# **Executive** summary

#### **Overview**

The Fay Fuller Foundation commissioned the South Australian Health and Medical Research Institute (SAHMRI) and The Australian Centre for Social Innovation (TACSI) to jointly conduct research into health and wellbeing priorities for South Australia based on:

- identifying and examining existing, high-quality research on local health issues and priorities.
- seeking insights from key stakeholders, including health consumers and people working within the system.
- identifying opportunities to improve quality of life and health outcomes for South Australians by highlighting community priorities, gaps in knowledge, areas for greater focus or effort and points where the health and community service systems could be more efficient or effective.

Together the documents that make up this report present a picture of South Australian health needs that is supported by a wide range of evidence, expertise and experience. Effectively, the joint project team has created a unique view into the health needs of South Australia from a range of different perspectives.

The opportunities that could be identified across these perspectives include:

- Addressing growing disease burdens or gaps in the current service systems. These opportunities have been drawn from existing information, and analysis by health condition, geographic region, age group and ethnicity. As one example: while currently the leading causes of death in SA are heart disease, dementia, stroke, lung cancer and chronic respiratory disease, in the future it is likely that dementia will lead the cause of death statistics. However, there is little state-specific research data available or strategies on how to prevent, delay, or manage the expected burden of dementia in this state.
- Grow efficiency or effectiveness of the health system based on insights reflecting the experiences and perceptions of health consumers and stakeholders. During interviews with consumers and stakeholders, what constitutes 'health' was seen to have multiple interpretations. Stakeholders in health care spoke of the health system's focus on illness, intervention and monitoring activity. In contrast, consumers emphasised how they keep well and talked about health in terms of how well they feel, the quality of the care they receive and how family, friends and health care professionals can affect their "wellness". There was support for a stronger focus on wellness, health maintenance, prevention and monitoring outcomes.

#### The approach

This project took an evidence-based approach, both through examining secondary sources from existing research outputs and publicly available data that highlighted key issues, and then conducting primary research through ethnographic work, and questions included in the long-running Health Omnibus Survey¹. The ethnographic primary research consisted of semi-structured interviews over a two-month period with consumers and professional stakeholders including clinicians, researchers, people in the not-for-profit sector, advocacy bodies and those working to commission, fund or develop policy.

The specific questions included in the 2017 Health Omnibus Survey were asked in close to 3000 face-to-face interviews across the state. These data were used to broaden, challenge and validate the insights from the semi-structured interviews conducted with health consumers in four regions where there is above-average prevalence of disease burdens and risk factors.

The secondary research undertaken by the project team identified all relevant reports, documents and other material on the health and wellbeing needs of South Australians available in the public domain. It assessed this evidence, drew out themes, interpreted the data and identified gaps in the available information.

The project team then drew all these data points together in a purpose-built South Australian Health Needs System Map, which captures the key components of the health system, the links between them, where funding has changed and where gaps exist.



### Findings and opportunities

#### Findings from literature, research and data review

In broad terms, South Australia has some defining features that influence health needs and priorities:

- SA has an older age distribution than the country as a whole (median age 40 vs 37 years). South Australia had 306,589 people aged 65 years or over at the 2016 Census, representing 18.3% of the state's population, compared with 15.1% nationally.
- Consistent with national data, the SA Aboriginal population (about 35,000 people) has a significantly younger age profile with a median age of 23, compared with 41 for non-Aboriginal people - a gap of 18 years.
- Rural and remote populations comprise 23%
   of the SA population. Key differences with the
   metropolitan area include a lower proportion born
   overseas (11.2% vs 26.3%) and an older age profile
   (median age 44.3 vs 38.6).
- The ABS noted in its 2015 summary of the causes of death in SA that death rates for heart disease and cancer have been declining, while dementia has been increasing; it is expected that dementia will become the leading cause of death.
- From a biological health perspective, SA currently
  has official strategic plans that address suicide,
  mental health, cancer, alcohol and other drugs, and
  diabetes. However, the diabetes strategy is specific
  to the Aboriginal population and there is no such
  strategy for the wider SA population.

Literature identifies the following categories of **adults** as having particular health needs and priorities in South Australia (SA Health Atlas):

- adults without access to the Internet at home are more likely to have poorer health.
- adults in households with relatively large numbers of people living with a disability, or dependent on the Age Pension are more likely to have poorer health.
- adults with high or very high prevalence of psychological distress, and obesity.
- adults at high risk of premature mortality, i.e. <75 years of age.

 disadvantaged households, i.e. under financial stress from rent or mortgage payments; welfare dependent; high levels of disability; high or very high prevalence of psychological distress; no Internet access at home; inability to get support in times of crisis from outside the household, and limited participation in volunteering in the community.

The literature/data review also identified some key issues and priorities for consideration in relation to specific population groups in South Australia.

- Adult men: Suicide rates are three times than for women, and skin cancer, liver disease, lung cancer, and blood cancers feature more strongly for men.
   Older men have the highest levels of smoking, men in the lower sociodemographic group are more likely to consume alcohol at harmful levels and be obese.
- Adult women: There was limited material that explicitly defined gaps in needs, services or research, or particular priorities for action for the South Australian female adult population group. Relying on Australian literature then, the causes of death where the sex ratio is biased towards females (apart from breast cancer) are: dementia; hypertensive disease, cardiac arrhythmias, stroke and heart failure. Specific South Australian literature also points to a need to further raise awareness of the mental health needs of women in the perinatal period (Government of South Australia 2015) and improvement of the reach of maternal health campaigns in areas outside major cities, particularly in relation to Aboriginal women (PHIDU, 2015).
- Children and young people: The rate of child death in South Australia had shown a significant reduction, with the average death rate decreasing by 11% on average per year. The three leading causes of child death had remained the same: injuries, cancer and diseases of the nervous system. Children who lived in the state's more socioeconomically disadvantaged areas had higher death rates and these were not declining in the same way as for those who lived in South Australia's least disadvantaged areas (Child Death and Serious Injury Committee 2016). South Australia recorded above-average proportions of children who are "developmentally vulnerable", including close to one-quarter who were vulnerable on one or more domain (AEDC, 2009, 2012, 2015).

- Older people: Older people aged 65+, living in areas deemed to be socioeconomically disadvantaged and who are dependent on the aged pension, are at risk of poor health and wellbeing (PHIDU, 2016). There is a socioeconomic gradient associated with the prevalence of self-reported chronic conditions, specifically diabetes, respiratory conditions, behavioural and mental health issues and cancer rates peak at 80+ years of age (PHIDU, 2015). By 2020, SA is projected to see substantial increases in prevalence of dementia for people aged 80 years and over. These projections have significant implications for demand for health services, given that people with dementia are known to have multiple morbidities. People aged 80 years and over constitute only 5% of the population, but more than 25% of the overnight occupied bed days in South Australia. As a consequence, demand for hospital inpatient services is highly sensitive to increases in the number of people aged 80 years and older.
- Aboriginal people: Cardiovascular diseases represent the most frequent cause of death for Aboriginal South Australians. Aboriginal people experience heart disease and stroke at significantly younger ages than non-Aboriginal South Australians, peaking between 45 and 59 years of age, compared to 85 years of age for non-Aboriginal people (SA Health 2016). Lifetime risk of alcohol consumption is lower among Aboriginal men and women than their non-Aboriginal counterparts.
- People from culturally and linguistically diverse backgrounds: Mental health issues and trauma appear to be priority issues for the culturally and linguistically diverse population. Resilience in the adolescent refugee population has been demonstrated to be lower than indicated in other, non-refugee populations and lower levels of resilience have been associated with depression and emotional and behavioural problems (Ziaian, de Anstiss et al. 2012). There is no policy framework, action plan or monitoring process specific to health care services for the culturally and linguistically diverse population.
- LGBTIQ community: The greatest issues facing the LGBTIQ community are violence, discrimination and homelessness. Further, certain health conditions reflect patterns of health particular to the LGBTIQ

- community, including: specific cancers and sexually transmitted infections in gay men, cervical and ovarian cancers in lesbians and issues relating to hormone therapy and surgical intervention in transgender people.
- People living in rural and remote South Australia: Typically, people who live in rural and remote locations have worse health and wellbeing and are at greater risk of poor health than their metropolitan counterparts. Older adults in rural areas are a particularly vulnerable group (Health Consumers Alliance of South Australia, 2014). Rural and remote populations have been found to have poorer health outcomes in relation to chronic disease and associated risk factors than the general population. South Australians in regional and remote areas have higher incidences of behavioural risk factors such as smoking, high-risk alcohol consumption, overweight or obesity and physical inactivity than their urban counterparts. Mental health is a proportionally greater burden in rural and remote areas and help-seeking behaviours are reportedly reduced in comparison to metropolitan areas, one in five people with mental health problems who live in the metropolitan area reporting that they are seeking help, compared to less than one in ten country residents with a mental health problem.
- People in or leaving the justice system: Prisoners and people who have been involved in the criminal justice system, are recognised as being at risk of poor health and mental health issues in Australia, however no South Australian-specific published literature relating to the health and wellbeing status or needs of this underserved population was identified.

#### **Health Omnibus Survey**

Analysis of the Health Omnibus Survey elicited the following insights from health consumers in South Australia:

- their own physical health was the biggest health or wellbeing issue faced by 35 per cent of respondents, while 11 per cent cited mental health.
- one-quarter said their health limited their participation in work and moderate activities, such as climbing several flights of stairs.
- seventeen per cent said depression or anxiety meant they had accomplished less than they would have liked.
- issues relating to ageing were considered by one person in five to be one of the biggest health or wellbeing concerns for South Australia.

There was strong agreement between the literature and survey results in six areas:

- Prevention: There is a significant emphasis on prevention in state and national plans and health priorities. The survey results show prevention and holistic approaches to health are also of importance to the general population
- 2. **Mental health:** Mental health issues were prominent in seven of the ten population groups covered in the literature (Aboriginal people, children and parents, older people, rural and remote communities, migrants, LGBTIQ community and people in or leaving the justice system). Mental health-related issues were rated as their biggest health or wellbeing challenge for 11% of those participating in the survey (the second highest category, after physical health) and 48% of all respondents listed mental health as one of the most important issues for South Australia.
- 3. **Ageing and dementia:** Issues relating to ageing were considered one of SA's biggest health or wellbeing concerns by one in every five (20%) of the survey participants. The literature covered multiple issues related to ageing and dementia.
- 4. **Obesity:** Weight and obesity featured highly in the survey as an issue for South Australia and was also a feature of many reports in the literature, with concerns about children's and young people's obesity and the impacts on risks for chronic disease.
- 5. **Health services access:** Both survey respondents and the literature raised issues about health service access, especially with regard to people living in rural and remote areas and certain sub-populations such as the LGBTIQ community, Aboriginal people and people from culturally and linguistically diverse communities. It was notable in the survey, however, that while 11% of people mentioned this as SA's biggest health or wellbeing issue, just 1% mentioned it as their own biggest issue.

6. **Physical health:** Physical health was identified most often in the survey as the biggest health and wellbeing category they faced individually and for the state as a whole. Impacts on carrying out usual daily activities, including social interaction, were identified as the most important challenges. This aligns well with the emphasis of many national- and state-level reports and priorities such as the focus on cardiovascular disease, diabetes, musculoskeletal health and injury/disability.

In terms of variances between the literature results and the survey results, three main aspects emerged:

- The needs of children and the issues of maternal health did not emerge in the survey results, perhaps because they are not perceived as "illness" related, but also because the survey did not specifically ask about children's health or wellbeing issues.
- 2. Drug and alcohol issues were raised by only small numbers of people in the survey, although they did rate some mention as one of the issues for South Australian health and wellbeing. However, the issues of high tobacco use and excessive drinking in certain population groups was prominent in the literature, especially at national and state level planning and strategies.
- 3. People living in **rural and remote areas** rated their health higher than the literature suggested it really is, according to reports found in the literature review where health status is clearly at lower levels in some parts of rural and remote South Australia. This difference in perception may be driven by lower expectations of health services and by health being a lower priority in the broader set of issues affecting people in farming or remote communities.

## Ethnographic and semi-structured interviews with consumers and stakeholders

The themes that emerged from the ethnographic work and semi-structured interviews with health consumers and stakeholders from across the health system elicited a number of high-level opportunities for creating more effective and efficient health outcomes. Six themes were identified from the insights gleaned from this phase of the work.

- Wellbeing and wellness are integral to health.

While several existing policies appear to address health and wellbeing as a whole, the stakeholders spoken to who work in the health system believed that illness and wellness were considered mutually exclusive. For consumers, staying well and a focus on their own "wellness" were at the forefront of their discussions of how they interpreted their health. Interestingly, many indicated that a good relationship with a clinician plays a key role in helping them stay well, not just to treat or recover from illness. This theme suggests that opportunities for greater emphasis on integrating 'wellbeing' into health care, and approaches to strengthening the roles and relationships of core clinicians such as general practitioners, are critical to improving health and wellbeing experiences and outcomes.

"Emphasising wellbeing in discussions about health means the whole story of people and their health can be better understood and potentially reduce the amount of time people spend in the ill-health layer of the health system". (Health Professional)

- Mental health is a growing concern in the health system. Identified as both a national and state priority, mental health was high on the list of concerns expressed by health consumers and stakeholders, with both groups considering that the majority of focus was on treating symptoms rather than dealing with root causes. Costs, particularly for longer-term support and intervention, were cited as prohibitive and an opportunity was identified for developing more informal, peer-based and community-focused mechanisms for ongoing support of mental health.

"Wellbeing can't be maintained on, 'You have 10 appointments with me, and you're just going to be all better'." (Health Consumer)

Racism and low levels of cultural competency remains an issue in the health system. The interviews uncovered a number of incidents and experiences from health consumers where interactions with health care professionals were described as stressful and upsetting because cultural identity was not recognised or acknowledged. Stakeholders also shared perspectives about health policy and practice reinforcing inequalities and affecting access to care. There are clearly opportunities to scale and deepen genuine cultural competency within the health system and also to foster workforce strategies that increase the number of Aboriginal workers in the health system.

"I think we should ask ourselves why we're not reporting routinely on racism in the health system. We know it's a determinant of health. That's a culturally incompetent system." (Healthcare Professional)

- Evaluation of the health system remains focused on activity rather than outcomes. Evaluation was raised in a number of stakeholder interviews, with the argument made that the dominant measures focus on activity and outputs, rather than outcomes, and that methodologies used tended to favour endof-program evaluation rather than developmental methods that track changes across the longer term. Opportunities were identified to strengthen evaluation of health interventions across the lifecycle as an important complement to the growing use of data to track population outcomes.
- Funding distribution needs better integration.
  The flow of money around the Australian healthcare system is complex, which can make it difficult to navigate and understand. Stakeholders argued that funding is currently directed toward managing ill-health rather than prevention, to the point where the latter is increasingly considered to be underfunded. While coordination of funds was certainly identified as critical, stakeholders tended to argue that more investment was needed in prevention and early intervention. This is not a new argument, but there are increasingly opportunities to harness a more integrated commissioning of health and social services that could draw together prevention and a greater focus on investment in social determinants of

health and wellbeing.



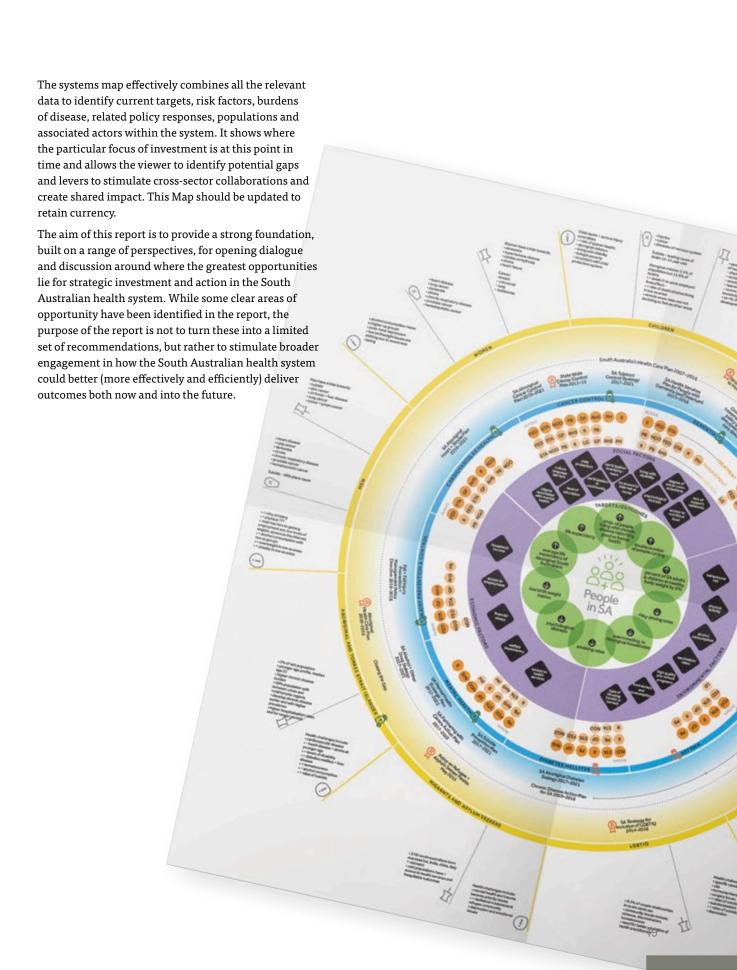
- Community-managed health is essential but often undervalued. The opportunity to strengthen community health and increase South Australia's capacity for managing ill-health was repeatedly championed throughout this phase of the work. The prevention and early intervention steps that happen at a community level, before people get to a hospital, are critical components in the creation of wellness. Furthermore, how well people are set-up to manage their health (chronic disease(s) in particular), at home and through the use of local services, holds some potential to decrease the burden on our hospitals and economy.

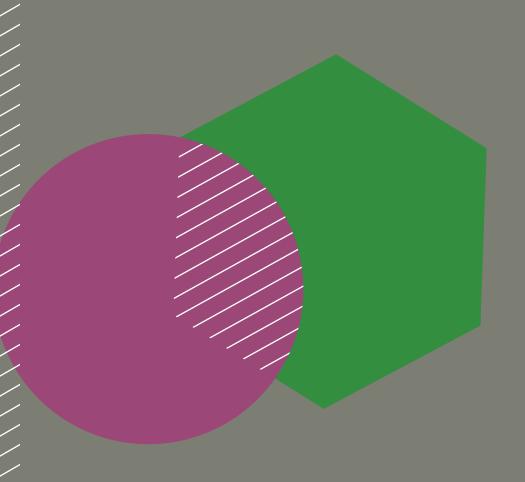
"The biggest, best, most cost-efficient health system in the country is self-management." (Health Care Professional)

- Finding and accessing appropriate support **remains difficult.** There are opportunities not only to improve system navigation, but also in ensuring both physical access to and positive experience of health and wellness services. Finding and accessing support services that are both local and suited to an individual's needs and preferences is increasingly a game of luck for many consumers, despite the rise of greater levels of information about options. There are opportunities to strengthen not only access and choice but also to engage people in new ways to support staying well and managing ill-health within communities and at home - some of which are technological but others of which may be around growing stronger well-being support networks in local communities.

"Well, I'd say a lot of stuff doesn't come out and hit you in the face. You hear from someone whose been and tried it." (Health consumer)

### Systems Map





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