

Mapping the hidden voices in rural mental health: a pilot study of online community data

Report Phase Two
March 2020

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Acknowledgements

We pay respects to the traditional custodians of all the lands on which we work, and acknowledge thier Elders, past, present and emerging.



About the Report

This report summarises insights from research undertaken to include the ‘hidden voices’ of people living in rural Australia that experience mental ill-health. It follows from a Phase 1 report that reviewed literature, policy and interviewed key stakeholders – with the goal of analysing current rural mental health need, services and service accessibility. The goal of that report was to highlight activities that could be done by a philanthropic organisation and that were not the remit of government.

The role of this Phase 2 report is to start to examine the potential of existing, ‘hidden’ datasets that exist, and that could explain the experiences of those with mental ill-health in rural areas. People with mental health challenges are known to be reticent to come forward; and those living in rural areas can be additionally left out of consultations due to distance from cities and challenges of travel. Insights were garnered through working in partnership with SANE, Beyond Blue, Patientopinion.org and the Royal Flying Doctor Service. Using rigorous ethical and governance processes, de-identified datasets containing ‘hidden voices’ material were obtained and analysed for themes about experiences of those experiencing mental ill-health, particularly in relation to services.

Based on analysis, we summarise the main issues raised in the ‘hidden voices’ material and suggest key areas for further research.

The report content is structured into three main parts:

- Background, aims and methods
- Findings
- Conclusions and recommendations

This report is presented by ‘The Orange Partnership’, a group formed by researchers from Swinburne University of Technology Social Innovation Research Institute, University of Newcastle Centre for Rural and Remote Mental Health and the Australian National University Centre for Mental Health Research. The group has a stated commitment to improve Australian rural mental health outcomes. The Orange Partnership has large and growing membership among rural mental health stakeholders across Australia.

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Executive summary

While the prevalence of mental illness across Australia is around 20%, people living in the most rural places, have higher rates of suicide, self-harm and mental health emergency admissions. We contend that this is not an irresolvable situation. Part of the path to a solution is having better quality evidence about rural peoples' mental ill-health experiences.

To provide insights, we partnered with Beyond Blue (BB), SANE, Patientopinion.org (PO.org) and the Royal Flying Doctor Service (RFDS). These organisations have various online community forums that can provide large repositories of previously unused data, that can give valuable insights into rural mental health and health services experiences.

We analysed datasets for one year (Sept 1st, 2018 - Aug 31st, 2019), across Australian rural-urban categories and by thematic topics arising. We used a novel, world-leading methodology to test the feasibility of analysing large qualitative datasets of consumer-generated information. Below, we summarise our evidence and conclusions in relation to three key research questions:

Question 1. Where, in the most rural parts of Australia, are participants engaging and not engaging, with partners' online health community forums?

- While there is engagement across rural Australia, there are 'hot-spots' and 'not-spots' of engagement that could align with the extent of promotion of these services.
- The considerable amount of data that we have collected from across Australia means that further study of rural-urban differences can be a next target for research.

Question 2. What are rural peoples' experiences of, and sentiments about, rural mental health services, as reported in online health communities?

- Supporting previous study, analysis highlights key issues of: stigma, feeling isolated, inaccessible services, lack of alternatives and accessibility of health literacy, information and navigation.
- A surprising emergent category of data was about the crisis of relationship breakdown and the cascade of negative effects it has on people's mental health when living in isolated, remote small places.
- Though evidence was limited, there was some expression of experiences of discrimination and lack of cultural sensitivity, for some Indigenous people that posted.

Question 3. What are the gaps revealed in relation to the current landscape of rural mental health activity and service provision in remote communities?

- Rather than highlighting problems with types of mental health services, data instead points to elements of the remote context that exacerbate or fail to support rural people with mental health issues.
- Analysis suggests potential areas for intervention or specific online support focus around dealing with isolation, feelings of being other, experiences of bullying and relationship breakdown.

- Online communities such as those of Beyond Blue, SANE and Patientopinion.org act to augment the service landscape for those that use them, enabling asking questions, giving feedback, sometimes simply saying 'help me'; and, significantly, gaining support back. Reciprocal discussions indicate benefits for both givers and receivers of help.

Future research should:

- Extend use of the innovative methodology generated, to: a) incorporate more types of organisations and services, and larger quantities of data, for rich analyses; b) conduct rural-urban studies to further understand differences and similarities in rural-urban experiences of mental health and mental health services.
- Consider developing and testing online interventions to help support relationships for those with mental health conditions; and support people to cope with relationship breakdowns in isolated rural places. Other online interventions around dealing with social isolation, bullying, stigma or discrimination, while geographically isolated, are also worthwhile.

Background, aims and methods

Background

In our Phase 1 Report, following a review of available evidence and insights from key stakeholders, we concluded that the 'problem with rural mental health' appeared to be a gap between the needs of those with mental ill-health and wellbeing challenges (demand); and uptake of appropriate services, in the right place, at the right time (supply).

The issues are that:

- From available data, mental ill-health prevalence appears similar across Australia – at around 20%; but rates of suicide, self-harm and emergency retrievals for mental health crisis, all increase with rurality/ remoteness.
- Available evidence indicates: a tendency for mismatch between available services and the nature of need; difficulty for rural people to access appropriate services in their locale; lack of widespread knowledge of the service available - plus multiple, complex challenges related to accessing services – e.g. transport, connectivity, stigma.

From our Phase 1 Report, we also concluded that major gaps exist in advocacy and philanthropic funding specifically targeted at rural mental health; as well as gaps in data and research evidence. Rural mental health tends to fall through the gap between rural health and mental health.

There is a specific gap in knowledge about the widespread experiences of people living in rural Australia, and who experience a range of mental ill-health challenges, from wellbeing issues through to experience of acute mental ill-health. In this report, we sought to target large, latent, untapped datasets of consumer and rural resident experiences, to assess if these have potential for providing a rich picture of rural experiences, and in relation to different rural places across Australia.

Given the short time-frame of undertaking the project (Oct 2019-March 2020), and the innovative nature of the methods, the study described in this report should only be regarded as a pilot project. However, it does show the enormous potential of tapping into hidden data and engaging in collaborations with NGOs and other providers to pool data for insights.

The first section of the report summarises information about the datasets used. We then show maps of data. The mapped data mainly show the activity of 'online community members' from Beyond Blue (BB) and SANE's online peer support forums; and Patientopinion.org (PO.org) online consumer feedback service. We initially sought to analyse Royal Flying Doctor Service (RFDS) social media (on Facebook); however, this was impossible to collect within the timeframe of the project due to lack of time to engage with Facebook to gain access to the data. Thus, for RFDS, we focused on examining what could be done with their pick-up and drop-off data, which were readily available. Also, given the timeframe, we tended to focus on the 'most rural' data. That is, we focused on analysing data for/from Outer Regional, Remote and Very Remote areas according to the 2016 Australian Bureau of Statistics (ABS) Remoteness Index . We considered these Remote areas to be the places for which the least is known, and also represent the least accessible areas of Australia. In the report that follows, we highlight key themes related to experiences of mental ill-health, mental health services and rurality/ remoteness.

Aims and research questions

The research evidence that is available, suggests that – at area level – rural mental health service systems could be overly focused on acute care rather than ongoing social supports, may be mobile/peripatetic or in distant towns/cities, rather than readily available locally; and could be challenging to access due to costs. In addition, there may be widespread lack of knowledge about which services exist, partly due to increasing fragmentation of the

service system in recent times. Rural Primary Health Networks, intended to commission rural mental health services, can have difficulty in understanding the needs of individual rural communities. They have to cover large areas with limited resources.

In such a situation, online services such as the online communities offered by BB and SANE could be ways for rural people to access support for their mental health and wellbeing conditions. Services such as PO.org's online feedback service can be a way for rural residents to highlight service gaps and good practice. In addition, analysing aggregated datasets from such services could highlight insights for commissioners and service providers, about rural residents' experiences and needs – providing 'on the ground' intelligence without having to conduct place-by-place local consultations that would be expensive and might not attract reticent people. This study aims to reveal insights from the 'hidden voices' of rural people experiencing mental ill-health, captured through online community datasets, by:

- exploring place-based differences via spatial analysis of four organisations' data.
- capturing rural consumer perspectives about rural mental health services obtained via online forum postings.
- surfacing key topics about Indigenous people's experiences of mental health in remote communities.
- featuring a key emergent topic around 'relationship breakdown' and their impacts on mental health.

In achieving the aims, we address three key research questions:

1. Where in the most rural parts of Australia are participants engaging and not engaging, with the online health community forums?
2. What are rural peoples' experiences of, and sentiments about, rural mental health services, as reported in online health communities?
3. What are the gaps revealed in relation to the current landscape of rural mental health activity and service provision in remote communities?

Objectives

One challenge with existing evidence about the problem with rural mental health is a lack of data capable of showing the lived experiences of people with mental health challenges who live in particularly rural places. In this small, pilot study, we endeavoured to reveal some of the hidden voices by partnering with Beyond Blue (BB), SANE, Patientopinion.org (PO.org) and the Royal Flying Doctor Service (RFDS), to:

- understand their datasets and the nature of data contained
- find out how these datasets could be accessed using appropriate legal, ethical and governance procedures
- obtain, clean, manage and analyse the de-identified data.

Nature of data

SANE, BB and PO.org have developed their own individualised online platforms for collecting and collating their members' activity within their organisation. SANE and BB, for example,

have developed their own online mental health support forum that requires people who use the forum to sign-up as members, while completely maintaining member anonymity. PO.org have developed their own publicly available website to give healthcare consumers the opportunity to share their healthcare experiences, within a transparent but safe online environment. Although their forums are broadly similar in design, each organisation collects, stores, monitors and filters their members' activity differently. These differences and increasing pressure to improve online security make it difficult to relate multiple organisations data together but, through the spatial mixed methodology developed here, we integrated all the datasets within a spatial software program for analysis. For a full description of how this was accomplished, see Appendix.

Further complicating access to this sensitive data is its financial cost. At the start of this project, we assumed that – as the organisation online forums generate the data – these data would be freely available for BB, SANE, PO.org (and RFDS) a) to access; b) to use. However, this transpired not to be the case and there were costs for obtaining the data. At all times, the cost of obtaining these data should be weighed against the cost of conducting community consultations or surveys – which would be much more expensive.

For this project, SANE outsourced the cleaning and extraction of data for roughly \$2,500 AUD. BB cleaned and extracted the data internally, which requires roughly the same amount of employee time and financial commitment by the organisation (i.e. \$2,500 AUD). PO.org website required the purchase of a one-year API subscription to scrape the data, which cost \$5,582.50 (see Appendix). It was impossible to negotiate arrangements with Facebook to see if we could access RFDS Facebook data within the timescale of this project. Of course, Facebook sell aggregated data so we are not sure we would even be able to access RFDS Facebook data at all. This came as something of a surprise that an organisation cannot access the data that is generated about it and calls into question Facebook's commercial model and whether NGOs should continue to engage in Facebook's social media offerings.

As Facebook data were unavailable, but still wishing to engage with RFDS, instead, RFDS location data for where people were picked-up and dropped-off for rural mental health services, were used. These data were extracted internally by RFDS, at cost to RFDS. We estimate this would cost approximately \$2,500. This makes the estimated total of collecting one year of data from the four participating organisations to roughly \$13,000 AUD.

Ethics and sensitive data

An ethics submission to analyse these data under the appropriate conditions was approved by Swinburne University Ethics Committee. It is worth highlighting that this methodology is innovative internationally - and involves emerging techniques. It took three months simply to navigate legal and ethical frameworks, in order to gain legal and ethical access to the datasets. By undertaking this 'first of a kind' process, we have established a legal governance framework that enables this kind of work to occur more readily in future (see Appendix).

Our partner organisations

Beyond Blue (BB) works to address issues associated with depression, suicide, anxiety disorders and other related mental health disorders. BB approaches mental health related issues including anxiety and depression through a public health framework, focusing their efforts on improving the health of the entire population and over the entire lifespan of an individual. BB works with specific population groups in a range of settings including, educational settings, workplaces, health services and online - in order to be accessible to as many people as possible. The Beyond Blue Online Forums are moderated by a team at

BB to ensure the safety of participants and readers of the forums to increase visibility of the threads most recently posted. This involves 'hiding' threads that are no longer active. In the exploratory pilot study reported here, the forum data (which are already anonymised through member sign-up and forum moderation processes), were analysed between September 1st, 2018 to August 31st, 2019.

Data sampled from BB for this project represent a broad range of mental health related topics and issues that people experience across rural Australia. BB forum data is national in scope and has the highest number of members and posts compared to the other datasets in this pilot project. Members of BB online mental health support forums typically post by choosing from a variety of existing 'Threads' – or choosing to start their own – in order to engage with other forum members, often seeking advice from people with similar experiences with mental health.

SANE Australia (SANE) is a national mental health charity that supports Australians affected by complex mental illness. SANE's work includes mental health awareness, online peer support (i.e. online forum), stigma reduction, specialist helpline support, research and advocacy. SANE forums have a unique syndication model funded by the Department of Health where they partner with other mental health organisations across Australia, at no cost to those organisations. They also have forums published on their website with SANE's header and footer, branding, look and feel. SANE has been in operation since August 2014 and is promoted by videos, texts, advertisements and images on digital advertising (Facebook, Instagram), media, regional TV/radio ads, through partners and referrals. SANE's forum is moderated and 'filtered'.

SANE's online forum data used in this project represent both the direct and indirect experiences of more complex mental illness in rural areas. This means that the SANE data is more often underpinned by specific questions about mental illnesses and medications compared with the BB data. Members of SANE's online forum, for example, will sign up to SANE recently after they have been diagnosed with a mental health condition, often to seek support and advice from people who have had a similar diagnosis. Unlike BB, SANE members more often discuss the symptoms of specific medications or treatments or diagnosis and treatment options, making SANE data an additional and valuable source of understanding how people experience complex mental illness in rural Australian communities.

Patient Opinion was first established in the United Kingdom in 2005 'to facilitate honest and meaningful conversations between patients and health services'. Its purpose is to give patients and healthcare consumers the opportunity to start conversations with providers about their healthcare experiences, within a transparent but safe online environment. Patientopinion.org Australia (i.e. PO.org) was established in 2012 and, similar to its UK counterpart, is registered as an independent not-for-profit charitable institution that believes that transparent feedback to consumer stories can improve health services. Over 50 health services and organisations subscribe to PO.org, with over 7,000 stories published. This is the source of data for this pilot study. Promotion is conducted on a partnership model between PO.org and a health service provider. The use of social media channels is another avenue used for promoting the platform. PO.org also have a presence on Facebook, Instagram, Twitter and LinkedIn. The display and distribution of promotional materials via these forums, is in the hands of the subscribers, with freedom to choose the most ideal physical areas to place advertising materials about using the online platform. For example, posters are placed on noticeboards in Emergency Departments on all doors within certain departments, business cards and flyers included in discharge packages.

Due to the nature of PO.org, the data that we have collected represents consumers/clients positive or negative experiences with mental health professionals, organisations and health care facilities. This means that PO.org data provides a good understanding of how health care facilities and workers are successfully/unsuccessfully meeting the needs and wants, of people experiencing mental ill-health in remote communities. A good example that we picked up in our analysis is that the PO.org data reveals the specific and often hidden ways that travel

assistance schemes can fail to help rural people to access some supports. Also from this dataset, we were able to gain insight into some experiences of Indigenous people who seek mental health supports.

The **Royal Flying Doctor Service** (RFDS) is an aeromedical organisation that provides emergency and primary health care services for those living in rural and remote areas of Australia. It is one of the largest aeromedical organisations in the world, providing emergency services to an area over 7.5 million square kilometres. The RFDS also use a Service Planning and Operational Tool (SPOT) to assist in their planning allocation of RFDS services. The tool helps to map existing 'on-the-ground' local services location data with population data. For the pilot project discussed here, we used the location data of RFDS client/consumer pick-up and drop-off. Pick-ups and drop-offs apply to people in need of emergency assistance; in our case, focusing on the data for those with mental and behavioural health episodes. The location, for these RFDS data, is an approximate location of the local airfield used to, for example, pick-up someone in need of emergency assistance.

RFDS data have additional attributes that can be used in future mapping projects. For example, they can include a 'service provider', 'type' of mental or behavioural disorder and 'diagnosis' of the client being picked-up. Due to time constraints, the RFDS data used here is representative of where people have needed emergency mental and behavioural disorder assistance, with less focus on why they needed emergency help.

Methods

There are several classifications used by government health programs to measure the rurality/remoteness of a community, including the Australian Bureau of Statistics (ABS) Remoteness Areas, the Modified Monash Model (MMM) and the Accessibility and Remoteness Index of Australia (ARIA). Each classification uses the distance from an urban centre as a means of understanding whether an individual may or may not have access to services. In this study, we used the 2016 ABS Remoteness Index. Given limited time and a focus on 'really rural' experiences, our analyses tended to focus on Outer Regional, Remote and Very remote categories (Figure 1). For each specific analysis, we describe the data and remoteness category that applies. The remoteness areas demonstrated in Figure 1 were uploaded from the Australian Bureau of Statistics (ABS) in a shapefile format and imported into ArcGIS so we could visualise where the most remote areas in Australia are.

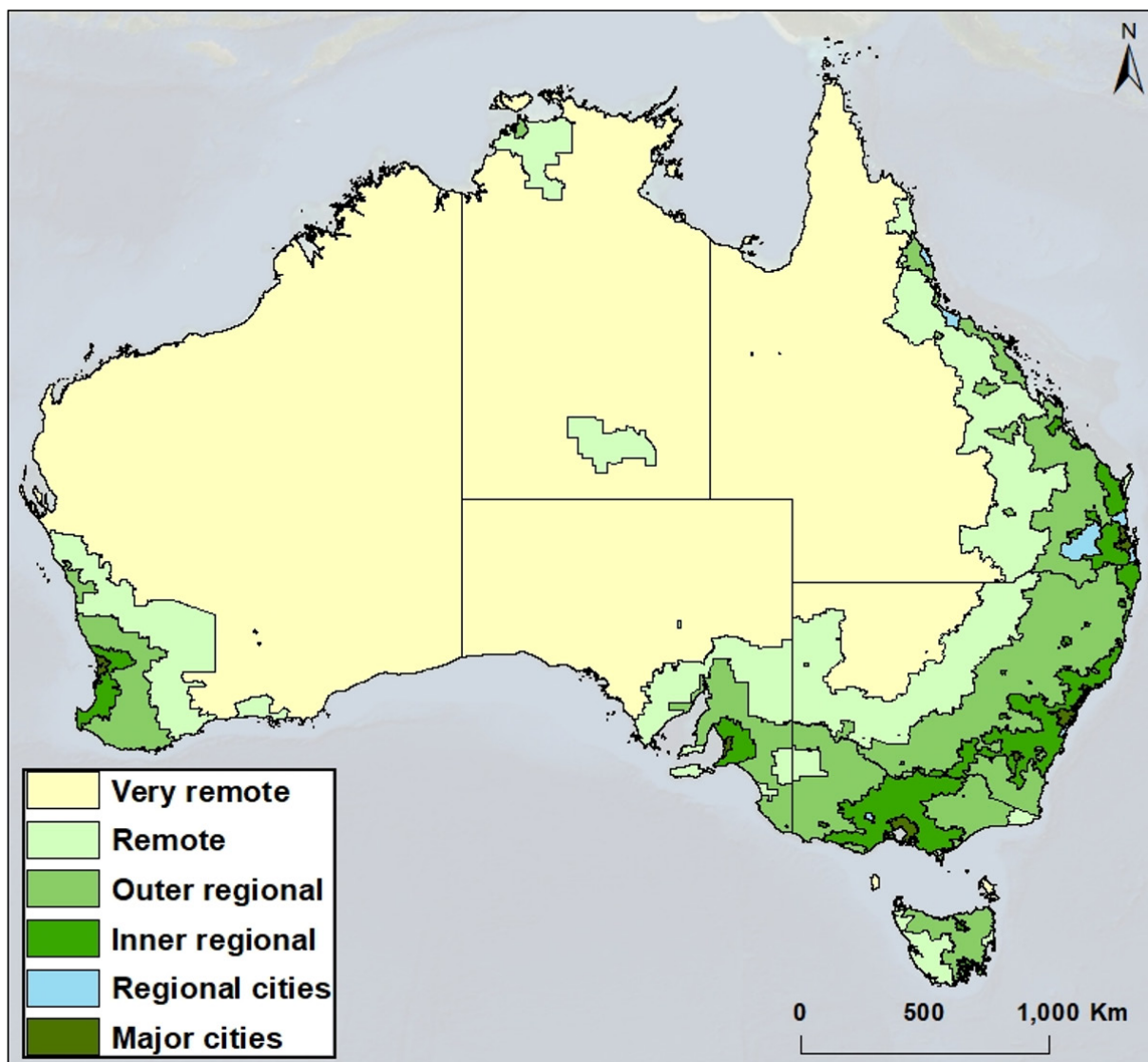


Figure 1 - ABS Remoteness index and Regional cities

To map and overlay all of the organisations data in the same place and overtop the Australian Bureau of Statistics (ABS) remoteness index, we identified a common spatial delineation between all four organisations datasets. Spreadsheets containing posts and spatial identifiers were then mapped for each organisations dataset to form the maps shown in this report. Datasets were also coded for main themes. For a more detailed account of how we mapped and analysed all organisations data, please see the Appendix.

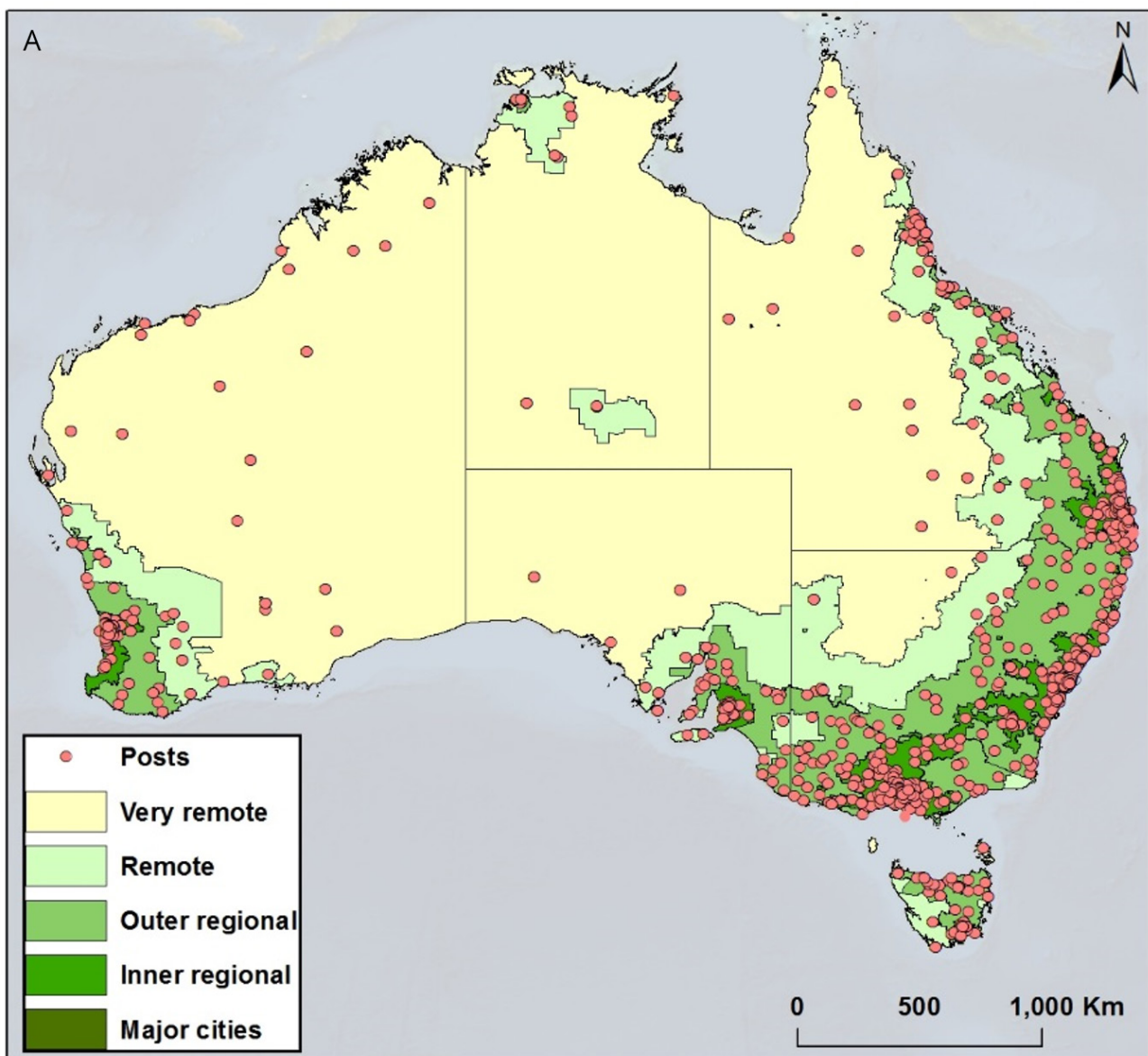
Findings

Mapping online community data

A one-year sample (September 1st, 2018 to August 31st, 2019) of posts were collected from BB, SANE and PO.org online community forums (overall total: 1,006,433 posts) (see Table 1). These posts were then mapped overtop of the 2016 ABS Remoteness Index Categories by their post code location to categorise the locations (i.e. post codes) from where members are posting (Figure 2).

Table 1 - Aggregated datasets by Remoteness classifications

Remoteness category	BB	SANE	PO.org
Very remote	288 (<1%)	96 (<1%)	340 (53%)
Remote	151 (<1%)	2,228 (3%)	183 (29%)
Outer regional	3,219 (<1%)	6,623 (8%)	118 (18%)
Inner regional	285,348 (31%)	20,201 (26%)	N/A
Major cities	637,734 (69%)	25,954 (33%)	N/A
TOTAL	926,740	79,052	641



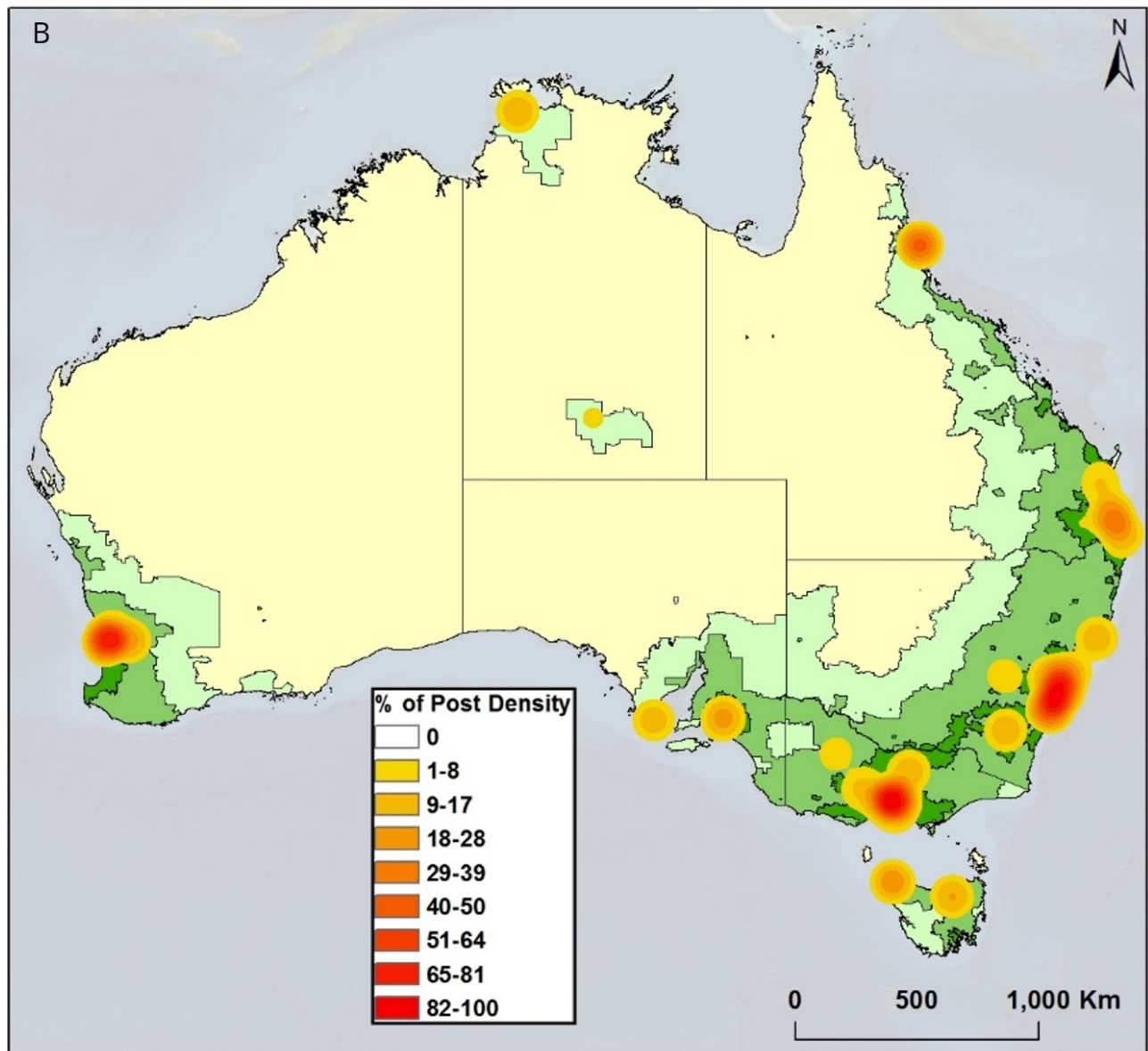


Figure 2 - 2A shows all posts across Australia; 2B maps the density of posts or 'hot spots'

Figure 2 shows that, not surprisingly, the highest concentration of posts is in State capital cities due to highest concentrations of population. It is significant to note that - Figure 2B 'hot spots' shows the 'relative amounts of posting' across Australia, while Figure 2A demonstrates that there are still considerable numbers of posts in Outer regional, Remote and Very remote areas (total number of posts = 13,246). This confirms that it is possible to use these data to capture narratives from the most rural (i.e. most remote) areas of Australia.

To show some capability of RFDS data, we mapped all 1,149 pick-up and drop-off locations from the RFDS between September 1st, 2018 to August 31st, 2019 (Figure 3). These locations represent the pick-up and drop-off locations of people experiencing a mental and / or behavioral condition. Of the 1,149 individuals that were picked-up and dropped-off, 330 of them were picked-up in Very remote areas, while 303 were picked-up in Remote areas. Of the 1,149 drop-off locations, only 43 drop-offs were in Very remote areas, while an additional 224 were in Remote areas. When the RFDS pick-ups and drop-offs in Remote and Very remote areas were mapped, we can see a spread of retrievals and drop-offs in relation to mental ill-health emergencies, across the country (Figure 3).

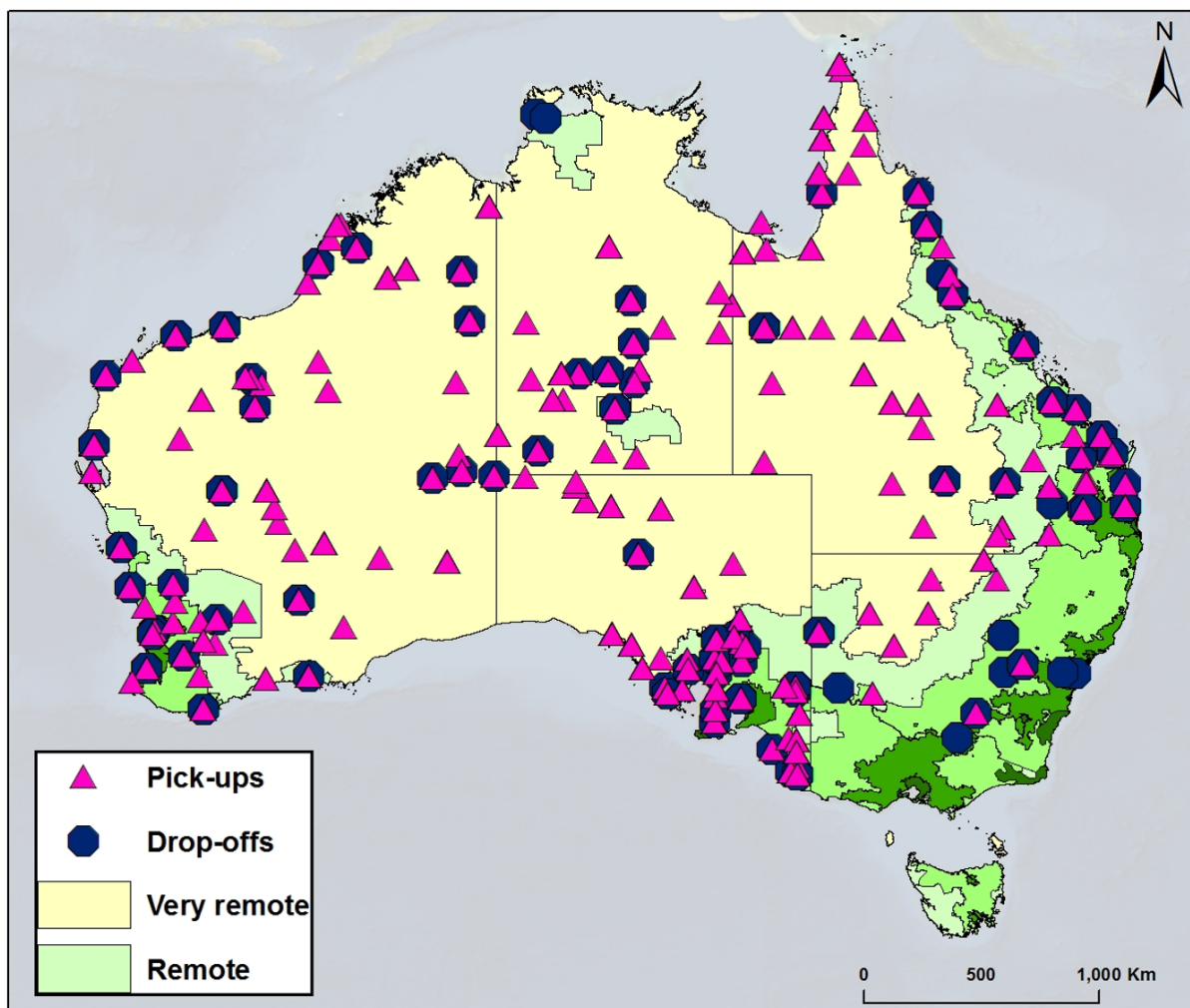


Figure 3 - RFDS pick-up and drop-off locations

As highlighted, we made the decision to focus analysis on the most rural areas of Australia in order to give us greatest insights about issues for rural residents in the time available. To ensure that the data represent only rural, remote and very remote experiences, as well as not analysing 'Major cities' and 'Inner regional' data, we removed posts that were within 100 km of remote, rural or regional cities (henceforth 'Regional cities') (these are listed at Table 2).

This means that the posts that we analysed here represent the concerns and experiences of people living in the most inaccessible geographical reaches of Australia. This still leaves a considerable amount of data that can be analysed in future research, particularly to compare experiences across rural-urban categories.

Table 2 - Regional cities in Remote and Very remote Australia with a population > 100,000

Regional City	State
Cairns	Queensland
Gold Coast	Queensland
Wollongong	New South Wales
Ballarat	Victoria
Sunshine Coast	Queensland
Toowoomba	Queensland
Townsville	Queensland
Hobart	Tasmania
Newcastle	New South Wales
Darwin	Northern Territory

Within the data, we also found a phenomenon of ‘frequent posters’ (>250 posts per year). These were people who posted a very high number of times – sometimes someone would have posted so many times that their posts alone accounted for 30% of the entire sample. As this study is focused on exploring a range of issues across different people; rather than over-emphasising very active users, we removed frequent posters from data analyses. After removing posts for ‘Regional cities’, Inner regional areas, Major cities and posts from frequent posters, we were left with 11,054 posts for analysis, as displayed in Table 3, and mapped in Figure 4.

Table 3 - Posts by organisations and remoteness category

Remoteness category	BB	SANE	PO.org
Very remote	288 (8%)	81 (1%)	340 (53%)
Remote	151 (4%)	141 (6%)	183 (26%)
Outer regional	3,219 (88%)	6,623 (74%)	118 (21%)
TOTAL	3,658	6,845	641

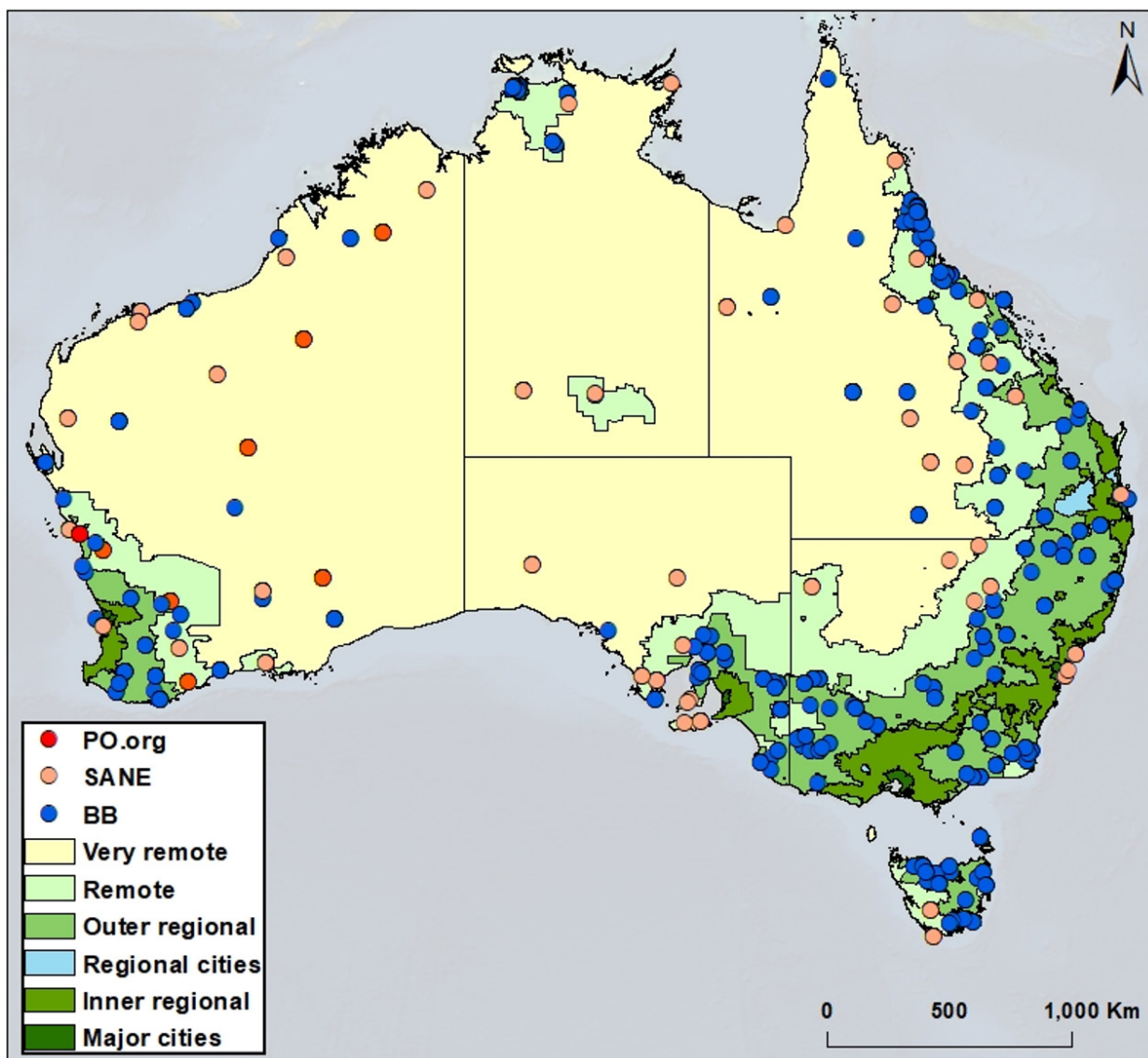


Figure 4 - Map of three organisations' posts across Australia

From Figure 4, it can be seen that all PO.org posts are located in Western Australia (not surprising as PO.org has been established and in-use, in WA for longer than in other states). SANE and BB posts are spread across the country. There are more posts from SANE within Remote and Very remote areas while BB data is more concentrated in areas around the edges of the vast remote hinterland.

From the mapped RFDS dataset, we can see that these also show a spread of retrievals and drop-offs in relation to mental ill-health emergencies, across the country (Figure 5).

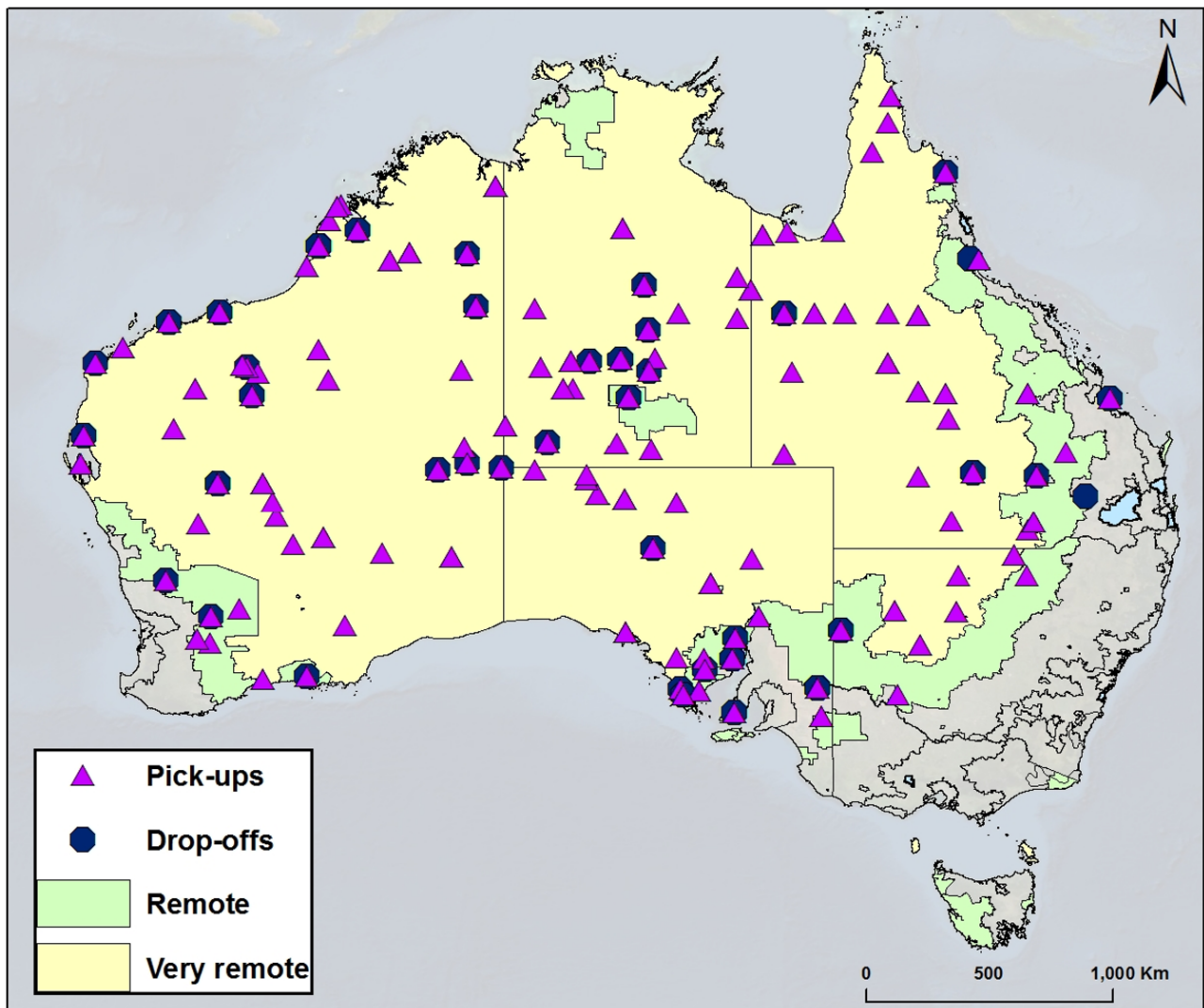


Figure 5 - RFDS pick-up and drop-off locations across Remote and Very remote Australia

Place-based differences and spatial analysis

To show how it is possible to explore place-based insights by mapping multiple types of data relating to the same topic, we conducted a density analysis across the SANE, BB and RFDS data at a national scale. This enables a visualisation of any apparent spatial associations between locations of people's discussions of mental health on online community forums and locations where the RFDS emergency services were deployed. The highest density of RFDS pickup locations that took place during our one-year sampling time frame, was in Remote areas of South Australia (see Figure 6).

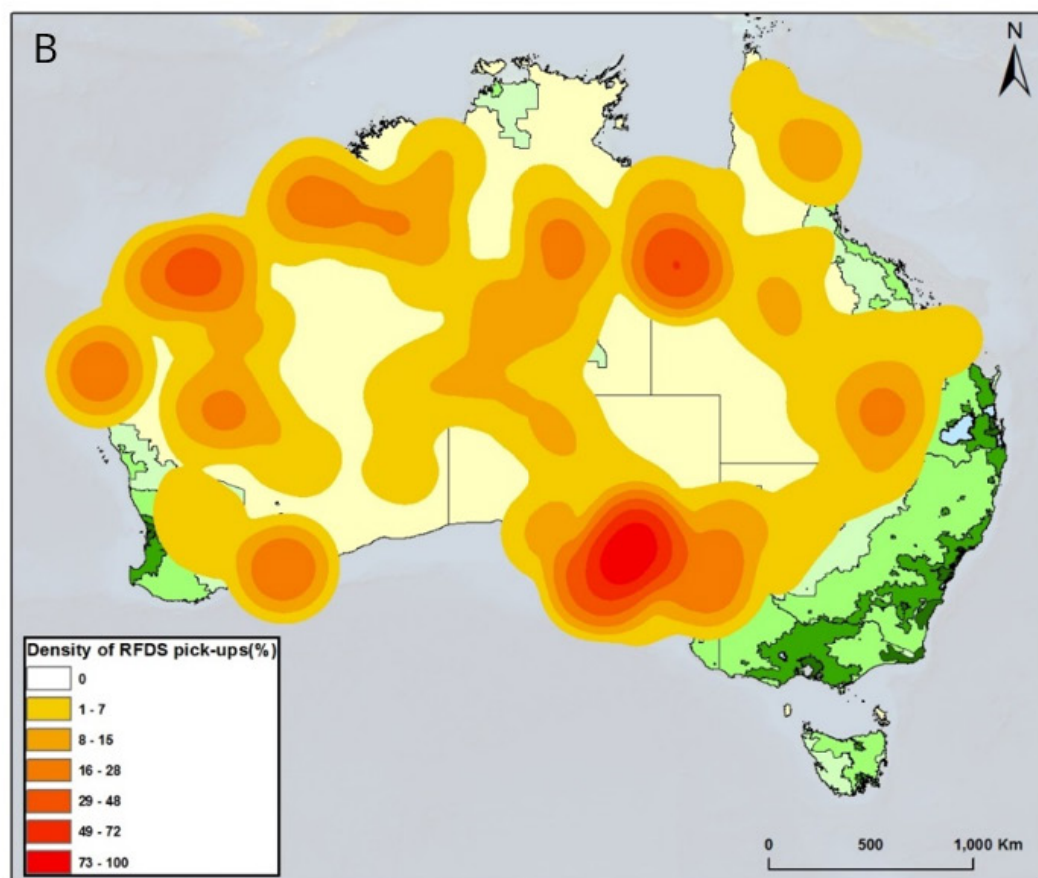
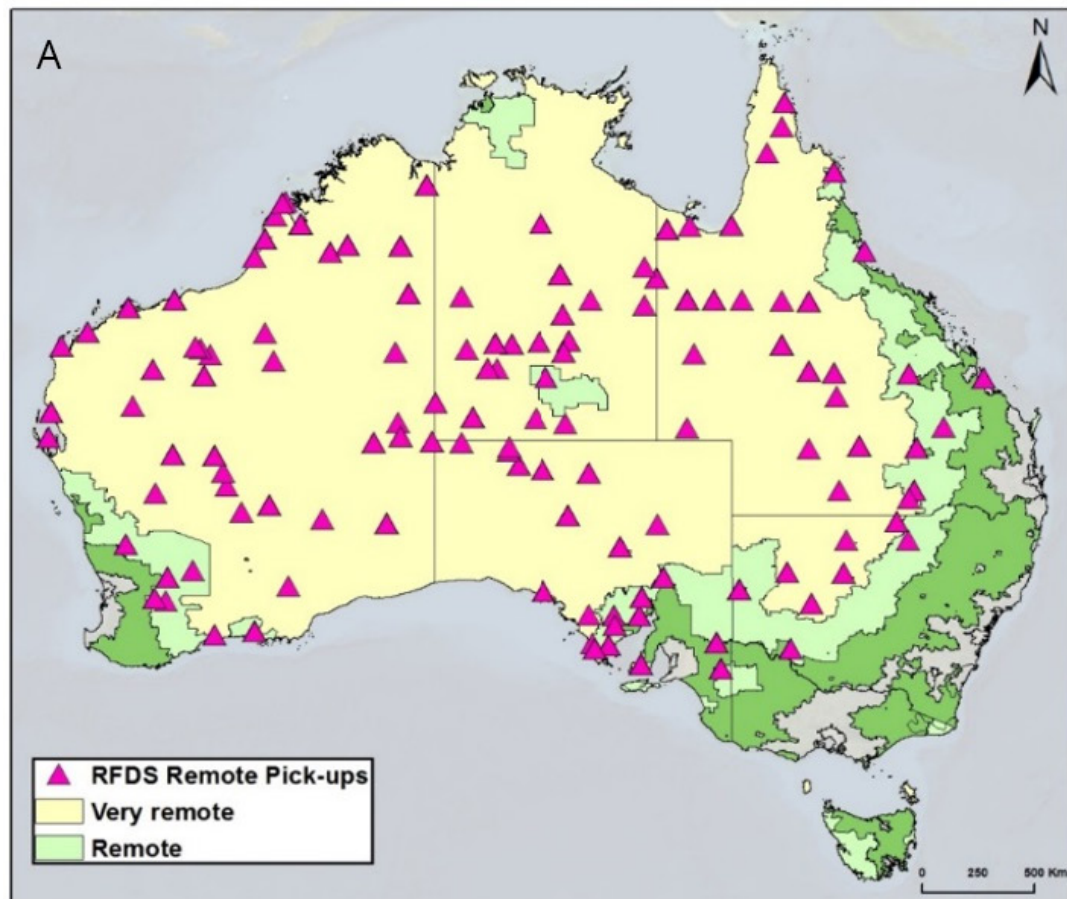


Figure 6 - 6A shows locations of the Very remote (n=330) and Remote (n=303) RFDS pick-up locations and 6B shows the density of Very remote and Remote RFDS pick-ups.

From an initial look, there appears to be a similar spatial density of posts between SANE online community data and RFDS pick-up data (see Figure 7A). The pattern is dissimilar when comparing BB data with RFDS data (Figure 7B).

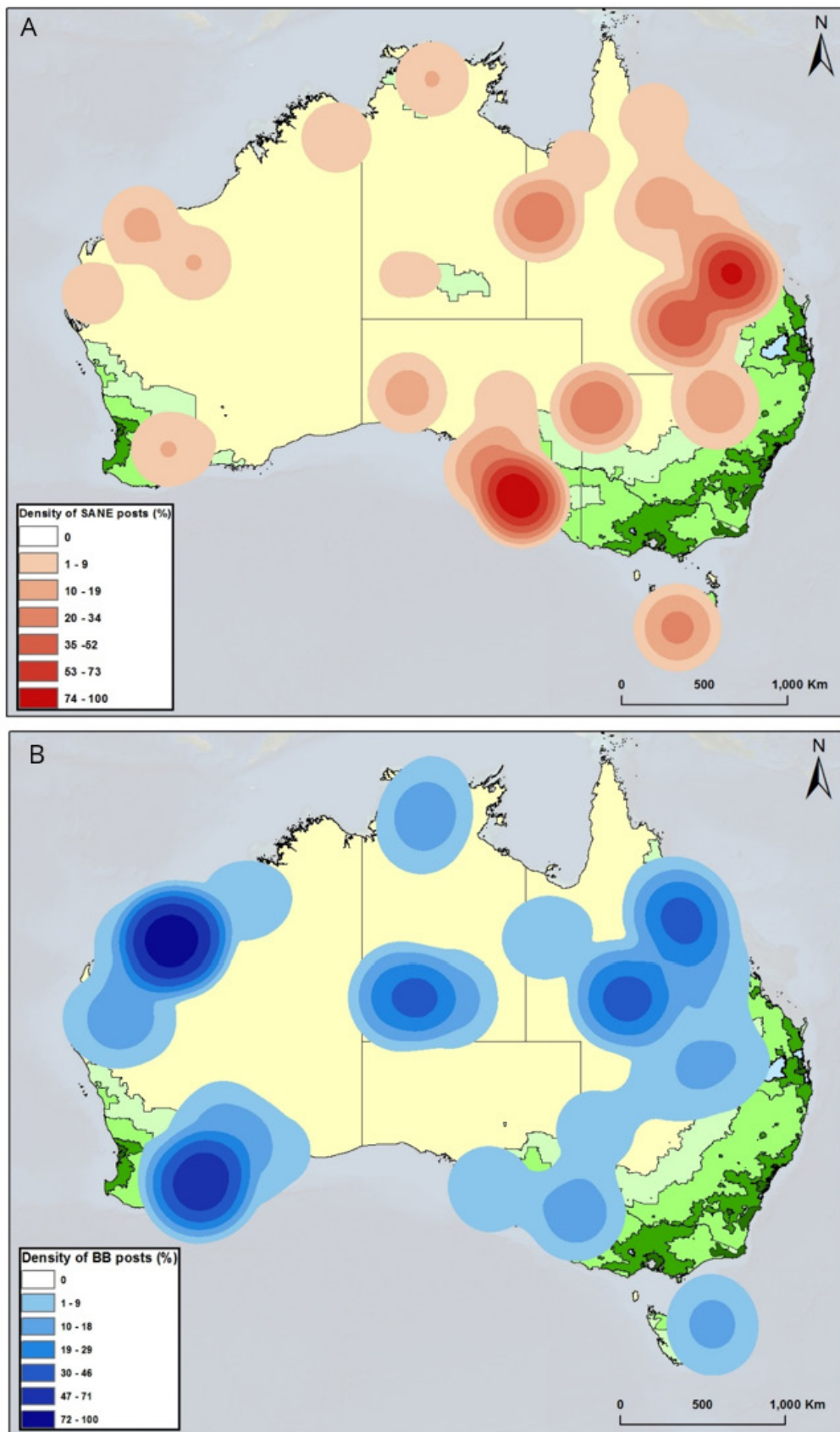


Figure 7 – Density of SANE (7A) and BB (7B) posts

SANE posts are typically related to complex/more acute mental ill-health conditions, while BB is targeted at more general mental health discussion. It is possible this could account for the apparent similarity between SANE and RFDS spatial density of postings. However, this would require further examination.

Mapping and visualising datasets in these ways does show the potential of this methodology to identify potential high-risk areas if different types of data and large datasets are available. Examples could be overlaying the SANE and BB datasets with data in the RFDS SPOT tool, Primary Health Network (PHN) data, and SEIFA (Socio-economic Indexes for Areas) data, to explore variables and complex relationships between variables, that may be contributing to rural people's mental health experiences.

Insights from hidden voices

Following considerable discussion, exploration and testing ideas, it was decided that the most useful type of analysis that could be done within the limited timeline was to explore the whole corpus of data for topics that would most likely arise in rural mental health data. Initially, we turned to the Phase 1 Report, and the problem 'disaggregation'. This has six categories that were derived originally from analysis of submissions to the Senate Inquiry on Remote and Rural Mental Health Services (2018). Thus, the initial categories we applied to the data were: stigma, rural challenges, contextual risk, cultural competence, service accessibility, and service fragmentation. Initial analysis of our data (i.e. from BB, PO.org and SANE), for Remote and Very Remote areas, indicated that actually, there are three overall categories that are most meaningful in capturing what might be understood as issues specifically significant for/related to, rurality/rural experiences.

Ultimately, the 594 posts relating to these specific rural issues were grouped into themes of:

- Stigma
- Rural life and accessing services
- Health literacy and navigation

We summarise these themes below and illustrate with some excerpts in Tables.

Stigma

These posts were about experiences of 'stigma' associated with having a mental health condition or being associated with someone with a mental health condition. Examples included discussions from those experiencing mental ill-health about attempting to overcome challenges 'on their own' or perceptions of being seen as 'weak'. Other examples included not wanting to be seen in their community as being weak and not receiving support or empathy from family and friends. More specifically, five ways that people discussed stigma emerged - see Table 6 and Figure 9.

Table 6 - Coded categories around stigma

Theme	Descriptive examples	N=
Coping	I guess I have always felt I can cope on my own (BB Remote line 10). I keep telling him I'm concerned for him and his family and he needs to get proper help, but he won't listen he said he doesn't need it (BB Remote line 41).	6
From others	I moved here for a job but when I was honest to the employer about my problems suddenly the job had disappeared. My last job I had to leave due to a breakdown (BB Remote line 25). It's a completely different world. Unfortunately, many of the people around me have never been exposed to mental illness or they carry "The Judgement" which also makes it difficult to communicate with them however sometimes I just want to stay home and curl up in a ball and sleep (BB Very remote line 141).	11
Fitting in	I believe there are a lot of us lonely people out there but somehow, we miss each other on the street. Maybe it is because we are all so busy trying to look and behave 'normal' (SANE Remote line 433). I would be feeling that I didn't belong and feeling that there was something deeply, fundamentally wrong with who I am. I thought that I was broken. I was convinced that I was defunct (SANE Remote line 330).	5
Weakness	I never tell anyone that I have it as I feel weak, Sometimes I think I would better off just letting the all of the people I know that I have it would somehow relieve the stress. I would like to hear other suffers thoughts on this issue (BB Remote line 86).	4
Burden	I felt the hospital didn't want him there they had no beds. He was in emergency for a while and then in a temporary ward and I believe they just wanted to move him on (PO.org line 157). I've been non-stop crying for the past half an hour I was so close to reaching out to lifeline and calling but I just feel so useless and such a burden I couldn't even bring myself to call them (BB Very remote line 41).	6
TOTAL		32

Stigma (n=32)

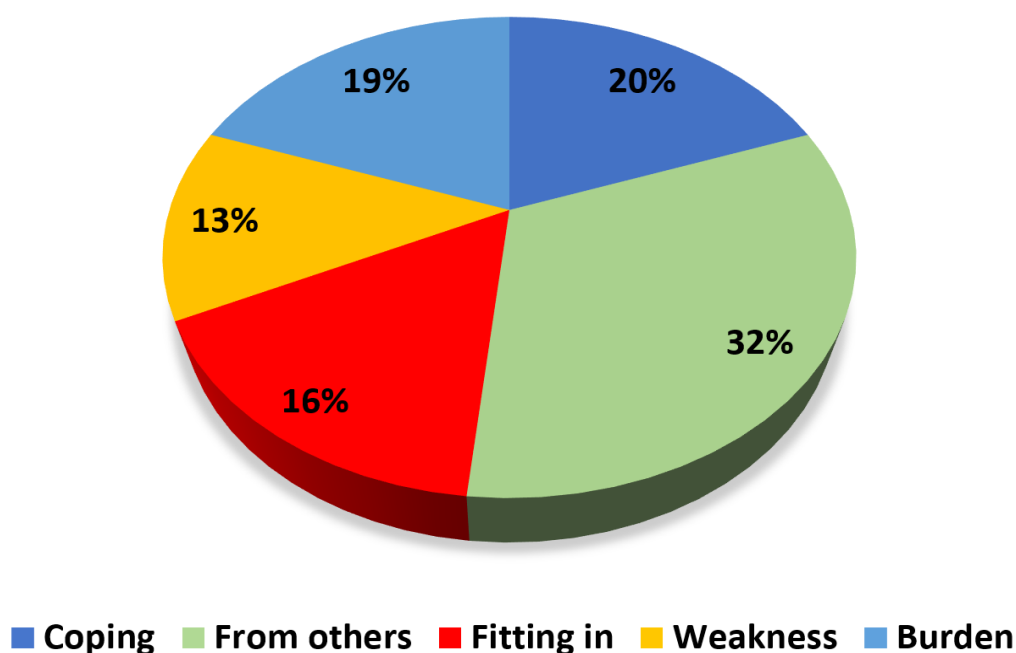


Figure 9 – Chart displaying the proportion of data coded to stigma themes

There were multiple examples of people who said they did not want to reach out to formal mental health supports due to ‘others having it worse’ and not wanting to be a burden on services for ‘people with real problems’.

As, within the time available, we have not analysed these data about stigma from Remote and Very remote areas, against the other rural-urban categories, we cannot say whether the way Remote residents discuss/experience stigma is distinctive from other spatial areas. What we can say at this point is that we identified discussion of stigma. This confirms evidence from the literature and policy reports suggesting that stigma and perceptions of stigma, in rural areas, is a barrier to approaching and potentially accessing mental health supports.

Rural life and accessing services

This category includes a range of issues related to living in Remote areas including: long distances to services; feelings about remoteness; lack of access to the services that people want; financial hardship; climatic events; unemployment and/or lack of access to employment opportunities; social isolation; pessimism about the future; and a ‘sense of having nothing to do’. This category emphasises the obstacles faced by people in Remote communities in accessing day-to-day amenity and services, including comment about: wait times, transport, lack of knowledge about what or where to access services, and financial barriers. Seven specific ways emerged of how people discussed that rural life is associated with aspects of their mental health condition. These are summarised in Table 7 and Figure 10.

Table 7 - Categories about rural life and accessing services

Theme	Descriptive examples	N=
Limited access	Last week I talked to my dad about it for the first time, and he recommended that I go see a GP. I live in a remote area and that's the only health service we have as far as I know (BB Very remote line 37).	20
Ineligible	This staff member explained that she will contact myself to advise whether travel would be approved for my child and myself. The day prior to the expected departure date for travel, I still had no response (PO.org line 6).	6
Waiting	I can't get a GP appointment, living in a new place with very little services available and not being an existing patient there's a waiting list currently of 2 weeks (BB Remote line 103).	8
Isolated / Stuck	I have had what could be called a very traumatic few years after an acrimonious breakup and as a result lost all the friends I had. I too live in a country town and it is lonely, very lonely I have no friends, am very far away from family, I do have 2 children who I try to absorb my time in but I have also been so stuck in my torn world (BB Remote line 56).	19
Professionals	I live in a very small town and the only GP available is someone I am not comfortable with at all (BB Very remote line 268).	12
Distance	The last shrink I was sent me refused to help me at all. The closest major town is too far for me to travel (BB Remote line 23).	10
New to area	Il didn't get to see my best friend [...] cause my dad wouldn't let me go which the reason is stupid and doesn't include me. I wish things could be back to the way they used to be (BB Very remote line 73).	8
TOTAL		83

Rural life and accessing services (n=83)

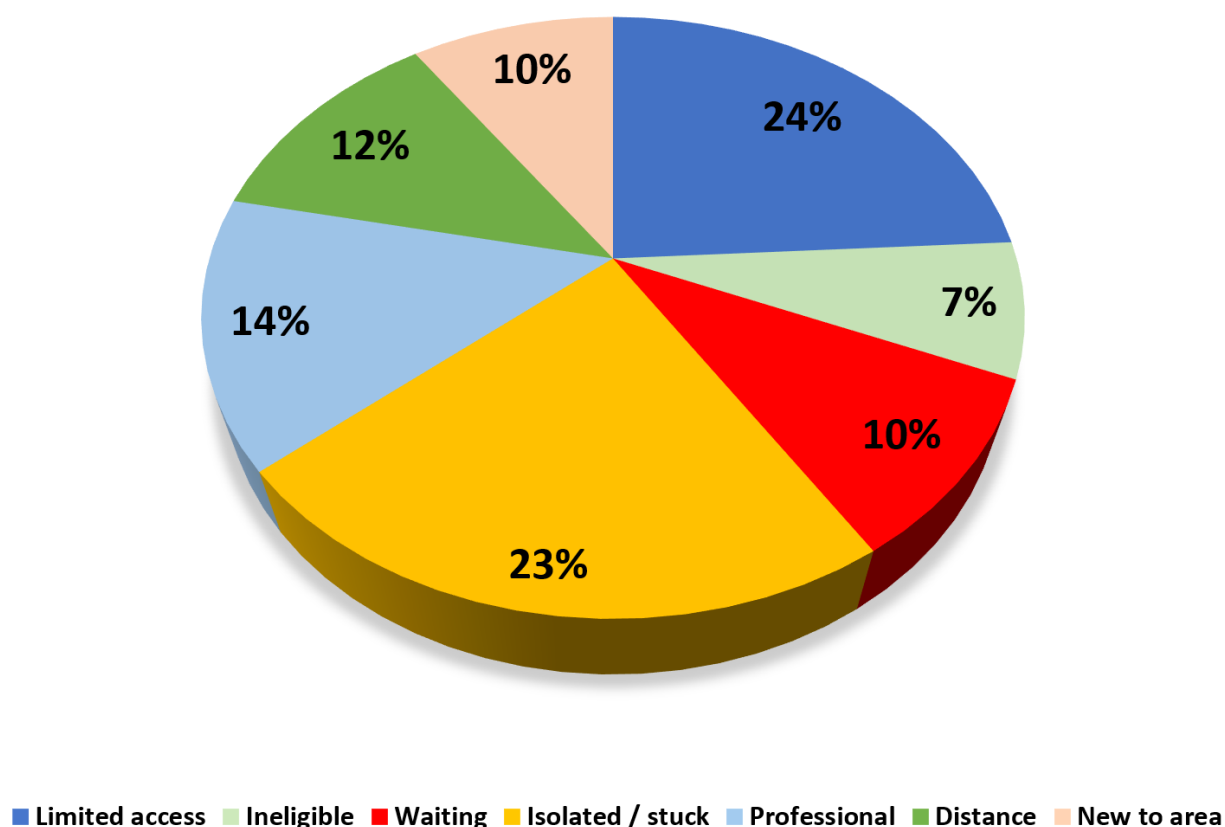


Figure 10 - Chart displaying the proportion of data coded to rural life and accessing services themes

Health literacy and navigation

These posts are related to questions that online community members post about their mental health condition, treatment options, confusion about their diagnosis, and asking others online whether they think assistance should be sought. Posts describing discontinuous services due to transient doctors in Remote communities or the lack of options after being diagnosed and switching medications are currently included in this theme. Five specific ways were identified about people raising questions about their health and navigating health services - as shown in Table 8 and Figure 11.

Table 8 – Categories about health literacy and navigation

Theme	Descriptive examples	N=
Unsatisfactory	Yes I am on anti-depressants and seeing my doc regularly but I just had the thought that when someone attempts to kill themselves they get all the help but someone who's not there yet but close doesn't. It seems screwed up (BB Remote line 3).	32
Confused	It can be so so hard to judge for yourself how 'bad' your anxiety is, because one part of you might be saying "this can't be normal, I can't go on like this" but another part is saying "you just need to suck it up, you're being weak" (BB Remote line 93). I don't want to be that person who diagnoses themselves from stuff they read online. All I know is this can't be normal, right (BB Very remote line 37).	11
Seek strategies	PLEASE PLEASE someone has to have a cure for this! I have had blood tests and MRI, etc. and a have come back normal...I am terrified I am going to live with this forever (BB Remote line 8). I don't want to feel like this but this feeling has been happening for more than a week. How will I feel better (BB Remote line 212).	19
Worried re seeking help	I don't know if this is maybe normal. I'm also worried I'm just making this up and overthinking. Should I see a therapist? I don't think anything is wrong with me anymore so I wouldn't want to waste my money and their time (BB Remote line 9). I kinda want to come straight out and tell her so she can organise all the proper help, referrals and tell my parents but at the same time I have no idea how she'll react (BB Remote line 129).	11
Next steps	My [...] of 15 years is in full depression and rejects doctors' advice to see a counsellor as she doesn't believe they can help. I am worried for her wellbeing and trajectory but do not seem to be able to talk with her (BB Very remote line 107). Thanks so much. Is it really hard to get a definite diagnosis? [...] has been in the past bipolar, acute depression, anxiety. Different meds obviously treat different things. Mental health is such a complex issue. Has such an effect on families (SANE Very remote line 41).	4
TOTAL		77

Health literacy and navigation (n=77)

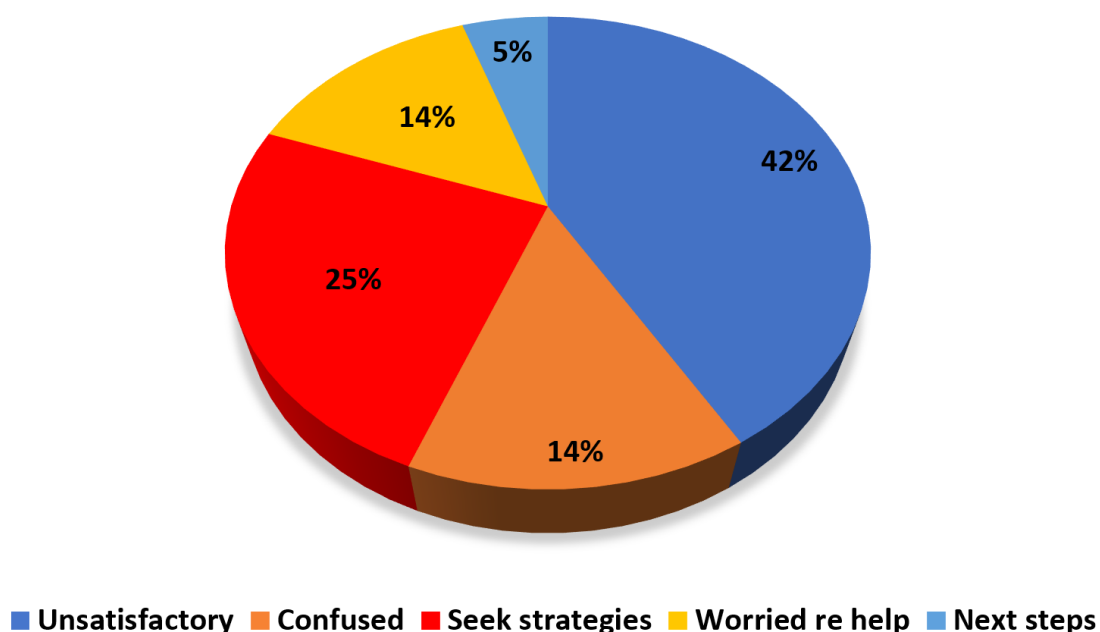
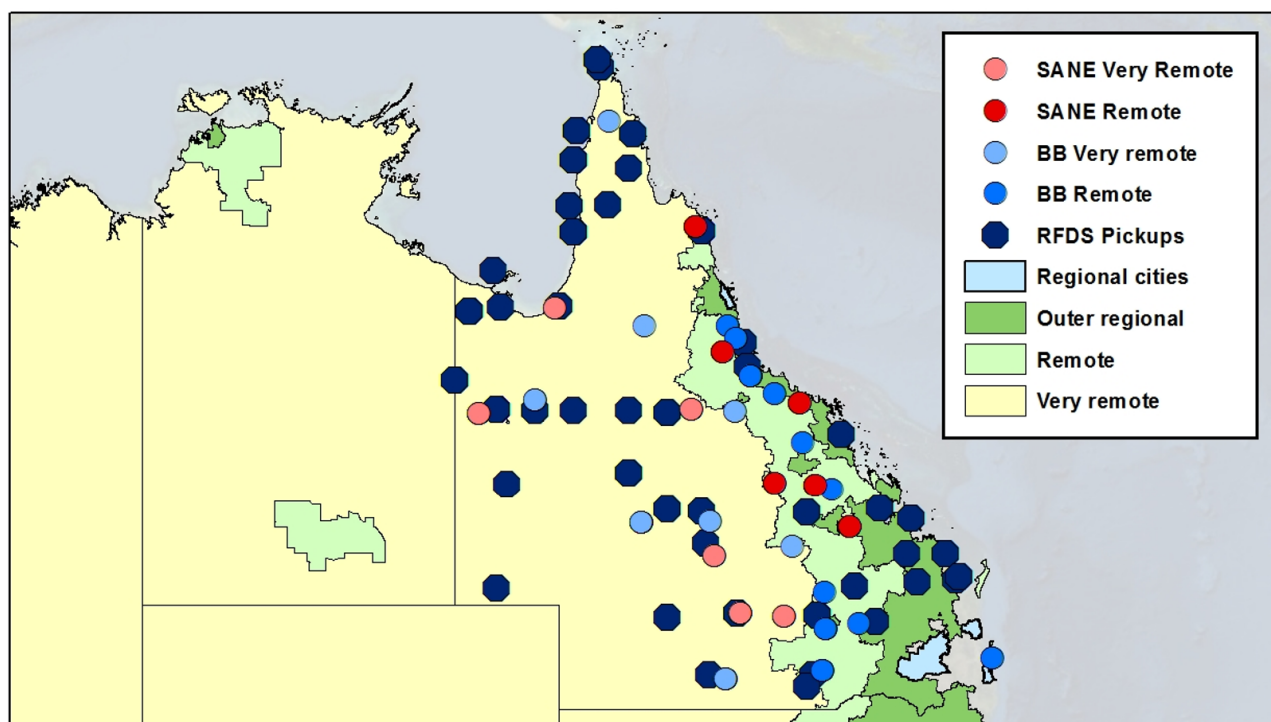


Figure 11 - Chart displaying the proportion of data coded to health literacy themes

Drilling-down into a state-specific example: Queensland

We also explored the potential of finer-grained analysis – looking at the potential to over-layer multiple datasets at state level to understand the potential for insights. There were 101 posts (across the datasets) for Outer regional parts of Queensland that were not within 100 km of a Regional city (Figure 12).



One of the potentially interesting phenomena observed through this analysis was different posting about certain themes between Outer Regional and Remote and Very Remote areas. We found a higher percentage of posts coded to the themes - stigma, rural isolation (coded as

challenges of rural life and accessing services), and health literacy in Remote and Very remote areas, when compared with Outer regional areas (see Table 9).

Table 9 - Coded categories of Stigma, Rural life and accessing services and Health literacy

Areas in Queensland	Stigma	Rural life and accessing services (rural isolation issues)	Health literacy	Total
Remote (n=189)	3 (1%)	14 (7%)	13 (7%)	30 (16%)
Outer Regional (n=101)	1 (1%)	5 (5%)	4 (4%)	10 (10%)
Total	4	19	17	40 (26%)

This result could be explained by more intense rurality/remoteness bringing with it more of the issues associated with rural isolation, but this requires further examination of data across the whole of Australia. This analysis can be done with the data that we have, but for reasons of time constraints, was not conducted at this stage.

Across the three rural themes – topics with the highest rates of discussion were: i) fear of, experience of, worry about stigma from others; ii) limited options around accessible services (i.e. only one GP, etc); iii) being/feeling lonely, stuck and isolated; and iv) going online to ask questions and seek strategies. This shows that a key function of online services for rural people is to gain access to a community where issues can be discussed, questions asked, and strategies gained. Given well documented challenges of accessing services, this indicates that online forums could have a significant role for accessing information and health navigation, particularly for people living in remote Australia. It is significant to emphasise, again, that a useful next step would be to analyse data across spatial categories to understand if experiences discussed online, or uses of the forums, are different depending on rural/urban location across Australia.

Coverage of Indigenous Australians

In addition to the themes discussed above, we specifically explored how Indigenous people living in rural areas, describe their experiences of accessing mental health support. To accomplish this, the key words 'Elder', 'Aboriginal' and 'Indigenous' were searched in all the Remote and Very remote datasets. A total of 39 posts were identified. From these, we identified four themes (see Table 10).

Table 10 - Coded categories about issues related to Indigenous people's accessing mental health services

Aboriginal Issues	Descriptive examples	N=
Cultural Competence	A lot of patients in [PLACE] are Aboriginal and have complicated health problems and many do not have English as a first language so extra time and care is needed to communicate properly (PO.org line 21) A nurse who has been EXCELLENT with my relative was using local Yawuru language to communicate, which is a REALLY good thing. But she used the same language when attending to another indigenous patient from the Fitzroy Valley area Wangkatjungka/Walmatjarri Language groups. This is not appropriate as the language she used was not understood by the patient and sometimes can cause unwanted behaviour and even be offensive (PO.org line 23).	4
Identity	Hi some my family are of mixed race, and aboriginal sometimes I feel like the maintaining of my culture is too much. We are the most disadvantaged and have poor socioeconomic outcomes. Struggling to get ahead in an ever-changing world is the most stressful and that's the thing. Why we fit in the western ways is there a place for culture? (BB Remote line 52213)	1
Discrimination	The doctor's response was that they had been dealing with aggressive Aboriginal adolescents all day and they'd had enough. The doctor left it to me to explain to the patient that there was nothing they could do for them and that they should go home, rest and take Panadol. (PO.org line 109). A few days later, I went to the Nookenhah Clinic when it was open, one of the health staff told me not to come there, he would not let me in the clinic. He said I was humbug, but I asked to wait in the waiting room and use the toilet. The nurse then called out to me and seen me in her office. I believe she was the only one who was helpful and assisted me properly all morning (PO.org line 129).	6
Indigenous health access funding schemes	After my appointment I asked the Aboriginal Liaison Officer for a lift to my group that I attend on that particular day of the week. The Aboriginal Liaison Officer (ALO) asked who brought me to the Clinic and I said the Mental Health mob dropped me to my appointment. The ALO said that they couldn't drop me off and told me that Mental Health mob had to come pick me up. I felt the way she spoke to me was aggressive and very angry (PO.org line 27).	6
TOTAL		17

Posts by/involving Indigenous people most often cited negative experiences of discrimination (n=6) and difficulty accessing government funded schemes (n=6) that provide financial assistance for travel to distant mental health services. One example described how funding schemes can break down and further impact people's mental health:

In going to town, many of them get lost from their cultural identity. Having services in country closer to home and keeping our families in community helps to avoid these social issues. Recently my wife required a cardiac appointment in [PLACE]. This involved a morning flight from [PLACE] to [PLACE]; waiting for the Greyhound bus; then leaving at 10 pm that evening to ride to [PLACE] (8 hours to the west). All this was booked through the Patient Assisted travel Scheme office (PATS). After her appointment my wife was left in [PLACE] with no money, no return bus fare and no accommodation. She spent the night homeless (PO.org line 27).

Relationship breakdown and impacts on mental health

One emergent theme that surprised us, and had multiple posts that cut across SANE, BB and PO.org data was expressions of the impact that personal/intimate or practitioner/professional relationship breakdowns have on people's mental health. From our initial reading of data, three of us independently, noticed that there seemed to be considerable data around relationship issues. Consequently, we conducted specific targeted searches to explore personal/intimate and practitioner/professional, relationship issues discussed. We found that topics discussed include the additional challenges of relationship breakdown in a small-town, experience of isolation and needing to move for work after relationship breakdown. To explain the issues around relationship breakdown, we first discuss people's personal or 'intimate' relationship breakdowns and how these personal relationship breakdowns can specifically impact on mental health when located in a rural place. Second, we discuss relationship breakdowns with health practitioners/professionals and how living remotely intersects with these relationships.

Personal / intimate relationship breakdown

To explore how relationships and relationship breakdowns were affecting people's mental health, we used a key word search of 'relationship', 'spouse', 'partner', 'girlfriend', and 'boyfriend' across the SANE, BB and PO.org datasets. This identified 162/1184 (14%) posts. From these, five different ways personal relationship breakdowns affect people's mental health were identified (see Table 11).

Table 11 - Coded categories about relationship-related mental health concerns

Relationship Issues	Descriptive examples	N=
Preventing	I am 41 and have struggled my whole life to maintain jobs, relationships etc and am currently single with a mortgage on a half-renovated house (SANE Remote line 2956). I don't want to hurt this man or to have the relationship fall apart as a result of my inability to be Intimate/emotionally close to him as he wishes to be with me (BB Very remote line 894).	7
Influencing	I recently started a relationship with a new man. He is one that believes depression isn't a real thing or just a sign of weakness (SANE Remote line 1428)	18
Broken down	Last week I separated from my partner of 5 years, this was his choice, I am completely devastated. I have been researching help online and all I can find is the No Contact rule- is this the way to go? (BB Very remote line 29547).	4
Separating to self-help	We spoke about 3 weeks ago and he said that he will start counselling and if it goes well, we can get back together (SANE Remote line 810).	6
Rurality and accessing services	My suggestion to him seeming as that I am not able to get into a DBT course until mid-next year due to where we live (and I am required to move) is to take our relationship back to basics. My suggestion is that I move out, to try and allow that small distance between us in order for me to focus on myself and also to give him space to feel he can do and plan things with his friends as he pleases and for me to then see where I can fit into it and build the trust back up (SANE Very remote line 32)	15
TOTAL		50

We discovered that in 29 of the 50 cases that people describe their relationship breakdowns impacting their mental health in three different temporalities: past abuses preventing them from being in relationships (past) (n=7), to mental illness influencing their current relationships (present) (n=18) to people feeling a sense of despair after a relationship broke down (n=4). Six people also mentioned that they needed to separate from their current relationship in order to self-help before they were able to participate in a healthy relationship.

Personal relationship breakdown and links to rural life

We were interested in specifying the extent to which personal relationships are affected by aspects of rural life and accessing services. To do this we took the whole data set (162 posts) from the section above and analysed these posts for mention of issues specifically linked to rurality, including themes about 'rural life and accessing services' (i.e. we used the same coding framework as in section titled 'Insights from hidden voices' to analyse the influence rurality has within the personal relationships data subset). Table 12 shows themes/examples of where personal relationship-related posts specifically mentioned rurality-related issues. We found that many of the issues that people state have influenced their capacity to access needed mental health services also appear to influence their relationships. Long-distance relationships affecting mental health and living near ex-partners were two other themes that emerged at this stage.

Table 12 - Coded categories about personal relationship issues in Remote areas

Theme	Descriptive examples	N=
Limited access	It's quite a scary time for me at the moment coming to terms with this [relationship breakup] and I haven't confided in anyone outside of my mental health, GP and nurse practitioner (I am in an isolated setting so sometimes we have a GP other times only the nurse practitioner is here) (SANE Remote line 21)	3
Waiting	I am on the waiting list for the local DBT institute, but what can I do in the meantime? I don't want to lose him (SANE Very remote line 43)	1
Isolated / Stuck	Hey I'm new here, but my partner and I are isolated to the max where it is making things worse (SANE Remote line 6501). My hubby, best friend and soul mate had to move for his job and I was unable to go due to the care of my 2 children and their father refusing to allow me to take them...I live in a country town that's isolated and just don't know what to do (BB Remote line 26148).	4
Distance to services	The closest health providers are 4 hours away for my partner to take part in DBT, she's on a medication dose that was set 2 years ago but we don't have anyone that can talk to her through it except me. I'm worried it's just hurting her more? (SANE Remote line 2503). But in all honesty the anxiety side is hard to control for me, hyper arousal kicks in and I'm gone for days. I have been seeking help but where I live the closest doctors is 370ish kilometres away. I don't drink or anything. For me isolation is best, but it's not for everyone (BB Remote line 30387).	2
Distance to relationship	We're not sure when he will be home, this will be dictated by his roster and being able to afford the excessive airfares (BB Remote line 24990).	2
Proximity to triggers	I've decided to move because I was made redundant and I don't have many friends or family in this town. I moved here for the relationship (SANE Remote line 1110).	3
TOTAL		15

Within these data about personal relationships, feelings of isolation were mostly experienced by people who recently suffered a traumatic relationship breakup and now feel isolated in small towns. This could be heightened if someone moved to a specific remote town to be with their partner, and then broke-up; as described in this example:

I live in remote Australia with no family or friends to rely on for support and I didn't want to feel lonely, I wanted to feel good, and I did at the time [when I started new relationship] (BB Remote line 37572).

In other cases, people described that they were in healthy relationships but still experienced feelings of isolation due to living in remote communities:

I live on a cattle station 500kms from the nearest town and have a 1 year old baby. As positive and easy going as I normally am, I find myself unhappy every day or struggling to cope with looking after a small child. I have no energy or motivation for anything. Now that

i Am a mum all I am really able to do in terms of work is take phone calls, do bookwork and cook and clean. My partner is amazing and will turn himself inside out to help in any way he can, but has been having a hard time figuring out how to help me, his job is pretty full on the cattle station and he is out a lot and I am alone with the baby a lot with nowhere to really go as we are so isolated (BB Remote line 52529).

Limited access to services that offer their partner – or themselves – mental health support was the second most cited cause of mental health affecting their relationship. This perspective is exemplified here:

My suggestion to him seeming as that I am not able to get into a DBT course until mid-next year due to where we live (and I am required to move) is to take our relationship back to basics (SANE Remote line 1366).

Physical distance from accessing mental health services was cited as affecting relationship:

We live rurally and finding a doctor has confused me also being statistically rare to find a GP with experience here. I would love to hear about some success stories in the Bipolar community of people who managed their relationships and becoming a mum with support (BB Very remote line 28822).

Issues specific to living in the same small community (i.e. small town), relying on the same people and places for resources, and constantly feeling triggers for mental illness by living near an ex-partner or abuser are also mentioned. One post describes the difficulty of living in the same small town as a former abuser. There are many similar posts that disclose highly personal stories that often describe violent or sexual abuse. This shows that people are willing to share horrific stories of abuse that have affected their mental health on these online forums. Within the context of this study, mental illness was sometimes catalysed by someone's ex-partner remaining in the same town due to parental responsibilities and a lack of alternatives, as described below:

I don't suffer from depression, but I do get bouts of anxiety after a bad marriage break up which seen him divide an conquer friends which left me in a very isolated location with no friends apart from my best friend who is also my hubby. Sadly, he has had to move away for work but I'm still stuck and can't leave due to parental care arrangements for my children (I need permission to move which isn't forthcoming (BB Remote line 26154).

This makes these datasets highly valuable for people interested in exploring people's lived experiences of suicide, sexual or physical abuse, or domestic violence.

Professional/practitioner relationship breakdowns

The data from PO.org provides a particularly useful resource for evaluating people's experiences of successful / unsuccessful relationships with service practitioners/ professionals. By the nature of the material posted on PO.org (a service for online feedback about health service experiences), material tends to divide quite naturally into posting about positive and negative aspects of relationships with practitioners. Below, we separated all posts related to relationships with service practitioners into positive and negative material (see Table 13) and provide descriptive examples (see Table 14).

Table 13 - Coded categories of positive vs negative experiences on PO.org

Type of experience	Most common themes	N=
Negative	Challenges with staff, health service buildings, equipment, poor accessibility (remoteness) and funding schemes	32
Positive	Positive rapport built between practitioners/teams and clients/patients	7
TOTAL		39

Table 14 - Coded categories about negative experiences shared on PO.org

Negative Themes	Descriptive examples	N=
Problems with care/service offering	No health assessment was conducted to establish if he was mentally fit to work in the Mines. No health assessment was offered during the years of him working in the mines (PO.org line 26).	16
Inaccessible information	Having the reality thrown at me after staff I dealt with realised the mistake, and then not taking the time to listen to me and my concerns really impacted my day twenty times more than what it needed to be (PO.org line 14)	2
Breach of privacy	On several occasions nurses spoke directly in front of myself and other patients about inappropriate personal matters. In a place where there are many vulnerable people, dealing with a lot of emotional concerns - how that's acceptable behaviour is beyond me (PO.org line 6)	2
Funding schemes	Without financial support to pay for these flights from family my child would of not have received such high-quality care from the service PATCHES provided due to the doctor's decision to not approve PATS even though this doctor has never evaluated or seen my child (PO.org line 7).	4
Lack of access	I had occasion to take my child to the emergency once and they were treated quickly and well. Counselling & mental health services are not great as they are referred outside the health services to a private provider who actually doesn't have any staff at all in [PLACE] and only offer phone consultations (not even video conference or SKYPE which are so easy to arrange these days) (PO.org line 12) Since moving to [PLACE] I have not been able to find any information on what psychiatric services are available and how to access them. It is frustrating as I shouldn't have to fork out \$100 for a GP appointment to find this information out (PO.org line 37).	5
Questioning diagnosis	I feel that this misdiagnosis and constantly being fobbed off by several other doctors is horrendous. It's not only cost me a lot of money so far (as still not fully recovered), but it's almost cost me my life. I don't want this to happen to anyone else (PO.org line 34).	3
TOTAL		32

Further unpacking the topics in Table 14, it can be seen that problems with care/ service offerings were most often the source of negative feelings about a relationship with a health professional /practitioner (n=16). A range of issues are included in this category, but the most common sources of negative feeling were either that a mental health service was unavailable

or discontinuous services due to aspects such as 'shift changes' or poor communication between practitioners. Example posts are below:

The Consultant Liaison Team (CLT) came up with a plan for me to be discharged into their care when the doctor finished work so I would not be left alone. However, with the change of shift, I was shoved out of Short Stay and taken up to the Ward Discharge Lounge. No one was watching me, let alone knowing I was there (PO.org line 37).

Negative feelings were also posted in relation to: small rooms, a lack of privacy, and patients feeling unsafe when near other patients who were experiencing mental or behavioural ill-health. Hospital and emergency services were cited as the place where these poor relationships were experienced most often (n=19), followed by a mental health 'unit' or 'ward' (Table 15). We also looked at the specific issue at the centre of the positive and negative feedback. Six negative experience coding themes were identified, as well as three positive themes.

Table 15 - Coded categories of central issues in negative posts on PO.org

Central issue being commented on	Descriptive examples	N=
Mental Health Unit / Ward	My doctor tried to contact the psychiatrist but was told she is not in until Monday. I feel that I am entitled to receive care under another psychiatrist and that I was discharged too soon after being taking off forms. I did nothing wrong whilst I was an inpatient and the psychiatrist was more than happy at the time. I was in there for me to seek a second opinion. I am home now, and my mental health has rapidly declined because of all that has happened (PO.org line 29).	7
Hospital / Emergency room	I requested the patient be assessed by the mental health unit. The doctor said we needed to book an appointment with them (PO.org line 19).	19
Patient Assisted Travel Scheme (PATS)	In our view, the result of the application process for PATS failed to meet minimum standards of safety and quality in healthcare. The cost of the return airfare for my child and I was \$1923.44 (PO.org line 7).	2
Community Treatment Order (CTO)	Even though he was on a CTO he never once had anyone visit him at home or attempt to develop any kind of rapport with him, despite it being made very clear that he needed some psychosocial support. We attended brief monthly meetings, obviously held to comply with the conditions of the CTO, but none of the support offered in these meetings ever came to fruition (PO.org line 59).	1
Aboriginal Liaison Officer	I got frustrated at the thought of walking while it was hot and being pregnant. I walked around the corner to Mental Health and asked one of the Aboriginal Mental Health Workers (AMHW) to drop me to my group. I feel angry, upset and discriminated against. I won't be asking the Aboriginal Liaison Officer (ALO) for lifts anymore (PO.org line 107).	1
Policy	I think (out of date) info highlights the need for a new vision locally in meeting the accreditation criteria of engaging with consumers and carers in accordance with WA health Service policy and the Mental Health Commission engagement policies (PO.org line 15).	2
TOTAL		32

Sometimes, inaccessible / ineffective funding schemes including, the Patient Assisted Travel Scheme (PATS) and Community Treatment Order (CTO) were cited as a contributor to poor relationships between patients and professionals (n= 3). Specific service provisions of Indigenous (i.e. ALO) funding schemes were also discussed on PO.org.

Notable, there were also positive examples of successful relationships between clients/ patients and professionals/practitioners. These tended to be complimentary of helpful nurses and midwives (n=4) by being offered something as simple as privacy (n=2) (see Table 16).

Table 16 - Coded categories of central issue in positive posts on PO.org

Positive Themes	Descriptive examples	N=
Offered privacy	I was a mess, weeping. The nurses behind the emergency windows were extremely caring and kind in how they spoke to me. When I said I felt embarrassed - because it's a small town and I someone I know might see me crying - they arranged for me to wait in a little room area away from the emergency department waiting area (PO.org line 5)	2
Considerate	A Clinical Nurse specialist called [NAME] was really compassionate and understanding he told me there are other people like me with my issues and illness and that I'm not the only one (PO.org line 32). She needs credit for her utmost professional help (PO.org line 44).	4
TOTAL		6

Those online community members that post on SANE and BB also encourage others to develop new 'professional relationships' with mental health support staff, if available:

Hi @[member], the best advice I can probably give is (if you haven't already) to see your GP to get a referral to a counsellor/psychologist. It's one of the first things I did because I knew this was bigger than I could deal with alone. I think without her help in the very beginning I'd have slipped into depression myself. She's been an incredible help with understanding why he acted this way and how he would be feeling etc, and she has helped me move on in some ways. Not necessarily from him but just getting back to my normal life in general. I also found her useful because as a professional her advice going forward was more mature and insightful then our mutual friends, some of whom suggested within days I just forget about him. Also, there is a website called Storied Mind, it has a section on Relationships and one discussion is "Why do depressed men leave". I'd recommend checking that out. Hope today is a little better for you (SANE Remote line 1108).

Conclusions and recommendations

Conclusions

This report presents a 'first of its kind' proof of concept showing that it is feasible to partner with non-governmental organisations to prepare and analyse data generated through their online community forums. Previously, these datasets have been growing in size, but largely have remained unanalysed. Analysis of NGOs' community member datasets shows that it is feasible to analyse 'unusual' data for insights and highlights the potential for more of this work. Considerable progress was made, even in this small-scale short-term project, to navigate legal and ethical frameworks and to actually find out where data reside and how to access them. This provided some surprises – particularly around the costs to organisations of recovering 'their own' data as it is managed by external organisations.

It is particularly challenging to access the lived experiences of rural people with mental health conditions – firstly due to reticence of people with mental ill-health coming forward, and secondly because rural residents may be so remote from places where consultations are carried out. Analysis of online forum data gives people living all across Australia access to providing a voice and informing policy and practice decision-making. In this project, we were only really able to establish feasibility, relationships and provide some early insights.

A summary in relation to the specific research questions is provided below:

Question 1. Where in the most rural parts of Australia are participants engaging and not engaging, with the online health community forums?

We found engagement in online communities across Australia, highlighting that analysis of client/patient data generated has potential for comparing experiences in different places across Australia (e.g. Remote areas vs Inner regional vs Major cities). In this project, in the interests of time, we focused on the 'most rural' experiences. We found that there were 'hot-spots' of activity. We are exploring reasons for the existence of these 'hot-spots' and contrasting areas of low or no activity ('not-spots'), with SANE and Beyond Blue. At this stage, it seems this is potentially due to local health services varying in their promotion of these online communities. Given our analysis, the online communities are clearly useful for many people that use them, so more widespread promotion of the online communities across Australia, would appear to be beneficial. Patientopinion.org is most active in Western Australia as that is where that online community commenced, but it is progressively rolling out its services across the rest of Australia.

The potential for richer spatial analyses would be increased by: working with more NGOs/ other organisations and incorporating more types of data plus open data and that of ABS/AIHW; using larger datasets from the partner NGOs in this project (we only used one years' worth of data); and further exploration of accessing RFDS social media and other datasets.

Question 2. What are rural peoples' experiences of, and sentiments about, rural mental health services, as reported in online health communities?

Resonating with other work on rural mental health challenges, key categories of issues arising include:

- o Dealing with stigma
- o Issues of rural life, isolation and poor access to services

o Health literacy and navigation.

Within these, we do not know if the experiences (as evidenced by 'posting' activity) differ from those living in Major cities or Inner regional areas, and this is a significant next area for study. It is clear that using the online communities was helpful for members who often posted to ask for help or simply as an outlet to voice their experiences. It was clear that the online communities provide a valuable 'space' where people can speak out, express themselves and ask for help, where it would be very difficult for them to do that in their own (small, isolated) rural community.

Surprising emerging issues were the impact of personal relationship breakdown and how its traumatising effects can be compounded by aspects of rural living, including access to employment and living alongside your ex-partner and their friends and family. The stresses of having a mental health condition, upon a relationship, and compounding issues of rural living were similarly highlighted.

As well as personal relationships, several issues around problematical relationships with health professionals were raised such as lack of choice of alternative practitioners.

Turning to the online community forum was one way to express frustration or sadness about relationship problems and a place to ask for help and support that allowed access to resources beyond the immediate locale. We also found some expression of experiences of discrimination and failures to be culturally aware, for Indigenous people that posted.

3. What are the gaps revealed in relation to the current landscape of rural mental health activity and service provision in remote communities?

Rather than specifically highlighting problems with types or aspects of mental health services, the data that we analysed (which pertains to the most rural parts of Australia) tends to highlight that remoteness exacerbates or negatively affects access to a range of social supports, for people with mental health issues. In particular, people are turning to the online communities, to: express frustration with their perception of poor/lack of services or choice; ask for and receive, help/ opinions around diagnoses, medications, symptoms and next steps; ask for and receive, support in situations of desperation around issues to do with personal relationships.

Data analysis highlights the potential to develop specific interventions or specific online supports for dealing with: the social isolation aspects of rural geographical isolation; feelings of being other, stigmatised, bullied or discriminated against; navigating relationships and relationship breakdown; and navigating health practitioner relationships and relationship breakdown.

We conclude that online community peer support forums such as those of Beyond Blue and SANE significantly augment the services that are already available to rural residents. They appear not only to help people who live isolated from multiple services and social supports, but potentially ease the burden on the services that are available. They do this by enabling people to ask questions and gain support - from each other; sometimes simply enabling people to ask 'help me' in a more anonymous environment than would be feasible in a small rural community. Reciprocity between people asking for help, and those giving help appears to have benefits for both givers and receivers of help. These services may be particularly helpful in rural communities by providing people access to an 'anonymous and wider world of people', beyond their tight-knit locale, where people can seek solace and help for mental health and wellbeing challenges. Patientopinion.org too, provides an important service in giving a way for people living in rural areas to draw attention to improvements they would like and need, for services.

Recommendations for next steps in research

Key recommendations for further research are:

- Using/extending our methodology: This would involve 1) fully exploring the current dataset to extend analysis across rural-urban spatial categories (e.g. to understand if stigma and relationship breakdown, for example, are raised as such significant topics – and experienced similarly/differently – across all categories); then 2) supporting extension of this methodology by bringing in new collaborative partners and datasets to enrich the quantity of data (such as other rural NGO service providers, online psychology services, etc).
- Developing and testing online interventions to help support relationships for those with mental health conditions; and supporting people through relationship breakdown in rural places, which can be highly isolating and additionally challenging due to limited employment and amenity opportunities. Other interventions around dealing with social isolation, bullying, stigma or discrimination while geographically isolated, also appear valuable.

Appendix

Research approach

Participating partner organisation (Beyond Blue, SANE, Royal Flying Doctor Service and Patientopinion.org) varied in their capacity to collaborate on this project due to their size, reach and financial resources. This meant that the time and support staff available to clean and collect data to feed into the project, also varied by organisation. To understand who was available to assist, initial meetings and phone calls were scheduled with each organisation. These initial informal conversations served as important introductions and established the primary contact for data collection within each organisation. During these conversations, we discussed:

- How the organisations generate and collect social media data (i.e. online forums, Facebook, or survey)
- How to geo-locate their posts (e.g. post codes)
- Duration of data collection
- Ideas about where online community members were located.

The question that we asked the organisation representatives initially was 'What do you think people talk about on your platform?' This emerged as useful in beginning to consider how to address the research questions. Themes that the organisations thought would be discussed on their online community forums, were:

- Wait times
- Access to GPs
- Access to specialists or expertise (i.e. specialists in local hospitals)
- Distance from services
- Affordability
- Quality and consistency of services
- Confidentiality
- Next steps after diagnosis

These themes proved useful as a start, as they influenced decisions about the coding process. Data from the organisations was then collected. This was accessed and organised differently for each, as follows: 1) Beyond Blue and SANE - a one-year sample (Sept 1st, 2018 – August 31st, 2019) of all posts made on Beyond Blue's and SANE's online forums were extracted; 2) PO.org - an API subscription was purchased for one year from PO.org where all posts between Sept 1st, 2018 and August 31st, 2019 were extracted (we focused on Western Australia because PO.org has been running there for longer than other areas of Australia); 3) RFDS pick-up and drop-off locations between Sept. 1st, 2018 and August 31st, 2019 were extracted from the RFDS database and sent to Swinburne researchers.

SANE uses Khoros, a social media management software to facilitate their online forum. SANE Australia does not have access, nor the ability to export data directly. As a result, a representative of SANE contacted Khoros to extract a month-long sample of the forum data for us to view. Once we learned the requested cleaned month-long sample fit our aims, the same process was repeated to receive one full year of data (Sept 2018-August 2019). Beyond Blue uses a similar online forum and thus, similar methods were used to request the same year long sample of data for comparison.

Data from PO.org required a different methodology due to their data coming from a website as opposed to a privately owned and operated forum. To accommodate this, we purchased a year-long API subscription, allowing us to 'scrape' and collect data according to our desired criteria. The API supports filtering based on location information that is contained in user profiles, and the date a comment has been published. In order to provide geospatial analysis of the posts based on the level of remoteness, the collected data was mapped to where the health service in Western Australia is located. The full metadata associated with the retrieved dataset include: {author, authorRole, authorRoleId, title, body, criticality, dateOfPublication, dateOfSubmission, links, progress, readBy, source, tags, no_resp, responses}.

Due to many of the PO.org posts not being affiliated with mental health-related issues, to select only the posts with mental health related issues, the key word 'mental' was used to isolate and code posts that were directly linked to mental health. Although SANE and BB online forum data was exported in a similar format, each organisations' dataset possessed a unique set of descriptors or columns in an excel spreadsheet that represent the types of data associated with each post (Table A).

Table A - Columns available for analysis (x= data available).

Post descriptors	SANE	BB	PO.org	RFDS
<i>Subject</i> – name of thread	X	X	X (opinions)	
<i>Body</i> – content can be categorised	X	X	X (response)	
<i>Replies</i> – number of replies to a post	X			
<i>Tags</i> – group posts by tag	X		X (opinion)	
<i>Views</i> – most popular	X			
<i>Last edit author</i> – could be the influencer / key member	X			
<i>Time of post and last time there was a comment</i> – look for sensitive times of the year (Christmas, etc.)	X			
<i>Health service</i> – named health services			X	x
Treatment functions			X	x

In order to map all three organisations posts, we needed a common spatial delineation to match the posts locations to a similar spatial scale. During initial correspondence, it was discovered that members of Beyond Blue and SANE's online forums are asked to give their post code as a part of signing up. This means that most of the posts in their online forums are connected to an underlying post code, allowing us to connect each member's post to a post code. SANE and BB each sent us two separate spreadsheets to perform this analysis: one was with all individual users' names and post codes and the other with all of the post's details and user names. These spreadsheets were joined so each post would also be connected to a post code for mapping purposes. A similar process was undertaken for the PO.org and RFDS data but instead of coding a post to the post code of a member, the post code of health service or the XY coordinates of an airstrip, respectively were used to map these datasets.

To map the posts that were now connected to a post code, we needed to connect the post code to a X and Y coordinate. To accomplish this, the XY coordinates of each post code was extracted by first converting the Australian Bureau of Statistics (ABS) 'post code polygon' in ArcGIS into points using the 'feature to point' tool. Once the post codes were converted into points, the 'Add XY coordinates' tool was used to connect each post code to an XY coordinates, which was exported from ArcGIS into a .csv and joined with the spreadsheet that has all posts connected to a post code. The outcome is one spreadsheet that has all posts – connected to a particular post code – and XY coordinate. This was then imported back into ArcGIS and mapped using the 'Display XY data' tool. This process was repeated for all organisations data-sets.

A qualitative content analysis was conducted on the whole dataset within Remote areas. Qualitative data analysis of post content was chosen because it provides a nuanced basis to identify patterns and themes in relation to the research questions, while also being in line with best practice in online forum research.

This method allows for a systematic approach to analysing the content of a substantial sized sample corresponding with the geographical areas targeted. Analysis involved an initial open coding process to identify key themes, combined with a priori coding categories that related to the research questions. Ultimately, this led us to focus on three key themes:

- Stigma
- Rural life and accessing services
- Health literacy and navigation

An initial sample of 1,184 posts was blind coded by each of three researchers (i.e. blind triple coded) to ensure reliability, with categories adjusted where there was disagreement or difference of interpretation. The analysis presents a synthesis of data relevant to each of these three core themes, in addition to other themes that arose (e.g. relationships) or that were specifically explored (e.g. Indigenous peoples' experiences) during the research process.

To explore spatial patterns, posts from all three organisations were imported into a spatial software program to visually analyse posting 'hotspots' and areas void of posts (i.e. 'cold spots'). This allowed focus to be placed on both common patterns of posting content across four organisations, and a more in-depth examination of spatial patterns of posting.

Although the forum data and posts on PO.org are publicly accessible and participants are double de-identified, due to the sensitive nature of mental illness, it is important to impose strict ethical processes so as to guard community member anonymity. We have taken considerable steps to ensure that no identifying information, including original pseudonyms, is presented in this report. While undertaking this research, we have attempted to observe activities within the forum sensitively and to remain respectful of the challenging circumstances and painful experiences of those who post. This means that only anonymous portions of posts and exchanges from each dataset have been reproduced in this report. This includes replacing the pseudonymous usernames of members with individual reference numbers that refer only to the original dataset. We have also anonymised place names. Some highly sensitive material about abuse is also contained in the datasets and we have not posted these posts verbatim, as examples; rather, we have tried to summarise key themes.

With these procedures in place, we have attempted to maintain the content of the posts to help contextualise peoples' diverse and complex experiences of mental ill-health in the most rural and Remote areas of Australia. The posts that have been quoted in this report should not be reproduced more broadly without taking into consideration highly sensitive ethical issues. As a result, we have attempted to refrain from including forum posts that reveal intimate and recognisable personal or location detail, favouring more general statements over larger areas. The forums are publicly accessible by organisational policy because they also stand as a resource for others to read, follow, and learn from, and this is made clear to participants in the terms of use. Any possible harm in reproducing them in this research is also weighed against those objectives.

This project received ethics approval from Swinburne University, which was compliant with the RFDS, SANE and PO.org if the raw (though de-identified) datasets provided were not shared beyond the immediate researchers from Swinburne University that were involved in direct data analysis. Sensitive data files from BB and SANE, for example, were sent to the

research team via a secured link in OneDrive, where the data was only analysed on secure servers at Swinburne University. BB however had concerns with how the data would be used and altered during our analysis. To resolve the issue, we worked with the legal team at BB to establish the License Deed for access to and use of their data. An aim is to explore how we can adapt this deed for agreements with other organisations on future projects.

We requested that the license deed would state that we will not sub-license the data to other research partners, that only we (the core Swinburne University data analysis team, and all on the ethics applications) will be receiving the raw data and analysing it. We also requested removing the clause that restricts us from transforming or altering the data in any way. This is because we wish to map and visualise patterns of posts, which slightly alters the original form of the data from a excel spreadsheet to a visual representation of categorised text. To accommodate these concerns, we suggested words like aggregate, taxonomize and geo-spatially analyse, but the preference originally was to remove the clause altogether for ease of analysing the posts.

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