Extreme Behavioural and Psychological Symptoms of Dementia (BPSD)

Project Report
Acknowledgements

NSW Health would like to acknowledge the lived experience of people living with dementia and their carers, family members and friends. We would like to particularly thank the family members of people who have experienced extreme BPSD who volunteered to be interviewed. Their contributions have significantly shaped this work.

We also acknowledge the contributions to this project by frontline health professionals and service managers. Their honest feedback in consultation meetings and follow-up conversations reflects their commitment to delivering quality health care to people with dementia.

Finally, we would like to extend thanks to the Extreme BPSD Expert Reference Group for giving their time and expertise to guide this project. The list of Expert Reference Group members is provided in Appendix 7.
Executive summary

Care for people experiencing the most extreme behavioural and psychological symptoms of dementia (BPSD) is one of the most difficult challenges in health care. This report describes the characteristics, prevalence and current health service use of this group. It makes recommendations for NSW Health organisations to improve health services for this vulnerable group who have complex needs that are not being well met in many NSW Health services currently.

NSW Health has a significant ongoing role to play in ensuring quality, person centered care for the person experiencing extreme BPSD. Improvements to NSW Health hospital and community services need to be made in conjunction with improvements to aged care services. These improvements have the potential to improve the quality of life of this group and their families, reduce the use of seclusion and restraint, and improve the wellbeing of staff. Current operational costs and risks related to very long hospital stays, the use of 1 to 1 nursing, physical damage to units and staff wellbeing, may also be able to be reduced.

Approach

This is the first project to estimate prevalence of the top tier of the Brodaty triangle\(^1\) and describe NSW Health’s current services for this group. It considers the original recommendations of Brodaty et al. and recommends a path forward for NSW Health to provide appropriate and safe care to people living with some of the most challenging symptoms of dementia.

The project builds on the published literature and existing NSW and national policies. This information gathering included consultations with over 100 frontline NSW Health staff, interviews with family members, analysis of administrative data sets and wide consultation on a draft of the report. An expert reference group of researchers and experienced clinicians guided synthesis of the findings.

Findings

Between 30 and 60 people in NSW will be experiencing persistent extreme BPSD at any point in time. While estimating extreme BPSD is not straightforward, it is likely that every Local Health District (LHD) in NSW will be providing care for at least one person experiencing extreme BPSD at a point in time and that this number will increase in the future.

Currently both older people’s mental (OPMH) health services and aged health services in NSW have a role in caring for people experiencing extreme BPSD. Care is often provided in unsuitable physical environments within large general acute medical wards. The complex needs of this group of people are stretching the scope and capacity of both aged health and mental health services. Improved service responses
will require joint effort across these two service streams, policy oversight from both aged health and OPMH policy teams, guidance for both OPMH and aged health services, and strategies to support collaboration across LHDs and services.

Commonwealth initiatives to enhance and support aged care services, most notably the Specialist Dementia Care Program (SDCP), are improving long term care options for many people experiencing BPSD. However, caring for people experiencing extreme BPSD is generally beyond the capacity of residential aged care providers, including SDCP providers. This means NSW Health will need to continue to provide hospital care for these people when their behaviour and symptoms mean there are no other care options available to them.

NSW Health has an ongoing role in providing specialist clinical assessment and care for people experiencing significant BPSD through hospital, community and outreach services. Understanding and meeting the needs of these individuals is challenging and requires: strong engagement with families; multi-disciplinary, specialist assessment and care; services with the required mix of staff skills and experience; and an appropriate physical environment.

**Recommendations**

This report recommends that NSW Health pursues a distributed capacity network model for providing inpatient care for people experiencing extreme BPSD. The report includes recommendations for LHDs. The Ministry of Health and pillar organisations to support implementation of this model and improvements in care. Project recommendations, including key aspects of quality care for people experiencing extreme BPSD, are summarised in Figure 1.

Implementing some of the LHD recommendations will mean changes to physical environments which may need to be delivered through planned infrastructure developments. Some improvements to physical environments may be achieved through minor capital works. Other recommendations, particularly those related to care, staffing and workforce training and support, may be able to be implemented in short to medium timeframes.

The statewide initiatives recommended in the report will help support, drive and monitor service improvements. They will also develop workforce capacity, and guide appropriate facility design for LHD inpatient services caring for people experiencing extreme BPSD. Ongoing research in this area will improve our understanding of people experiencing extreme BPSD and how health and aged care services can support them and their families.
NSW Health pursues a distributed capacity network model for providing inpatient care for people experiencing extreme BPSD.

All LHDs ensure they have a planned service response for people experiencing extreme and persistent BPSD.

LHDs consider guidance about key aspects of quality care when improving existing inpatient services providing care for people experiencing BPSD and in planning new inpatient services.

All LHDs explore opportunities to improve their service responses for people experiencing severe-extreme BPSD through capital projects, including new capital developments, redevelopment of existing facilities, and minor capital works.

Ministry of Health and pillar organisations support implementation of the recommendations in LHDs.

Ministry of Health and pillar organisations continue to drive and monitor service improvements through statewide activities.

Health Infrastructure and Ministry of Health promote appropriate health facility design guidance.

Ministry of Health and pillar organisations promote project findings beyond NSW Health.

Relevant experts and researchers prioritise continued research into BPSD to support ongoing service improvement.
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Introduction
This project aimed to better understand the numbers, needs and characteristics of people experiencing extreme Behavioural and Psychological Symptoms of Dementia (BPSD) in order to inform policy and service planning by NSW Health, and ultimately improve care and service responses for this group. There have been significant NSW and national service developments over the last fifteen years aimed at better supporting people with severe BPSD. However, no policy work has focused on the needs of people experiencing the most extreme BPSD, and there is little guidance in the published literature on best practice service models for this group.

**The Brodaty Triangle**

Most people with dementia experience behavioural and psychological symptoms of dementia (BPSD) during their illness\(^2\). People experiencing extreme symptoms, often expressed through physical violence, are a rare but highly vulnerable group. These behaviours and symptoms are distressing for the people who experience them and their families. The behaviours are often very difficult to manage, even in dementia-focused care environments, and present a high risk to other patients, staff, carers and the people with dementia themselves.

Brodaty et al. described people experiencing extreme BPSD as the top tier of their seven-tiered model of service delivery\(^1\). People move up and down the tiers depending on the symptoms they are experiencing and the interventions they require, as summarised in Figure 2.

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**Figure 2: Seven tiered model of management of behavioural and psychological symptoms of dementia**

<table>
<thead>
<tr>
<th>Level of disturbance increases</th>
<th>Use of interventions is cumulative</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dementia with extreme BPSD (eg physical violence)</td>
<td>Tier 7</td>
</tr>
<tr>
<td>Prevalence:* Rate(^1)</td>
<td>Management: In intensive specialist care unit</td>
</tr>
<tr>
<td>Dementia with very severe BPSD (eg physical aggression, severe depression, suicidal tendencies)</td>
<td>Tier 6</td>
</tr>
<tr>
<td>Prevalence: &lt;1%(^\dagger)</td>
<td>Management: In psychogeriatric or neurobehavioural units</td>
</tr>
<tr>
<td>Dementia with severe BPSD (eg major depression, psychosis, screaming, severe agitation)</td>
<td>Tier 5</td>
</tr>
<tr>
<td>Prevalence: 10%(^\dagger)</td>
<td>Management: In dementia-specific nursing homes, or by case management under a specialist team</td>
</tr>
<tr>
<td>Dementia with moderate BPSD (eg major depression, verbal aggression, psychosis, sexual disinhibition, wandering)</td>
<td>Tier 4</td>
</tr>
<tr>
<td>Prevalence: 20%(^\dagger)</td>
<td>Management: By specialist consultation in primary care</td>
</tr>
<tr>
<td>Dementia with mild BPSD (eg night time disturbance, wandering, mild depression, apathy, repetitive questioning, shadowing)</td>
<td>Tier 3</td>
</tr>
<tr>
<td>Prevalence: 30%(^\dagger)</td>
<td>Management: By primary care workers</td>
</tr>
<tr>
<td>Dementia with no BPSD</td>
<td>Tier 2</td>
</tr>
<tr>
<td>Prevalence: 40%(^\dagger)</td>
<td>Management: By selected prevention, through preventative or delaying interventions (not widely researched)</td>
</tr>
<tr>
<td>No dementia</td>
<td>Tier 1</td>
</tr>
<tr>
<td>Management: Universal prevention, although specific strategies to prevent dementia remain unproven</td>
<td></td>
</tr>
</tbody>
</table>

* Prevalence is expressed as estimated percentage of people with dementia who currently fall into this category.
\(\dagger\) Estimate based on clinical observations. \(\dagger\) Estimate based on Lyketsos et al.\(^6\)
In this model, several suggestions were made, based on the clinical experiences of the authors, regarding the care required by people experiencing extreme BPSD:

- ‘a high-security specialist care unit with a large ratio of male staff to patients’
- ‘only one such unit for each of the larger states (of Australia) may be required.’
- ‘Such an intensive specialist unit would far exceed the type of care able to be provided in residential aged care facilities, even those with a dedicated focus on dementia care.’

Part of the work in this project has been to consider these suggestions in consultation with NSW Health staff and other key stakeholders.

The differing care needs for people experiencing severe and very severe BPSD (Tier 5 and 6 of the Brodaty BPSD Triangle) from those who present with extreme BPSD (Tier 7) was reiterated in the Review of the Oakden Older Persons Mental Health Service in South Australia (The Oakden Report). The review found that Tier 7 services should be provided by the public health sector. In response, SA Health has built a new statewide Neurobehavioural Unit.

**Project context and drivers**

The [NSW Older People’s Mental Health Services (OPMH) Service Plan 2017-2027](#) commits the NSW Ministry of Health to ‘progress policy work to determine the need for statewide/tertiary intensive care models for ongoing longer-term care for older people with persistent, very severe/extreme BPSD’ (p28).

O’Connor et al. found that Australia’s state-funded aged persons’ mental health services varied widely in their capacity to provide community, inpatient and specialist residential support to people whose dementia is complicated by severe and persistent behavioural symptoms. South Australia’s Oakden review in 2017 highlighted the potential for long term abuse and neglect if appropriate services are not provided for this group.

The Australian Royal Commission into Aged Care Quality and Safety’s final report identifies many issues relevant to care of this group and makes a number of relevant recommendations. These include:

- recommendations related to the use of psychotropic medications
- recommendations about the needs for enhanced dementia care training and skills for the aged care workforce
- recommendations about the need for enhanced nursing staff in residential aged care
- recommendations for the Commonwealth to review the capacity of the Specialist Dementia Care Program to meet the needs of people experiencing severe to extreme BPSD

It is likely that the reforms triggered by the Royal Commission will take some years. The implementation of the recommendations in this report will need to be responsive and build on aged care developments and initiatives.

Care for people experiencing extreme BPSD may involve temporary restraint, and less frequently seclusion, to ensure the person’s safety along with the safety of staff and other patients in a hospital environment. Policies and strategies have been developed to promote alternatives to seclusion and restraint and to ensure these are used as a last resort across NSW Health, particularly in NSW mental health inpatient units.

The recommendations from this project have the potential to reduce the use of seclusion and restraint in the care of people experiencing extreme BPSD.

Aggressive behaviour of people experiencing extreme BPSD has an impact on safety in the hospital environment. [Preventing and Managing Violence in the NSW Health Workplace – A Zero Tolerance Approach](#) provides guidance on managing incidences of violence. The [NSW Health Protecting People and Property Manual](#) and the reports from the review into the safety of staff, patients and visitors in NSW public hospitals (‘The Anderson Review’) provide guidance to services on supporting staff, patient and visitor safety, and the role of security staff.
There are several strategies and policies that guide the provision of care for people with dementia who are experiencing BPSD. These are relevant to the care of people experiencing extreme BPSD:

- The National Framework for Action on Dementia 2015-2019 has recently been evaluated through a national multi-jurisdiction project. Recommendations regarding a future national dementia strategy are being considered by the Commonwealth and States and Territories. The evaluation identifies some of the successful initiatives implemented in NSW, including workforce initiatives, the BPSD Handbook, MHACPI units and the Confused Hospitalised Older Persons Program (CHOPs). Future NSW dementia initiatives will support national directions and build on the NSW Dementia Services Framework 2010 - 2015.

- The NSW Older People's Mental Health Service Plan 2017-2027 is guiding continued development of OPMH services around the state and is supported by models of care for community services and acute inpatient units. The model of care for T-BASIS units for people experiencing severe BPSD is particularly relevant to this project.

- There are several guidelines to support services and clinicians providing care for people experiencing BPSD. These include the Assessment and Management of People with Behavioural and Psychological Symptoms of Dementia ("the BPSD Handbook") from the Royal Australian and New Zealand College of Psychiatrists and NSW Health as well as guidelines published by the Royal Australasian College of General Practitioners, the Australian National Health and Medical Research Council and the Dementia Collaborative Research Centre. The International Psychogeriatric Association has guides for specialists, nurses and primary care physicians. In other parts of Australia, Victoria has published standardised care processes for responsive behaviours targeted to residential aged care, along with consumer and carer information. Queensland has a section on behavioural emergencies in their guidance for acute care pathways for residents of aged care facilities.

**Project scope and approach**

The focus of the project was on people experiencing extreme BPSD. However, the findings also consider other tiers of BPSD, most commonly severe and very severe, because:

- The interpretation of symptoms as ‘extreme’ is somewhat subjective.
- Individuals with dementia move between tiers of BPSD over time.
- Services for people experiencing extreme BPSD will most often also provide care to people experiencing lower tiers of BPSD.

This project has used multiple sources of information to understand the challenges of extreme BPSD, for the person with dementia, their family members, NSW Health services staff and aged care organisations. The project approach is described in Figure 3.

Existing literature and policy and practice guidelines were identified and reviewed, with few publications found that were specifically relevant to this small group of people. The project has been informed by existing models of care for people with severe BPSD such as the T-BASIS unit model in NSW OPMH services. Relevant administrative health services data was also extracted and analysed.

Over 100 frontline clinicians and managers attended ten internal NSW Health group consultations and were involved in follow up conversations and emails. Seven family carers were recruited via NSW Health services for seven in-depth interviews. These interviews aimed to understand the experience of both the person with dementia and the family members. Quotes from these interviews have been included in this report with names and other identifying information changed to protect the privacy of individuals and families. The lack of engagement directly with people experiencing BPSD is a limitation of this project.

A draft of this report was circulated to over 40 organisations including all NSW LHDs. More than 600 feedback items were received from 23 organisations and considered in development of the final version.

More detail on the project methods is provided in Appendix 2.
Figure 3: Project approach

- Published research
- Existing policies and guidelines
- Consultation meetings
- Carer interviews
- Health services data

Report and recommendations

Expert Reference Group review

Other stakeholder review

Care options for people experiencing BPSD in NSW

In NSW, people experiencing severe-extreme BPSD may be cared for in a variety of environments. Care is often provided in residential aged care, funded by the Commonwealth Government, and hospitals, funded by the NSW Government. These services currently vary in their capacity and their approach to providing care for people experiencing persistent, extreme BPSD. Key hospital services include:

- Aged health and acute medical units, including specialist behavioural units in some major hospitals
- Mental health inpatient units, including Older People’s Mental Health (OPMH) acute inpatient units, non-acute OPMH Transitional Behaviour Assessment and Intervention Service (T-BASIS) units, high dependency areas of adult acute mental health inpatient units and mental health intensive care units.

More detail on current health service use is included in section 5. This report uses the term ‘aged health’ to refer to hospital and community based health services that have older people as their target population. This includes geriatric medical services. The term ‘aged care’ is used in this report to refer to community and residential aged care services provided to support older people in their daily lives.

There have been several changes in the last fifteen years in the services provided to people experiencing BPSD in NSW. Key changes include:

- OPMH services have increased their capacity to provide specialist clinical care and support for people experiencing moderate-severe BPSD in the community (including generalist residential aged care facilities (RACFs) and specialist transition units within RACFs), and some OPMH non-acute inpatient services have been redesigned to provide good practice care for people with severe BPSD

- Dementia Clinical Nurse Consultants have been established in most Local Health Districts (LHDs) as a part of aged health services
• The Australian Government has funded additional support for people with severe BPSD accessing aged care services and their formal and informal carers through the Dementia Behaviour Management Advisory Services (DBMAS) and Severe Behaviour Response Teams (SBRT) programs.

• The Australian Government has designed and begun to implement the new Specialist Dementia Care Program. The program is targeting people experiencing severe, but not extreme, BPSD. The first Specialist Dementia Care Unit (SDCU) in NSW opened in February 2020. The SDCU model is similar to the NSW Mental Health Aged Care Partnership Initiative (MHACPI) transition unit model, but dementia-specific. In NSW, specialist clinical support is provided by NSW Health mental health services.

The challenges of describing changed behaviours in dementia

This project uses the term ‘behavioural and psychological symptoms of dementia’ (BPSD). The term BPSD is not used as a diagnosis, rather it describes the various ways a person with dementia behaves differently to how they did previously. This report also uses the term ‘changed behaviours’. There are critics of the term BPSD, often using #BanBPSD on social media. These campaigns often highlight very real challenges of over-medicalisation, chemical restraint and inadequate efforts to understand the person with dementia.

The seven tiered model of BPSD was created as a model to support service planning. It provides a framework for grouping together individual diverse people with dementia by the interventions that they may require. The model acknowledges that a person may move between tiers over time, and that interventions at a higher tier will support a person to move to a lower tier.

This project report follows the Dementia Australia Dementia Language Guidelines, which suggests that the term BPSD is appropriate to be used in a clinical context.
Recommendations
For all of NSW Health

Recommendation 1.
NSW Health pursues a distributed capacity network model for providing inpatient care for people experiencing extreme BPSD

Under this model, all Local Health Districts (LHDs) will need to provide inpatient care for people experiencing extreme BPSD. They will be supported by improving connections between individual clinicians and between services throughout NSW. This will create a network of capacity distributed throughout NSW, hence the term ‘distributed capacity model’.

All districts are currently providing clinical care for people experiencing severe BPSD in various settings, within aged health and/or older people’s mental health (OPMH) services. Many districts currently provide specific inpatient units for people experiencing severe BPSD. The project findings support a distributed capacity approach that builds on and enhances the care provided in these units, so that they can better respond to the needs of people experiencing extreme BPSD when this is required. We estimate that each district may need to provide inpatient care for between one and eight people experiencing persistent extreme BPSD at a time.

These units may be operated by mental health or aged health services, but should have clear clinical governance arrangements and clinical input from both OPMH services and aged health services. A distributed capacity model would be supported by:

- Pathways within and between different health districts to manage capacity and patient mix.
- Connections between teams working in these units, through existing and possibly new mechanisms (e.g. statewide OPMH and aged health committees and communities of practice, the activities of the Aged Health Network of the Agency for Clinical Innovation.

The benefits of a distributed capacity model are:

- People experiencing extreme BPSD can receive care closer to their families and communities and families and carers are enabled to be partners in care and care planning.

- Each unit can collaborate with the range of other local services to provide pathways into and out of the service and support people remaining close to their families and communities.

- Skilled staff within the team can be rotated to manage the workforce impacts of violence and aggression.

- As there are lower numbers of people experiencing extreme BPSD, people with dementia can be more easily separated into different physical spaces when they trigger each other’s behavioural symptoms.

- The existing specialist skills of unit staff can be utilised.

- In many cases, existing physical spaces that have been designed in a dementia friendly way can provide an appropriate physical environment for people with extreme BPSD and be safe for staff. In other cases, units can be made more appropriate with specific modifications.

This model of inpatient hospital care will continue to complement aged care services, including residential aged care, DBMAS, SBRT and SDCP.
Recommendation 2.
All LHDs ensure they have a planned service response for people experiencing extreme and persistent BPSD

The project findings indicate that all LHDs will need to provide inpatient care for small numbers of people experiencing extreme BPSD. Project consultations indicated that current services are often failing to meet the complex needs of people experiencing extreme BPSD and that this has serious impacts on staff and other patients. Therefore urgent and proactive service improvements are needed. These will require support by LHD leadership, and by local service and infrastructure planning, clinical governance and quality improvement teams, workforce units and others.

It is recommended that districts develop their service response and care pathways for this consumer cohort, and incorporate this into relevant local clinical service plans such as aged health and mental health clinical service plans. Strong clinical and operational leadership will likely be required to bring various clinical service streams together for this work. New and enhanced services may require enhanced funding in both the short and long term.

Service plans need to include:

- Suitable service options for a person experiencing extreme BPSD. Multiple options may be required to support fluctuating patient numbers and individual needs. In certain circumstances, Mental Health Intensive Care Units (MHICUs) may be an appropriate care setting for behavioural emergencies.
- Collaborative and integrated approaches between different services within a district, particularly collaboration between services that have a focus on BPSD. A designated leader to steer this collaboration during planning and service development should be considered.
- Arrangements to engage additional specialist clinical assessment and advice from other LHDs or sources, where required.
- Pathways for people who present to emergency departments for behavioural emergencies where no physical health cause is found.
- Responsive staffing approaches such as rotation of staff, so that quality care is provided and workforce wellbeing is managed when a unit is caring for one or more people experiencing extreme BPSD.
- Flexible physical environments that can allow units to adapt to meet the needs of people experiencing extreme BPSD when required.

It is likely that the service response in rural and regional LHDs will be quite different to that of metropolitan LHDs. Enhanced services in a small number of major hospitals with strong connections with smaller health services are likely to play a large role in rural and regional LHDs.
**Recommendation 3.**
LHDs consider guidance about key aspects of quality care below when improving existing inpatient services providing care for people experiencing extreme BPSD and in planning new inpatient services.

Most metropolitan health districts already have one or more inpatient services with a focus on BPSD. These units are likely to be providing care for a small number of people experiencing extreme BPSD. In rural and regional health districts the service response may include a small number of inpatient beds that are available for people experiencing extreme BPSD when this is required.

The key aspects of high quality care for people experiencing extreme BPSD outlined in this report can inform service improvement and clinical service planning.

The model of care for T-BASIS units, that provide transitional or non-acute inpatient care for older people with severe BPSD and/or mental illness, includes many of these key aspects\(^5,29\). More detail on the key aspects of high quality care for people experiencing extreme BPSD is in section 6 of this report.

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**Recommendation 4.**
All LHDs explore opportunities to improve their service responses for people experiencing severe-extreme BPSD through capital projects, including new capital developments, redevelopment of existing facilities, and minor capital works.

Existing financial constraints, workforce availability and physical space are likely to constrain the pace at which LHDs can implement the recommendations in this report.

Capital projects in each LHD, including those being delivered through the Statewide Mental Health Infrastructure Program, can provide an opportunity to enhance existing services and develop new services to better meet the needs of people experiencing severe-extreme BPSD.
Key aspects of high quality care – a summary

More detail on these recommendations is provided in Section 6.

Philosophy of care

- Adopt a person centred, trauma informed approach to care
- Protect the rights of people experiencing extreme BPSD and their families
- Plan specific responses for priority populations, including Aboriginal people and people from CALD backgrounds
- Invest in ongoing service improvement including through collaborative research

Target population

- There must be capability to manage a mix of people with different levels of BPSD, particularly severe-extreme BPSD.
- In services specifically for people experiencing extreme BPSD, limit admissions and protect capacity when required to manage one or more people experiencing extreme BPSD so that the unit can provide appropriate care.

Governance arrangements and key functional relationships

- Unit may be operated by mental health or aged health services, but should have clear clinical governance arrangements and clinical input from both older people’s mental health services and aged health services.
- Acute medical services are available to support people in a timely way and limit transfers and delays in receiving care.

Functions and clinical processes

- The unit needs to be able to provide iterative, comprehensive, multidisciplinary assessment and care planning.
- Family, carers and supporters must be engaged as partners in care
- Assessment will require the input of both aged health and older people’s mental health clinicians to address physical health and mental health dimensions of extreme BPSD.
- Care should reflect best practice for BPSD care, including physical health care, behaviour management strategies, psychological engagement, medications, and care for the carer18.
- Therapeutic and meaningful activities that support individual choice and control should be available.
- Care must align to relevant seclusion and restraint policies and guidelines.
- Safety huddles can be a useful strategy for briefing staff on the incoming shift on changes in behaviour and patient management plans. Health and Security Assistants or other security staff who may be required to respond to the unit during that shift should be included in these huddles.
Pathways and partnerships

• Pathways into the hospital service should include intake directly from the community, residential aged care, other services within the same district and in other districts. Pathways that avoid emergency departments are preferable.

• Development of assertive outreach services, particularly into residential aged care, will increase timely access to clinical support and promote smoother transitions into hospital when required.

• Clear pathways out of the hospital service to support people as they move between tiers of BPSD are important. These require significant partnership work with capable local residential aged care and disability providers, and additional clinical in-reach to aged care facilities to support the person with dementia to remain in residential aged care or specialist disability accommodation.

• Local pathways for people experiencing significant BPSD, including extreme BPSD, need to be documented and updated as services change. Collaboration with local residential aged care and disability service providers is particularly important.

• Partnerships and collaboration with other key BPSD services will support quality care for people with complex needs associated with extreme BPSD, and may include being involved in assessments, case reviews and education initiatives. This includes the Severe Behaviour Response Team (SBRT) and Specialist Dementia Care Program (SDCP).

Physical environment

The physical environment plays a key role in ensuring the safety of people with dementia, frontline staff, other patients, family members and other carers.

• People experiencing extreme BPSD need to be in a single room.

• The physical environment needs to allow regular access to outdoor space.

• The physical environment needs to have a variety of indoor and outdoor spaces to support meaningful activities.

• The unit should support functional segregation of different areas to help manage the mix of patients in the unit and ideally allow physical separation of people experiencing extreme agitation or aggression with appropriate observation and care strategies, when required.

• The unit should include physical spaces for carers, who in some cases play an essential role in behaviour management particularly during times of transition. This may include carer zones in common areas, which should be appropriate for older carers.

• Staff safety should be considered including: having a safe space to work away from patients, such as for updating patient notes, limiting entrapment points and use of safety glass.

• A space should be available for assessments and to meet with families.

• Flexible physical environments that include swing or surge beds with ample space (including access to outdoor space, where possible) should be considered as these can create capacity for managing people experiencing extreme BPSD in an appropriate physical environment.

• Other principles of a dementia friendly environment should be implemented.

• Involve consumers and carers using co-design principles when designing new units or refurbishing existing units.
Staffing

- Units need to be staffed by nurses with skills and experience working with people with dementia, including those with severe-extreme BPSD. A nursing unit manager and/or other senior nurses with significant experience in this area can provide leadership, staff support and training.
- The number of nurses on each shift should reflect the number and acuity of the patients.
- Units need regular clinical input from both a geriatrician and an old age psychiatrist, with minimum levels of medical staff coverage and access specified.
- Multi-disciplinary teams including psychologists, occupational therapists and social workers need to be involved in assessment, care planning and provision of care.
- Patient management plans should include strategies to eliminate or manage known triggers for patients. This approach may also involve identifying staff members who are a good fit and/or have developed rapport with the person experiencing extreme BPSD.
- Health and Security Assistants, or other security staff, may assist clinical staff in the management of patient behaviour, but not as the first or only approach to managing behaviour.
- Units should consider arrangements to engage additional specialist clinical assessment and advice from other districts or sources, where required.
- Units need responsive staffing approaches, such as rotation of staff, so that quality care is provided and workforce wellbeing is managed when a unit is caring for one or more people experiencing extreme BPSD.
- Services should include ‘outreach clinicians’ to promote linkages with residential aged care and other services, support transitions into and out of the unit and prevent hospital admissions where possible. This can be integrated with other partnerships and outreach services in the district.

Workforce training and support

- All staff should have access to ongoing education and training specific to the care of people with dementia and severe-extreme BPSD, including training in complex behavioural management, trauma informed care, partnerships with families/carers and psychological literacy specific to older people.
- Investment should be made in mentoring and clinical supervision to support the safe and effective operation of the unit.
- A focus on a positive team culture will support person-centred care.
- Strategies to build and maintain workforce in each district should be developed, such as efforts to rotate staff through units providing care for people with severe-extreme BPSD with a view to identifying those with the interest and compassion to work in this setting. Values based recruitment may play a role in this.
- LHDs should have systems in place to safeguard the wellbeing of the team, including access to informal and formal support programs and the use of duress alarms.
For NSW Ministry of Health and pillar organisations

Key policy teams in the NSW Ministry of Health and the NSW Health pillars should collaborate to provide statewide policy oversight, clinical service collaboration, and monitoring to support the implementation of report recommendations.

**Recommendation 5.**
Ministry of Health and pillar organisations support implementation of the recommendations in LHDs:

- Promote the findings of this project in relevant forums and to key decision makers in LHDs.
- Use this project report to provide advice and guidance to districts about quality improvement in existing services and when developing new services with a role in the care of people experiencing severe-extreme BPSD.
- Support collaboration between services providing care for people experiencing extreme BPSD to share expertise and practice improvement initiatives.

**Recommendation 6.**
Ministry of Health and pillar organisations continue to drive and monitor service improvements through statewide activities:

- Explore options to work with one or more districts to develop specialist consultation liaison services to support statewide access to expert clinical review and advice. This could be informed by models being developed in the intellectual disability mental health specialist hubs.
- Use the findings and recommendations of this report to inform statewide workforce and practice development initiatives in aged health and mental health. This may include identifying available training and opportunities for new initiatives. For example, the ongoing work on the Confused Hospitalised Older Persons (CHOPs) resources produced by the Agency for Clinical Innovation’s Aged Health Network, or new initiatives that may support the development of behaviour management skills in staff working in aged health, mental health and other settings.
- Revise the existing Assessment and Management of People with Behavioural and Psychological Symptoms of Dementia (BPSD) resource to align with emerging evidence of best practice care and updated policies and guidelines.
- The Ministry, along with research partners, should use linked administrative data sets to improve our understanding of the prevalence, characteristics and health service use of people experiencing extreme BPSD. Since data from inpatient services, community based services and emergency departments will be combined, this linked data project will create a more comprehensive profile than what was possible for this project using health services data.
- Further examine the complex sociolegal issues relating to consent, guardianship and application of the Mental Health Act to people experiencing significant BPSD and consider the need for further guidance on this topic for clinical services.
- Develop an approach to monitoring implementation of the recommendations in this report, and challenges and improvements in care.
- Explore opportunities to improve identification of people experiencing extreme BPSD to enable monitoring of service performance and patient outcomes.
**Recommendation 7.**
**Health Infrastructure and Ministry of Health promote appropriate health facility design guidance**

Key Ministry of Health policy teams should work with Health Infrastructure and other facility design and clinical experts to explore the development of specific design guidance that reflects the physical environment needed to support people experiencing extreme BPSD.

The existing Older Peoples Acute Mental Health Inpatient Unit health facility guideline provides principles and design requirements that can support safe care for people experiencing extreme BPSD. Units providing care for this group should specifically consider:

- Designing units with smaller, physically distinct pods and/or using high dependency areas to allow for physical segregation of particular patients.
- Ensuring that sufficient outdoor space, including space for safe movement and wayfinding, is available.
- Choice of fixtures, fittings and furniture to ensure safe, dementia friendly spaces for people experiencing extreme BPSD, staff, other patients and visitors to the unit.

The Adult Acute Inpatient Unit health facility guideline (which would inform the development of new aged health units) has been recently updated to include principles for designing environments for patients with dementia. However this guideline does not include common features used in mental units to support patient and staff safety such as the use of safety glass.

Specific design guidance for people experiencing extreme BPSD could consider:

- The most important design features from the guidelines for Adult Acute Inpatient Units and Older Peoples Acute Mental Health Inpatient Units.
- Aspects of this project’s findings that are not already included in existing guidelines, particularly those that support physical separation of patients and provide for surge or swing beds.
- Options for retrofitting or adapting existing physical spaces.
- Examples of purpose designed spaces for people experiencing severe-extreme BPSD.

**Recommendation 8.**
**Ministry of Health and pillar organisations to promote project findings beyond NSW Health:**

- Share the report with other state and territory governments and with the Australian Government
- Use the findings and recommendations of this report to inform cross-jurisdictional work, particularly national dementia frameworks or strategies.
- Continue to work with Australian Government initiatives, including the Specialist Dementia Care Units, Severe Behaviour Response Teams (SBRT) and Dementia Behaviour Management Advisory Service (DBMAS), to ensure that NSW services and initiatives for people experiencing extreme BPSD are well coordinated with Commonwealth initiatives for people experiencing severe BPSD.
For the research community

**Recommendation 9.**
**Relevant experts and researchers prioritise continued research into BPSD to support ongoing service improvement**

Future research, cost analysis and evaluation should be conducted to support improvements in care for people experiencing extreme BPSD. Key areas for further work include:

- Improving our understanding of the experiences of hospital care by people with dementia and their family and other carers.
- Exploring outcome measures that may support service monitoring, such as the clinical outcome measures proposed by O’Connor et al.⁶
- Improving evidence to support the use of non-pharmacological interventions for BPSD.
- Understanding the training and support needs of health professionals providing care for people experiencing extreme BPSD.
- Publishing case reports of people experiencing extreme BPSD to increase what is known about approaches to care and to build on what we understand about characteristics of this group.
- More comprehensive analysis of the costs of providing care for people experiencing extreme BPSD and implications for funding models.

Research findings should be disseminated widely to support continuous improvement of health services and care for people experiencing extreme BPSD across Australia and internationally. People with dementia, their families and the health professionals providing care need to be involved in research planning, design and delivery.
Our understanding of people experiencing extreme BPSD
The classification of BPSD by tiers is not a measure of the degree of agitation or distress being experienced by the person with dementia. The classifications are determined by the impact of the person’s changed behaviours on themselves and the people around them, and the intensity of the interventions the person requires. There is no widely agreed objective measure of severity of BPSD.

People experiencing extreme BPSD have had extended periods of agitation, often expressed as severe aggression, with little improvement from usual first line management options.

Brodaty et al. described people experiencing extreme BPSD as those for whom their care situation has reached a crisis, having been so violent that they have harmed other residents or staff. Consultation meetings discussed an expanded list of characteristics prepared by the Expert Reference Group. This list is included in Appendix 2.

This project found that people experiencing extreme BPSD:

- are not a homogenous group
- have physically aggressive behaviour including throwing furniture and objects
- were often severely disinhibited, contributing to behaviour including removal of clothing, defecating in public areas, smearing of faeces and, in some cases, sexual assaults
- can experience suicidal and homicidal ideation
- often have changed behaviour that is considered by staff to be unpredictable, including physical and verbal aggression that was perceived to be unprovoked.
- can direct their behaviour at staff, other patients in hospital and visitors.

Frontline staff described significant challenges providing treatment and personal care. Consultation meetings reported that, when personal care was necessary in hospital, as many as nine staff members were required to support the person.

Carer interviews described the emergence of BPSD as the person’s dementia progressed. The combination of memory loss and a desire to walk was a common challenge for carers to manage at home. Verbal aggression, hallucinations and disinhibition were described:

- “If he got annoyed with someone, he would take them on”
- “His ability to express himself was becoming less and less, so he was becoming physical”
- “We can’t stop him. We don’t know why he is doing this”
- “It was the volatility that was the hardest for everyone”

One carer described unpredictable aggression in the context of providing personal care at home:

- “He was unpredictable. I’d think he was being compliant and then suddenly he’d kick or hit out. Sometimes he’d catch me, sometimes he wouldn’t. There was always the danger that I’d fall and one time I did fall.”

Carers also highlighted their inability to understand the behaviour of the person with dementia.

In other cases, carers were able to explain that violent behaviour could be explained as responses to needs not being met, being provoked and other symptoms such as hallucinations.

Once in hospital, carers described how the symptoms of the person with dementia became worse:

- “In the hospital he became a little bit aggressive and wanted to cause violence to others. Like the male nurses or the security staff.”
- “Sometimes he would talk about hating this, wanting to kill himself”
- “If he wanted to move a chair or table upside down, he had to do it.”
“He had this behaviour sometimes where he would do what you call targeting. He’d set his eyes on people and he’d go for them.”

Consultation meetings discussed that some people experience a long period of very severe behaviour disturbance or they may have episodic and unpredictable periods of extreme behavioural disturbance. We would not consider these individuals in the group of people experiencing persistent extreme BPSD, however many of the recommendations in this report will enhance care for them.

**Extreme BPSD is often experienced by people with challenges with verbal communication**

Consultation meetings and carer interviews both highlighted that the person experiencing extreme BPSD often has very limited ability to communicate, some having lost their ability to communicate through speech. If English was not their first language, they may have lost language skills, making it harder to communicate and understand, and exacerbating behaviour. One carer described that the person with dementia had lost all English language skills despite completing post graduate qualifications in Australia. This symptom has been described in research\(^{33}\).

One carer described how, although the person with dementia had lost their ability to speak during the time when their changed behaviour was more extreme, they began to use verbal language again after this time finished.

**Relatively younger males are more at risk of experiencing extreme BPSD, which may be related to their physical strength**

Brodaty et al. described people experiencing extreme BPSD as generally male and under the age of 70\(^1\). The person experiencing extreme BPSD was described in consultation meetings as more physically robust, often a male of a relatively younger age (e.g. 55-75) than the wider group of people with dementia. Although there may be more males in this group, there were females reported. This was discussed as being related to their physical size and strength, and therefore the impacts of their aggression on others, rather than being linked to differences in how dementia affects them or their level of agitation. In one Older People’s Mental Health (OPMH) inpatient unit, five out of six (83%) people experiencing extreme BPSD over a ten year period were male. In an Aged Health unit in another district, three out of five (60%) people experiencing extreme BPSD in the first five months of 2020 were male.

While the carer interviews were not of a representative sample, they also suggest that males are more likely to experience extreme BPSD. Five out of six interviews were of carers of males. The one female person with dementia was diagnosed with dementia at a younger age. Many were described by their carers as physically fit and strong.

Murphy et al. examined deaths from resident to resident aggression in Australian residential aged care facilities (RACFs). The majority of residents involved in aggression had dementia and a history of BPSD. They found that most (85.7%) exhibitors of aggression were male and were often younger than the target (mean age of 78)\(^{34}\).

Health services data identified 78 episodes of care in a five year period that were likely to be related to people experiencing extreme BPSD. 58% were male; 42% were female. They had an average age on discharge of 73 years old, with 22 out of 78 (28%) being under 65. Of these, 15 out of 22 (68%) were male. More information on this data is provided in Appendix 2.
People with some types of dementia and/or co-occurring mental illness may be more likely to experience extreme BPSD

Consultation meetings suggested that people experiencing extreme BPSD may be more likely to be diagnosed with vascular, frontotemporal or alcohol related dementia. Attendees at consultation meetings also identified that there were often other co-occurring mental health diagnoses and symptoms, such as delusions, psychosis and schizophrenia, that may have not been previously recognised. A sub-group of people with intellectual disability who develop dementia later in life was identified, a group that often has a history of institutionalisation. Consultation meetings also described several people who had experienced extreme BPSD who also had experiences of family violence, drug and alcohol use and possible personality disorders. There was some consensus that ex-footballers and boxers may be at greater risk, possibly linked to traumatic brain injury.

Carer interviews, while not representative, supported some of these hypotheses. For example, one person presented with dementia complicated by manic episode secondary to a stroke. Another had a history of anxiety and a diagnosis of post-traumatic stress disorder in middle age.

Murphy et al.’s examination of deaths caused by resident to resident aggression in residential aged care found a proportion of people exhibiting aggression had a diagnosis of schizophrenia\(^34\).

Consultation meetings suggested that people from Culturally and Linguistically Diverse (CALD) backgrounds, particularly refugees, may be at greater risk of extreme BPSD. This could be due to a history of trauma, dementia-related language loss and delays in seeking health care.

The person experiencing extreme BPSD may have complex physical health needs

Consultation meetings identified that people experiencing extreme BPSD may have multiple physical health conditions but are medically stable. Health services data also suggested that people experiencing extreme BPSD often have complex health needs. More than half of the patients in the data had more than ten comorbidities recorded.

People with extreme BPSD are highly likely to be prescribed a psychotropic medication and to have multiple trials of medications to help manage changed behaviour over a long period of time. This means they are at significant risk of iatrogenic illnesses.

Extreme behaviours may be part of end-stage dementia

Some consultation meetings suggested that for some people with dementia, behavioural symptoms can become extreme and persistent in the months before their death, described as “intractable agitation”. This may be related to the natural progression of dementia, but there is a lack of published research describing this phenomenon. While medication, including morphine, can be useful for management of pain and agitation, managing side effects can be challenging. One carer interview represented this situation. The person with dementia experienced increasingly severe BPSD in the last 18 months of their life. In the last nine months of their life they were hospitalised and it was only as their physical health and cognition declined that their changed behaviours were no longer difficult to manage in the hospital environment.
Extreme behaviour can strain or worsen already strained family relationships

The people with dementia who were discussed in consultation meetings frequently had a history of violence, including domestic and family violence and in some cases sexual assault. Consultation meeting attendees reported that it was common for people experiencing extreme BPSD to have strained relationships with their families. The NSW Public Guardian was often involved. People experiencing extreme BPSD may be taken by police to hospital and be made an involuntary patient under the Mental Health Act, which is traumatic for the person, their family and any other observers of this event.

The process of recruitment for carer interviews illustrated these strained relationships. Many services reported that they could not identify any carers that would be able to be interviewed and that a lack of involvement of family members in the care of people experiencing extreme BPSD was common.

In contrast, the carers that were interviewed showed signs of strong family support and reported that this was important when navigating aged care and hospital services.

“Communication is the point that was frustrating. But now I am used to it and know how to deal with them”

Carers and other family members are affected by extreme BPSD

Interviews with carers highlighted the impact that the person with dementia had on them and on other members of the family. This included practical, emotional, occupational and financial impacts.

Families were often providing significant personal care and other support. One spouse recalled a time with their partner at home:

“It was so dangerous. My daughter and I kept watch over her for 24 hours per day.”

One carer, when talking about their father, said:

“I think Mum copped a lot. She cried a lot... My younger brother, because he was the last one who used to live (with parents), he was affected as well. Emotionally, it’s been a roller coaster for us”

One husband spoke about a particularly difficult time in hospital for his wife:

“I couldn’t look after my wife directly (due to her aggression), but I could watch her. I cried alot outside.”

Several carers highlighted struggling when the person with dementia moved from residential aged care to hospital.

“I said ‘I understand that you have to also look at the other residents’ safety... but you need to guide me as well.’”

The resilience and love shared in carer interviews is illustrated by this reflection of one family carer:

“One day I went to help John and he started beating my back with his fist. My back hurt a lot and I started thinking that if my back hurts like this, then John’s hand will hurt as well.”
Carers reported impacts on their work and other activities.

“I had to give up golf because I could no longer leave him at home... he wouldn’t accept being away from me.”

“I struggled. I lost a lot of weight. I was really stressed. My business suffered. My patience levels went out the door because I was so stressed, dealing with it all and having young kids.”

Carers interviewed were very involved in advocating for the person with dementia while they were in hospital and in aged care. This included visiting daily when concerned about the quality of care their family member was receiving. Both carer interviews and consultation meetings highlighted that many spouse carers are older themselves, sometimes making it more challenging to provide care.

While all people with dementia can be considered vulnerable group, people experiencing extreme BPSD are particularly at risk of their needs not being met. Many of the characteristics in this section contribute to this, including: an inability to communicate verbally and the absence of family carer involvement and advocacy.

People experiencing extreme BPSD can be made more vulnerable when services are not able to meet their complex needs. They may be prescribed high doses of medication for long periods of time, they may have impaired access to physical health care and have their movement and activity restricted to protect the safety of others.

**This situation is challenging for the people experiencing extreme BPSD**

We asked several carers to describe what this experience has been like for their family member and what they would want NSW Health to know:

“The feelings that he must have had. That he was scared. He thought he was going to die, going to drown.”

“He would say ‘It’s bloody awful. It’s embarrassing. I never wanted anyone to have to wipe my bum.’”

“He’d say to me ‘am I a baby? Why are they treating me like this?’
Mr Brown

This persona was developed to illustrate some common characteristics of people who have experienced extreme BPSD, and is based on clinical experiences with multiple patients in NSW Health services.

**Personal history**

Mr Brown, now 63, was born in Ireland. When he was six, after the death of his father, he migrated to Australia with his family. He did not speak until aged 7. His mother remarried but this relationship was marred by his stepfather’s alcoholism and violence.

Mr Brown worked as a labourer and security officer before achieving some success as a professional footballer and then professional boxer. In his forties and fifties he worked intermittently as a storeman but had difficulty sustaining employment in the context of increasingly heavy alcohol use.

He married and had four children. He is currently estranged from his daughters and has limited but supportive contact with his two sons. A public guardian was appointed during this admission because of ongoing conflict between his wife and children.

**Health history and health service use**

Mr Brown has experienced six years of disinhibited behaviour, including aggression towards his wife. He was diagnosed with frontotemporal dementia (FTD) two years ago during a three month admission to a private hospital. During this stay Mr Brown also received treatment for post-traumatic stress disorder and depression.

At home, Mr Brown became increasingly violent towards his wife, including demands for alcohol and sex during the night. His wife had been unable to leave him alone as he would walk around their neighbourhood, bringing back toys that had been left for kerbside collection. His wife had also found a number of tools which she suspected had been stolen.

Respite care for Mr Brown was arranged in a local RACF. After two days the facility called an ambulance because Mr Brown had threatened to kill an elderly confused man who had mistakenly gone into his bedroom. Although Mr Brown was calm while in the hospital Emergency Department, when he was asked about his behaviour he told the registrar that he would “punch the f*** out of the old man” if he tried it again.

The team in the Emergency Department conducted a physical assessment and concluded there was no medical cause for Mr Brown’s behaviour. Mr Brown was returned to the RACF.

Mr Brown continued to have episodic agitation and was returned to the emergency department several more times without an admission to hospital. On one occasion, Mr Brown threw a fire extinguisher through a window at the facility and staff were barricading themselves in the nurse’s office for safety. Police were called and transferred him to the Emergency Department. He was admitted to the OPMH Acute Inpatient Unit where he has been a patient for 17 months.
Current behaviour and management

Mr Brown continues to have daily outbursts of aggressive behaviour. Mr Brown is also at risk of being assaulted by other patients in the unit. Mr Brown has received care in the Mental Health Intensive Care Unit on several occasions for extended periods. Seclusion has sometimes been used to reduce the risk of serious harm to both staff and other patients in the intensive care unit.

Mr Brown often cannot explain his behaviour but appears to feel threatened by other people in the unit and complains that they want to hurt him. His difficulty communicating often leads to his misinterpreting the intentions and actions of others. Mr Brown has caused damage, including broken doors and windows in the unit, damage to flooring in a seclusion room within the Mental Health Intensive Care Unit and damage to mattresses.

At times Mr Brown's physical and verbal aggression may have been due to medical reasons including pain and constipation. At other times his aggression may be due to psychological and environmental factors. He is particularly sensitive to large numbers of people and noisy environments. Mr Brown can be sexually disinhibited towards female staff and on one occasion attempted to drag a female staff member to his room.

While Mr Brown has a 1:1 nursing special during the day, staff safety has also been maintained by not allowing any staff member to be alone in a room with him. At all times Mr Brown is within line of sight of the staff. Some members of the nursing staff describe high levels of anxiety regarding working with Mr Brown, and more than one staff member has cited this as a reason to resign from their positions.
The number of people experiencing persistent extreme BPSD in NSW
Estimating extreme BPSD is not straightforward

This project confirmed that estimating the prevalence of extreme BPSD is not straightforward. There are three key reasons for this:

1. A range of factors, including the care environment, will have an impact on the severity of a person’s behavioural and psychological symptoms.

2. The interpretation of symptoms as ‘extreme’ is somewhat subjective.

3. Individuals with dementia move between tiers of BPSD over time.

The consultation meetings identified many specific challenges with estimating prevalence, including:

Over-classification can occur when suitable services are not available: Consultation meetings suggested that even health professionals working with people with dementia may over-classify people experiencing severe and very severe BPSD as extreme in these circumstances. This can lead to the label of extreme BPSD being applied to people who have needs that overwhelm the ability of the service to cope.

Physical health influences behavioural and psychological symptoms: Temporary extreme behavioural and psychological symptoms can emerge due to a delirium caused by a physical health issue such as an infection, or related to medication. When physical health issues are resolved, this may reduce behavioural and psychological symptoms. The focus of this project is people experiencing extreme BPSD that does not resolve in response to first line treatments. Although larger numbers of people will seek healthcare for acute behavioural disturbance, the majority will resolve within weeks with first line treatments for delirium and psychosis.

People experiencing less severe symptoms may fluctuate up to an extreme level: Some services reported that while persistent extreme BPSD was rare, there was a larger group of people experiencing severe BPSD who have shorter periods of extreme unpredictable behaviour. This means there is likely to be a period of time in which it is not clear whether extreme behaviours will persist or if these can be resolved through medication, environment or other approaches.

Differences between residential aged care and hospital environments influence severity of BPSD: A patient experiencing extreme BPSD in a residential aged care facility (RACF) may not display these behaviours in a hospital setting with individual patient specialising and other care arrangements. Justice and Forensic Mental Health Network reported that patients who may have experienced extreme BPSD outside of the justice system are at a lower level when in a corrections environment. While in this setting, people with dementia are supported by familiar staff and routines, are within a restricted physical environment, and may decline physically, so that when they are released they are experiencing a lower level of BPSD.

Conversely, a patient experiencing a lower level of BPSD in a home-like environment may have more extreme BPSD in a hospital environment. One carer explained that during the same period while their family member was aggressive in residential aged care, when they came back to the family home for a visit, they were confused but not aggressive.

There is no reliable administrative data recording BPSD: BPSD is not a diagnostic code, so it is not straightforward to identify people in this group through routinely collected health information. In addition, because people experiencing extreme BPSD are receiving care in a variety of settings, it is difficult to collect estimates directly from services.
**Between 30 and 60 people in NSW will be experiencing persistent extreme BPSD at any point in time**

Taking into consideration the significant challenges in estimating prevalence, the project did estimate the number of people experiencing persistent extreme BPSD in NSW. During consultation meetings, we collected estimates from various aged health and older people’s mental health (OPMH) services to create an estimate of prevalence in NSW. This produced a prevalence estimate of 34 people in 2020 in NSW. These estimates were based on clinicians’ evaluations of the people using their services. In some cases the estimates were later verified through a more systematic approach using medical records and incident logs. The basis of these estimates is described in Appendix 4 Detail of prevalence estimates from consultation meetings. Although this approach has significant limitations, to the best of our knowledge, this is one of the first empirical estimates of extreme BPSD prevalence.

Brodaty et al. estimated, based on clinical observations, that less than 1% of people with dementia will experience very severe BPSD and noted that extreme BPSD is ‘rare’.

The National Mental Health Service Planning Framework estimates the population of people requiring a health service that provides very long stay non-acute intensive hospital service. The framework adopts an estimated prevalence for the most extreme level of BPSD of 1.7 people per 100,000 people over 65 years, or 0.0017%. This corresponds to 0.025% of the population over 65 with BPSD. Using HealthStats NSW population projections, the framework suggests that there will be 24 people in 2020 and 31 people in 2030 requiring hospital services due to extreme BPSD in NSW.

Deloitte Access Economics have estimated that the prevalence of dementia will increase significantly in the next decade, including a 70% increase between 2020 and 2030. There has been no research that confirms whether rates of BPSD would also increase at the same or similar rates. If the number of people experiencing extreme BPSD increases at the same rate as the dementia prevalence estimated by Deloitte, the numbers in NSW could be as high as 58 people by 2030.*

There is a larger group of people with severe, but not extreme BPSD, requiring inpatient hospital services

This project is recommending LHDs develop their capacity to provide inpatient hospital services for people experiencing extreme BPSD. These services are likely to also be providing care for the larger group of people experiencing severe, but not extreme, BPSD.

The National Mental Health Service Planning Framework estimates the population of people 65 and over requiring acute mental health inpatient care related to BPSD across NSW to be 92 people per year, which is significantly more than the estimate for those requiring acute hospital care related to extreme BPSD.

* Applying a 70% increase to the estimate of 34 people made through consultation meetings.
Improving services has the potential to reduce the prevalence of extreme BPSD

Brodaty et al. highlighted that appropriate and effective interventions in less severe BPSD (the lower tiers of the 7-tiered triangle) could be expected to reduce the numbers of people experiencing more severe or extreme BPSD

Carer interviews, although small in number, support this. Carers reported that the hospital environment was the situation where the person's behaviour was at its most extreme and frequently described how services could have managed behaviour better. Consultation meetings also suggested that improvements to in-reach support to residential aged care, particularly by geriatricians, old age psychiatrists and BPSD specific services, can play a role in reducing escalation of BPSD.

We suggest that with improvements highlighted in this report, the level of distress and agitation experienced by people with dementia can be reduced. This will not eliminate extreme behaviours or long hospital stays, or reduce the need for comprehensive, iterative assessment and care planning, but it may reduce the severity and frequency of extreme changed behaviours and has the potential to reduce the number of people in NSW who fall into the definition of extreme BPSD.
How people experiencing extreme BPSD use NSW health services
**NSW Health provides services for people experiencing extreme BPSD in both aged health and mental health units**

Consultation meetings found that NSW Health provides hospital care for people experiencing extreme BPSD in both Aged Health and Mental Health units. There were no services specifically targeted at people experiencing extreme BPSD identified in consultation meetings. Usually these services are also providing care for people experiencing less extreme BPSD (severe and very severe).

Consultation meetings highlighted that available services vary significantly between districts, particularly based on whether the district direction was to care for people experiencing severe BPSD in aged health or mental health services. For example, some older people’s mental health (OPMH) inpatient units accept people experiencing extreme BPSD and some do not.

**NSW Health services providing care for people experiencing extreme BPSD**

These services were identified during consultation meetings and the list is not exhaustive.

- Hospital emergency departments
- Mental health intensive care units, often with relatively long stays
- Aged health inpatient services including acute wards and units with a focus on delirium, dementia and behaviour.
- OPMH acute inpatient units
- OPMH non-acute acute inpatient units, including T-BASIS units
- Adult mental health acute inpatient units

Carer interviews identified that people experiencing extreme BPSD may also spend time in general medical wards. These interviews, input from key informants and feedback on the draft report all suggest that many of these wards do not offer a suitable physical environment or staff with the skills to provide appropriate care. These environments have been reported to exacerbate behaviour and can lead to a focus on reducing distress through medication and restraint.

The analysis of health services data for people potentially experiencing extreme BPSD provides some insights into the health services used by this group. Episodes of care covered one or more wards. An analysis of the last ward for each episode showed a mix of both mental health and medical wards, some of which were aged health units. More information on this data is provided in Appendix 2.

**There are some specific units, services and approaches for managing BPSD**

Some aged health services have been established specifically to manage patients experiencing BPSD, including extreme BPSD, such as the Aged Care Extension Ward in Prince of Wales Hospital and the Killara unit in Sutherland Hospital in South East Sydney. Other services accept these patients when no other services are available.

Three districts have OPMH non-acute T-BASIS inpatient units targeted specifically for people with severe BPSD, and these units cater to some people with extreme BPSD. Within OPMH services, the T-BASIS unit model of non-acute inpatient care for people with severe BPSD was noted as a positive model to build on, with good links to residential aged care.
Some districts identified specific service initiatives for people with dementia that assist in care for people experiencing BPSD. For example, the Central Coast district has an aged health led Dementia and Behaviour Support Service and monthly joint OPMH-aged health BPSD-focussed grand rounds meeting to review patient cases.

The Hospital Dementia Services Project found that NSW hospitals with both an older people's mental health and an aged health service had the highest levels of dementia related services. The project also found that hospitals with neither aged health services nor older people's mental health services had clinics for dementia assessment or secure beds. The same project found rural hospitals had fewer secure beds for providing care for people experiencing BPSD.

A survey of state-funded older people's mental health services in Australia for people with very severe and persistent behavioural symptoms found wide variation in services. The authors argue for further examination of existing services and comparison of service outcomes based on clinical indicators such as prescribing patterns, re-admissions and consumer and carer experiences.

People experiencing extreme BPSD take a variety of paths through community, aged care, disability and hospital environments

Consultation meetings discussed the most common pathways into NSW Health services. This included a common scenario of the person experiencing extreme BPSD being taken to hospital from a RACF, sometimes through the emergency department (ED). For some people with dementia this was not long after moving from home to a RACF where more extreme BPSD emerged, possibly due to this transition or the change of environment triggering or exacerbating behaviour. In some cases the person had been refused entry to or removed from a facility. Some examples of people experiencing extreme BPSD, usually associated with younger onset dementia, living in NDIS funded supported living and specialist disability accommodation (e.g. ‘group homes’) were discussed in consultation meetings.

Although carer interviews were not representative of the wider group of people experiencing extreme BPSD, the care pathways of people experiencing extreme BPSD during the time of behavioural changes give some indication of the variation of experiences and service responses.

### Example care journeys taken by people experiencing extreme BPSD

These services were identified during consultation meetings and the list is not exhaustive.

- Home > Generalist residential aged care > Hospital aged health unit > Specialist residential aged care
- Home > Generalist residential aged care > Ambulance to ED > Hospital aged health unit > Generalist residential aged care
- Home, with some in-home aged care > Ambulance to ED > General medical ward > Older people's mental health acute inpatient unit > Specialist residential aged care
- Home > Hospital aged health unit > Home > Hospital aged health unit (same) > Generalist Residential aged care
- Home > Hospital > Generalist residential aged care > Generalist residential aged care (different) > Hospital
- Home, with some in-home aged care > Generalist Residential aged care > Hospital aged health unit > Generalist Residential aged care (different)
- Home > Hospital > Specialist Disability Accommodation
- Home > Hospital > Home > Hospital

Consultation meetings discussed that it was less common for community based teams to identify someone living at home experiencing extreme BPSD. This can occur when a family ‘hangs on’ for a long time when a person’s dementia is progressing. One
consultation discussed a situation where a carer would need to lock herself in the bedroom to be safe from her mother’s violence. Often these families are known to police and it is police that bring the person with dementia to hospital.

There may be people experiencing extreme BPSD who enter the forensic system after committing a serious offence. It is not known how many people fall into this group.

One service hypothesised that the numbers of people they were seeing were increasing due to both increasing aged population and people staying at home longer, rather than in residential aged care, as they age. They may be receiving services through aged care when at home, but struggle to get appropriate support when behaviours worsen.

One carer described their experience caring for their spouse at home as their dementia progressed and their aggression increased. One of the key reasons for staying at home was the attachment that the person with dementia had to their spouse, right up to the point of having to use a family or disabled toilet facility when out together.

“It is sad and unfair for residents to be subjected to people with extreme behaviours in their home.”

A small number of specialist RACFs are able to admit some people experiencing severe-very severe BPSD, and these facilities are not generally able to manage someone experiencing extreme BPSD. Those involved in consultation meetings described not being able to manage people who target their aggression to specific other residents.

Carer interviews described experiences of residential aged care calling an ambulance when they could not manage aggressive behaviour. For some, this resulted in a long stay in hospital, for others it was a repeated event, which would result in the carer spending the night with the person with dementia in hospital, and returning to the aged care facility the next day. For one person with dementia, this occurred four times in a three week period, closely followed by a longer stay in hospital.

When behaviour has become less extreme, people can move to residential aged care. This was described in consultation meetings occurring when:

- physical health issues, such as pain or delirium caused by an infection, are resolved;
- medication and behavioural strategies are effective to reduce the severity of behavioural symptoms;
- the person becomes more frail, or experiences a physical health event such as a stroke, so that their behaviours do not pose as much of a risk to others.

People experiencing extreme BPSD often move between hospital and residential aged care

Many people experiencing BPSD will be cared for in residential aged care, however consultation meetings discussed that someone experiencing persistent extreme BPSD is unlikely to be admitted to residential aged care. It is more likely that a RACF would have a resident whose behaviour becomes extreme on occasion. Consultation meetings consistently identified the role of NSW Health services in providing care for people when their changed behaviour was not able to be managed in residential aged care. This may follow one or more incidents of physical and/or sexual assault. The impact of extreme behaviour on other residents in residential aged care was described in one consultation meeting:
RACF types that may provide care for people experiencing moderate-severe BPSD

These services were identified during consultation meetings and the list is not exhaustive.

- Generalist RACFs, including some that have expertise in providing care for people with dementia
- NSW Health-operated RACFs (State Government RACFs), such as Garrawarra in South Eastern Sydney
- Specialist mental health aged care partnership initiative (MHACPI) transition units in RACFs that receive top up funding from NSW Health and have partnerships with older people’s mental health services.

Since the consultation meetings were held, the first NSW specialist dementia care unit (SDCU) has opened as a part of the Australian Government-funded Specialist Dementia Care Program. The SDCU model is similar to the NSW MHACPI transition unit model, but is dementia-specific, and is expected to be further expanded across NSW and nationally.

Families and carers can be partners in care

Consultation meetings identified that some families are very involved in care, involving weekly meetings to discuss care. They also described many people experiencing extreme BPSD who were estranged from their families and had minimal social support.

Interviews with carers described the involvement of family members in care while in hospital. During a hospital stay of many months, one spouse visited every evening for multiple hours, bringing dinner and watching videos together. Carers described their involvement in medication decisions, personal care and planning for discharge. This was particularly for the use of PRN medications when permission from the family member, as the person responsible, was required. Some carers were called at various times of day and night to talk to the person with dementia as a strategy to manage behaviours in hospital.

People experiencing extreme BPSD have very long hospital stays

Consultation meetings confirmed that long length of stay in hospital was very common. One attendee at consultation meetings summarised this as “at least one month and up to one year”. Key informants have identified several individuals experiencing extreme BPSD who have spent longer that one year in acute inpatient units. When one older people’s mental health inpatient unit reviewed their records for people experiencing extreme BPSD over a ten year period, they recorded lengths of stay between 132 and 438 days.

Interviews with carers described hospital stays that ranged from two weeks to nine months, consistent with the information shared in consultation meetings. In all of the long hospital stays the main reason was the lack of options for longer term care. During the stay, it is likely that several different medications will be trialled to assist with managing changed behaviours.

In the health services data, obtained for episodes of care with a length of stay of at least 42 days, half of the episodes had a stay of 72 days or more. One quarter were longer than 125 days and the longest stay was 489 days. The data also suggested that long hospital stays can impact the health of the person; hospital acquired comorbidities were recorded for just over half of episodes represented by the data. More information on this data is provided in Appendix 2.
Hospital care for people experiencing extreme BPSD requires significant staff time

Consultation meetings discussed that people experiencing extreme BPSD frequently require high staff numbers while in hospital. One example was a patient requiring nine staff members for personal care. Individual patient specialling (IPS) is commonly used and can place a financial strain on the service. Key informants shared one example of a nursing team increasing by over three full time equivalent staff to provide care for one person experiencing extreme BPSD.

Security staff are in place in some services for as much as 24 hours per day. Both of these practices are expensive for health districts. One unit reported their monthly costs for security services was $40,000. Considering the long periods of time that people experiencing extreme BPSD can spend in hospital, many districts are using significant resources to provide this care.

Senior staff members often spend additional time on the complex clinical assessment and management of a person experiencing extreme BPSD and also on difficult decisions of how best to manage their impact on staff, other patients and the operation of the unit, such as time managing additional compliance requirements due to work safety concerns.

Consultation meetings also discussed the high costs that some districts are incurring related to staff time off work and worker’s compensation claims related to caring for people experiencing extreme BPSD.

Providing care is challenging for staff working with people experiencing extreme BPSD

Providing care for people with extreme BPSD has an impact on staff, particularly due to the high risk of significant assaults. Stories were shared in consultation meetings of units that had very high injury rates and large amounts of compensation paid to staff. Several examples were shared of people experiencing extreme BPSD being involved in an average of one violent incident per week; and often responsible for serious injuries to staff during their stay in hospital.

Some services reported industrial action. Stories of staff burnout were frequently raised in consultation meetings and examples shared of multiple staff members leaving units citing the impact of a single person experiencing extreme BPSD. Research has linked violence at work to depression, secondary traumatic stress, burnout and compassion fatigue. When staff are impacted, this can have a negative impact on patient care.

One nursing unit manager provided this example:

“We had one man (experiencing extreme BPSD) and he escalated the behaviour of some other male patients. There has been a huge impact on staff who have felt anxious prior to coming to work, on edge when at work, and worried that they will go home injured. We had several staff members leave and a number of worker’s compensation claims.”

Implementing the recommendations in this report may assist in preventing violence in hospital associated with this patient group and increasing the safety of patients, staff and others. A project in an older people’s mental health ward in the UK was able to reduce physical violence by 50% using a series of interventions in line with the recommendations of this report (e.g. physical environment changes, increased meaningful activities).
Staff may also experience negative impacts unrelated to violence. For example, when staff have to make difficult decisions and perceive that there are no appropriate options or pathways for the person with dementia. One consequence can be therapeutic nihilism, after significant clinical effort is made and the person with dementia is not perceived to improve.

**Bed availability in a unit can be reduced in order to meet the needs of a person experiencing extreme BPSD**

During consultation meetings and follow up conversation, strategies were shared that involved reducing the number of patients in a unit in order to provide safe care for a single person experiencing extreme BPSD and other staff and people in the unit. This included:

- Having a person experiencing extreme BPSD occupy a two-bed room as no single bedrooms were available
- Reducing the capacity of a unit to ensure sufficient staff numbers were available to meet the needs of the person experiencing extreme BPSD
- Leaving other rooms off the same corridor unoccupied so that the person experiencing extreme BPSD would be the only occupant of that physical space.

These strategies all have an impact on bed availability, occupancy and efficiency in inpatient units managing people experiencing extreme BPSD.

**The physical environment of inpatient units can be damaged by behaviour of people experiencing extreme BPSD**

Damage to windows, doors, furniture and other spaces was frequently recalled in consultation meetings and by key informants. In one example, during the stay of one person experiencing extreme BPSD there were repairs required to 1 window, two doors and two mattresses. The unit secured $15,000 additional funding for changes to the unit to make it more dementia-friendly and prevent further damage.
Key aspects of high quality care
This project used the opinions of health professionals and carers of people experiencing extreme BPSD to identify the characteristics of high quality care and some of the challenges services are facing in providing quality care. These are described in this section, combined with what is known from current service models, policy directions and published literature.

The need for more appropriate care for people experiencing extreme BPSD is well recognised

Attendees at consultation meetings were generally aware of the challenges of providing appropriate care for this population and motivated to assist this project to drive improvements. Success stories were shared, including successful transitions for people who had been in hospital for 12 months or longer.

The teams from each district generally believed that their district needed capacity to assist people who experience short periods of very severe and extreme behaviour. Due to small numbers, attendees suggested that a whole unit or ward dedicated to only this group was not feasible. Key informants favoured an approach ensuring appropriate bed capacity, unit design and configuration, staffing and care processes within existing inpatient units to enable a ‘step-up step-down’ model of care. While some regional health districts do move people to larger centres, this takes them away from family and community and was discussed as not being ideal. In this context, the benefits of having capacity within the district were discussed.

Another way that this idea was discussed was each Local Health District (LHD) developing an extreme BPSD response plan, describing what should happen for a person experiencing extreme BPSD, including how aged health and older people’s mental health services should work together. This plan could also address how to help staff, residential aged care facilities (RACFs) and families navigate these services.

One attendee explained that they understood that services that can cater for people experiencing extreme BPSD were expensive to run:

“it is incredibly space and resource intensive, but there is no way around it.”

Carers also explained that improving care was important to them:

“I hope that something does come out of it. That they fix something. That they realise that they need to put more money into it. More people should be working there too, so that they have the ability to treat each one of these dementia patients with dignity and attention. Not just as someone sitting there. That’s what I feel.”

“his quality, that’s our goal: to make sure that he has a better quality of life”

“Isn’t there a dementia place where dementia patients come into hospital where there is more specific care nurses for their sort of illness? That know how to deal with them. Rather than pushing them into a normal hospital ward where they had to care for a number of patients with a number of illnesses.”

A literature review of units providing care for people with extreme BPSD identified common elements of quality care

The Sax Institute completed a review of evidence regarding the management and care of people with very severe and extreme BPSD. The review included 25 publications about 17 units in Australia and other comparable countries. The review reported little consistency in findings across these studies. The authors also found that evidence of effectiveness in managing very severe-extreme BPSD was limited, with only one study identified as being relevant to this group and also based on a good study design.
The review identified eight common elements of quality care:

1. Unit philosophy/approach to care
2. Supportive physical environment
3. Education, skills and training
4. Medical staffing
5. Allied health staffing
6. Therapeutic and meaningful activities
7. Assessment and care planning
8. Multidisciplinary approach.

The findings of this review have been considered in developing the key aspects of high quality care for people with extreme BPSD in this project.

The T-BASIS service model can inform service improvements

There are three T-BASIS units in NSW providing transitional or non-acute inpatient care for older people with severe BPSD and/or mental illness. The model of care is included in Appendix 5 and includes many of the key aspects of high quality care developed in this project.

The evaluation of T-BASIS units found that when fully implemented, "they are a cost-effective way of assessing, managing, and successfully discharging people with complex challenging behaviours".

In recent years T-BASIS units have provided care to people experiencing more severe levels of BPSD, due to a re-focussing of their role and improvements in other services that support people experiencing BPSD to remain in residential aged care. Consultation meetings suggested that T-BASIS units are providing care for some people experiencing extreme BPSD but they may experience challenges when they do not have appropriate medical support for this complex group of people. Some units have been co-located with older people's mental health acute inpatient units.

The model of care and the experiences of T-BASIS clinicians provides a foundation to build on. Services providing care for people experiencing more extreme BPSD will require access to acute medical care in combination with many of the clinical processes and practices that have demonstrated effectiveness in T-BASIS units.

Expansion of other existing models of care was discussed in consultation meetings. This includes suggestions that each LHD should have access to a mental health aged care partnership (MHACPI) transition unit or Specialist Dementia Care Unit and that Older People's Mental Health inpatient units can provide appropriate care when they are resourced and designed to do this.

There are interactions and interdependencies between elements of good practice care

Findings from consultation meetings and carer interviews suggest that elements of good practice care need to be considered as a whole. Improvements in one are required to drive improvements in other areas. Enhancements in some areas can be used to overcome challenges in others. For example:

- Governance arrangements can stifle or enable multi-disciplinary assessment and care planning
- Limitations in a service’s physical environment may be able to be overcome by more staff while capital projects are developed
- A lack of trained staff disrupts the consistent use of behaviour management approaches
- An inappropriate physical environment may make safe participation in meaningful activities difficult
- A physical environment that can be divided into separate areas for walking and other activities can allow a different mix of patients to one where no separation is possible.
- Improved partnerships between health and aged care services can improve transitions out of inpatient services and ensure hospital beds are available when needed.
A review of non-pharmacological interventions for BPSD highlights the importance of the physical environment, the social environment, and ongoing staff education and training to their effectiveness42.

**Philosophy of care**

**Recommendations:**

**Philosophy of care**

- Adopt a person centred, trauma informed approach to care
- Protect the rights of people experiencing extreme BPSD and their families
- Plan specific responses for priority populations, including Aboriginal people and people from CALD backgrounds
- Invest in ongoing service improvement including through collaborative research

**Person-centred care is vital for this group**

Person centred care for people with dementia is built around the needs of the individual and relies on fostering an interpersonal relationship with the person with dementia43. Recognition of personhood, respect and trust are all essential. The benefits of this approach include reduced agitation, decreasing behavioural symptoms and reduced psychotropic medication use44. There is also some evidence suggesting that these approaches have a positive impact on staff wellbeing45. Although most research into person centred care has taken place in residential aged care settings, there is still evidence to support the implementation of person centred care in hospital settings46,47.

Stakeholder review of the draft project report emphasised the importance of person-centred care. Services can seek guidance from tools and frameworks successfully implemented in residential aged care. For example, the Caring Conversations framework48.

**A trauma informed approach can support quality care**

This project found that many consumers had a history of trauma, including trauma related to the care provided in health and residential aged care related to their BPSD. Carer interviews also highlighted the role of trauma in their experienced with BPSD.

Trauma informed care and practice will support services to be sensitive to the impacts of trauma and the risk of re-traumatisation for people experiencing extreme BPSD and their families and carers. Trauma informed approaches also reduce the risk of vicarious and secondary trauma for staff members. The TICPOT Toolkit is one resource that can support services to improve their practice49.

Services for people experiencing extreme BPSD can be involved in facility or LHD wide initiatives to improve service culture and should be considered high priority for initiatives in these areas.

**The rights of the individual must be upheld through relevant sociolegal frameworks, policies and safeguards**

The project found that people experiencing extreme BPSD are at risk of discrimination based on their age and their symptoms. Services must recognise the rights of the person experiencing extreme BPSD to quality health care.

Concerns were raised during consultation meetings, carer interviews and in feedback on the draft report that complex sociolegal issues were not always well managed. These issues include processes around consent, guardianship and involuntary patient status. Legal frameworks, policies and safeguards differ between aged care, aged health and mental health settings which adds complexity. For example, the Official Visitors Program allows mental health consumers, their families and carers and appointed official visitors to identify issues related to patient safety, care or treatment. There is no similar program outside of mental health services. Volunteer programs for people with dementia in hospital have excluded
people experiencing extreme BPSD due to safety concerns. It is beyond the scope of this project to develop specific guidance on sociolegal issues. Services should ensure that relevant processes are documented and followed consistently.

Carer interviews highlighted that many family members played a significant role in advocating for the person experiencing extreme BPSD. Consultation meetings also suggested that many people experiencing extreme BPSD do not have involved family or friends to play this role. The potential role for patient advocates for people experiencing extreme BPSD should be considered, because:

- Many do not have strong family or other social connections
- They are likely to have cognitive decline and limited verbal communication
- They may need to navigate both health and aged care

Services need to ensure that high quality care that upholds the rights of the individual is provided to all patients.

**Meeting the needs of people from priority populations is critical**

Services need to ensure they meet the diverse individual needs of people experiencing extreme BPSD. Aboriginal and Torres Strait Islander Australians experience dementia at higher rates and younger ages than other Australians. Research also suggests that social risk factors for dementia for Aboriginal Australians may include childhood trauma and a history of un-skilled work. Medical risk factors may include a history of stroke, head injury and epilepsy. Dementia may be differently understood Aboriginal communities and there may be specific obstacles faced by Aboriginal people with dementia accessing culturally safe care. The project found no research specific to the experiences of BPSD or opportunities to improve care for Aboriginal people experiencing BPSD. Review of the draft project report with the NSW Older People’s Mental Health Aboriginal Working Group suggested that receiving care close to family, community and country may be specifically important for Aboriginal Australians. Hospital care may be re-traumatising for older Aboriginal people who have experiences of institutionalised living. Culturally safe care for this group, including culturally responsive meaningful activities, is crucial.

The project consultations suggested that people from CALD backgrounds may be at higher risk of experiencing more significant BPSD and may be more likely to have a history of trauma that contributes to these symptoms. Research suggests that immigrant groups have particular needs for dementia care. There is a lack of research into the needs of CALD consumers with dementia in a hospital setting, but services can be guided by research in residential aged care settings. For example, long hospital stays may exacerbate the impacts of culturally unfamiliar food. Consumers are likely to require extensive interpreter use to support iterative assessment and meaningful activities while in hospital. Although carers and family members can be valuable partners in care, they do not replace the use of interpreters.

**A planned quality improvement program within each service will support cultural change**

Existing services for people experiencing extreme BPSD will be improved through focused effort on change. New services can be established with a culture of ongoing quality improvement. The Clinical Excellence Commission provides tools and resources to support quality improvement and patient safety initiatives. The Safer Wards project demonstrates how quality improvement initiatives can be successful in hospital settings to reduce violence and associated costs. Staff time needs to be set aside by services to support these initiatives. Services should consider publication of the results of their quality improvement initiatives. Connections between services throughout NSW will help to disseminate results widely.
Target population

Recommendations:
Target population

- There must be capability to manage a mix of people with different levels of BPSD, particularly severe-extreme BPSD.
- In services specifically for people experiencing extreme BPSD, limit admissions and protect capacity when required to manage one or more people experiencing extreme BPSD so that the unit can provide appropriate care.

Getting an appropriate and manageable mix of patients in one environment is challenging in current services

In many of the care settings discussed in consultation meetings, people experiencing extreme BPSD shared spaces with frail older people. Unpredictable aggressive behaviour is a significant risk for frail older people. Examples were cited where serious injuries resulted from this mix. Some attendees suggested that units caring for frail older people are not appropriate for people experiencing extreme BPSD for this reason. Murphy et al.’s examination of deaths from resident to resident aggression in Australia’s RACFs found most (60%) occurred in common areas and that this was consistent with other studies.

The combination of multiple patients experiencing BPSD of different types and severity is also a challenge. For example, a person with dementia who regularly screams for long periods of time can trigger aggressive behaviour for a person experiencing extreme BPSD.

Gender is often a factor in this mix. Consultation meetings discussed females who interpreted any approach from a male as a confrontation and some males who had less aggressive behaviour in all male units.

The patient mix also has an impact on visitors. Visitors of other people in the same physical environment may need to be restricted for their own safety.

Some services described strategies to ensure they only had one person experiencing extreme BPSD in a unit at a time. This included deliberately dispersing people experiencing extreme behaviours to different aged health units and limiting admissions to reduce numbers. Other services reported they were not able to do this due to being at full capacity frequently. Some services suggested that having multiple options can assist with this. Specialist RACFs described using different cottages to separate people.

A situation was described of a single aged health unit having the ability to manage one or two people experiencing extreme BPSD, and this resulting in them having a reputation for doing so. The result is that they are saturated with people experiencing changed behaviours so that the unit loses their ability to provide quality care.

Maintaining target group integrity and protecting capacity

Discussion at consultation meetings highlighted the need to maintain the integrity of the target population and admission criteria for units caring for people experiencing severe-extreme BPSD, to ensure an appropriate mix of patients and ensure appropriate capacity to manage extreme BPSD when required.

Delays in admission can make a difference to the time a person experiencing extreme BPSD spends in hospital and to their longer term outcomes and quality of life. Key informants discussed the importance of protecting the capacity of relevant units when required to manage one or more people experiencing extreme BPSD so that the unit can provide appropriate care.

This is challenging as it can result in lower occupancy and therefore perceived under-utilisation of a unit. Strong clinical operational leadership will assist in protecting capacity in the medium and long term.
Governance arrangements and key functional relationships

Recommendations: Governance arrangements and key functional relationships

• Unit may be operated by mental health or aged health services, but should have clear clinical governance arrangements and clinical input from both older people’s mental health services and aged health services.
• Acute medical services are available to support people in a timely way and limit transfers and delays in receiving care.

The roles of aged health and mental health services are not clear, resulting in care that is inconsistent and difficult to navigate

One of the most common challenges identified in consultation meetings was people experiencing extreme BPSD fall outside of target population and current capacity of both older people’s mental health and aged health services. This is partly because their numbers in any one LHD are relatively small and is likely to be a key reason that targeted services have not been developed for this population. Consultation meetings often described having no pathways or options for people experiencing extreme BPSD.

This is a challenge for general practitioners, RACFs and family members when trying to seek help for the person experiencing extreme BPSD. People in consultation meetings reported that often multiple concurrent referrals are made. One attendee suggested that the path a person with extreme BPSD takes within a single hospital was variable, giving the example that a person coming to hospital on a weekend would be more likely to be admitted to mental health intensive care unit than if they came to hospital during the week.

Functions and clinical processes

Recommendations: Functions and clinical processes

• The unit needs to be able to provide iterative, comprehensive, multidisciplinary assessment and care planning.
• Family, carers and supporters must be engaged as partners in care
• Assessment will require the input of both aged health and older people’s mental health clinicians to address physical health and mental health dimensions of extreme BPSD.
• Care should reflect best practice for BPSD care, including physical health care, behaviour management strategies, psychological engagement, medications, and care for the carer\textsuperscript{18}.
• Therapeutic and meaningful activities that support individual choice and control should be available.
• Care must align to relevant seclusion and restraint policies and guidelines.
• Safety huddles can be a useful strategy for briefing staff on the incoming shift on changes in behaviour and patient management plans. Health and Security Assistants or other security staff who may be required to respond to the unit during that shift should be included in these huddles.

Assessment and Management of People with Behavioural and Psychological Symptoms of Dementia: A Handbook for NSW Health Clinicians (’The BPSD Handbook’)\textsuperscript{18} should be the starting point for NSW health professionals providing care for people experiencing BPSD, including in acute settings.
The BPSD Handbook describes priorities for care including addressing the person’s physical health care needs, behaviour management strategies, psychological engagement, medication and engaging with carers.

Consultation meetings revealed inconsistency in how care was provided, including in medication use and the role of physical segregation. One common characteristic discussed was that there are few, if any, treatments that seem to make a positive difference for people experiencing extreme BPSD. It has also been highlighted that some people with extreme BPSD may have had multiple unsuccessful trials of medication yet may still not have been prescribed the medication for which there is the best evidence of efficacy.

The use of PRN, or “as needed”, medications was discussed as a key reason why people experiencing extreme BSPD require an acute hospital environment. PRN medication use requires medical support in case a reversal is required. This was identified in consultation meetings as a specific barrier to a person experiencing extreme BPSD being cared for in a subacute hospital environment, or in residential aged care. Several carers explained that the regular use of PRN was a significant barrier to moving their family member to residential aged care.

Safety Huddles are a brief, focused and structured exchange of information about potential or existing safety risks which may affect patients, staff and any person accessing the healthcare environment. These may be a useful tool for inpatient units providing care to people experiencing extreme BPSD being cared for in a subacute hospital environment, or in residential aged care. Several carers explained that the regular use of PRN was a significant barrier to moving their family member to residential aged care.

The Sax Institute’s review of units providing care for people experiencing very severe and extreme BPSD identified assessment and care planning as a common element. Many of the units that were included in the review had implemented individualised and rapid assessment and care planning processes. This is also a key feature of the model of care of NSW T-BASIS units:

*Nursing and care staff being active participants in devising, monitoring, adapting and sharing biopsychosocial treatment strategies, with structures put in place to ensure this occurs* p 51

Carer interviews, although not representative of all services in NSW, did not suggest that families were always heavily involved in this assessment process. For example, some carers were aware that physical health causes were being looked for and that medications were being trialled, but did not have any deeper understanding of the approach being taken by their family member’s clinical team.

In other cases, carers described both the process and the outcomes of the hospital stay positively:

“I don’t think we could have had a better outcome... I think this is because the geriatrician and his team really put hard focus and depth on the patient case. And what he did, I liked this, he took every avenue and explored it. Even with the medications, he was very careful in how to apply it. He was very communicative, updating us and we could get calls from the nurses to update us.”

**Assessment is both crucial and difficult**

A thorough assessment was discussed in consultation meetings as requiring multi-disciplinary team input and an iterative approach over a period of time. This includes assessment of physical health issues that may be contributing to changed behaviour.

There was some suggestion in consultation meetings that comprehensive assessment was sometimes complicated by challenges such as:

- the reduced capacity for the person experiencing extreme BPSD to communicate
- overlapping co-morbidities including brain injury
- not having family involvement to contribute to the assessment
- difficulties with obtaining history if the person has moved frequently between different health and aged care services in different districts.
Partnering with carers and families

Consultation meetings raised the importance of engaging with carers and families formally and informally. Research that examines carer perspectives on acute hospital care found that their experience was more positive when carers were informed, involved and supported during the hospital admission67. Services need to value the skills and knowledge that carers can provide and the critical role they play in enabling person-centred care. They also need to consider the impacts of BPSD on the carer or family member including any history of domestic violence. Services should also seek to involve carers in service improvement initiatives using co-design approaches.

Carers explained in interviews the varying amounts of support they received in hospital. Some described being visited in hospital by many different people offering them help and support. Another highlighted that the only time the hospital offered them support was after they made a complaint regarding the care of their family member.

Several carers explained they were given very little information on BPSD when their family member was diagnosed with dementia. There may be an opportunity to improve support for carers through referral to non-government organisations (such as Dementia Australia) and community health services.

TOP 5 is one tool that has been successfully implemented for people with dementia. This tool uses up to 5 personal tips from carers to improve communication and promote personalised care58. This may provide a useful starting point for services looking to improve their partnerships with carers.

Behaviour management and psychological strategies need more consistent focus

Expert recommendations and guidelines for care for people experiencing BPSD prefer non-pharmacological approaches as first line approach and the continuation of these when medications are necessary18.

Many carer interviews gave examples of when behaviour management approaches did not seem to be in use.

“I don’t think anybody did that (talk to me about the person with dementia’s triggers for agitation and aggression), I certainly don’t think they did enough of that. I don’t think they saw it as their role because it was a general ward, even though there was one room with four beds set aside for people with dementia, who were difficult to handle.”

“They didn’t see it (behaviour management) as their role. Their attitude was that he didn’t have a physical problem they could handle.”

“I was over it. I said ‘I need to know what is going on. You can’t just keep putting my Dad on medication’. It got to the point that my Dad was like a zombie. He was literally sleeping walking around. He didn’t know where he was. He was totally incoherent.”

Other carer interviews suggested there may have been a gap between planned approaches and how these were used in the day to day care of patients in hospital, such as a communication folder about the person with dementia that the carer was surprised to learn existed, having seen no evidence of staff having an understanding of the person with dementia.

The consultation meetings discussed the use of medication in the management of extreme BPSD in hospital. Some carers described the care as being very focused on getting the medication right in order to get behaviour under control.
“I wonder if they just keep them sedated, or it just the dementia. When I ask them they say it is for his pain. But when I spoke to another wife, she had the same feeling.”

This concern extends to PRN, or “as needed” medications. Some consultation meetings suggested that medication might be overused. Many carers noted this as well.

“When it (use of emergency medication) got over the top, I jumped up and down and said ‘You lot are not trying to re-direct him enough. He gets out of hand and the first things you do is go to medicine’.”

This same carer noted that PRN medications were being used by some staff in anticipation of changed behaviours when medical interventions were necessary, while other staff were able to use behaviour management strategies for the same intervention.

Several carers identified flexibility in providing person-centred care as a particular difference between hospital and residential aged care, but also something that could be done in a hospital environment.

“Some nursing staff were able to work through it with him. They knew when he said no at times, it was no. They said if they could let it go, they’d let it go. But if it had to be done, it had to be done.”

There may be a lack of meaningful activities in some hospital services

The Sax Institute’s review of unit providing care for people with very severe and extreme BPSD identified therapeutic and meaningful activities as a common element of care, with some units describing that these activities were increased due to increased staffing.

Meaningful activities was a key theme in the design principles for the development of the South Australian neurobehavioral unit for this same target population. In this project, The Australian Centre for Social Innovation engaged carers and consumers to developed six design principles, reflecting what was important to carers for their family members with dementia. Several of these are particularly relevant:

Meaning and Purpose

“As the condition of the person I care for declines over time, I’ve noticed it’s become more difficult for them to do the things that create meaning and purpose in their life.

No matter what the future holds, it will always be important for them to connect with others, actively contribute and participate in life, and do the things that make them happy.”

Enabling Choice and Control

“The person I care for lives their best life when they don’t feel limited by the place they live and the people that surround them.

I recognise dementia presents many restrictions. However, minimising the degree they feel limited can go a long way towards enabling a sense of freedom, independence and a better quality of life. Their individual needs need to be recognised and supported.”

None of the carers who were interviewed described any consistent meaningful activities that their family member was involved in in hospital.

“They had an outdoor area where they could walk to, they had a common area where they were. But I saw very little efforts to engage them. They had an OT who went in there sometimes, but I saw her only once and he was there 8 months”

“If I could take him something that he could fix. He had to have a purpose, he couldn’t just sit there. He was never one to just sit there and do nothing or watch TV…. At the hospital they did things in the morning like craft... but nothing specific for my Dad in the hospital.”
One carer’s family member could no longer communicate in English, only their native language. The carer described the delight that the person with dementia would show when a staff member who spoke their native language arrived.

Some programs for people within hospitals rely on volunteers to provide meaningful interactions with people with dementia. These programs may not be available to people experiencing extreme BPSD due to legitimate concerns for the safety. Units need to consider availability of meaningful activities which may require additional allied health staffing.

**Delirium management is closely linked to providing care for people experiencing extreme BPSD**

While delirium management is beyond the scope of this project, delirium is a complicating factor for many people experiencing extreme BPSD. Stakeholder review of the draft project report identified key issues relating to delirium management:

- People experiencing significant BPSD can be discharged from Emergency Departments when basic delirium screens find no physical cause of their changed behaviour. This may be a factor in delaying admission for more extensive specialist assessment for some people.
- When a person with dementia experiences delirium, this can create temporary increases in their level of BPSD. This can also occur when a person experiencing severe BPSD has hospital acquired physical health complications.

**Pathways and partnerships**

**Recommendations: Pathways and partnerships**

- Pathways into the hospital service should include intake directly from the community, residential aged care, other services within the same district and in other districts. Pathways that avoid emergency departments are preferable.
- Development of assertive outreach services, particularly into residential aged care, will increase timely access to clinical support and promote smoother transitions into hospital when required.
- Clear pathways out of the hospital service to support people as they move between tiers of BPSD are important. These require significant partnership work with capable local residential aged care and disability providers, and additional clinical in-reach to aged care facilities to support the person with dementia to remain in residential aged care or specialist disability accommodation.
- Local pathways for people experiencing significant BPSD, including extreme BPSD, need to be documented and updated as services change. Collaboration with local residential aged care and disability service providers is particularly important.
- Partnerships and collaboration with other key BPSD services will support quality care for people with complex needs associated with extreme BPSD, and may include being involved in assessments, case reviews and education initiatives. This includes the Severe Behaviour Response Team (SBRT) and Specialist Dementia Care Program (SDCP).
Current pathways into hospital can be difficult and make behaviour worse

Several carers highlighted the impacts of pathways into hospital through ambulance and emergency departments. One family, who had some involvement with local community services, called an ambulance when in crisis. The ambulance used a fast acting sedative to control the person with dementia who interpreted the ambulance officers as intruders in his house.

“I thought I can’t carry on and I called the ambulance. I regret it. I totally regret that I did it that night. By the time the ambulance came forty minutes later he had calmed down. As soon as he saw these two burly guys come into the place, he didn’t know what was happening, I hadn’t explained it to him. Because I didn’t know, I went inside. I was afraid of how he would take it. They were not very compassionate, they were not very understanding, they were brutes. Because he was showing aggression, they pushed him down on the lounge and every time he wanted to get up they pushed him down. They treated him like someone on ice. They showed no understanding of the situation.”

The ambulance trip was followed by a day in the emergency department and transfer into a general ward, with physical restraint used in both:

“They would not let him out to go to the toilet. I watched that man writhe and writhe as he wanted to get out. It is no wonder he became incontinent. He was not allowed out of the bed to go to the toilet. They were probably afraid and not sure what he would do because of his aggression.”

Other carer stories highlighted challenges with pathways into hospital, including:

- Family members being unable to drive the person with dementia, as they would try to escape the car or hit at the driver.
- Ambulance only being available to take the person to the closest hospital, not the hospital with appropriate services or where care had been previously received.
- Spending long periods of time in the emergency department.

This challenge is not limited to scenarios when a person with dementia needs help for their behaviour. One carer, after several very difficult experiences with their family member in hospital emergency departments, including for falls, described the change she would most like to see in the care for people with severe-extreme BPSD:

“Being able to provide more medical treatment in the residential aged care facility. This would be better for staff at the hospital, the staff at residential aged care, and better for the patient.”

Finding appropriate residential aged care or other long term care is challenging

The inability to find suitable residential aged care placements was a common theme in consultation meetings. Specific issues identified included:

- RACFs were not able to implement behaviour management plans and/or had a strong preference for medication use.
- After one or more incidents of assault, the person experiencing extreme BPSD has a ‘reputation’ and RACFs refuse to admit them.
- Sometimes the only option available is a lower quality facility.

Several carers described understanding that their family member was in hospital as there was nowhere else for them to go.
“Most said no when they learnt about this unpredictable violence. They would say ‘woah, we can’t take him’.”

The shortest length of stay reported in carer interviews involved a move from a hospital into a NSW Health-operated RACF, suggesting this pathway can work well. For one person with dementia, their age (being under 65) was described as a barrier to their entry into a RACF, but it was not clear to the family that other options, such as supported disability accommodation, were being pursued.

Consultation meetings suggested that the focus on hospital services to reduce length of stay can create pressure to discharge. The result of this in some services was the use of medication primarily to reduce behaviour to enable transfer to residential aged care, an approach that is not appropriate.

‘Bounce back’ was identified in consultation meetings as a common event. This is when a person returns to hospital after a short amount of time in residential aged care. This may be due to a ‘honeymoon effect’ when they come to hospital environment with security staff and medication. Consultation meetings suggested that in some cases the person would have benefited from longer observation time in hospital.

**Hospital teams need to invest in partnerships to support transitions**

People experiencing BPSD move between tiers and as they do so, they often move between hospital and residential aged care. Some people also move directly to hospital from their homes, suggesting that partnerships with community aged care providers may also be important. One attendee at a consultation meeting said:

“Residential aged care is not just a discharge destination, they are our partners.”

Examples of successful transitions from hospital to residential aged care were described in meetings as being successful because of open and frequent discussions between teams in the two settings. The residential aged care team includes medical staff such as General Practitioners. The importance of minimising and managing transitions was highlighted. Key partnership strategies discussed included:

- Training and clinical in-reach from NSW Health clinical services into residential aged care
- Having a clear path back to hospital, and where possible a path back into hospital that bypasses the emergency department.

Some key informants suggested the potential for a specialist consultative model described as a strengthened version of the Specialist Behaviour Response Team (SBRT) approach, providing statewide access to expert clinical review and advice. The T-BASIS model of care includes outreach clinicians to promote linkages with RACFs and other services, support transitions into and out of the unit and prevent hospital admissions where possible. This has been highlighted by T-BASIS services as a key element of good practice.

For people with younger onset dementia, specialist disability accommodation may be an appropriate housing option. Hospital teams need to be able to support the person with dementia through the NDIS eligibility and planning processes. They will also need to work with local disability service providers to support the person with dementia.
### Physical environment

**Recommendations: Physical environment**

The physical environment plays a key role in ensuring the safety of people with dementia, frontline staff, other patients, family members and other carers.

- People experiencing extreme BPSD need to be in a single room.
- The physical environment needs to allow regular access to outdoor space.
- The physical environment needs to have a variety of indoor and outdoor spaces to support meaningful activities.
- The unit should support functional segregation of different areas to help manage the mix of patients in the unit and ideally allow physical separation of people experiencing extreme agitation or aggression with appropriate observation and care strategies, when required.
- The unit should include physical spaces for carers, who in some cases play an essential role in behaviour management particularly during times of transition. This may include carer zones in common areas, which should be appropriate for older carers.
- Staff safety should be considered including: having a safe space to work away from patients, such as for updating patient notes, ensuring safe exit points, and use of safety glass.
- A space should be available for assessments and to meet with families.
- Flexible physical environments that include swing or surge beds with ample space (including access to outdoor space, where possible) should be considered as these can create capacity for managing people experiencing extreme BPSD in an appropriate physical environment.
- Other principles of a dementia friendly environment should be implemented[^10].
- Involve consumers and carers using co-design principles when designing new units or refurbishing existing units.

Many people experiencing extreme BPSD spend a significant amount of time in an acute ward environment, particularly when no other services are available. Many consultation meetings identified that the hospital environment can exacerbate behaviour and the impacts of behaviour. The result of this may be the overuse of psychotropic medications, with the clinical challenge of balancing the risks of sedation with the risks posed by behaviour.

The NSW Agency for Clinical Innovation published *Key Principles for Improving Healthcare Environment for People with Dementia* in 2014[^30]. Discussions in carer interviews and consultation meetings suggest that five of these are particularly important for people experiencing extreme BPSD. These are in bold in the list below. There was no suggestion that any of these principles would not assist people experiencing extreme BPSD.

**Key Principles for Improving Healthcare Environment for People with Dementia[^30]**

Principles in **bold** were found to be particularly relevant for people experiencing extreme BPSD

1. **Unobtrusively reduce risks – safety**
2. **Provide a human scale – size**
3. **Allow people to see and be seen – visual access**
4. **Reduce unhelpful stimulation – stimulus reduction**
5. **Optimise helpful stimulation – highlighting useful stimuli**
6. **Support movement and engagement – provision for wandering, circulation and access to outside area**
7. **Create a familiar space – familiarity**
8. **Provide a variety of spaces to be alone or with others**
9. **Provide links to the community – community links**
10. **Support the values and goals of care**

[^10]: Other principles of a dementia friendly environment should be implemented.
[^30]: The NSW Agency for Clinical Innovation published *Key Principles for Improving Healthcare Environment for People with Dementia* in 2014.
Some changes to environments to reflect these principles can be done with only minor costs (such as highlighting useful stimuli through colour coding of doors and walls); others may need to be delivered through planned infrastructure developments. It is likely that an environment designed according to these principles would improve care for people experiencing many levels of BPSD and may help to reduce the frequency and/or severity of behavioural symptoms.

The Sax Institute review found that most studies included described at least some environmental modifications in the units providing care for people with very severe to extreme BPSD, and these largely aligned with the key principles above. The most commonly mentioned were those aspects of the physical environment related to ‘optimise helpful stimulation’ and ‘support movement and engagement’. They also concluded that although a supportive environment for people with dementia is one of the ‘common elements’, there is considerable room for improvement in the way these units are designed.

A separate review into the design of mental health facilities to prevent the use of seclusion and restraint found very similar design features were important:

“These include privacy, adequate space, no overcrowding, exposure to daylight and other appropriate lighting, use of colour, reduced levels of unpleasant noise, access to gardens, art that features nature, a homelike environment, and easy wayfinding and opportunities for consumer agency. These amenity features promote both consumer and staff safety, and reduce distress and environmental triggers for conflict, which are central to the prevention of seclusion and restraint.”

The review also found that noise reduction and wayfinding was particularly important for older people.

When consultation meetings discussed what could be done when these physical environments were not available, the importance of having flexibility in available options was discussed. This can allow services to manage patient and staffing mixes in the absence of ideal physical environments.

Consultation meetings and carer interviews both described the impact on people with dementia when supportive physical environments are not available. In the words of one person experiencing extreme BPSD as reported in carer interviews:

“What am I doing here? It looks like I am in a mental institute. What is going on? Everyone is crazy.”

And another in a similar environment:

“What am I? In a psychiatric house? All white walls, doors can’t open.”

In general, our findings are consistent with the design principles for the development of the South Australian neurobehavioral unit for this same target population.

Two of these are particularly relevant to the design of the physical environment for a person experiencing extreme BPSD:

Creating an environment where my loved one can live their best life

“Dementia presents a perpetual set of challenges to the life of the person I care for. It’s important where they live actively facilitates environments where they can be their best selves, while minimising negative and distressing triggers.”

Homes, not Institutions

“Having a place they can call home is key in providing a sense of safety and stability in their life – a place where they can be themselves. It’s also important in enabling us to be together as a family.”
The layout of the neurobehavioural unit is included in Appendix 6 as one example of a design response to the physical environment needs of people experiencing extreme BPSD.

The model of care for NSW older people’s mental health inpatient units guides units to be as domestic as possible to encourage older consumers to use their abilities. While recognising that people experiencing extreme BPSD often have long hospital stays, hospitals are not homes and therefore this principle underpins the importance of services having a strong focus on enabling a person’s pathway out of hospital either to their own home or to a RACF.

Safety is challenging in the acute care hospital environment

Aligns with principle 1 of Key Principles for Improving Healthcare Environment for People with Dementia.

Some hospital spaces were described in consultation meetings as being appropriate for people experiencing BPSD who liked to walk (or ‘wander’) and were slightly agitated, but not suitable for people experiencing extreme BPSD due to the difficulty in removing all objects that could be used as weapons. The presence of fragile medical equipment and objects that can be weapons in an acute hospital environment made it difficult to create a safe environment. A villa on hospital grounds was suggested as a homelike environment with suitable medical support available.

One carer interview described how one hospital service managed when a person experiencing extreme BPSD was placed in an unsafe physical environment. The carer explained that all furniture was removed from the room, including the bed frame and that the 5th floor windows were boarded up to prevent the person with dementia from kicking through them.

Another carer identified the layout as the key challenge:

“The worst place was that ward. It was like a maze…. if some of the patients that they know are aggressive, are walking towards the back, there’s two of them that are aggressive, there’s every chance they are going to find each other and then one of them is going to hit the other. That’s what happened to my (family member) and it happened to other patients as well.”

Space for physical movement, including outside space, is essential

This aligns with principle 6 of Key Principles for Improving Healthcare Environment for People with Dementia.

One carer interview described the patterns of the person with dementia as mimicking his daytime routine for most of his working life. He would wake early and walk the corridors as if he was at work. When he came home from ‘work’ and could not replicate his evening routine, his behaviour was often difficult for hospital staff to manage.

When outdoor space was available in the unit their family member spent time in, carers highlighted how this space was a positive, including being a space them to spend time together during visits.

Consultation meetings discussed that some environments used to care for people experiencing extreme BPSD do not allow access to outside space or other spaces to walk around. Carer interviews described the impact this had on the person with dementia:

“He felt like he was in a prison”
One carer described their frustration, which was exacerbated by the person experiencing a long stay in hospital, as is common for people experiencing extreme BPSD:

“It's not the right environment for him. He was not allowed out. We couldn't even take him outside to a courtyard. He was indoors for (many) months. He kept looking out windows.”

LHDs in metropolitan areas may find the recommendation for outside space particularly challenging where facilities are built in multi-story buildings. However, this project found expert consensus and relevant evidence-based guidance supporting the importance of outdoor space compelling.

**Space for meaningful activities, with reduced stimuli**

*Aligns with principles 4, 5, and 6 of Key Principles for Improving Healthcare Environment for People with Dementia*.30

Consultation meetings explained that space for meaningful recreational activities and diversional therapy without unnecessary stimulation, such as from other people, staff or visitors was important.

Some carers described their family members being left with no meaningful activities due to safety concerns, such as not being able to use writing implements due to safety concerns.

People experiencing extreme BPSD need to be able to be on their own and/or separated from other patients who may be at risk

*Aligns with principle 8 of Key Principles for Improving Healthcare Environment for People with Dementia*.30

Both consultation meetings and carer interviews agreed that each person experiencing extreme BPSD needs to be in their own room.

Consultation meetings discussed that care was being provided in units where private rooms were often not available for people experiencing extreme BPSD. One carer described this:

“They (The hospital) had him in just a normal room with four other patients. Some of them were more extreme. There was a particular lady who would just get up and punch people. It was a very sad story.”

Carer interviews described how behaviour improved when the person experiencing extreme BPSD was able to be moved to a single room. Carers also described a single room as essential when they were looking for suitable residential aged care, when behaviour would no longer be considered extreme.

A physical environment that allows separation of groups of patients can improve safety. For example, this may be appropriate if a person experiencing extreme BPSD is sexually disinhibited.
Staffing

Recommendations: Staffing

- Units need to be staffed by nurses with skills and experience working with people with dementia, including those with severe-extreme BPSD. A nursing unit manager and/or other senior nurses with significant experience in this area can provide leadership, staff support and training.
- The number of nurses on each shift should reflect the number and acuity of the patients.
- Units need regular clinical input from both a geriatrician and an old age psychiatrist, with minimum levels of medical staff coverage and access specified.
- Multi-disciplinary teams including psychologists, occupational therapists and social workers need to be involved in assessment, care planning and provision of care.
- Patient management plans should include strategies to eliminate or manage known triggers for patients. This approach may also involve identifying staff members who are a good fit and/or have developed rapport with the person experiencing extreme BPSD.
- Health and Security Assistants, or other security staff, may assist clinical staff in the management of patient behaviour, but not as the first or only approach to managing behaviour.
- Units should consider arrangements to engage additional specialist clinical assessment and advice from other districts or sources, where required.
- Units need responsive staffing approaches, such as rotation of staff, so that quality care is provided and workforce wellbeing is managed when a unit is caring for one or more people experiencing extreme BPSD.
- Services should include ‘outreach clinicians’ to promote linkages with residential aged care and other services, support transitions into and out of the unit and prevent hospital admissions where possible. This can be integrated with other partnerships and outreach services in the district.

Carer interviews consistently highlighted staffing as the area of care presenting the biggest opportunities for improvement. This is consistent with priorities of carers identified in other research\(^5\). All carers spoke about the staff members that had a positive impact on their family member. One carer said:

“Some of them, I take my hat off to them. These front line workers – what they have to go through. I saw it, how they are treated and stuff like that.”

“The geriatricians and the doctors are amazing, they are fantastic.”

“There was one lovely lady (a clinical nurse consultant aged care liaison) who was absolutely wonderful. She got on to all the RACFs that would take someone with dementia and put his name down. She encourage me to go to Centrelink and sort things out financially. Every time I saw her she was wonderful to talk to. She even did a bit of (family members)’s care.”

Consultation meetings also consistently highlighted the important role staff play in care. This was particularly emphasised as medication often has a limited role, and behaviour management approaches are the key. Consultation meetings described the importance of staff developing a relationship with people experiencing extreme BPSD, being familiar with their triggers and sharing this information within the team. This is consistent with staffing features described in the T-BASIS model of care (6 and Appendix 5).

Carer interviews also consistently highlighted that while some staff are having an extremely positive impact, they also experienced staff members who did not. One carer identified this as the single change she would make to the hospital environment:

“If I could change things, I would have (name of nurse), who was wonderful with my Dad, he would respond to her. She would sing, walk around, talk to everyone, hold their hands. Others did nothing like that. Dad responded very well. Not like the others that were just there because they had to.”
Multi-disciplinary staff team are needed for thorough assessment, behaviour management and meaningful activities

In addition to nursing, a multi-disciplinary approach was highlighted in consultation meetings as important. Occupational therapy was discussed as important to create meaningful activities and diversional therapy programs, with allied health assistants and diversional therapists implementing these programs.

Medical staff play an important role for many people experiencing extreme BPSD, particularly in identifying and treating physical health issues and mental health comorbidities. Intramuscular PRN or “as needed” medications will require medical staff to manage.

Medical staffing from multiple disciplines, allied health staffing and a multi-disciplinary approach were found to be common elements of care in the units included in the Sax Institute review. The medical disciplines described included: geriatricians, old age psychiatrists, psychiatrists, and neurologists. Allied health staffing patterns differed in each unit, but commonly included psychology, occupational therapy and social workers.

Carers highlighted in interviews that non-nursing and non-medical disciplines were important to them as well:

“Having a social worker and a CNC was good. They explained things in ways that we (the family) could understand.”

Several carers mentioned the help that social workers provided them during the process of finding suitable residential aged care for their family member.

Sufficient staff numbers are required to support people experiencing extreme BPSD

Consultation meetings raised that units needed to have enough staff to manage the patient mix and keep patients who trigger each other away from each other. Brodaty et al. described that a service providing care for people experiencing extreme BPSD would require a high ratio of staff to patients.

Several consultation meetings discussed units providing care for people experiencing extreme BPSD that did not have sufficient staff numbers for this purpose. One example was a ward with three nursing staff during the day for 12 patients. When a person experiencing extreme BPSD required a shower, this involved all staff and the nursing unit manager, limiting their capacity to attend to other patients. Many Aged Health units reported that they felt they were not staffed to provide the level of care required for their patient profile.

Several carers also highlighted this was an issue in some services:

“Very understaffed. There were times when there was only three staff on and 30 patients. That’s ridiculous.”

Consultation meetings discussed that individual patient specialling (IPS) was commonly required for people experiencing extreme BPSD in an acute hospital ward environment. Services reported that in many cases there is pressure to reduce this due to the high cost and that using one nurse to combine specialling of two people requiring IPS was usually not appropriate as this resulted in more injuries and falls.
This project did not aim to determine an appropriate nursing staff ratio for this group. However several examples may inform service planning:

- South Australia’s response to the Oakden Report provides an example of nursing staff numbers for this group. Both of the Older People’s Mental Health units playing a key role in response to the report have an nursing ratio of approximately one nurse for every two patients and over 13 nursing hours per patient day.

- One NSW Older People’s Mental Health Inpatient Unit was able to reduce the use of 1 to 1 nurse specialising by increasing the nursing staff ratio for nine beds to one nurse to three patients. People with either significant BPSD and/or high falls risk were prioritised for these beds.

- The Aged Care Extension ward in South East Sydney LHD has six beds with two nursing staff 4 hours per day, or one nurse to three patients.

**Flexibility in staffing plays a significant role, including the use of security staff for some people experiencing extreme BPSD**

Having physically strong staff was mentioned in some consultation meetings. Brodaty et al. suggested that security and male staff may be important for a service providing care for people experiencing extreme BPSD\(^1\). For some people experiencing extreme BPSD, the presence of physically larger and stronger staff plays a role in managing their aggression. For others it may trigger changed behaviour. The T-BASIS model of care emphasises the importance of appropriate security arrangements to support the safe and effective operation of these units\(^5\).

Some units reported using one security staff member for one patient experiencing extreme BPSD for long periods of time. Both positive and negative stories were shared about this approach. Although security staff cannot assist with clinical care, they were reported to provide reassurance and support to clinical and non-clinical staff. One consultation meeting reported that there were fewer incidents in their unit when security staff were used compared to using Assistants in Nursing.

Consultation meetings suggested that when security staff are used these staff need to be engaged on an ongoing basis. This can work well when they develop positive relationships with patients and understand behaviour triggers.

Carers described understanding why security staff were necessary for their family member and also some positive experiences with these staff:

“Some of them were just amazing. (They’d say) “We’re treating your Dad like our Dad”. (Dad would) talk to them and wander around the ward with them.”

“I could point my finger at which ones my Dad liked – when they came into the room his eyes would light up. You could tell how they treated him.”

“Some of them were really nice, they knew how to handle him. Some of the (security staff) who knew how to speak Arabic... knew how to talk to him and get him to agree with them, listen to them.”

Carers also shared stories where security staff may not have provided appropriate care:

“The security staff in the wards were a little heavy handed. A bit physical as well.

The NSW Health *Protecting People and Property Manual*\(^12\) and the reports from the review into the safety of staff, patients and visitors in NSW public hospitals (*The Anderson Review*)\(^13\) provide guidance to services on the role of security staff. Services should ensure that Health and Security Assistants have training to support their interactions with people with dementia and experiencing BPSD.
Workforce training and support

Recommendations: Workforce training and support

- All staff should have access to ongoing education and training specific to the care of people with dementia and severe-extreme BPSD, including training in complex behavioural management, trauma informed care, partnerships with families/carers, violence prevention and management, and psychological literacy specific to older people.

- Investment should be made in mentoring and clinical supervision to support the safe and effective operation of the unit.

- A focus on a positive team culture will support person-centred care

- Strategies to build and maintain workforce in each district should be developed, such as efforts to rotate staff through units providing care for people with severe-extreme BPSD with a view to identifying those with the interest and compassion to work in this setting. Values based recruitment may play a role in this.

- LHDs should have systems in place to safeguard the wellbeing of the team, including access to informal and formal support programs and staff safety strategies (e.g. the use of duress alarms) in line with the NSW Health Protecting People and Property Manual.

Staff require a combination of skills, experience and values to provide quality care

It was a consistent view across multiple consultation meetings that specialist staff, particularly nurses, are required. As one consultation attendee said:

“Nursing care is the cornerstone.”

The knowledge and skills of staff were consistently highlighted as critical. One service reported that they would not use agency nursing staff any more for this reason. The skills needed to do this role were discussed as being primarily acquired through practice and experience, including on-the-job coaching and professional supervision. Once these skills have been developed, one medical team member said they should be seen as a prized resource. One consultation identified a history of losing skilled staff when services changed. As one unit was closed, the nursing staff that had built specialised skills and worked well as a team moved to many different roles and services. This was described as a lost opportunity to retain these professionals.

Education, skills and training were some of the common elements identified in the Sax Institute evidence review. Some of the units in this review described training programs covering:

- Knowledge and skills in behaviour management
- Management of behaviour problems without recourse to physical or pharmacological restraint
- Recognition of delirium and dementia
- Montessori activity training
- De-escalating aggressive incidents.

One unit in the review highlighted the importance of this training being both about knowledge and about putting this training into practice. It is important that this training is tailored to the needs of older patients with dementia.

One consultation meeting raised the issue of how to retain staff and suggested that recognising their skills and experience and the challenging environment they work in through financial incentives may be appropriate and effective.

The model of care for T-BASIS units identifies several practices to support staff, including having senior clinicians to provide training and mentoring and having weekly mentoring meetings. South Australian Health, as a part of their response to the Oakden Report, has implemented values based recruitment. This is modelled on approaches being used in the National Health Service and other settings in the United Kingdom.
Although carer interviews were not designed to be an assessment of current services, the opinions shared do suggest that some services are challenged in recruiting staff with the appropriate skills and experience.

“I just don’t think the nursing staff were equipped at all in treating dementia patients. Some yes, and I saw a few of them, you could tell that they’ve worked with dementia patients before. Others really shouldn’t be around them. They escalated situations.”

“The ward that my dad stayed in the nurses in particular, some of them are not prepared to deal with dementia patients or deal with their behaviour. Some found my Dad is very intrusive, very rude and aggressive, not realising he is a dementia patient. So their reaction to him was not the right one. It caused him to be more aggreviated.”

Providing care for people experiencing extreme BPSD has a significant impact on staff

Several consultation meetings identified high performing teams providing person-centred care, including through end of life care.

“We are fortunate to have very loyal and committed staff.”

One social work team reported that they balance their workload to ensure that each member only has one or two people experiencing extreme BPSD in their caseload at a time.

Consultation meetings raised that this challenge would be a significant barrier to having one statewide unit.

“How can you sustain a team with constant risk of assault?”

Providing care for people with extreme BPSD has an impact on staff, particularly due to the high risk of significant assaults. Stories were shared in consultation meetings of units that had very high injury rates and large amounts of compensation paid to staff. Some services reported industrial action. Stories of staff burnout were frequently raised in consultation meetings. When staff are impacted, this can have a negative impact on patient care.

It was suggested that when staff do not have appropriate skills and experience, they can over-perceive risk. An example was given of a referral to an older people’s mental health service that included over 70 code blacks related to a male patient walking around the unit at night. Skills and experience are also important to identify early signs of agitation and distress and intervene appropriately to prevent aggression where possible.

Ways to protect and enhance staff wellbeing were discussed in many consultation meetings, including:

- rotating staff between units of different types to avoid burnout
- having processes to allow staff to take a break or move to other duties when needed
- actively encourage staff to seek support, either through existing employee assistance programs or through specific programs and activities in the service
- being proactive and not only waiting for staff to raise that they are not coping
- having debriefs after incidents
- clinical supervision
- ensuring staff receive positive feedback including stories of good outcomes and feedback from RACFs.

* incidents where staff safety is threatened
Other project findings
Most of the work of this project has been described in the previous sections of this report. However some discussions in consultation meetings and carer interviews are outside the scope of key findings and recommendations and are described below.

Experiences with residential aged care and dementia services in aged care were mixed

Providing care for people experiencing severe-extreme BPSD in residential aged care is challenging. The two services provided by Dementia Support Australia and funded by the Commonwealth Government were discussed in consultation meetings and carer interviews: the Severe Behaviour Response Team (SBRT) and Behaviour Management Advisory Service (DBMAS). SBRT can play an important role in supporting aged care services to respond to needs of people experiencing severe BPSD within the residential aged care environment and preventing escalation of behaviour and hospital admission.

Challenges with some dementia-specific aged care services were identified in consultation meetings. DBMAS was described in one consultation as ‘present, but stretched’. One consultation reported that one of their teams offered similar services to the Specialist Behaviour Response Team (SBRT), saying:

“When SBRT does come, they replicate what we are already doing.”

Stakeholders who reviewed the draft report identified challenges with the capacity of aged care services, including SBRT and DBMAS. Specific challenges in aged care services related to the training of staff in residential aged care, and the willingness of providers to accept a person experiencing significant BPSD. DBMAS and SBRT services were described as not available fast enough and not providing the necessary ongoing support.

The project also heard frustrations with the lack of specialist residential aged care places. This may improve as more SDCUs are opened in NSW by the Commonwealth.

One carer was positive about the impact SBRT had on care in a generalist residential aged care facility (RACF) for their family member, but identified many recommendations that were not implemented by the facility. One carer described a positive experience with a dementia helpline.

Some carers spoke about unsuccessful attempts to receive home based aged care services while their family member was experiencing BPSD at a lower tier. One person with dementia living at home alone was assessed to only be eligible for two hours per week of home care. They moved to residential aged care shortly after this. Other people with dementia were unable to access aged care in their home as it may place aged care staff at risk of aggression.

Carers also shared challenges of finding an appropriate RACF for their family member. Carers visited over ten, and some up to 25 facilities before they found a suitable new home for their family member. One carer described a very positive experience with a brokerage service to support them through this process.

Continued efforts to improve services for all people with dementia will support people experiencing extreme BPSD

People experiencing extreme BPSD benefit from many services and initiatives, particularly:

- Information resources about dementia and changed behaviours.
- Community services, including outreach to families living at home and into residential aged care to support effective behavioural management and environmental modification strategies.
- Strategies to support appropriate care that meets the needs of the whole community, including people from Culturally and Linguistically Diverse (CALD) backgrounds and Aboriginal and Torres Strait Islander people.
• Workforce training and support to assist people working with people with dementia in both hospital and other settings. For example, the inclusion of dementia training in nursing qualifications.

Challenges with services for lower level of severity of BPSD were discussed during consultation meetings, including: limited access in some areas to specialist medical staff (e.g. geriatricians) with skills in the area of severe BPSD; and lack of outreach and flying squad style services in some areas to provide timely interventions without the need for the person with severe BPSD to transfer to hospital.

Improvements in these services are likely to:
• Reduce the impact of extreme BPSD on the person and their family
• Improve access to appropriate early intervention, possibly reducing the severity of changed behaviours and therefore reducing the prevalence of extreme BPSD

Consistent definitions of BPSD severity can support ongoing development of a stepped-care model

The lack of a widely agreed definition of the tiers of BPSD along with the involvement of both Commonwealth (aged care) and NSW (health) funded supports combine to make coordinated service planning very challenging. Further collaboration between the states, Commonwealth and relevant agencies and services on common language, well targeted stepped care options, and clear care pathways could improve the experience and quality of care for people experiencing extreme BPSD.

Long hospital stays have a significant impact on people with dementia

Carers described challenging aspects of their family members’ stays in hospital that are not specifically related to the care of people experiencing extreme BPSD. One example was the quality of food in hospital, which can contribute to physical decline when combined with having movement restricted due to a lack of safe spaces to move and a lack of meaningful activities.

Other Australian states have varying approaches to services for people experiencing extreme BPSD

In South Australia, one recommendation of the Oakden Report³ was the development of a purpose built 24 bed Neurobehavioural Unit (NBU) to meet population demand. However, the decision to reactivate the Repat Health Precinct provided an opportunity to re-design an existing contemporary building, which was previously an older person’s inpatient unit to become an 18 bed NBU. Although located in the South of Adelaide, the NBU is a statewide service for all people with Tier 7 (extreme) BPSD in South Australia including those from regional areas. Northgate House, which was initially established a temporary facility to house people who were in the Oakden facility, is also continuing to provide care to people with BPSD. Northgate House is located in the North of Adelaide with an additional 16 beds of care and the two services operate on a single service, multiple site model.

Key informants in older people’s mental health in other Australian states suggested that no other state has a specific service response or pathway for people experiencing extreme BPSD, but many individuals saw value in improving this. Some other states have developed information resources and documented patient pathways for responsive behaviours to assist consumers and aged care providers²³.
References


Appendices
## Appendix 1. Glossary of Terms

<table>
<thead>
<tr>
<th>Term</th>
<th>Explanation</th>
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<tbody>
<tr>
<td>DBMAS</td>
<td>Dementia Behaviour Management Advisory Service. Commonwealth funded program that supports staff and carers in the community, residential aged care, acute and primary care settings.</td>
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<tr>
<td>HETI</td>
<td>A NSW Health pillar organisation that designs and delivers education and training programs for the NSW Health workforce and others.</td>
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<tr>
<td>LHD</td>
<td>Local Health District</td>
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<tr>
<td>MHACPI</td>
<td>Mental Health Aged Care Partnership Initiative</td>
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<tr>
<td>NDIS</td>
<td>National Disability Insurance Scheme</td>
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<tr>
<td>OPMH</td>
<td>Older People’s Mental Health</td>
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<tr>
<td>RACF</td>
<td>Residential Aged Care Facility</td>
</tr>
<tr>
<td>SBRT</td>
<td>Specialist Behaviour Response Teams. A Commonwealth funded program that offers expertise and advice to Commonwealth funded approved residential care homes, multi-purpose services, or flexibly funded services needing assistance</td>
</tr>
<tr>
<td>Service</td>
<td>A smaller part of a larger health organisation</td>
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<tr>
<td>SDCU/SDCP</td>
<td>Specialist Dementia Care Unit</td>
</tr>
<tr>
<td>T-BASIS</td>
<td>Transitional Behaviour Assessment and Intervention Service</td>
</tr>
<tr>
<td></td>
<td>These NSW Health services provide transitional or transitional or non-acute inpatient care for older people with severe BPSD and/or mental illness</td>
</tr>
<tr>
<td>Unit</td>
<td>A single service providing in-patient hospital care</td>
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Appendix 2. Project approach to information gathering

1. **Published research**
   
   The recent literature review to inform the establishment of the Specialist Dementia Care Program had summarised available literature about models of care for people experiencing severe and extreme BPSD(41).

   A small number of other relevant publications were identified.

2. **Existing policies and guidelines**

   Policies relevant to NSW were identified, and key policies considered.
3. **Consultation meetings**

Ten internal group consultations were held in 2019 with over 100 frontline professionals working with people experiencing BPSD along with follow up conversations and emails.

These consultations involved a mix of mental health, aged health and aged care staff/services. The districts were approached through key contacts of the Mental Health Branch Older People’s Mental Health (OPMH) Policy Unit and the Extreme BPSD Expert Reference Group, with these key contacts asked to identify individuals with relevant experience who should attend the meeting. This approach targeted Districts with specific services catering to this target group.

The consultation meetings were facilitated by members of the Mental Health Branch Older People’s Mental Health Policy Unit. The topics discussed are included in Appendix 3: Consultation Background Document. Themes and findings were derived from the notes taken in these meetings.

### Local health district (LHD) teams

Meetings were attended by teams from both Aged Health and OPMH services. Some meetings were also attended by residential aged care services. Districts included were:

- Central Coast
- Hunter New England
- South Eastern Sydney
- Sydney
- Western Sydney
- Justice and Forensic Mental Health Network

### Other stakeholders

Members of the MH-RAC Network, comprised of LHD OPMH services and aged care providers operating NSW Health-supported mental health-residential aged care partnership services.

OPMH TBASIS unit in Tamworth (Hunter New England LHD). All TBASIS units were invited and one psychiatrist from the Wagga Wagga TBASIS unit provided input.

South Western Sydney LHD OPMH service along with HammondCare mental health-residential aged care partnership service (MHACPI unit).

Members of the NSW network of dementia clinical nurse consultants.

The OPMH Policy Unit also received:

- Individual email responses from some meeting attendees and some people who were unable to attend the meetings
- Information from key informants who were contacted by email and by phone.
- Information from two inpatient units estimating prevalence and characteristics of patients experiencing extreme BPSD. One was from an Aged Health unit and the other from an OPMH Unit.
- One written, de-identified case report that was mentioned in one of the consultations.
4. **Carer interviews**

Family member carers were recruited through having had contact with a NSW Health aged health or mental health service. Carers were selected based on the health service’s assessment of the severity of their BPSD.

Telephone interviews were conducted with members of the OPMH Policy Unit asking open ended questions. Seven people from six families were interviewed, a mix of spouses and adult children of people who had experienced extreme BPSD.

5. **Health Services data**

An extract of administrative data (from the Health Information Exchange Inpatient Statistics Collection) of long episodes of care for people with a diagnosis of both dementia and a behaviour disorder was examined. Length of stay is used as an indicator to a person who may be experiencing extreme BPSD. The extract found 78 episodes of care for 73 people over a five year period (2014 - 2019)

The data was consistent with our current understanding of extreme BPSD, including age, sex and use of health services. Limitations in the use of episode of care data means that results are neither inclusive of all people experiencing extreme BPSD or representative of this group. A data set that can link multiple episodes of care will add to our understanding of this group and their use of health services.

6. **Expert Reference Group review**

Throughout the project, findings and recommendations were reviewed with the Expert Reference Group. The members of this team are listed in Appendix 7.

7. **Other stakeholder review**

A consultation draft version of this report was sent to key stakeholders for their feedback. Over 600 feedback items were received and considered in development of the final version. Responses were received from:

- ten local health districts
- Justice Health and Forensic Mental Health Network
- other NSW Health organisations
- South Australia Health
- Aged and Community Services Australia (ACSA)
- Australian Association for Gerontology (AAG)
- Dementia Australia
- Leading Age Services Australia (LASA)
- NSW Nurses and Midwives Association (NSWNMA)
- Psychogeriatric Nurses’ Association (PGNA)
- Royal Australian and New Zealand College of Psychiatrists (RANZCP)
Appendix 3.
Consultation document

What we’re doing
NSW Health is undertaking a project to scope the numbers, characteristics and needs of people with persistent, extreme (Tier 7) behavioural and psychological symptoms of dementia (BPSD).

We have established a small project team for expert advice, and are:
- consulting with staff and services around the state
- interviewing key stakeholders and informants within NSW and other jurisdictions
- conducting a literature scan of relevant service models, and
- reviewing available data.

We will then prepare a draft report, consult on its findings and release a final project report. A policy response including potential service approaches will then be prepared.

This is a scoping project, without predetermined solutions or resources allocated at this stage.

A draft list of characteristics of people with ‘extreme’ BPSD has been prepared in consultation with the project team. It is worthwhile noting people are not likely to be permanently at the extreme tier of BPSD – this is likely to fluctuate. The set of characteristics is as follows:

- cognitively impaired
- persistently very severely behaviourally disturbed OR have episodic and unpredictable periods of very extreme behavioural disturbance
- pose a high risk of serious harm or death to other frail older people, to staff and to themselves
- physically robust, ambulant, often strong
- extremely physically aggressive
- often male
- often of younger age (i.e. under 65 years) but have early ageing issues (i.e. are ‘functionally old’) 
- may have significant communication or language problems
- may have severe sexually disinhibited behaviour
- medically stable (i.e. they are not currently suffering from an acute medical condition or post-acute delirium), although they may have multiple medical problems
- often have multiple co-existing conditions (e.g. cognitive disorder + treatment-resistant psychosis + medical needs), and a high level of complexity
- are at risk of premature death due to iatrogenic causes such as over sedation and restraint
- psychosocial and environmental strategies have resulted in minimal change in presentation
- trials of psychotropic medication have been unsuccessful.

The person is likely to have experienced
- a long inpatient stay of over three to six months, or
- a shorter inpatient stay with significant risk or safety issues or incidents apparent quickly,
- inability to secure a residential aged care placement, and/or
- multiple unsuccessful hospital admissions or residential aged placements.
Why we’re doing it
The aim is to understand better the cohort of people with persistent, extreme BPSD to inform policy and service planning. This will lead to improved care and service responses for this group.

Currently in NSW, people with extreme BPSD may be cared for in a variety of services and environments. These services currently vary in their capacity and approach in providing care for people with persistent, extreme BPSD and in the care environment they provide. They may not be equipped to offer the most appropriate care for the small number of people who experience extreme BPSD, and the care environment they can provide may even exacerbate behaviours and increase a person’s risk of harm to self, other patients or staff.

What we want to find out through our consultation with you
Please consider the following consultation prompts:

1. What does your LHD (or geographic location) have in place for people with severe (as opposed to extreme) BPSD?
   
e.g. MHACPI unit, TBASIS unit, SBRT, specialist RACF, specific pathways in the absence of specialist services, and so forth.

2. After reading the description of extreme BPSD, do current or past people experiencing extreme BPSD come to mind?
   *Please focus on cases in the last five years, as there have been a lot of changes within services and service availability in the last decade
   
   a. What year and what location?
   
   b. What were the characteristics (ie from blue box list or other characteristics) that make you define this person as experiencing extreme (versus severe) BPSD?
      
i. Are these related to the person (e.g. aggression) or the environment (e.g. inability to source a suitable residential placement)?
   
   c. What was their service/care pathway?
   
   d. What was their service endpoint/where are they now?
   
   e. What worked in providing care for them?
   
   f. What didn’t work?
   
   g. What was the impact of the care environment on the person, their family and care staff?

3. Would you be interested in providing more in depth information about this person/people and their experiences, in the form of a case study or an interview?
Appendix 4. Detail of prevalence estimates from consultation meetings

This table summarises the estimates provided during consultation meetings and follow up conversations from various aged health and older people’s mental health (OPMH) services. From these, the project has built a district and a statewide estimate of prevalence in NSW. For more information, see section 4.

<table>
<thead>
<tr>
<th>Local Health District (LHD)</th>
<th>Estimate provided by</th>
<th>Estimates provided (mix of prevalence and incidence)</th>
<th>Estimated number of people at any point in time (prevalence)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Central Coast</strong></td>
<td>Central Coast – geriatric medicine, clinician estimation.</td>
<td>Up to three people at any point in time.</td>
<td>3</td>
</tr>
<tr>
<td><strong>Far West</strong></td>
<td>No estimate provided, assumption made</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td><strong>Hunter New England</strong></td>
<td>Hunter New England – OPMH team, based on review of patients with high number of incidents in IMS system</td>
<td>Six people between 2009 – 2019. Length of stay ranged between 132 and 438 days.</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Hunter New England – T-BASIS</td>
<td>One person at a time</td>
<td></td>
</tr>
<tr>
<td><strong>Illawarra Shoalhaven</strong></td>
<td>No estimate provided, assumption made</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td><strong>Justice and Forensic</strong></td>
<td>Justice and Forensic Mental Health, clinician estimation</td>
<td>None</td>
<td>0</td>
</tr>
<tr>
<td><strong>Mid North Coast</strong></td>
<td>No estimate provided, assumption made</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td><strong>Murrumbidgee</strong></td>
<td>No estimate provided, assumption made</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td><strong>Northern NSW</strong></td>
<td>No estimate provided, assumption made</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Local Health District (LHD)</td>
<td>Estimate provided by</td>
<td>Estimates provided (mix of prevalence and incidence)</td>
<td>Estimated number of people at any point in time (prevalence)</td>
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<td>----------------------------------------------------------</td>
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<tr>
<td><strong>Northern Sydney</strong></td>
<td>No estimate provided, assumption made</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td><strong>Southern NSW</strong></td>
<td>No estimate provided, assumption made</td>
<td></td>
<td>1</td>
</tr>
</tbody>
</table>
| **South East Sydney**      | South East Sydney – St George, based on nurse file review of patients in behavioural unit between January and May 2020. | Five | 7  
This assumes five people in St George, one person in Sutherland and one person in Prince of Wales. |
|                           | South East Sydney – Sutherland, clinician estimate | Two per year | |
|                           | South East Sydney – Prince of Wales, clinician estimate | Four or five per year, only one at a time. | |
| **South Western Sydney**   | No estimate provided, assumption made | | 1 |
| **Sydney**                 | Sydney LHD – Jara unit in Concord, clinician estimate. | Eight per year, including delirium. Alternate estimation was one at the moment, two in last 12 months. | 4 |
|                           | Sydney LHD – Aged care at Concord, clinician estimate. | Average of two at any point in time | |
| **Western NSW**            | No estimate provided, assumption made | | 1 |
| **Western Sydney**         | Western Sydney LHD – Blacktown Aged Care Ward | Six patients in six month period | 9  
This assumes four people in Blacktown and five people in Westmead. |
|                           | Western Sydney LHD – Westmead Aged Care | Five patients at any point in time | |

**Total** 34
Appendix 5. T-BASIS Model of Care

As a result of the 2006 Review of Confused and Disturbed Elderly (CADE) Units in NSW(29), the Transitional Behaviour Assessment and Intervention Service (T-BASIS) model of care was developed and implemented. The key components of the T-BASIS Model of Care is described below:

**Functions and target population**

The T-BASIS units will provide multi-disciplinary assessment, care planning, and person-specific bio-psychosocial treatment for older people with severe behavioural disturbance associated with dementia and/or mental illness which cannot be managed at their current place of residence. The units will provide both a ‘step-up’ function by taking admissions direct from the community (either home or residential care), and a ‘step-downs’ function by taking admissions from acute medical or psychiatric inpatient services (where appropriate). The model of care includes outreach services to RACFs and community care providers to enhance the capacity of these providers in the care of older people with severe BPSD, and thereby to reduce admissions to and facilitate the discharge of consumers from T-BASIS units.

**Governance and security/operational arrangements**

Key governance-related recommendations relate to clear lines of reporting and accountability within the Local Health District (LHD) and formal mechanisms for regular consultation between mental health, aged health and LHD managers on planning and service issues affecting T-BASIS units. These issues address previous issues relating to T-BASIS unit accountability and reporting and the importance of these units to both the Older People’s Mental Health (OPMH) and aged health spectrum of services. The T-BASIS MoC emphasizes the need for appropriate security arrangements, risk management strategies, environment and fittings to support the safe and effective operation of these units.

**Staffing**

Key staffing recommendations in the MoC include the need for a Medical Director for each T-BASIS unit, and regular access to clinical input from both a geriatrictian and old age psychiatrist (with minimum levels of medical staff coverage and access specified). Nursing and allied health staffing recommendations include the need for an experienced nursing unit manager, senior clinician (to train, mentor and supervise staff and students on placement, run staff mentoring and behaviour support meetings, and raise the profile of psychosocial interventions in clinical reviews), nursing staff, diversional therapist, and access to sessional allied health such as physiotherapists and...
speech therapists. ‘Outreach clinicians’ to promote linkages with all community aged services across the LHD including the RACF sector, facilitate admissions and discharges, and increase capacity for people to be managed in situ, are a key staffing element. The T-BASIS MoC emphasizes the need for appropriate staff education and training, supervision and support to support the safe and effective operation of these units.

**Clinical process and practice**

Specific clinical process recommendations relate to: nursing and care staff being active participants in devising, monitoring, adapting and sharing bio-psychosocial treatment strategies, with structures put in place to ensure this occurs; weekly staff mentoring and behaviour support meetings, and weekly multidisciplinary clinical review meetings including medical staff, NUM, senior clinicians, social worker/discharge planner, a representative of the outreach service and, where appropriate, other service providers such as Aged Care Assessment Teams (ACATs).

**Performance**

Measures of good clinical practice relate to timely, multidisciplinary and comprehensive care planning (including psychosocial interventions), regular clinical review, and family and carer involvement in care planning, medication review, and transfer of care plans.
Appendix 6. Example layout from South Australian Neurobehavioural Unit

As a part of their response to *The Oakden Report*², SA Health have refurbished an existing space as the location of a new neurobehavioural unit. The design of the unit has been informed by consultation with carers⁴. It is included as an example of one design response to the needs of people experiencing extreme BPSD.

Key design features include:

- Multiple pods to allow separation of patients
- Accessible outdoor space in each pod
- Spaces for meaningful activities
- Separate spaces for carers and family gatherings
- Co-location with Older People’s Mental Health Inpatients Unit and a Specialised Dementia Care Unit
Appendix 7. Expert Reference Group members

- Dr John Dobrohotoff – Clinical Advisor, Older People’s Mental Health (OPMH) Policy Unit, Mental Health Branch, NSW Ministry of Health
- Dr Kate Jackson – Director, Older People’s Mental Health (OPMH) Policy Unit, Mental Health Branch, NSW Ministry of Health
- Ms Clare Stuart – Policy Officer, Older People’s Mental Health (OPMH) Policy Unit, Mental Health Branch, NSW Ministry of Health
- Ms Maria Passarello – Manager, Aged Care Unit, Health and Social Policy Branch, NSW Ministry of Health
- Professor Henry Brodaty – Scientia Professor of Ageing and Mental Health, University of NSW
- Professor Brian Draper – Conjoint Professor, School of Psychiatry, University of NSW
- Associate Professor Lee-Fay Low – Associate Professor in Ageing and Health, University of Sydney
- Dr Sharon Buxton, Western NSW LHD – Clinical Psychologist, Older People’s Mental Health, Western NSW Local Health District
- Ms Katryna Harman – Clinical Nurse Consultant, Older People’s Mental Health, Hunter New England Local Health District
- Dr Dev Lakshmanan – Clinical Director, Older People’s Mental Health, Illawarra Shoalhaven Local Health District
- Dr Natasha Spalding – Staff Specialist, Geriatrics, Sydney Local Health District
- Ms Katie Conciatore – Dementia and Delirium Clinical Nurse Consultant, Western Sydney Local Health District
- Ms Cindy Stoupas – Clinical Nurse Consultant, Older People’s Mental Health, Justice Health and Forensic Mental Health Network

With acknowledgements to Ms Lindsay Penson, Senior Policy Officer, Older People’s Mental Health (OPMH) Policy Unit, Mental Health Branch, NSW Ministry of Health for project consultations and early project work