

# Access to Health and Aged Care Funding for Forgotten Australians

## Part 1 Scoping Exercise

### **Final Report**

23rd December 2016



# Access to Health and Aged Care Funding for Forgotten Australians – Final Report

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## Abbreviations

ABS	Australian Bureau of Statistics
ACT	Australian Capital Territory
AIHW	Australian Institute of Health and Welfare
ATAPS	Access to Allied Psychological Services
AFA	Alliance for Forgotten Australians
NDIS	National Disability Insurance Scheme
DVA	Department of Veterans Affairs
FA(s)	Forgotten Australian(s)
HACC	Home and Community Care
LOFA	Long Term Outcomes for Forgotten Australians
MP	Member of Parliament
NDIS	National Disability Insurance Scheme
NSW	New South Wales
PTSD	Post Traumatic Stress Disorder
UNSW	University of New South Wales

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## 1. Executive Summary

This report presents the findings from a scoping exercise into access to health and aged care funding for Forgotten Australians. The 'Forgotten Australians' refers to people who were in institutional and foster care in the twentieth century. It is estimated that more than 500,000 Australians have experienced life in an orphanage, home or other forms of out-of-home care during this period<sup>1</sup>. Forgotten Australians include child migrants and the stolen generation.

Forgotten Australians today are aged somewhere between their 50's to mid-80's. They experience poorer physical, mental and oral health than their Australian counterparts due to the trauma, abuse and neglect experienced as children whilst institutionalised or in out-of-home care. Forgotten Australians have greater and more specialised health and aged care needs than the average Australian and are not formally recognised as a group with special needs. Forgotten Australians are ageing before their time and are fearful of being placed in aged care facilities and being "re-institutionalised". Schemes and brokerage funding exist in some Australian state and territories, but these are not adequate to meet their needs. There is no national health and aged care funding scheme for Forgotten Australians.

As Forgotten Australians age, their health and aged care needs will continue to increase. This report makes a number of recommendations, namely for a national and equitable approach to funding the specialised needs for Forgotten Australians. While the anticipated costs to administer such a scheme are substantial, so too are the costs to the Australian tax payer and the increasing burden on the health and aged care sectors over the coming decade of not funding timely and accessible services. As Forgotten Australians age and go without access to preventative, necessary and specialised health and aged care services, their needs will increase, become more acute, more complex and more costly over time. They are likely to experience increasing demand for emergency care, increasing need for acute hospital beds, more diagnostic and treatment services, more specialist services, increased medications, increased likelihood of adverse events such as falls, increased need for rehabilitation services and higher levels of aged care supports.

This report makes 10 recommendations in relation to increasing access to health and aged care services for Forgotten Australians. It has been 12 years since the Senate Committee report on the Forgotten Australians was released, with little action on the recommendations that relate to health care, housing and aged care programs. This report also follows the recently released study from the University of New South Wales into the Long Term Outcomes of Forgotten Australians which supports a national approach to meeting the health and aged care needs for Forgotten Australians, along with the recommendations from the Royal Commission into Institutional Responses to Child Sexual Abuse which also supports a national response to redress.

While the issues of Forgotten Australians are complex and challenging, these people, through no fault of their own, have experienced a lifetime of physical, emotional and mental health problems in response to childhood abuse and trauma. Forgotten Australians are a vulnerable and ageing group, and they require an appropriate response to their increasing health and aged care needs by the Australian government.

This report makes the following recommendations:

<b>Recommendation 1</b>	Progress a nationally funded Health and Aged Care Scheme for Forgotten Australians.
<b>Recommendation 2</b>	Conduct a business case with economic modelling on a national health and aged care funding scheme.
<b>Recommendation 3</b>	Continue to seek advice on the legal rights of Forgotten Australians to health and

<sup>1</sup> Commonwealth of Australia. Community Affairs Reference Committee. 2004. Forgotten Australians. A report on Australians who experienced institutional or out-of-home care as children

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	aged care funding, and the roles and responsibilities of the state, territories and Federal government to meeting their health and aged care needs.
<b>Recommendation 4</b>	Develop a communications plan to support the nationally funded Health and Aged Care scheme.
<b>Recommendation 5</b>	Further scope options for different models of care for aged care services for Forgotten Australians.
<b>Recommendation 6</b>	Explore Option 3: AFA (or similar) to establish a philanthropic trust scheme and administers health and aged care funding packages to Forgotten Australians.
<b>Recommendation 7</b>	Identify and seek support from a senate member to “champion” the cause and progress legislation through the Parliament of Australia for a national health and aged care funding scheme for Forgotten Australians.
<b>Recommendation 8</b>	Develop a media campaign to raise community awareness and garner support for a health and aged care funding scheme for Forgotten Australians.
<b>Recommendation 9</b>	Develop a centralised repository of expertise and knowledge on the specialised health and aged care requirements for Forgotten Australians to inform health and aged care workers/professionals, service providers and aged care facilities.
<b>Recommendation 10</b>	Identify adequate resources to drive and support the recommendations in this report.

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## 2. Introduction

This is a final report on the recommendations to increase access to health and aged care funding for Forgotten Australians. The Alliance for Forgotten Australians (AFA) engaged Manning Consulting between October 2016 to December 2016 to scope a component of work that investigated the viability of increasing access to funding for health and aged care services for Forgotten Australians. This report details the findings of this scoping exercise, and makes recommendations for a nationally funded health and aged care scheme for Forgotten Australians.

## 3. Scope

The scope of this exercise includes investigating options for access to health and aged care funding for Forgotten Australians. The initial brief included health, aged care and housing, however due to time limitations, it was agreed that the scope for this component of work would be limited to health and aged care services.

## 4. Methodology

The methodology to inform this exercise has involved:

1. Review of background information, reports and research on Forgotten Australians and issues relating to their health and aged care needs, services and funding. (Refer to Appendix A for references).
2. Developing and implementing a survey to Find and Connect Services across the States and Territories to gather data on the key health and aged care issues for Forgotten Australians including:
  - a. Identifying health and aged care issues and demand for services;
  - b. Current funding mechanisms and barriers to accessing services;
  - c. The criticality and importance of increasing funding to health and aged care services;
  - d. Suggested policy or system changes to improve access to services and funding. (Refer to Appendix x for survey results).
3. Articulating the key arguments/issues on health and aged care services for Forgotten Australians to inform consultations and final report recommendations.
4. Consultations with key people in the Australian political, health and legal sectors to inform this work.
5. Regular meetings/teleconferences with AFA to ensure that the scoping exercise is progressing satisfactorily.
6. Synthesis of data and information, options analysis and development of recommendations.
7. Report delivery. Two reports were delivered as part of this exercise- a midway report and a final report.

## 5. Situational Analysis

### Health and Aged Care Issues of Forgotten Australians

The health and aged care issues experienced by Forgotten Australians are well documented across a range of publications including the three Australian Senate Committee Reports dated from 2004 to 2015 and the recently released study from the University of New South Wales<sup>2</sup> into the long term outcomes of Forgotten Australians (LOFA Study). While no formal study has been conducted, anecdotal evidence supports that Forgotten Australians experience greater rates of morbidity and mortality than the average Australian, and these health issues are a result of the physical, emotional and sexual abuse and trauma experienced as children whilst institutionalised and in out-of-home care.

Health issues particularly relating to oral health and mental health are well documented. The Find and Connect Services across the states and territories identify the top three health services in highest demand for Forgotten Australians as 1. Dental services 2. Counselling/psychology and mental health services (equal second) and 3. General Practitioners. The poor nutrition and lack of good dental care from early childhood was reported to have impacted on the poor oral and dental health of Forgotten Australians. The mental health issues of Forgotten Australians reported by the Find and Connect Services included PTSD, depression and anxiety. The LOFA Study identified these, in addition to flashbacks, self-harm, dissociation and suicidality. It was reported that the percentage of Forgotten Australians reporting “very high” levels of psychological distress was 14.4 times greater than the percentage found in a community sample of the National Survey of Mental Health and Wellbeing (2007).

Forgotten Australians also experience a higher than average rate of physical health issues and disability than the average Australian. These issues are reported to be a result of the physical work and abuse experienced as children, or a result of inadequate or in some cases complete absence of medical care. The States and Territories reported that their Forgotten Australians experience a broad range of physical health issues including arthritis, diabetes, back problems, emphysema and cancer. The senate report noted that “the consequences of lifestyle for many since leaving care such as drug and alcohol additions, homelessness, unemployment, unsafe sex practices and other destructive behaviours have also had a damaging impact on their health<sup>3</sup>”.

Aged care issues for Forgotten Australians appear less well documented in the literature however issues mostly relate to the fear and anxiety Forgotten Australians have with ageing, with being placed in an aged care facility and being re-institutionalised. Anecdotal reports of Forgotten Australians ageing before their time are common. The Find and Connect services report the aged care service in highest demand for Forgotten Australians is assistance with daily living tasks.

### Access to Funded Services

In Australia, there are many schemes to assist people with accessing affordable health and aged care services. At the Federal level some of these include Medicare funded programs, Australian Government Health Care Cards for low income earners, Pensioner Concession Cards, the National Insurance Disability Scheme (NDIS) and the Department of Veteran Affairs (DVA) health cards. In some cases these schemes cover transport costs to access services. Some Forgotten Australians are eligible for these schemes however depending on the scheme or program, services are capped, have restrictions or out of pocket costs. The state and territory schemes include Priority Access to services for special needs groups where medical, dental and allied health services are fully funded through community health services. There is no national funding scheme specifically for Forgotten Australians.

Mechanisms to support Forgotten Australians access health and aged care services across the states and territories are inconsistent and inequitable. Queensland and Northern Territory Find and Connect Services report that their

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<sup>2</sup> Fernandez, E.2016. LOFA: Long Term Outcomes of Forgotten Australians Study. UNSW.

<sup>3</sup> Commonwealth of Australia. Community Affairs Reference Committee. 2004. Forgotten Australians. A report on Australians who experienced institutional or out-of-home care as children.

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Forgotten Australians have priority access to health services (full cost coverage for dental and allied health services), while NSW, ACT, Queensland and Victorian Find and Connect Services offer brokerage funding. Forgotten Australians in Western Australia, Tasmania and South Australia have no specific funding mechanisms or schemes to assist Forgotten Australian's to access health and aged care services. These states report that access to services occur through the Australian public health system of Medicare. Western Australia report that almost none of their Forgotten Australians can afford private health care. South Australia report that their Forgotten Australians access services through the disability pension and/or public access however they experience long waiting lists for health care.

The LOFA Study stated that "the biggest barrier to accessing services was reported to be participants' inability to afford the costs involved (69%). About one third of survey participants reported that lack of information about services (34%) and stigma (30%) were barriers". When surveyed on how effectively the health and aged care needs of Forgotten Australians are being met, 43% provided a 1 out of 5 (poorly met) ranking, while 57% providing a 2 out of 5 ranking. 86% of the states and territories ranked the issue of accessibility and affordability of health and aged care services for Forgotten Australians as highly critical (5 out of 5).

### Forgotten Australians to be recognised as a "special needs" group

It is evident that Forgotten Australians have experienced incredible disadvantage and trauma, and due to this, they have special needs and require specialised health and aged care services. The Find and Connect services across the states and territories reported of the lack of understanding by health and aged care workers of who Forgotten Australians are, what they have experienced and how this has impacted their health and aged care needs. When providing care to Forgotten Australians, it is critical to ensure that work practices do not re-traumatise people when they access and receive services e.g. not being required to repeat distressing details of events. It was suggested that services and aged care facilities need to have ongoing education and reviews around being a trauma informed service.

## 6. Key Health and Aged Care Issues for Forgotten Australians

In summary, the key health and aged care issues for Forgotten Australians can be summarised as follows:

1. Forgotten Australians today are aged somewhere between their 50's to mid-80's. They experience poorer physical, mental and oral health than their Australian counterparts due to the trauma, abuse and neglect experienced as children whilst institutionalised or in out-of-home care.
2. Forgotten Australians have greater and more specialised health and aged care needs than the average Australian.
3. Forgotten Australians are not formally and universally recognised as a group with special needs in the health and aged care sectors.
4. There is no national funding program or scheme to meet the health and aged care needs of Forgotten Australians.
5. The existing health and aged care funding programs in place for Forgotten Australians vary across the states and territories. Some state and territories have brokerage funding (which is insufficient to meet their needs), two states have "priority access" to services, and three states have no health or aged care funding schemes for Forgotten Australians.
6. There is no national data collection system to identify Forgotten Australians for demographic analysis and service planning purposes e.g. ABS census.
7. Forgotten Australians who do not have access to the existing state based funding schemes are expected to access and pay for health and aged care services including out of pocket costs through existing commonwealth and state funded programs (e.g. Medicare, ATAPS) as per other Australian citizens. These programs are capped and the level of health cover is inadequate to meet their specialised needs.
8. Due to the lack of education and life skills, and the physical, emotional and sexual abuse suffered whilst in care, Forgotten Australians have lower income levels and lower levels of health literacy. This creates barriers when accessing services.
9. The greatest barrier to accessing health and aged care services for Forgotten Australians is cost.
10. Forgotten Australians who do not have their health and aged care needs met experience increasing hardship and will need greater levels of care, more acute levels of care and require more services into the future.
11. Not meeting the health and aged care needs of Forgotten Australians now will increase the health and aged care costs for tax payers in the future, and will increase the burden on the health and aged care system as these people age.
12. Forgotten Australians are fearful of ageing and being re-institutionalised.
13. The health and aged care workforce and sectors require specialised training and knowledge to understand and care for Forgotten Australians.

## 7. Health and Aged Care Funding Options Analysis

Following the analysis of the consultations, data and research collected during this scoping exercise, it is evident that Forgotten Australians do not have adequate and equitable access to health and aged care services. This is a critical issue that needs to be addressed as this cohort ages and their health and aged care needs increase, both in demand and the complexity of services. Three options for increasing access to health and aged care services for Forgotten Australians were developed and considered. These are:

- Option 1: Each State and Territory funds a health and aged care scheme i.e. priority access to services for Forgotten Australians**
- Option 2: The Federal Government funds a national health and aged care scheme for Forgotten Australians**
- Option 3: AFA (or similar) establishes a philanthropic trust scheme and administers funding nationally to Forgotten Australians for their health and aged care needs (similar model to brokerage funding)**

Each of these options were considered against the Base Case of doing nothing and maintaining the status quo.

These options are considered in table 1: Assessing the Options for Health and Aged Care Funding for Forgotten Australians.

**Table 1: Assessing the Options for Health and Aged Care Funding for Forgotten Australians**

Options	Base Case	Option 1	Option 2	Option 3
	<b>Maintain the status quo. No change to current arrangements</b>	<b>Each state and territory funds a health and aged care scheme (i.e. priority access) for Forgotten Australians</b>	<b>The Federal Government funds a national health and aged care scheme for Forgotten Australians</b>	<b>AFA (or similar) establishes a philanthropic trust scheme and administers funding nationally to Forgotten Australians</b>
<b>Benefits/ Limitations</b>	<ul style="list-style-type: none"> <li>Governments are not mandated to change current arrangements</li> <li>Access to services for FA's remains inconsistent, ad hoc and inequitable across the states and territories</li> <li>The Federal government and the State/Territory Governments that do not currently fund specialised services assume no responsibility for the poor management of children and past crimes that were committed whilst these children were in their care</li> </ul>	<ul style="list-style-type: none"> <li>Potentially easier to roll out /administer than a national scheme as it can be administered from existing state/territory government departments</li> <li>Federal government assumes no responsibility, responsibility rests with states and territories</li> <li>Difficult to monitor/enforce rollout resulting in potential inconsistent experiences of access to services depending on where people live (as per current arrangements).</li> <li>Risks that there is no national approach to service provision for this special needs group.</li> <li>Priority access at the state and territory level only provided through community health services.</li> </ul>	<ul style="list-style-type: none"> <li>Ensures a consistent and universal approach and access to health and aged care services for Forgotten Australians</li> <li>Opportunities for a central point of expertise, education for service providers, data collection and service planning for Forgotten Australians</li> <li>Is aligned with the recommendations from the Royal Commission into Institutional Responses from Child Sexual Abuse, which recommends a national response.</li> </ul>	<ul style="list-style-type: none"> <li>Likelihood of good/high interest, support and participation from the private, religious and philanthropic sectors</li> <li>Potential for increased brokerage funding to Find and Connect services</li> <li>Provides a trusted foundation that FAs may donate personal funds and/or their estates.</li> <li>Funds can be invested, earn interest and remains in perpetuity</li> <li>Increases the resources/pool of funding for health and aged care services for FAs in addition to government funding</li> <li>Potentially difficult to administer funding equitably across the states and territories</li> <li>Potentially removes accountability of governments to address specialised health and aged care services for FAs</li> </ul>
<b>Likely outcomes</b>	<ul style="list-style-type: none"> <li>Inequitable access for Forgotten Australians to services</li> <li>For Forgotten Australians that do not have access to funded services, there will be increased demand on the health and aged care system and the tax payer as needs will increase over time</li> </ul>	<ul style="list-style-type: none"> <li>Access to funding and services across the states and territories for Forgotten Australians but potential for inconsistent responses</li> <li>No single body to oversee and ensure a consistent national approach</li> </ul>	<ul style="list-style-type: none"> <li>Expensive to establish and administer for the Federal government but reduces burden on services, the health and aged care sectors and the tax payer in the medium to long term</li> <li>Better health outcomes for FAs as needs are addressed</li> </ul>	<ul style="list-style-type: none"> <li>Increased funding for health and aged care services to Forgotten Australians but risks that funding may be donor limited and unreliable</li> <li>Would not recommend this option in lieu of a government response</li> </ul>
<b>Recommendations</b>	Not recommended	Not recommended	<b>Recommended option</b>	For further consideration

## 8. Recommendations

This scoping exercise has worked through a methodology that has resulted in 10 recommendations to address the health and aged care needs for Forgotten Australians. These recommendations are listed in table 2.

**Table 2: Recommendations to address the Health and Aged Care Needs for Forgotten Australians**

<b>Recommendation 1</b>	Progress a nationally funded Health and Aged Care Scheme for Forgotten Australians.
<b>Recommendation 2</b>	Conduct a business case with economic modelling on a national health and aged care funding scheme.
<b>Recommendation 3</b>	Continue to seek advice on the legal rights of Forgotten Australians to health and aged care funding, and the roles and responsibilities of the states, territories and Federal government to meeting their health and aged care needs.
<b>Recommendation 4</b>	Develop a communications plan to support the nationally funded Health and Aged Care scheme.
<b>Recommendation 5</b>	Further scope options for different models of care for aged care services for Forgotten Australians.
<b>Recommendation 6</b>	Explore Option 3: AFA (or similar) to establish a philanthropic trust scheme and administers health and aged care funding packages to Forgotten Australians.
<b>Recommendation 7</b>	Identify and seek support from a senate member to “champion” the cause and progress legislation through the Parliament of Australia for a national health and aged care funding scheme for Forgotten Australians.
<b>Recommendation 8</b>	Develop a media campaign to raise community awareness and garner support for a health and aged care funding scheme for Forgotten Australians.
<b>Recommendation 9</b>	Develop a centralised repository of expertise and knowledge on the specialised health and aged care requirements for Forgotten Australians to inform health and aged care workers/professionals, service providers and aged care facilities.
<b>Recommendation 10</b>	Identify adequate resources to drive and support the recommendations in this report.

## Recommendation 1: Progress a nationally funded Health and Aged Care Scheme for Forgotten Australians.

This report has highlighted that Forgotten Australians have specialised health and aged care needs and these needs are not adequately being met through the existing Australian health and aged care funding schemes. In response to this, a nationally funded health and aged care scheme designed specifically to meet the needs of Forgotten Australians is proposed. This scheme would ensure that Forgotten Australians have:

- affordable and timely access to health and aged care services
- equitable and universal access to services regardless of which state or territory they live in
- good preventative care so that they do not require increasing and more costly acute level services as they age and their conditions deteriorate.

### Description of scheme

A scheme similar to the White and Gold Cards administered by the Department of Veterans Affairs is proposed. This health and aged care scheme for Forgotten Australians would be funded at the Federal level to ensure universal access and equity across the states and territories, and would replace the Medicare card and existing priority access and brokerage funding schemes across the states and territories. The scheme acknowledges that Forgotten Australians:

- Are recognised as a special needs group
- Have specialised health and aged care requirements as a result of the abuse and trauma they were subjected to as children in out-of-home or institutionalised care.

Similar to a Gold Card for Australian veterans, the scheme would provide:

1. Full cost coverage for all services including:
  - a. Medical- GP, specialist appointments, inpatient services
  - b. Public and private hospital services
  - c. Dental services
  - d. Allied health services including:
    - i. Physio, OT, psychology, dietetics, osteopathy, social work, optical, rehabilitation
  - e. Aged care services including residential aged care and Home and Community Care (HACC) services
  - f. Ambulance cover
  - g. Transport to services
2. A streamlined administrative process, whereby the card holder only has to present their card when receiving treatment and not need to seek reimbursement or obtain receipts and invoices for payment.

### Government Administration of the Scheme

To effectively administer the scheme, it is proposed that a governing department or body be established. This could be a:

- Department for Forgotten Australians which may report to a Federal Minister for Forgotten Australians (similar governance structure to the Department for Veterans Affairs) or
- A branch of the Federal Department of Health reporting to the Federal Minister for Health and Aged Care.

This Department for Forgotten Australians could assume a number of roles including administering the redress scheme for the victims of sexual abuse following the recommendations from the Royal Commission into Institutional Responses for Childhood Sexual Abuse.

Individual service providers would invoice this department/branch for service costs.

### **Role of the Department for Forgotten Australians/Branch of Federal Department of Health**

This Department or Branch would:

1. Establish the scheme
2. Administer the scheme
3. Fund service providers
4. Collect demographic and service related data on Forgotten Australians for service planning purposes
5. Acts as a repository of information with expertise on the specialist needs for Forgotten Australians
6. Commission research
7. Prepare and disseminate evidence based education and information for:
  - a. Service providers
  - b. Service based organisations e.g. community health services
  - c. Aged care facilities.

### **Access to scheme**

Forgotten Australians may access the scheme through a hot line set up for enquiries and service providers. Forgotten Australians may be supported to apply for eligibility for the scheme through the Find and Connect services or their General Practitioner. Service providers would apply to be a “recognised” service or provider and be reimbursed for their services.

### **Eligibility criteria for the scheme**

It is assumed that Forgotten Australians would provide:

- a. Evidence that they were institutionalised or in out-of-home care
- b. Information or evidence of the abuse and trauma suffered.

Once this information is provided and the Forgotten Australian is deemed eligible for the scheme, they would present a card, similar to a Gold Card, and never be required to repeat any information in relation to their health and aged care entitlements.

### **Education and information Services**

The Department or branch would act as a centralised repository of information and education on Forgotten Australians. This may include:

- Housing information on the health and aged scheme, applications, eligibility etc.
- Providing information to service providers on the specialist health and aged care needs of Forgotten Australians
- Hosting a website for Forgotten Australians, their families and service providers with a range of information and education materials e.g. information brochures, videos, podcasts, social media etc.

### **Issues for Consideration**

Establishing a national health and aged care scheme for approximately 500,000 Forgotten Australians is a significant undertaking by the Federal government. While a model exists for Australian veterans through the Department of Veteran’s Affairs, an extensive process to establish new policies and procedures will need to be developed and worked through. There will be many complexities with such a scheme. Eligibility criteria, levels of cover and what services are included are likely areas of complexity. For example, while the majority of Forgotten Australians experienced harrowing and lifelong trauma as a result of their out-of-home care, this is not the case for everyone- such as Steve Irons MP, Federal Member for Swan (who identifies himself as a “Forgotten Australian”) and reports of positive experiences in out-of-home care. Also, would all health and aged care costs be covered by

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the scheme, or just those which are a result of the trauma and abuse? The DVA program which is well established and administered, will offer an excellent model when working through such complex issues.

### **Recommendation 2: Conduct a business case with economic modelling to support a national health and aged care funding scheme.**

It is recommended that a business case be conducted with detailed economic modelling to cost a national health and aged care funding scheme for Forgotten Australians. This will provide the Alliance for Forgotten Australians with a more detailed case and evidence to pursue with government.

As part of this business case, it is recommended that the base case of not funding such a scheme be costed. While the anticipated costs to administer the recommended scheme are substantial, so too are the costs to the Australian tax payer and the increasing burden on the health and aged care sectors over the coming decade of not funding timely and accessible health and aged care services. As Forgotten Australians age and go without access to preventative and necessary health and aged care services, their needs will increase, become more acute, more complex and more costly over time. They are likely to experience increasing demand for emergency care, increasing need for acute hospital beds, more diagnostic and treatment services, more specialist services, increased medications, increased likelihood of adverse events such as falls, increased need for rehabilitation services and higher levels of aged care supports.

It has been proposed that the The Australian Institute of Health and Welfare (AIHW) and The Kirby Institute at the UNSW may be interested in conducting these studies.

### **Recommendation 3: Continue to seek advice on the legal rights of Forgotten Australians to health and aged care funding, and the roles and responsibilities of the state and territories versus the Federal government to meeting their health and aged care needs.**

Given that the health issues of many Forgotten Australians are a result of the physical, sexual and emotional abuse experienced as children whilst in the care of the state, advice is being sought on the legal rights of Forgotten Australians to having their health care costs funded by government. As a national health and aged care scheme is recommended, advice is also being sought as to the roles and responsibilities of the Federal, state and territory government in addressing these issues. It is anticipated that this advice will continue to build the case for a nationally funded health and aged care scheme administered and funded by the Commonwealth government.

### **Recommendation 4: Develop a communications plan to advocate for the nationally funded Health and Aged Care scheme.**

It is recommended that a communications plan be developed to advocate for a nationally funded health and aged care scheme for Forgotten Australians.

As part of this communications plan, it is recommended that the Alliance for Forgotten Australians prepare correspondence to:

- The Hon Sussan Ley MP, Minister for Health and Aged Care. This correspondence would advise the Minister of the proposed scheme, request a deputation to brief her and seek her support.
- Steve Irons, MP, Federal Member for Swan, informing him of the recommended scheme and seek his support.

### Recommendation 5: Further scope options for different models of aged care services for Forgotten Australians.

Findings from the Find and Connect Survey, the Forgotten Australians Senate Committee Report and the LOFA Study all recommended the need for increased options and alternative models of aged care for Forgotten Australians, beyond traditional residential aged care facilities. It is recommended that non-institutionalised models be researched and explored. These models would:

- Seek to maintain Forgotten Australians in their own homes/environments for as long as possible
- Empower Forgotten Australians in their decision making on their aged care needs
- Increase the Forgotten Australians' knowledge of aged care services and supports
- Provide supports to navigate the complex aged care system
- Maximise social, emotional, spiritual and community supports for Forgotten Australians as they age
- Educate the aged care workforce and service providers to ensure services, care, practices and environments do not re-traumatise people
- Ensure that Forgotten Australians in aged care feel as supported, nurtured and cared for as possible
- Explore the viability of a specialist aged care facility(s) designed specifically for Forgotten Australians
- Ensure that Forgotten Australians experience a peaceful and painless end of life and death.

### Recommendation 6: Explore Option 3: AFA (or similar) to establish a philanthropic trust scheme and administers health and aged care funding packages to Forgotten Australians.

While it is proposed that a national health and aged care scheme be funded by the Federal government, it is recommended that establishing a philanthropic trust scheme for Forgotten Australians be explored. It is suspected that a trust or foundation could attract a high level of interest from philanthropic, public and private donors. Forgotten Australians and their families may donate to this scheme knowing that the funds will be appropriately managed and dispersed. Funds would be invested, attract interest, and then dispersed through the Find and Connect Services in the form of brokerage funding for health and aged care services for Forgotten Australians.

### Recommendation 7: Identify and seek support from a senate member to “champion” the cause and support legislation through the Parliament of Australia for a national health and aged care funding scheme for FAs.

It is recommended that an appropriate Australian Senator be identified to “champion” the cause for Forgotten Australians. This senator will assist with raising community awareness on the health and aged care issues of Forgotten Australians, as well as supporting the bill through the Australian parliament. It is recommended that AFA request meetings with:

1. Nick Xenophon
2. Derryn Hinch given his “mandate” around childhood sexual abuse and his potential interest in championing “the cause” and
3. Jacquie Lambie given she is doing similar work for Australian veterans.

AFA may also consider pursuing the support of senators who were involved in the past three Community Affairs References Committees, and in particular the August 2004 report on Forgotten Australians.

**Recommendation 8:** Develop a media campaign to raise community awareness and garner support for a health and aged care funding scheme for Forgotten Australians.

It is recommended that the health and aged care needs of Forgotten Australians be given as much media attention as possible to raise community awareness and garner support for a health and aged care funding scheme. A media campaign may be run by AFA or through the office of the Senator “championing” the scheme. The media campaign may include:

- Media releases and media events
- Increasing awareness of the recent LOFA Study from the University of NSW
- Increasing the exposure of the needs of Forgotten Australians through social media platforms.

**Recommendation 9:** Develop a centralised repository of expertise and knowledge on the specialised health and aged care requirements for Forgotten Australians to inform health and aged care workers, professionals, service providers and aged care facilities.

Caring for victims of childhood trauma requires specialist knowledge, education and services. The Find and Connect services recommended that there is a need to increase the knowledge of Forgotten Australians as a special needs group amongst health and aged care workers. It is proposed that as part of the national health and aged care funding scheme, that a central repository of expertise and knowledge of the specialist health and aged care requirements for Forgotten Australians be established to inform health and aged care workers, professions, service providers and aged care facilities.

This education:

- May include written information, training videos, research studies, pod casts etc.
- Will be evidence based and up to date
- Will assist family members, service providers, health professionals and the full team of staff caring for Forgotten Australians in an aged care environment
- Should be centrally located, web based and easily accessible
- May include guidelines on facility design and the environment
- Will include recommended guidelines, policies and procedures when caring for Forgotten Australians to ensure that they are not being re-traumatised when accessing and receiving services e.g. not being required to repeat distressing details of events.

It was suggested that services and aged care facilities need to have ongoing reviews around being a trauma informed service. This would require an active policy that is lived out by the culture of the organisation.

**Recommendation 10:** Identify adequate resources to drive and support the recommendations in this report.

Advice received suggests that achieving a health and aged care funding scheme for Forgotten Australians in the current political environment will be challenging, it will take time and will require significant resources. Implementing the recommendations in this report will require an investment in resources, and this needs to be appropriately funded with suitably skilled staff. It is recommended that AFA dedicate appropriately skilled resources to delivering the recommendations in this report.

## 9. Implementation Plan

In progressing a nationally funded health and aged care scheme for Forgotten Australians, consultations have advised that this will be a challenging task in the current economic and political environment. While there is enormous support and empathy for the plight of Forgotten Australians, progressing a nationally funded scheme will take time, resources and a well thought through strategy. It was advised that at the Federal level, additional spending in health and aged care will be enormously challenging particularly as the Federal government has committed to rolling out the National Disability Insurance Scheme (NDIS) at a cost of \$22 billion. It is also been advised however that the timing is good for advocacy and to garner public awareness and support for a national health and aged care scheme for Forgotten Australians, given the recommendations of redress from the Royal Commission into Institutional Responses to Childhood Sexual Abuse which has bipartisan support.

In summary, three key messages were apparent:

1. There is a need for robust data, evidence and arguments to support the case for a nationally funded health and aged care scheme for Forgotten Australians, including how Forgotten Australians are differentiated from other groups in needs;
2. There needs to be a clear ask with a well-articulated and costed scheme, including the cost to government and future impact on the health and aged care sectors of not funding the health and aged care services for Forgotten Australians;
3. A political “champion” in the Australian senate is required to drive the cause and support the policy and bill through parliament.

Table 2 provides a suggested implementation plan for the Alliance for Forgotten Australians to progress a nationally funded health and aged care scheme for Forgotten Australians.

**Table 3: Draft Implementation Plan**

Area	Actions
<b>Common vision and agreement</b>	<ol style="list-style-type: none"> <li>1. AFA to agree to progress a nationally funded health and aged care scheme</li> <li>2. AFA to endorse the Final Report on Access to Health and Aged Care Funding for Forgotten Australians, December 2016.</li> </ol>
<b>Resources</b>	<ol style="list-style-type: none"> <li>3. AFA to appropriately resource the implementation of the recommendations in the Final Report</li> </ol>
<b>Business case and consultations</b>	<ol style="list-style-type: none"> <li>4. Continue with consultations to seek advice to inform the details of the scheme and business case development. Consultations have been requested with:                         <ol style="list-style-type: none"> <li>a. Australian Human Rights Commission</li> <li>b. Pradeep Phillips, Ex Vic Department of Health, Victorian and QLD. DPC, Office of the PM.</li> <li>c. Ken Wyatt AM MP, Assistant Minister Health and Aged Care</li> <li>d. Julia Gillard, Board Director Beyond Blue.</li> </ol> </li> </ol>
<b>Communications Plan</b>	<ol style="list-style-type: none"> <li>5. AFA to write to The Hon Sussan Ley, Minister for Health and Aged Care to inform her of the proposed scheme and to seek a deputation with her.</li> </ol>

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	<p>6. AFA to write to Steve Irons, MP, Federal Member for Swan, informing him of the proposed scheme and seeking his support</p>
<b>Senate Support</b>	<p>7. Consider gaining support from one of the following Australian Senators to “champion” the nationally funded scheme:</p> <ul style="list-style-type: none"><li>a. Derryn Hinch</li><li>b. Nick Xenophon</li><li>c. Jacque Lambie</li></ul> <p>8. Prepare correspondence requesting a meeting with each Senator</p> <p>9. Secure the support of a Senator to “champion” the cause and to work with relevant MPs.</p>
<b>Business case</b>	<p>10. Progress a business case with economic modelling for a nationally funded health and aged care scheme</p> <p>11. Approach the following institutes to seek their interested in conducting a study and business case on a national funded health and aged care scheme:</p> <ul style="list-style-type: none"><li>a. The Australian Institute of Health and Welfare (AIHW)</li><li>b. The Kirby Institute, UNSW.</li></ul>
<b>Media Strategy</b>	<p>12. Develop a media strategy, potentially in conjunction with the Senator’s office, to increase community awareness and garnering community support for the scheme</p> <ul style="list-style-type: none"><li>a. Involving media events, media releases</li><li>b. social media</li></ul>
<b>Aged Care Options</b>	<p>13. Seek funding to work with the states and territories to develop comprehensive models of care for Forgotten Australians to meet their aged care needs.</p>
<b>Philanthropic trust scheme</b>	<p>14. AFA to explore the viability of establishing a national philanthropic trust scheme that would be supported by private and public donors to assist in meeting the health and aged care needs for Forgotten Australians.</p>

## Appendix A: References

Alliance for Forgotten Australians. 12<sup>th</sup> October 2015. [AFA Response to the Public Consultation Paper: A Victorian Redress Scheme for Institutional Child Abuse.](#)

Alliance for Forgotten Australians. March 2015. [Royal Commission into Institutional Responses to Child Sexual Abuse. Response to the Royal Commission Consultation paper: Redress and Civil Litigation.](#)

Australian Healthcare Associates. July 2014. [Evaluation of the Find and Connect Services. Final Report.](#)

Baxendale, R. November 4, 2016. [Abuse Redress: child victims to get up to \\$150,000 compensation.](#) The Australian Newspaper.

Commonwealth of Australia. Senate Committee Report. August 2004. [Forgotten Australians. A report on Australians who experienced institutional or out-of-home care as children.](#)

Commonwealth of Australia. Senate Committee Report. June 2009. [Lost Innocents and Forgotten Australians Revisited. Report on the progress with the implementation of the recommendations of the Lost Innocents and Forgotten Australians Reports.](#)

Commonwealth of Australia. Senate Committee Report. August 2015. [Out of home care.](#)

Frederico, M, Long, M. December 2013. [Evaluation of Open Place 2010-2013. Final Report.](#) LaTrobe University.

Fernandez, E.2016. [LOFA: Long Term Outcomes of Forgotten Australians Study.](#) UNSW.

[Open Place Newsletter.](#) May 2016, Volume 26. (Reviewed re issues pertaining to brokerage funding).

Open Place. November 2015. [Sustainability of brokerage Funding at Open Place.](#)

Open Place. November 2015. Submission in response to: Royal Commission Issues Paper 10. [Advocacy and support, and therapeutic treatment services.](#)

Open Place. June 2014. [Submission in response to Issues Paper 6: Redress Schemes.](#)

### Websites reviewed:

Alliance for Forgotten Australians  
Australian Government Department of Health  
Australian Government Department of Social Services  
Australian Government Department of Veterans' Affairs  
Care Leavers Australasia Network  
Child Migrants Trust  
Change.org  
Parliament of Australia, Parliamentary Business  
The Forde Foundation  
Victorian State Government Department of Human Services

## Appendix B: National Survey on Health and Aged Care Issues

### Survey methodology

A national survey was developed by Manning Consulting to gather further data on the health and aged care issues for Forgotten Australians, particularly with reference to understanding funding mechanisms/schemes and access to services across the states and territories. The survey tool used an online survey and this was distributed to all Find and Connect managers across Australia. The feedback represents information on health and aged care issues from Find and Connect managers across the states and territories on behalf of the Forgotten Australians.

### Survey results

#### Question 1: Which State/Territory is your service located in?

All states and territories responded to the survey. As NSW and ACT are the same service, there were 7 unique responses.

#### Question 2: How many Forgotten Australians do you service?

There are a total of approximately 8,200 Forgotten Australians serviced by the states and territories. Given that the literature reports of approximately 500,000 Forgotten Australians, only a small number (approximately 1.6 %) are accessing the Find and Connect services. Victoria and Queensland reported the highest number of Forgotten Australians with 3,300 and 3,000 respectively.

**Table 1: Number of Forgotten Australians serviced by state/territory**

State/Territory	Number of Forgotten Australians Serviced
New South Wales/ACT	945
Queensland	3,000
Northern Territory	20
Western Australia	334
Tasmania	100
South Australia	500
Victoria	3,300
<b>Total</b>	<b>8,199</b>

NSW reported that there are 449 Forgotten Australians serviced from NSW state funding and 496 from Federal funds and includes Forced Adoptions Support Service and Royal Commission Support Service. Tasmania reported that not many of their clients are actively engaged in the service on a regular basis.

#### Question 3: What health issues are your Forgotten Australians facing?

All states and territories reported a broad range of health issues faced by Forgotten Australians encompassing physical health, mental health and dental/oral health issues. The poor nutrition from early childhood was reported to have impacted on oral health and dental problems with Forgotten Australians. The physical abuse experienced was reported to impact on physical health problems such as back issues. Mental health issues included PTSD, depression and anxiety.

**Table 2: Health issues by state/territory**

State/Territory	Health Issues
<b>New South Wales/ACT</b>	Dental, cancer, breathing and lung issues (emphysema and asthma), arthritis, diabetes, vision issues, injury related ageing issues e.g. back issues from beatings across back as a child, poor nutrition (not knowing how to cook and too ashamed to ask)

<b>Queensland</b>	Complexities of living with mental health conditions in a system that isn't responsive with adequate support. Dental services are always in high demand. Primarily health issues associated with aging.
<b>Northern Territory</b>	Mental health, physical health.
<b>Western Australia</b>	Mental health including PTSD, depression, anxiety. Dental, optical, hearing, mobility, arthritis, osteo arthritis, continence, nutrition.
<b>Tasmania</b>	A broad range of medical and dental issues, mental health issues, health issues stemming from poor childhood nutrition, dental decay and tooth loss, cancer, ageing-related health issues are some that have been mentioned.
<b>South Australia</b>	Dental, need to access aged care services but hesitant to receive services, secure housing, financial difficulties, isolation /mental health issues, transport to get to medical services.
<b>Victoria</b>	Specifically dental, chronic health, joint replacement, allied health. Early aging without resources.

**Question 4: What health services are in highest demand for your Forgotten Australians?**

The top three health services in highest demand (weighted average) across all States and Territories included:

1. Dental
2. Counselling/psychology and mental health services (equal second)
3. GP services.

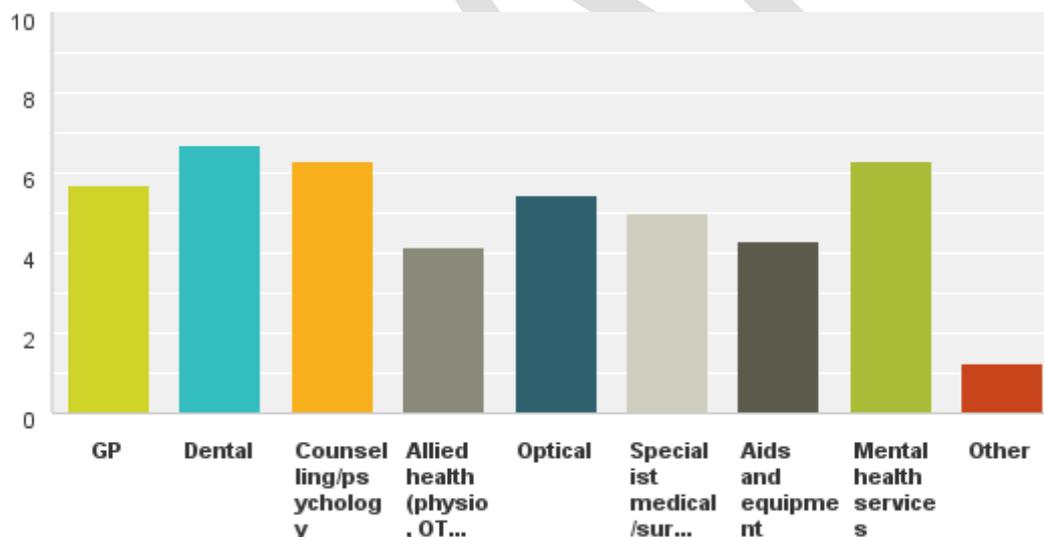


Figure 1: Health services in highest demand

**Question 5: If you responded other, please comment**

Other health services in demand for Forgotten Australians specified by respondents included:

- specialist psychiatry
- arthritis
- hearing
- nutrition
- continence
- emergency department care as Forgotten Australians were observed to often present in crisis rather than seek preventative care
- Aged care assessment teams – “My Aged care”.

**Question 6: What aged care issues are your Forgotten Australians facing?**

The predominant theme that the states and territories reported in relation to aged care issues was the fear that Forgotten Australians have with ageing and being re-institutionalised.

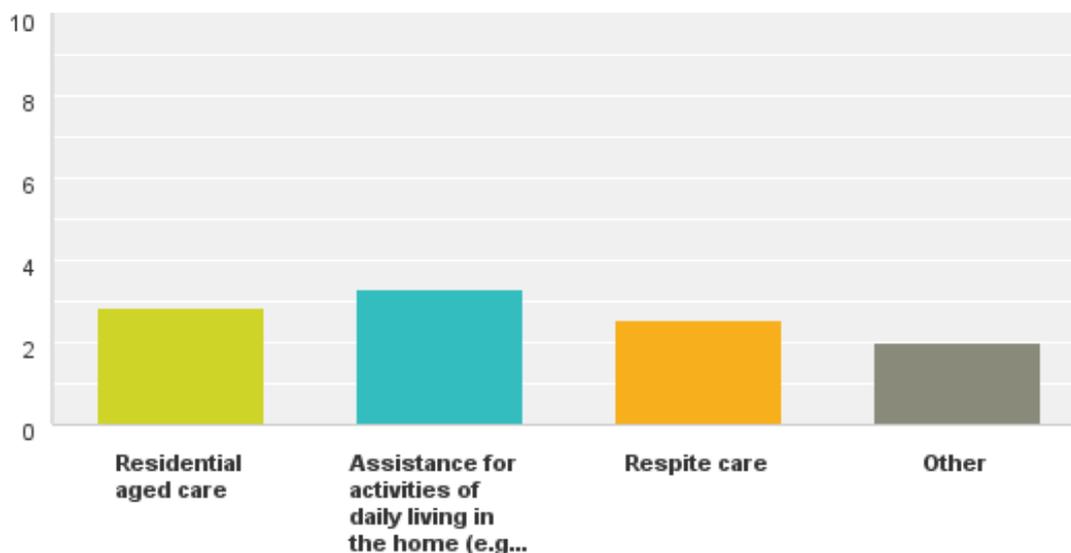
**Table 3: Aged care issues by state/territory**

<b>State/Territory</b>	<b>Aged Care Issues</b>
<b>New South Wales</b>	Housing and fear of re-institutionalisation, access to aids / equipment
<b>Queensland</b>	Fear of aging and being institutionalised. Limited access to health services which will meet their needs within the community. Community health care is a confusing system for individuals to navigate without support and advocacy.
<b>Northern Territory</b>	Issues surrounding being put in an aged care facility
<b>Western Australia</b>	Financial. Financial counselling. Assistance with legal issues. Residential care. Dedicated Centrelink person to speak to. Wait times and menu options on the phone when you call a place like Centrelink are confusing and unacceptable. More and more requirement to complete applications on line. FAs are not comfortable with this. Not all have IT access or expertise on the computer.
<b>Tasmania</b>	Primarily the fear of being institutionalised again, and lack of viable options.
<b>South Australia</b>	The need for all of these services including to understand trauma informed practice. I have heard many stories that FA's did not receive a service as they walked out because the approach for service triggered memories of being institutionalised. Many will then be labelled as 'difficult' or 'aggressive' rather than traumatised.
<b>Victoria</b>	Ageing without resources. Fear of institutional care. Lack of knowledge of FAs.

**Question 7: What aged care services are in highest demand for your Forgotten Australians?**

Aged care services in highest demand (weighted average) for Forgotten Australians included:

1. Assistance for activities of daily living
2. Residential aged care
3. Respite care.



**Figure 2: Aged care services in highest demand**

**Question 8: If you responded “other” to the above question, please comment.**

The Northern Territory reported a demand for aged care villages for their Forgotten Australians.

**Q9: Through what mechanisms are your Forgotten Australian's able to access health and aged care services?**

Mechanisms for access to health and aged care funding are inconsistent across the states and territories. Queensland and Northern Territory reported that they have priority access to health services (full cost coverage for dental and allied health services), while NSW/ACT, Queensland and Victoria had brokerage funding.

Forgotten Australians in Western Australia, Tasmania and South Australia had no funding mechanisms/schemes to assist Forgotten Australian’s to access health and aged care services. These states reported that access to services occurred through the Australian public health system of Medicare. Western Australia reported that almost none of their Forgotten Australians surveyed were able to afford private health care. South Australia reported that their Forgotten Australians accessed services through the disability pension and/or public access and reported of long waiting lists for health care.

**Table 4: Funding mechanisms for health services by state/territory**

State/Territory	Priority access to health services	Brokerage funding
New South Wales		Yes
Queensland	Yes	Yes
Northern Territory	Yes	
Western Australia		
Tasmania		
South Australia		
Victoria		Yes

**Q10: What is your service’s role in meeting the health and aged care needs for your Forgotten Australians? Please describe.**

The states and territories reported varying roles in meeting the health and aged care needs for Forgotten Australians. In addition to managing brokerage funding and having a special relationship with a service provider, other roles included accessing funds through a foundation, advocacy, care coordination, and project coordination and design.

**Table 5: Service’s role in meeting health and aged care needs by state/territory**

State/Territory	Managing brokerage funding	Special relationship with a service provider	Other (please specify)
New South Wales/ACT	Yes	Yes	
Queensland	Yes		Limited access to brokerage funding, access to some health care support through the Forde Foundation
Northern Territory		Yes	
Western Australia			Advocacy, assistance to access
Tasmania		Yes	
South Australia			Currently at the start of our Aged care project where we are connecting with the key aged care providers in a co-design project with the consumers.
Victoria	Yes	Yes	

**Question 11: What are the key service issues and/or gaps faced by your Forgotten Australians in accessing health and aged care services?**

The main issue reported for Forgotten Australians related to the cost of health and aged care services. For states that have brokerage funding, the costs of health care exceeds the brokerage funding available. One state reported that they negotiate access to free services first, and then utilise the brokerage funding but this is still inadequate. The out of pocket costs for health services meant that services and care were not accessed in a timely manner and either the person was faced with living with the condition (which caused additional hardship), or the condition deteriorated e.g. an infection developed. This resulted in the need for emergency department care/accessing the acute public hospital system.

Other issues included navigating a complex health system and the long waiting times for public health services, as very few Forgotten Australians have private health insurance due to the cost.

The lack of understanding by health and aged care workers of who Forgotten Australians are, what they have experienced and how this has impacted their health, was reported as an issue. Forgotten Australians need to be regarded and acknowledged as a group with special needs. This will increase the understanding of the special requirements for Forgotten Australians, in relation to their health and aged care needs, and the special resources they require.

**Question 12: What system redevelopments/policy changes are needed to improve access and affordability to health and aged care services for Forgotten Australians? (E.g. Gold Card, Priority Access etc.) Please describe**

Responses to this question related to three distinct areas:

*1. Forgotten Australians to be acknowledged as a special needs group*

States and territories reported that Forgotten Australians need to be acknowledged as a group that have experienced incredible disadvantage. As a result of this, they have special needs and require specialised health and aged care services in response to these needs.

*2. A funding mechanism/scheme similar to a Gold Card for Veterans*

State and territories reported that Forgotten Australians would like access to a funding scheme that provides for their health and aged care needs. This scheme would be a national health care card similar to a Gold Card for Australian Veterans. Though this funding, there would be increased access to specialist services and assistance with navigation of the complex health and aged care systems. Without this, Forgotten Australians will continue to be excluded from services that are available and need to be accessed. Access to free transport to and from appointments is also required.

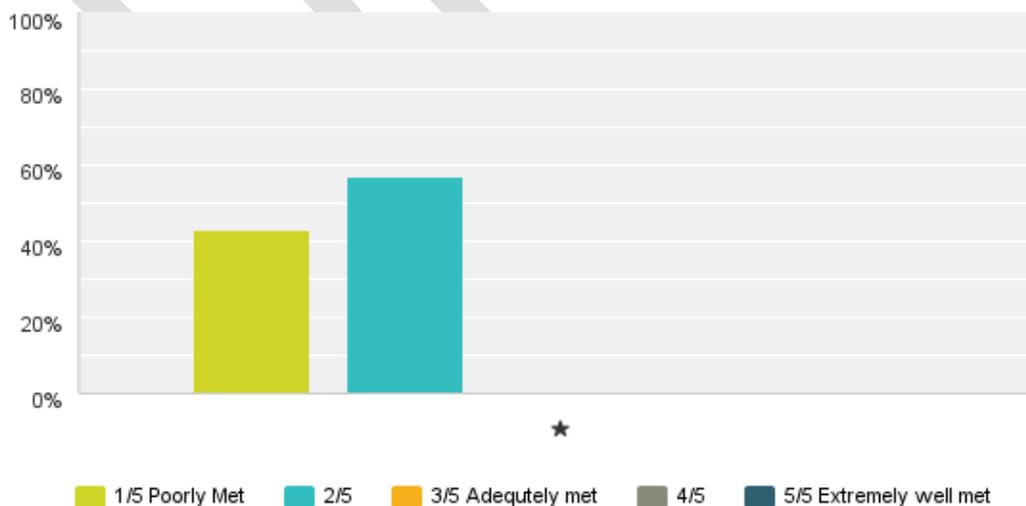
*3. Increased knowledge of Forgotten Australians amongst health and aged care workers/staff*

Increasing knowledge of Forgotten Australians as a special needs group amongst health and aged care workers is required. This will improve the care provided to Forgotten Australians and ensure that they are not being re-traumatised when accessing and receiving services e.g. not being required to repeat distressing details of events. It was suggested that services/aged care facilities need to have ongoing reviews around being a trauma informed service. This would require an active policy that is lived out by the culture of the organisation. Aged care services need to be equipped with specialist knowledge to service this group.

**Question 13: How effectively are the health and aged care needs of your Forgotten Australians being met?**

Responses to this question were consistent and demonstrated that the health and aged care needs of Forgotten Australians are being poorly met with:

- 43% providing a 1 out of 5 (poorly met) ranking
- 57% providing a 2 out of 5 ranking.



**Figure 3: How effectively are the health and aged care needs of Forgotten Australians being met**

**Question 14: How critical an issue is improved accessibility and affordability of health and aged care services for your Forgotten Australians?**

86% of states and territories ranked the issue of accessibility and affordability of health and aged care services as highly critical (5 out of 5) for Forgotten Australians.

DRAFT

## Appendix C: Consultations

The following people were consulted during October 2016 – December 2016.

<b>Name</b>	<b>Organisation</b>
Mr Simon Gardiner	AFA Board Secretariat
Ms Caroline Carroll	AFA Board Chair
Mr Julian Pocock	Director, Public Policy, Berry Street
Mr Cesar Melham	Member for Western Metropolitan, Victorian Parliament
Dr Mukesh Haikerwal	Board Director Beyond Blue, President World Medical Association (2011-2015), President AMA (2005-2007),
Dr Stephen Parnis	National Vice President Australian Medical Association (AMA) (2014 - 2016)
Professor Gregory Blatch	Dean of the Faculty of Health Sciences, Victoria University
Professor Gillian Triggs	President, Australian Human Rights Commission (initial discussion only)
Ms Nicole Bartholomeusz	Deputy CEO, Cohealth

During the consultancy period, requests for consultations were made to the following people:

- Jill Hennessey, Victorian Minister for Health
- Jenny Mikakos, Victorian Minister for Families, Children and Youth Affairs
- Pradeep Phillips
- Ken Wyatt MP
- Julia Gillard, Board Director Beyond Blue.

The following people were contacted to seek their advice however declined to be interviewed:

- Nicola Roxon, Past Federal Minister for Health and Ageing