

How patient centric is health policy development? The case of the Parliamentary Inquiry into Sleep Health Awareness in Australia

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Abstract:

Objective: Parliamentary inquiries into health-related issues empower everyday Australians to contribute to the development and reform of health policy. We explored how patient and family/carers concerns are translated by this process, using a less well-known disease, narcolepsy, as an example.

Methods: Written submissions made to the *Parliamentary Inquiry into Sleep Health Awareness in Australia 2018* by self-identified patients or family/carers with narcolepsy (n=13) were extracted and thematically analysed using the Framework Approach. Each submission was systematically coded and abstracted into emergent themes before being evaluated against the final policy recommendations.

Results: While patients and their family/carers prioritised issues that affected their daily lives (i.e. mental health sequela, workplace accommodations), the policy recommendations in the report focused mainly on issues of healthcare infrastructure, funding and engagement. Our analysis highlighted several barriers that patients and their family/carers face when contributing to this part of healthcare policy formation.

Conclusions: Our findings suggest that the Parliamentary Inquiry process in its current form is not an ideal vehicle by which patients and family/carers can contribute or influence healthcare policy. Despite calling for submissions from patients and their family/carers, the final report and subsequent health policy recommendations made by the inquiry do not appear to be patient-centric or reflective of the submissions written by these stakeholders. Increased transparency,

development of processes to balance stakeholder priorities and improved accessibility for stakeholders to participate are needed if health-related parliamentary inquiries are to produce healthcare policy that ultimately meets the needs of patient and family/carers.

Key Question Summary

What is known about the topic?

Parliamentary inquiries are one of few instances where patients and their families and carers can directly contribute alongside other, often more powerful stakeholders (i.e doctors, non-government organisations) to the development of high-level healthcare policy.

What does this paper add?

While healthcare and health policy have become increasingly patient-centric, stakeholder engagement is often driven by other, more powerful stakeholder groups (doctors, non-government organisations etc). A Parliamentary Inquiry represent a unique approach towards engaging stakeholders as it allows for the direct contribution and empowerment of everyday Australians. This is the first study that explores how patient and family/carer concerns are translated by the parliamentary inquiry process and the extent to which these concerns are addressed by policy reform.

What are the implications for practitioners?

While a Parliamentary Inquiry has the potential to develop and reform high-level healthcare policy, it lacks transparency and processes for balancing stakeholder perspectives. This may lead to misaligned stakeholder priorities and inefficient

healthcare policy, programmes and services that do not adequately meet the needs of patients or their family/carers.

Introduction:

Policymakers rely on key stakeholder groups (i.e. patient/carers, healthcare professionals, professional organisations) to deliver effective, transparent and trusted healthcare and research policy (1, 2). Balancing the diverse and sometimes divergent priorities of stakeholders can be challenging (i.e. for-profit entities vs patients). Established processes are needed to ensure stakeholders that are more financially powerful, highly vocal, or intellectually conflicted stakeholders do not dominate the policy development process (3). Seeking diverse opinions not only between stakeholder groups but within these groups is also important to ensure healthcare policy is both equitable and inclusive. It is widely accepted that participation across stakeholder groups should be encouraged, with processes needed that facilitate participation from vulnerable groups (e.g. culturally sensitive communication materials) as well as increasing transparency around engagement and policy development process (3, 4).

In Australia, a form of stakeholder engagement employed by governments are parliamentary inquiries. These are used to seek citizen views of policy, government procedure or performance in the areas of health, aged care and education, amongst others (5). Individuals, organisations, patient advocacy and special interest groups are all given the opportunity to contribute. These inquiries represent one of the few platforms accessible to patients and their family and carers to contribute to the development of health policy. Each inquiry is limited in scope, where stakeholders are invited to share their perspectives and submit written responses to the *terms of*

reference set forth by the inquiry (6). Public hearings are also held by the inquiry, with select stakeholders invited to discuss concerns raised in written statements and to answer questions posed by parliamentary members who run the inquiry. On completion, the Committee's findings are summarised in a final report and submitted to parliament, typically recommending government intervention (i.e. introduction of legislature, change of administration processes). Response from the government is required within six months of submission, detailing which recommendations will be enacted (5).

In 2018, the federal Minister for Health, Aged Care and Sports directed the Standing Committee on Health, Aged Care and Sport to hold a parliamentary inquiry into sleep health awareness in Australia. This was in response to lobbying and advocacy work of peak sleep health professional bodies and support groups (i.e. Sleep Health Foundation and Australasian Sleep Association)(7).

The inquiry terms of reference invited interested individuals and organisations to respond to issues outlined below:

1. The potential and known causes, impacts and costs (economic and social) of inadequate sleep and sleep disorders on the community;
2. Access to, support and treatment available for individuals experiencing inadequate sleep and sleep disorders;
3. Education, training and professional development available to healthcare workers in the diagnosis, treatment and management of individuals experiencing inadequate sleep and sleep disorders;

4. Workplace awareness, practices and assistance available to those who may be impacted by inadequate sleep or sleep disorders;
5. Current national research and investment into sleep health and sleeping disorders.

The final report entitled “Bedtime Reading” is publicly accessible and has been submitted to parliament for acceptance. However, the final report does not inform the reader how submissions made to the inquiry were prioritised, disregarded, or even considered (be they from patients, family/carers or organisations), nor if they influenced the final reports findings and subsequent policy recommendations (8). Therefore, the purpose of this paper is to: (1) compare the patients and family/carers submissions against the final report and recommendations made by the inquiry, and (2) evaluate to what extent they appear to have been considered and incorporated into this influential health policy process.

We examined this through the lens of narcolepsy, a chronic and rare sleep disorder estimated to affect 1 in every 2000-5000 individuals, usually managed in the community. Currently, little is known of how the condition affects patients and carers in Australia as routine healthcare data better captures common conditions that incur hospitalisations (9, 10). The disorder arises in childhood or adolescence and affects the brain's ability to stay awake or asleep, causing the individual never to feel rested, fall asleep without warning and have trouble staying asleep at night (11). Other symptoms include vivid dreams and paralysis brought on by strong emotion such as laughter (11). Narcolepsy was chosen as it is characterised by a lack of public awareness, with a mean diagnostic delay of 15 years, along with substantial

personal and economic burdens (12-14). Further, as a rare disease, we wanted to examine how the concerns of a relatively small patient population are translated into policy.

Method

Data Extraction

All 131 written submissions received by the inquiry are part of the public domain and were downloaded from the inquiry website (15). Ethics approval for the study was granted by the University of Sydney Human Research Ethics Committee (2019/663). Each submission was read by two authors and included if the writer identified themselves as someone with narcolepsy or written by a family member or carer of someone with narcolepsy.

Analysis

Patient and family/carer submissions were thematically analysed using the Framework Approach (see supplementary material), an applied social policy research framework that results in a thematic framework (16-18). This approach is a five-step process involving:

1. Familiarisation of the data
2. Identifying a thematic framework
3. Indexing
4. Charting
5. Mapping and Interpretation

Relevant submissions were first read iteratively by two authors to become familiar with emerging ideas and concepts raised. A thematic framework was subsequently developed from integrating the *a priori* terms of reference with emerging concepts from patient/family/carer submissions. Individual submissions were then indexed against the thematic framework and subsequently organised into thematic matrices to map out cross-case and within-case descriptions of the phenomena of interest to identify emergent themes. A subset of submissions was selected to undergo cross-checking to ensure the reliability of the thematic categories identified for inter-coder reliability ($\kappa = 0.72$, averaged from three coding nodes by authors AS and MA). Any disagreement with the assignment of codes or thematic categories were discussed and resolved with the research team.

Emergent themes that resulted from our analysis were compared against the policy recommendations contained in the final report 'Bedtime Reading' that was submitted to parliament by the inquiry (8, 19). All analyses were carried out using NVivo (Version 12, QSR International).

Results

The inquiry received a total of 131 submissions, of which 67 (51%) were written by organisations, 56 (43%) by individuals, 7 (5%) classified as confidential by the government and redacted and 1 (1%) written by the Department of Health providing information requested by the Inquiry. Of the 56 written by individuals, 20 (36%) were written by members of the public regarding issues such as environmental factors on sleep (i.e. wind turbines, electromagnetic radiation), 17 (30%) by self-identified healthcare professionals, 17 (30%) by self-identified patients or family/carers with a sleep disorder and 2 (4%) by self-identified researchers. Of these 17 written by self-identified patients or family/carers, 13 (76%) were specific to narcolepsy, which formed the data for this study, 2 (12%) related to Obstructive Sleep Apnoea and 1 (6%) each related to Restless Leg Syndrome and Non-24-Hour Sleep-Wake Disorder.

The submissions made by patient and family/carers with narcolepsy accounted for 10% of the total submissions received. Our analysis identified nine thematic categories, which were abstracted into three overarching themes: *Pathways to Treatment & Care*, *Help-seeking Experiences* and *Patients' Lived Experience of Disease*. These, along with illustrative quotes, are contained in table 1.

Theme 1: Pathways to Treatment & Care

This overarching theme encompassed patient and family/carer concerns around lack of healthcare and research resource allocation for narcolepsy. Submissions received identified barriers in accessing newer treatment options that are available overseas but not widely accessible in Australia and a lack of sleep diagnostic infrastructure (i.e. sleep laboratories, polysomnography equipment), particularly in rural and

regional areas. This lack of infrastructure was purportedly worse in Tasmania and South Australia, which caused long wait times and, in some cases, (n = 2) required interstate travel to receive adequate care. A lack of narcolepsy research conducted within Australia was also identified by patients and family/carers as a concern, with the belief that 'what gets measured, gets managed', leading to oversight of patient and family/carer priorities.

Theme 2: Help-seeking Experiences

Barriers to help-seeking and accessing care were also frequently described in patient and family/carer submissions. Many perceived that primary and secondary/tertiary healthcare workers lacked knowledge of narcolepsy, which led to them receiving suboptimal care. Areas lacking included symptom recognition, treatment options and management strategies. Several patient and family/carer submissions also highlighted the importance of the therapeutic alliance in narcolepsy; those who had established rapport with their doctor experienced a positive impact on disease trajectory, namely a shorter delay in achieving a diagnosis. Online patient support groups were identified as an important resource for both information and support, particularly during the early phases of the help-seeking process. However, a lack of funding for support groups, specifically around programs associated with building community awareness and overhead costs were identified as a cause for concern.

Theme 3: Patients' Lived Experience of Disease

Patients' lived experience of disease theme related to the tangible effects that narcolepsy has on the daily lives of patient and family/carers. Of greatest concern

was the sequelae of narcolepsy, in particular mental health concerns (i.e. anxiety, depression, isolation) and psychosocial adversity (i.e. unemployment). This was not just experienced by patients but also by family members and carers who described dealing with feelings of grief and loss. Another concern that was identified related to difficulties accessing support/welfare services such as Centrelink (i.e. disability support pension) or the National Disability Insurance Scheme (NDIS), as well as limited support offered by workplaces and education institutions for those with narcolepsy to continue their employment and education. Several submissions detailed concerns related to current treatment options, the health impacts associated with long-term use of medications, and the potential for a build-up of tolerance associated with those medications.

When we compared the policy recommendations made by the inquiry to the results of our thematic analysis, four of the nine thematic categories identified by patients were specifically addressed by the report, with two specifically addressed while the other two were only partially addressed (8) (Table 1). These related to the structural and logistical issues of healthcare (i.e. funding, access to new medications) rather than addressing concerns of patients and their family/carers that have a tangible effect on their daily life (i.e. mental health support, employment accommodations).

This is despite the inquiry asking for the impact of sleep disorders on the community in the first term of reference.

1 **Discussion**

2 The analysis of public submissions to a parliamentary inquiry into health highlights
3 several issues regarding the involvement of patients and family/carers as part of the
4 stakeholder engagement process in shaping policy:

5

6 1. Avenues available for patients and family/carers to voice healthcare concerns

7

8 Despite narcolepsy being a rare sleep disorder with a prevalence of approximately
9 1/2000 to 1/5000 (20), patients and their family and carers with narcolepsy were
10 disproportionately represented in the inquiry submissions, accounting for 10%
11 (13/131) of total submissions and 76% (13/17) of all patient and family/carer
12 submissions received. Furthermore, 18% (2/11) of the recommendations made by
13 the inquiry specifically relate to narcolepsy. This over-representation may be
14 because patients with more common sleep disorders (i.e. Obstructive Sleep Apnoea,
15 Insomnia) have fewer concerns about their care, are less organised and engaged, or
16 alternatively, have access to pre-existing pathways to raise these concerns. Perhaps
17 the small population size of rare (sleep) disorders makes it difficult for these patients
18 to have their voices heard when accessing these same pathways. It may also be
19 attributed to the lack of systematic data collection of rare diseases in Australia and
20 simply be a case of 'what gets measured, gets managed' (9, 21). Our findings raise
21 an important question: What are the avenues available for patients and their
22 family/carers, particularly with those from disparate groups (i.e. chronic/rare
23 diseases), to voice their concerns in a way that result in a meaningful contribution to
24 healthcare policy?

25

26 2. Apparent discordance between the scope of the terms of reference, priorities of
27 patients' families, and recommendations identified in the final report/submissions
28 received.
29

30 The first term of reference of the inquiry specifically calls for information on the
31 'causes, impacts and costs (economic and social)' of sleep disorders on the
32 community. Our analysis showed that while patient and family/carers responded to
33 this, with emphasis placed on mental health and daily functionality, no policy
34 recommendations were made in these domains (Table 1). Rather policy
35 recommendations in the final report focused on healthcare engagement,
36 infrastructure, and funding (i.e. sleep laboratories, medication access). While these
37 recommendations represent a positive outcome of the inquiry for improving access
38 to care, clear recommendations addressing daily living priorities such as employment
39 support and welfare access remain lacking in the final report.. This suggests some
40 discordance between priorities identified in the recommendations made by
41 policymakers, and those held by patients and their family and carers with narcolepsy
42 (Table 1).

43
44 Overall, there is a lack of transparency around how stakeholder submissions were
45 translated and competing stakeholder priorities balanced. In the absence of a
46 transparent process and inclusion of patient/family/carer groups in the decision-
47 making process, what matters most to patients has been decided *for* patients rather
48 than *with* patients. This is of concern given that dissonance between patient and
49 health system priorities has been shown to lead to reduced engagement, lower
50 satisfaction with treatment and poorer patient outcomes (22). Perhaps the process of
51 the inquiry needs to be modified to allow patient, family and carer groups the

52 opportunity to give feedback prior to submission of the final report, similar to patient
53 co-design in research (23).

54 Another issue identified was the limited disclosure of (potential) conflicts of interests
55 by stakeholders who participated in the inquiry or those that facilitated it. The inquiry
56 received submissions from for-profit businesses and primary care providers writing in
57 the capacity of owners of private clinics. Care needs to be taken to ensure any party
58 with financial ties to industry not exert undue influence on the process of policy
59 development. This extends to managing the perception of conflict of interests and
60 may be achieved by increasing transparency of stakeholder engagement and
61 requiring conflict of interests declarations from all parties involved in the policy
62 development process (24).

63

64 3. Significant barriers for the community to participate in healthcare policy

65

66 The terms of reference specifically call for submissions regarding disadvantaged and
67 under-represented groups such as children and adolescents, culturally and
68 linguistically diverse backgrounds, rural, regional, and remote areas and Aboriginal
69 and Torres Strait Islanders. However, we identified several barriers to participate in
70 the inquiry that these groups would have encountered:

71 • Submissions could only be made via online submission or by posting a hand-
72 written response, precluding individuals that lack access to computer facilities
73 or who may have inadequate writing skills. While individuals were invited to
74 attend the hearing, these were selected by the inquiry from the pool of those
75 that wrote submissions.

76 • Terms of reference were written only in English.

77 • The terms of reference of the inquiry require a university graduate reading
78 level (Flesch-Kincaid readability score of 2.4 - scored by author AS). (25)

79

80 These barriers suggest that the inquiry process will result in only a self-selected
81 sample of the population being represented. This may result in patients and
82 family/carers from different backgrounds (i.e. cultural, socioeconomic) missing
83 opportunity to voice concerns they may have. There is a need to improve
84 stakeholder engagement through adopting more inclusive approaches that can
85 facilitate access and participation. For example, translation of the terms of reference
86 into different languages or involving Aboriginal and Torres Strait Islander leaders in
87 the developmental phase of parliamentary inquiries. Such approaches fosters a true
88 collaborative partnership with patients to genuinely influence the decision making
89 process and drive meaningful changes in policy (26).

90

91 4. The role of government and parliamentary inquiries in healthcare and policy
92 generation

93

94 The inquiry produced 11 policy recommendations that were informed through the
95 collaborative process between patients, physicians, and other stakeholders (8). The
96 report was submitted to parliament in early 2019; however, it is yet to be accepted or
97 responded to. The government is required to respond within six months of
98 submission; however, this is rarely adhered to, with delays of up to two years
99 common (5). While recent delays may be attributed to Covid-19, inquiries such as
100 the 'Inquiry into Chronic Disease Prevention and Management in Primary Health
101 Care' was submitted in May 2016 and is yet to receive a response. To ensure

102 recommendations are implemented, allocation of additional resources (i.e. funding,
103 staff) may be needed to ensure a quick response, given they contain the most salient
104 recommended policy changes that have resulted from collaboration amongst key
105 stakeholders.

106

107 The delayed response from government speaks to the wider question of whether
108 parliamentary inquiries are appropriate vehicles for health policy development and
109 reform. A key limitation of these inquiries is that there is no clear path for policy
110 change. The decision to implement recommendations of a parliamentary inquiry is
111 contingent on its alignment with the policy agenda of government and its perceived
112 importance by cabinet ministers (27). Ethically, is it fair to ask patients and their
113 family and carers to publicly share their lived experience with no guarantee that the
114 recommendations will be accepted let alone addressed? Typically, stakeholder
115 engagement is increasingly driven by more powerful stakeholders (i.e doctors, non-
116 government organisations, funding bodies). Of the patient and family/carers
117 stakeholders that do participate, they may only represent a small subset of wider
118 society (i.e more health literate, affluent, monocultural). In combination with issues
119 around transparency, balancing stakeholder bias, and accessibility, it suggests that
120 parliamentary inquiries are not ideal policy shaping tools. However, these inquiries
121 represent a unique form of stakeholder engagement that is rarely seen in healthcare.

122 The call for public submissions in response to the terms of reference allows any
123 Australian the opportunity to have their voice heard, empowering ordinary citizens to
124 get involved in shaping the healthcare system. This differs from other models of
125 patient and family/carer contribution to health policy development (e.g. Health
126 Consumers Australia), which instead advocate on behalf of their members. As seen

127 in the example of narcolepsy, niche healthcare issues that may not necessarily be on
128 the agenda when considering population-wide healthcare needs are given both a
129 platform and the opportunity to be heard. While far from perfect, these parliamentary
130 inquiries are representative of a bottom-up approach to stakeholder engagement and
131 perhaps should be used as a basis to expand future stakeholder engagement
132 initiatives.

133

134 **Strengths and Limitations**

135 The first author is a person with narcolepsy, which enabled greater insight into how
136 patients and carers experience the system however, may have led to researcher
137 bias. This was reduced by including experienced qualitative researchers with no
138 such lived experience in the thematic analysis. The study was limited by the number
139 of patient/family/carer submissions received by the inquiry that related to narcolepsy.
140 In addition participants represent a self-selected sample of the population with a
141 higher level of literacy, education, and interest in sleep disorders than the general
142 community.

143

144 **Conclusion**

145 Parliamentary inquiries represent one of few opportunities for patients and their
146 family and carers to contribute directly to the development and reform of healthcare
147 policy. While our study highlights some of the significant, practical barriers that
148 patient and their family and carers encounter when trying to shape healthcare policy,
149 at its core is a process that empowers everyday Australians to shape the healthcare
150 system. This is particularly important in the context of rare diseases like narcolepsy,
151 as limited population data, systems for patient data collection, and less research

152 places greater emphasis on the lived experience of the patient in determining
153 satisfaction, treatment success, as well as identifying any potential concerns that
154 may arise (9, 28). Where the parliamentary inquiry does falter is in its lack of
155 transparency when translating submissions, limited disclosure of potential conflicts of
156 interests amongst stakeholders and barriers that stakeholders may face when
157 contributing to the inquiry. While the underlying premise of an open, public domain is
158 sound, reform addressing these concerns is needed to ensure healthcare policy
159 remains targeted and trusted (3). As health policy forms the bedrock of healthcare,
160 more needs to be done to incorporate patients' and their family/carers' concerns and
161 priorities into its development. Only then can we cultivate truly patient-centred
162 healthcare systems.

163
164 **Declaration of Funding**

165
166 This research did not receive any specific funding

167
168 **Data Availability Statement**

169 The data that supports this study was obtained from the Federal Parliament of
170 Australia website. All submissions made are part of the public domain and are
171 accessible at
172 https://www.aph.gov.au/Parliamentary_Business/Committees/House/Health_Aged_Care_and_Sport/SleepHealthAwareness/Submissions
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- 241
- 242

243 **Supplementary 1 - Framework Analysis**

244

245 An overview of the five key stages to the framework analysis have been extracted
246 from Srivastava and Thompson (2009) and are listed below (17):

247

248 **1. Familiarization**

249 Familiarization refers to the process during which the researcher becomes
250 familiarized with the transcripts of the data collected (i.e. interview or focus group
251 transcripts, observation or field notes) and gains an overview of the collected data
252 (18). In other words, the researcher becomes immersed in the data by listening to
253 audiotapes, studying the field or reading the transcripts. Throughout this process the
254 researcher will become aware of key ideas and recurrent themes and make a note of
255 them.

256

257 **2. Identifying a thematic framework**

258

259 Identifying a thematic framework, the second stage, occurs after familiarization when
260 the researcher recognizes emerging themes or issues in the data set. These
261 emerging themes or issues may have arisen from a priori themes or issues
262 however it is at this stage that the researcher must allow the data to dictate the
263 themes and issues. To achieve this end the researcher uses the notes taken during
264 the familiarization stage. The key issues, concepts and themes that have been
265 expressed by the participants now form the basis of a thematic framework that can
266 be used to filter and classify the data (18). Although the researcher may have a set
267 of a priori issues, it is important to maintain an open mind and not force the data to fit
268 the a priori issues. However since the research was designed around a priori issues
269 it is most likely that these issues will guide the thematic framework. Ritchie and
270 Spencer stress that the thematic framework is only tentative and there are further
271 chances of refining it at subsequent stages of analysis (18).

272

273 **3. Indexing**

274

275 Indexing means that one identifies portions or sections of the data that correspond to
276 a particular theme. This process is applied to all the textual data that has been
277 gathered (i.e. transcripts of interviews). For the sake of convenience Ritchie and
278 Spencer recommend that a numerical system be used for the indexing references
279 and annotated in the margin beside the text (18). Qualitative data analysis tools such
280 as NVivo, are ideal for such a task.

281

282 **4. Charting**

283 Charting, the fourth stage, the specific pieces of data that were indexed in the
284 previous stage are now arranged in charts of the themes. This means that the data is
285 lifted from its original textual context and placed in charts that consist of the headings
286 and subheadings that were drawn during the thematic framework, or from a priori
287 research inquiries or in the manner that is perceived to be the best way to report the
288 research (18). The important point to remember here is that although the pieces of
289 data are lifted from their context, the data is still clearly identified as to what case it

290 came from. For clarity, cases should always be kept in the same order in each chart
291 (18).

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293 **5. Mapping and interpretation**

294 The final stage, mapping and interpretation, involves the analysis of the key
295 characteristics as laid out in the charts. This analysis should be able to provide a
296 schematic diagram of the event/phenomenon thus guiding the researcher in their
297 interpretation of the data set. It is at this point that the researcher is cognizant of the
298 objectives of qualitative analysis, which are: “defining concepts, mapping range and
299 nature of phenomena, creating typologies, finding associations, providing
300 explanations, and developing strategies” (18). Once again these concepts,
301 technologies, and associations are reflective of the participant. Therefore, any
302 strategy or recommendations made by the researcher echo the true attitudes,
303 beliefs, and values of the participants.

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Table 1: Alignment between the 11 policy recommendations made by the Parliamentary Inquiry into Sleep Health in Australia 2018 and thematic categories identified using qualitative framework analysis of patient and family/carers submissions related to narcolepsy

Theme 1: Pathways to Treatment & Care				
Sub-theme	Summary of Synthesis	Illustrative Quotations	Policy recommendations	Appraisal of recommendations
Access to newer medications to treat narcolepsy that are available overseas	<ul style="list-style-type: none"> Most submissions mentioned the lack of access to newer medications, particularly Sodium Oxybate. Participants who described the positive effects of these medications on quality-of-life contrasted it with current/previous treatments. Regulatory approval and cost of medication identified as main barriers 	<ul style="list-style-type: none"> "The other problem we face with effective treatment is that drugs that are readily available in either the USA or Europe are not quite so readily available here, and if they are, the price is prohibitive for many families." (Submission 42) "Since commencing Xyrem my son has been able to return to full time study and obtain his learners permit and is far more functional than he was on his previous treatments." (Submission 90) 	<p>Recommendation 7:</p> <p>The Committee recommends that if there is no distributor willing to put forward a submission, the Australian Government work with patient advocacy groups such as Narcolepsy Australia or the Sleep Health Foundation to make a submission for the listing or registration of Sodium Oxybate under the Orphan Drug Program.</p>	<p>Recommendation specifically addresses patient and family/carer concerns regarding access to new medications that are not accessible in Australia</p>
Access to diagnostic healthcare services	<ul style="list-style-type: none"> Public patient access to diagnostic sleep studies (polysomnography) 	<ul style="list-style-type: none"> "Not all Sleep centres are equipped to test or treat patients with narcolepsy. Instead, I must make an annual trip to Newcastle (2 	<p>Recommendation 4:</p> <p>The Committee recommends that the Department of Health</p>	<p>While the recommendation calls for a review of funding and referral of diagnostic sleep</p>

	<p>varies significantly state-by-state</p> <ul style="list-style-type: none"> • Rural access to sleep laboratories is limited, requiring lengthy travel to more urban centres, with significant travel being difficult for someone with narcolepsy • Perception that the lack of services contributed to lower quality-of-life 	<p>hours drive) to visit my Sleep Specialist for a 12 hour maintaining wakefulness and latency test (to keep my drivers license)." (Submission 116)</p> <ul style="list-style-type: none"> • "Being in Tasmania offers us little in the way of support groups, medical facilities designed to better understand this condition and treatment options. Yes, it is our choice to live here, but we also shouldn't be penalised because of that choice." (Submission 42) 	<p>undertake a review of the Medicare Benefits Schedule as it relates to sleep health services in Australia. The review should include, but not be limited to, the following:</p> <ul style="list-style-type: none"> • Ensuring recent changes to enable general practitioners to directly refer patients to diagnostic sleep studies are effective; 	<p>studies, it does not address concerns around inadequate infrastructure (sleep laboratories, equipment needed), and barriers that individuals in rural, regional locations, or in South Australia and Tasmania.</p>
<p>Limited narcolepsy research in Australia</p>	<ul style="list-style-type: none"> • Participants identified a lack of research into narcolepsy, highlighting that prevalence has not been studied in Australia • Perception that more research into the disease will lead to a reduction in delay to diagnosis, better 	<ul style="list-style-type: none"> • "To date there has been no study done in Australia to pin-point the actual number of people suffering sleep disorders... Narcolepsy in particular! So far all the information I've read has been based on the statistics provided in the USA." (Submission 116) 	<p>Recommendation 11: The Committee recommends that the Australian Government fund research focussed on:</p> <ul style="list-style-type: none"> • The prevalence of sleep disorders with a particular focus on under-researched 	<p>Recommendation specifically addresses patient concerns around lack of research of narcolepsy, particularly in under-researched populations (i.e Aboriginal and Torres Strait Islander peoples).</p>

	treatment options and improved quality of life	<ul style="list-style-type: none"> • “Whilst we are fully aware that at this point there is no cure for Narcolepsy, better treatment options should be researched, trying to get that blood/brain barrier crossed to be able to replace the lost orexins, or if gene/stem cell replacement may help.” (Submission 42) • “Research into the effects of disturbed sleep and how to better manage systems of work to avoid sleep disturbance - or better manage the impacts of sleep disturbance - is essential.” (Submission 67) 	<p>population groups such as women and Aboriginal and Torres Strait Islander peoples;</p> <ul style="list-style-type: none"> • The prevalence, causes, and mechanisms of rare or not well understood sleep disorders, including narcolepsy and idiopathic hypersomnia; <p>Further analysis of existing population health and longitudinal studies that have collected data relating to sleep;</p>	
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Theme 2: Help-seeking Experiences

Sub-theme	Summary of synthesis	Illustrative quotations	Policy recommendations	Appraisal of recommendations
Perceived knowledge of narcolepsy in healthcare workers	<ul style="list-style-type: none"> • Perception that sleep specialists and primary healthcare workers lacked knowledge of narcolepsy, its 	<ul style="list-style-type: none"> • “there is a lack of knowledge and understanding among health professionals, that there is a difference between narcolepsy and 	<p>Recommendation 10:</p> <p>The Committee recommends that the Australian Government investigate options to</p>	<p>Recommendation address concerns raised by patients, as an independent sleep speciality would allow</p>

	<p>symptoms and treatments</p> <ul style="list-style-type: none"> • Participants felt the lack of recognition of narcolepsy contributed to delay in diagnosis and/or misdiagnosis • This was a primary concern amongst family and carers • Some participants suggest that a good relationship with their GP had a positive impact on disease trajectory, namely shorter delay to diagnosis 	<p>cataplexy, what the differences are and as such that they may require different treatment and management.” (Submission 86)</p> <ul style="list-style-type: none"> • “Public money had been spent on proving what I don’t have. I believe that if general practitioners were more aware of sleep disorders, then less money would be wasted on needless health checks.” (Submission 99) • “It took many years for my diagnosis, and it certainly wasn’t due to a lack of trying, it was a lack of information and knowledge that caused the delay.” (Submission 10) • “We were lucky that we had an amazing GP who believed in what we said and was prepared to stick his neck out for us.” (Submission 42) 	<p>separate the existing ‘Respiratory and Sleep Medicine’ speciality into independent ‘Respiratory’ and ‘Sleep Medicine’ specialities under the Australian Health Practitioners Regulation Agency framework.</p>	<p>for an increased focus on sleep disorders.</p> <p>This approach was also supported by physicians who took part in the inquiry.</p>
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		<ul style="list-style-type: none"> • “My local GP was fabulous in my treatment and organised counselling amongst other small things to help me feel better.” (Submission 116) 	
The role of support / advocacy groups	<ul style="list-style-type: none"> • Participants felt online support/advocacy groups were knowledgeable and informative and supportive, helping some come to terms with the condition • Lack of adequate funding for support groups identified as a concern 	<ul style="list-style-type: none"> • “I have found my best support in Facebook groups (such as Narcolepsy Aust, Xyrem support). I still find family, friends, educators, GPs don’t fully understand the condition and don’t know how to support us best. (Submission 26) • “Organisations like Narcolepsy Support Australia have been a major support for us, but like any little not-for-profit organisations, lack the funds to be able to do so much more. Funding should be directed towards these types of things so that that on a professional and community level people are much more aware.” (Submission 42) 	No policy recommendations made addressing these concerns

Theme 3: Patient and Family/Carers' Lived Experience of Disease				
Sub-theme	Summary of synthesis	Illustrative quotations	Policy recommendations	Appraisal of recommendations
Sequelae of Narcolepsy	<ul style="list-style-type: none"> Participants' submissions suggest significant mental health sequela (particularly feelings of isolation, anxiety and depression) and psychosocial adversity (i.e daily functionality, unmet aspirations, ability to work) associated with narcolepsy Parents described aspirations and unmet goals of their child with narcolepsy and the associated grief both they and the child felt 	<ul style="list-style-type: none"> "Eventually the struggle to keep going can become overwhelming." (Submission 67) "Until I was diagnosed, I was perceived as being lazy, disorganised and a parasite." (Submission 99) "One's personal agency degrades dramatically" (Submission 14) "We have a 16-year-old daughter who has been advised that she will not be getting her licence, like all her friends, who is not allowed to swim on her own, for fear of her having a cataplexy episode and drowning." (Submission 42) 	No policy recommendations made addressing these concerns	
Disability recognition and social welfare	<ul style="list-style-type: none"> Concerns that narcolepsy is not recognised as a disability which can 	<ul style="list-style-type: none"> "If in the worst-case scenario, she is unable to work, what can the government do to help. 	No policy recommendations made addressing these concerns	

	<p>cause issues for patients and family/carers accessing National Disability Insurance Scheme (NDIS) and Centrelink (social security)</p> <ul style="list-style-type: none"> • Lack of awareness amongst administrative staff can add to delay in accessing services 	<p>Can this sleep disorder readily become part of the NDIS?" (Submission 42)</p> <ul style="list-style-type: none"> • "I was informed that my condition is not a recognised disability, and the person I spoke to had never even heard of narcolepsy!" (Submission 10) 	
<p>Limited workplace and educational support</p>	<ul style="list-style-type: none"> • Limited accommodations made by workplaces • Perception that there is not enough educational support to assist children with narcolepsy through schooling 	<ul style="list-style-type: none"> • "I love my job, I have a wonderfully supportive employer. But there is no capacity to make accommodations for my disorder, such as having a place to have a nap if needed to during the day." (Submission 99) • The costs of teachers' time to manage her through additional explanations of what she missed in class etc is a factor for the school and is limited." (Submission 26) 	<p>No policy recommendations made addressing these concerns</p>

Experience with treatment options	<ul style="list-style-type: none">• Participants worried about side-effects of medication and the long-term effects it will have• Concern that stimulant medication will lose effectiveness over time	<ul style="list-style-type: none">• “My teeth are becoming weak and rotting, and the stimulants are placing excess strain on my heart, which will lead to further complications as well as decrease my lifespan” (Submission 10)• “These medications are only masks that hide symptoms and become less effective over time.” (Submission 17)	No policy recommendations made addressing these concerns
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