psychiatrists, and child psychologists. We've worked in primary care clinics and specialty early childhood mental health clinics and are part of the Tulane Institute of Infant and Early Childhood Mental Health.

TECC supports primary care providers to promote mental health in children under 6 & their families through:

Mental Health Consultation

- Curbside consultations at your office
- Phone, e-mail, or secure video consultations
- We can also see children for a consultation evaluation to help clarify the diagnosis or make treatment recommendations.

In-service trainings/ "Lunch and Learns" for PCPs about early childhood mental health

Web-based resources to hand out to families or to learn more about the foundations of early childhood mental health

Enroll in TECC by calling us at 504-988-4653, by completing this enrollment form. We'll call you back to talk about how we can be most helpful. We'll probably set up a time to meet with you in your clinic or can jump right in with clinical questions or consultations.

Have a consult now? We'll still ask you to complete the enrollment form (above), but please do call or send us a consult question by fax (504-988-4264) or e-mail tecc@tulane.edu.

Want to share information with your colleagues? Feel free to share this flyer.

Want to know more about our work? Check out our poster presentations from the 2016 Zero to Three conference here and the 2016 American Academy of Child and Adolescent Psychiatry conference here.

TECC has received support from grants from local and national foundations and agencies including Baptist Community Ministries, Office of Public Health, Klingenstein Third Generation Foundation, Pfizer, William Josef Foundation, and Institute of Mental Hygiene. There is no cost to you or to patients. (Medicaid-eligible services will be billed to Medicaid)

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Royal Commission into
Victoria's Mental Health System

ATTACHMENT RB-37

This is the attachment marked '**RB-37**' referred to in the witness statement of Dr Ravi Subramanya Bhat dated 4 July 2019.

The Economist Intelligence Unit

Executive summary

Value-based healthcare: A global assessment

In many of the world's health systems, uneven access to care is matched by soaring costs and fragmented systems that put stress on both providers and their patients. In light of finite budgets and increasing costs, the status quo is unsustainable. Many are calling for fundamental change, with a shift away from systems that are siloed by medical speciality to integrated systems that consider and treat patients holistically. Moreover, redesigned payment systems can encourage these approaches, which can help to manage costs and improve patient outcomes. This is the promise underpinning value-based healthcare (VBHC).

The idea of connecting healthcare outcomes with costs—defined as value—was popularised in 2006 by Michael Porter and Elizabeth Teisberg in their book *Redefining Health Care*.[1] Since then, the concept has gained momentum, with policymakers across a diverse set of countries like the UK and Colombia putting in place high-level plans that begin to explicitly call for moving away from paying for services based on volume (such as fee-for-service) towards a system where payments are made based on value. To understand value, health systems take into account the cost of the full cycle of care compared with patient outcomes.

While the arguments for this approach are compelling—not only for managing costs and improving outcomes but also for facilitating more holistic care—countries are only beginning to implement the tenets of VBHC. Aligning with value-based approaches means reforming an entrenched system in which payments are made for every consultation or treatment and adopting a new approach of payments tied to value and quality.

In this study, the Economist Intelligence Unit

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[1] Michael Porter, Bishop William Lawrence University, Professor, Harvard Business School; Elizabeth Teisberg, Professor, The Dartmouth Center for Health Care Delivery Science.

(EIU) assessed the levels of alignment with the main tenets of VBHC. For the purposes of this study, the EIU defines VBHC as *the creation and operation of a healthcare system that explicitly prioritises health outcomes that matter to patients relative to the cost of achieving these outcomes.*

The purpose of this study is to set a standard of evaluation of VBHC alignment and establish the core components of the enabling environment for VBHC. The results capture a moment at which adoption of value-based care is still at its earliest stages. The research demonstrates the challenges that come with such a seismic shift in healthcare models, but also the areas where countries are pioneering in the adoption of the VBHC model. Readers can therefore use this study to look for best practices to guide their own health systems forward.

To gain a deeper understanding of how countries are aligned with the VBHC model, the EIU conducted research across 25 countries.[2] This research included a literature review (from health policy documents to academic literature and other health system studies), secondary research, recommendations from an international advisory panel, and interviews with experts encompassing a wide range of health system expertise (including practitioners, private insurers, policy analysts and academics). The research was organised around four main components of VBHC, comprising 17 total indicators:

- Enabling context, policy and institutions for value in healthcare (8 indicators);
- Measuring outcomes and costs (5 indicators);
- Integrated and patient-focused care (2 indicators); and
- Outcome-based payment approach (2 indicators)

In order to gain broader insights beyond the country-level assessments of alignment with VBHC components, the EIU grouped together similar countries in terms of macroeconomic environment, human development, health environment related landscape factors to look for trends and commonalities across countries. The results are detailed in this study.

As the research reveals, even though the rationale for implementing value-based approaches is strengthening, much work remains to be done if countries choose to realign their health systems around value. In fact, VBHC requires nothing less than a paradigm shift from a supply-driven model to a more patient-centred system where payments are no longer made to providers for the volume of services but for the outcome of treatment(s).

Building an enabling environment for VBHC will take time and, as this study shows, is happening incrementally. As value-based healthcare is a relatively new concept, few countries have in place the supporting institutions and policies needed to enable a transition to a VBHC model.

Europe is the leading region where VBHC components are being adopted. In the study, Sweden is the only country that emerges with *very high* alignment[3] with VBHC and the UK is the only country with *high* alignment. Most of the remaining developed countries in the study have *moderate* alignment with the components of value-based care. And most lower-income countries—still struggling with providing equitable access to care—have even more work to do to create an enabling environment for VBHC.

Budget constraints are a driver in Europe's advancement in adopting components of VBHC while rising costs are the impetus for a value-based focus in the US. Countries such as India and Indonesia, which are currently developing more sophisticated health systems with limited resources, have the potential to leapfrog directly into adopting VBHC principles as they improve and expand access to health coverage.

Some pioneering examples also emerge outside of Europe. For example, Colombia has

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[2] Asia: Australia, China, India, Indonesia, Japan, South Korea
Europe: France, Germany, Netherlands, Poland, Russia, Spain, Sweden, UK
Middle-east and North Africa: Egypt, Turkey, United Arab Emirates
Sub-Saharan Africa: Nigeria, South Africa
Latin America: Brazil, Chile, Colombia, Mexico
North America: Canada, US

[3] Individual indicator scores are rolled up by domain and countries are categorised into one of four groups—Low, Moderate, High and Very High—based on the level of alignment with VBHC. The EIU aggregates individual indicator scores into domain scores, and domain scores into an overall composite score. Each domain is equally weighted, and each indicator is equally weighted within each domain. (For more on the methodology behind the scoring, see the appendix at the end of the Findings and methodology report).

embarked on an ambitious programme[4] to provide broad access to healthcare, manage costs, and introduce some rationale in the prioritisation they must make due to budget constraints. Colombia's new national policy calls for the implementation of a management system that follows the patient through the lifecycle of an episode of care and for the creation of co-ordinated care programmes for 16 of the most high-cost diseases in the country.

In most cases, progress in reforming health systems is slow and piecemeal. For example, VBHC requires knowing and tracking, over time, patient outcomes and treatment costs as well as broad stakeholder buy-in. The presence of disease registries and efforts by many countries to implement electronic patient records have set the foundation on which to build the requisite infrastructure to track patient outcomes and costs. Currently, however, these sources of health data tend to lack co-ordination and the IT systems used are often not interoperable.

Every country in the study is working to reform and improve their health systems. High-income countries that dedicate a high percentage of their GDP to health spending are more likely to assign resources to align their health systems with the VBHC model. Overall health expenditure emerges as a strong indicator of a country's ability to move towards value-based care.

Nevertheless, high healthcare spending does not always correlate with the presence of supporting factors for VBHC: among the countries that spend more than 10% of GDP on health, neither Japan nor the US has a recognised national health technology assessment (HTA) organisation, an enabling component of value-based decision-making (although the US does have a number of private and state-level HTA agencies).

Some countries' healthcare expenditures are focused on local priorities such as access to care and quality improvements, while others face burdensome challenges. For example, South Africa, which emerges with low alignment with VBHC, is tackling diseases such as HIV/AIDS and tuberculosis along with high maternal and child mortality, high levels of violence and injuries, and a growing burden of non-communicable diseases. While the health system is still struggling to overcome the socio-economic legacy of apartheid, the Department of Health is in the early stages of developing and implementing its National Health Insurance policy[5], which aims to provide universal coverage, and a national e-health strategy, which will foster the development of new health IT infrastructure in the country.

Another correlation with the ability to move towards VBHC is a country's score on the Human Development Index (HDI), a composite statistic produced by the United Nations Development Programme of life expectancy, education, and income per capita indicators. Countries that have low- or medium-level HDI scores (South Africa, Indonesia, India, Egypt and Nigeria) do not have high-level VBHC plans, other stakeholder support, or independent HTA organisations (if they have any at all). Thus, a low HDI indicates poor levels of health, income and development, suggesting that moves to align with value-based care approaches may not be a top priority.

On the whole, even those countries that have been making explicit moves towards VBHC find it difficult to adopt integrated care, a core component of the model, because diverse groups of health system stakeholders may not be accustomed to working together. In many places, they face decades-old practices of supply-driven decision-making and entrenched interests that are hard to dismantle.

Given these challenges, strong policy support is essential for the adoption of VBHC. As the study shows, this tends to be present in wealthier countries. Of the seven countries with a high-level policy or plan for VBHC, only two—Turkey and Colombia—are developing countries. Policy does not exist only at the national level, however; it can also be set at the regional, state or provincial level. For example, in Sweden and Canada, health system decisions are decentralised: local

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[4] El Ministerio de Salud Protección Social, 2016, Política de Atención Integral en Salud; https://www.minsalud.gov.co/Normatividad_Nuevo/Resoluci%C3%B3n%200429%20de%202016.pdf (March 2nd 2016)

[5] Department of Health. 2015. "National Health Insurance for South Africa: Towards Universal Health Coverage." Version 40. 10 December 2015.

councils in Sweden, and provinces in Canada.

To determine value for patients, it is important to track the cost side of the equation over time in order to compare costs with outcomes. Redesigned payment approaches that tie payments to outcomes and quality are an important component of VBHC evaluated in this study. The presence of outcome-based payment approaches was found in countries that are on the way to adopting a VBHC system.

As this study reveals, while some countries are coming closer to aligning their health systems to the VBHC model, others have a longer way to go. Countries that have chosen to adopt components of value-based care are still in the very early stages of alignment. The good news is that the building blocks of VBHC, such as electronic health records, evidence-based guidelines for healthcare and national disease registries, have been present in the health systems of many countries for some time. On the whole, however, these components of VBHC have been implemented individually, and are not often part of a high-level policy or strategy. What is clear is that moving from a system focused on individual specialities and suppliers to integrated care—a key element of VBHC—remains challenging for many countries.

For mature economies, there is the challenge of shifting long-held industry norms in healthcare provision, moving away from payment systems based on fee-for-service and standardising legacy infrastructure, such as IT systems that are not interoperable. Developing countries are still struggling with issues of quality and universal access to healthcare, but some are focusing their emerging health systems on value. As technology innovations and new value-based approaches take hold in wealthy countries, nations that are still investing in developing their health systems have an opportunity to leapfrog directly to building systems with incentives geared towards VBHC, saving precious resources and delivering better care to their citizens.

Image: Getty Images/iStockphoto