17 September 2015

The Honourable Margaret Wilson QC Barrett Adolescent Centre Commission of Inquiry PO Box 13016 George Street Post Shop QLD 4003

Dear Justice Wilson

I began advocating for the people affected by the potential closure of the Barrett Adolescent Centre in November 2012 with no knowledge of, or contact with, the Centre prior to that time. However since then, in my continued efforts to support the patients, families and staff, I have learnt a considerable amount and gathered documentation relating to the closure that ultimately occurred in January 2014.

Based on that, it is my contention that the closure of this service without a suitable alternative in place – and the handling of the closure by several state government agencies – has caused considerable unnecessary damage to a community that was clearly vulnerable and in need of careful and considered management as well as the provision of specific vital services. The toll of the cessation of the Tier 3 service and the steps undertaken to achieve that tragically includes the

In addition, other young people now exist in Queensland who are dealing with significant deterioration in their health and no hope of progress until adequate replacement services to the Tier 3 inpatient facility exist. These young people include those who had been patients at Barrett but were required to move to other services upon its closure, young people who had been on the waiting list to be admitted to the Barrett Centre and young people whose mental health had not yet reached the level of severity that a Tier 3 facility was required at the time of the closure. The carers, family members and friends of all of these young people have also been significantly detrimentally affected by the closure, the mismanagement of the closure and transition of patients and the current lack of appropriate healthcare for adolescents in the severe/complex cohort.

This submission, therefore, aims to provide you with the information I have gathered since November 2012 in order that you have access to as a clear a picture as possible in relation to what transpired in order that you can ascertain whether such assertions are valid. The data I have collected is from the perspective of an interested party who was not directly involved in the daily operations of the Barrett Adolescent Centre i.e. background information, research documentation, correspondence and accounts of meetings with various government representatives and others in the mental health sector, evidence relating to community action etc. Clearly the impact of the closure will be best explained by those directly involved in the closure but I would like to assist in any way I'm able, having had the opportunity to gather data while many within the Barrett community have been unable to do so. As I am endeavouring to supply you with information relevant to the Terms of Reference of the Inquiry, I will not be providing all my documentation initially. However, if anything I raise in my submission requires clarification or additional support, I'd be grateful if you would contact me for more information as my primary goal is that you have as comprehensive understanding as possible to enable you to accurately assess the situation.

Unfortunately, there are numerous issues that would seem to require examination. These range from the reasons given for closing the Centre and terminating the service altogether to the lack of consultation with key stakeholders in the process and the mismanagement of the closure and transitioning of parents at many levels – from those with direct clinical involvement with patients to the Health Minister at the time. So although I will try to present my documentation as clearly as I can, some issues may fall under more than one heading. In those cases, I will aim to ensure that best comprehension of information guides my presentation.

Initially, I would like to explain my involvement in this issue.

I first became aware of the issue when the threat of closure of the Barrett Centre was made public in November 2012 when plans already underway were revealed by Dr Brett McDermott, Executive Director of the Mater Child and Youth Mental Health Service as he gave evidence to the Child Protection enquiry (Appendix 1). As a result of the revelation that the only extended inpatient mental health treatment service for adolescents in Oueensland was to be closed, I set up an online petition on 8 November 2012 asking the government to keep the Barrett Centre open indefinitely. My motivation was that, with adolescence generally being one of the more challenging periods of anyone's life, to suffer from not just mental health issues but severe and complex mental health issues at this time deserves the best kind of support available. Therefore if all the young people in the state were to be deprived of a key level of service provision, that would put a number of people at increased risk of significantly greater suffering and harm. (The petition has been signed by more than 4,500 people and can be viewed at www.communityrun.org/petitions/don-tclose-the-barratt-centre-for-adolescents-with-severe-mental-health-issues with further information relating to petition activity in Appendix 2.) Setting up the petition triggered contact with people directly connected to the Barrett Centre. So from November 2012, I have spoken at length to staff of the Barrett Centre School about the implications of a closure and have met and/or corresponded with some of the clinical staff, parents/family/friends and students/patients as well. I visited the Barrett Centre School on its site at Wacol in May 2013 and two more times on its temporary relocation site at Yeronga in 2014 to participate in activities relating to language and constructive ways to express ideas. And in December of 2014, I was honoured to be invited to the Barrett School's Awards night to speak to the students on the value of their strength, courage and compassion for others. For the last two years, I have worked with a dedicated parent of a former Barrett patient to convey the needs of this group of people to anyone with any power to assist and support them. We have done this through emails, letters, phonecalls, and meetings. In addition, I have kept those who signed the petition appraised of developments through regular emails and via a website I set up at savebarrett.org where a 'News' page is updated as appropriate, links to media coverage are posted and a 'Take Action' page provides contact information for the relevant government officials as well as links to email forms set up by CommunityRun (the arm of GetUp! that administers the petition site). Some sample pages of this site are included in Appendix 4. Through this contact with petition signatories, I have been made aware of the fact that hundreds of Queenslanders directly contacted the former Health Minister, the former Premier and Executives at West Moreton Hospital and Health Service, Children's Health Queensland, the Commissioner for Children and Young People and Child Guardian and the Queensland Mental Health Commissioner to indicate that they felt that the Barrett Centre should remain open and then, why they believed that a replacement Tier 3 service providing extended inpatient care and education should be provided when Barrett's closure became inevitable. As Appendices 2 and 3 should illustrate, well-informed community members with a variety of backgrounds (healthcare, education, lived experience of mental health issues etc.) expressed their concerns directly to Queensland Health and in public

statements and interviews in the mainstream media from November 2012 onwards. However, when responses came from the government, they were unfortunately generally the repetition of carefully worded public statements that included inaccuracies, misleading language and promises that were ultimately never fulfilled. My personal communication with government agencies is detailed in Appendix 5. In addition, I can also provide some evidence in relation to the communication from other members of the community. When online forms to facilitate emailing the government were set up, CommunityRun was able to provide data that showed that 400 people used these to email the former Health Minister, Premier and/or Director General of Queensland Health. And beyond those, many more used the contact information at savebarrett.org or through sourcing contact details via other means. Community members met with their own MPs, gathered at state parliament to demonstrate support for the Barrett Centre when the petition was entered and continue to this day to communicate the needs of these young people and their extended community to those charged with the provision of health and education services. I believe that my documentation will show that the reasoned content of that communication went largely ignored - even when it came from individuals and groups with professional and personal expertise in the area. And because that input was significantly relevant, disregarding it was both negligent and directly contrary to a number of stipulated procedural requirements (e.g. the Governance Framework ~ Consumer and Community Engagement Strategy – of the responsible Hospital and Health Service, included as Appendix 6.) Had the warnings been heeded, it seems logical to conclude that significantly less harm would have been inflicted on the people who are now still suffering considerably.

Beyond the community support – including that of health and education experts as well as those directly impacted by the closure and others with an understanding of the issues or compassion for those likely to be affected – a number of significant aspects of the closure seem in need of examination. Amongst those that the Inquiry undertakes to scrutinise, I hope the following will be included:

1) THE REASONS GIVEN FOR CLOSURE AND THE FACTS TO COUNTER THEM

Since November 2012, various government representatives have provided different reasons for the closure of the Barrett Centre. These have included:

a) That the Centre is not a contemporary model of care (sometimes referring to the National Mental Health Service Planning Framework)

- Why, then, are other similar centres open and continuing to be opened in other states (e.g. the Walker Adolescent Inpatient Unit in NSW) and in other parts of the world (e.g. the IWK Health Centre in Canada see Appendix 9)
- The Expert Clinical Reference Group made up of experts with recent and ongoing experience in the area indicated that a facility of its type was ESSENTIAL (See Appendix 7)
- The NMHSPF was not released prior to the closure; in June 2014, it was still not considered complete (a Senate hearing then indicated that it did not have "broad support" and therefore might be lacking in credibility); and in April 2015, the Qld Health website indicated the Framework was still in 'draft'. In addition, the Project Director of the NMHSPF indicated when I contacted him to query whether the Framework was likely to consider a service like the Barrett Centre as not in accordance with contemporary service provision, he replied saying that "inpatient care is regarded as necessary only for the most severe and complex young people" ~ this is exactly the group on whose behalf we have been advocating for a extended inpatient treatment/education facility like the Barrett Centre. (Details are in Appendix 8)

b) That extended inpatient care for adolescents is not "evidence based"

• Contemporary research at a local, national and international level clearly indicates that the small amount of research that has been done – predominantly outside Australia – has proven that extended residential care is an important element of a full suite of mental healthcare services for adolescents e.g.

"Critics challenge the necessity and effectiveness of inpatient and residential treatment programs. Over the years, research has emerged challenging the legitimacy of these critiques. Currently, the outcome literature of adolescent residential and inpatient treatment (Table 1) indicates that these therapeutic settings are successful interventions for many clients."

Bettmann, J. E., & Jasperson, R. A. (2009). Adolescents in Residential and Inpatient Treatment: A Review of the Outcome Literature. Child & Youth Care Forum, 38(4), 174.

(Further detail is available in Appendix 9)

- The track record (30 years) of the Barrett Centre clearly illustrates that an extended inpatient facility that provides intensive treatment and specialised education from a expert multidisciplinary team is the only model of care that works for a number of adolescent patients with severe and complex issues
- c) That the Wacol centre operating on a site with adult forensic patients in the vicinity posed a threat to young people (sample quotes in Appendix 13)
 - No incidences of harm/increased trauma caused by nearby adult patients were reported during Barrett's 30 years of operation. However, if the adult forensic service was to change in structure/size/operation and that increased the possibility of a negative impact on the adolescent patients, relocation of the centre rather than complete termination of the service would seem the logical step

- If the January 2014 closure deadline was forced by 'a new adult forensic unit on the Wacol site' (as referred to in a special report on ABC's 7.30 program on 7 November 2014) then why did the Barrett buildings still remain empty and untouched and the surroundings similarly unaffected more than a year after the closure?
- d) The Centre at Wacol was operating in 30 year old buildings in need of repair/maintenance (sample quotes in Appendix 13)
 - Again, renovation or relocation rather than closure would seem to be the appropriate solution in this situation. And with plans already underway under the preceding state government, finding a new location other than the Redlands site which apparently had been ruled out because of environmental concerns was the only hurdle. Architectural plans for a purpose built facility had already been drawn up and funding had been allocated. Halting the project and ceasing operation of a proven service when no other exists in the state does not seem to be a reasonable reaction to a problematic site. (Further details on the relocation plans under Labor are in Appendix 10.)

e) Poor occupancy rate

Occupancy statistics, in the case of this facility, are misleading and irrelevant where issues of need or efficiency of operation are concerned. (Dr Brett McDermott clearly indicated the error in measuring such a service using adult metrics at the *Child Protection Inquiry – Appendix 1). Judging a service whose practice is to* gradually transition patients from full-time inpatient status back to their own communities by the parameters of a '7 days a week/24 hours a day' model is totally invalid. Barrett's approach meant that some beds were vacant when patients were spending some nights each week back in the community transitioning from Barrett or visiting family – and a number of young people would have made sufficient progress that they had reached the level of accessing the service as day patients until the treatment and education available in the community was able to adequately support them. The flexibility of the program allowed for a focus on individual patient needs and re-integration into the community at an appropriate pace to ensure long-term recovery. The bed occupancy statistic, then, is not a valid indicator of the utilisation of the service but, in fact, an illustration of the successful approach of a treatment program that caters to the complex and unique needs of adolescents with severe mental health issues so effectively that they no longer require continuous professional care.

f) Small number affected

• Even now, the Queensland Health website justifies its closure of the Barrett Centre with minimising its value through statistics (inaccurate ones – as indicated above) i.e.

It provided care to 12-15 patients at a time with 28,000 young people receiving mental health treatment in Queensland each year. In the months prior to the closure the centre generally housed eight patients or less. -http://health.qld.gov.au/news-alerts/news/141118-barrett-centre.asp

This not only misrepresents the number of patients/students utilising the service by ignoring those who were transitioning from full-time inpatient care and those who had already done so and were attending as day patients but it fails to clarify that the reduction in "the months prior to the closure" was because many patients had already been 'fast-tracked' out to alternate services to meet the closure deadline.

 Most importantly, though, it is, in many ways, a highly offensive statement that diminishes the suffering – and even the existence – of a group of people who are at at the most high risk within our community. If Queensland Health were to apply the same justification to a different demographic group e.g. infants with rare liver conditions, saying that a specific surgical procedure wouldn't be offered to those in this category – even though it could be lifesaving – simply because there weren't a large number who required it, there would be an outcry. So to deny a proven service to a group for whom there is no valid alternative on the basis that the higher proportion of sufferers – those dealing with more common and/or milder forms of an illness – respond to other treatment methods is a justification that should be anathema in a well-resourced, first-world society. That it has been utilised in conjuction with teenagers suffering from mental illness is a telling indictment.

g) That there was a need for better provision of services to rural and regional Queensland

• The only logical step to address that is to provide ANOTHER inpatient extended care facility (as well as the Barrett Centre) where it is more accessible to patients from rural/regional areas (e.g. Townsville) as well as expanding the other levels

of adolescent mental healthcare in regional areas. Adolescents with severe and complex mental health issues from Far North Queensland to Western Queensland to the SouthEast corner were <u>all</u> deprived of a Tier 3 service option when the Barrett Centre closed. Regional centres all need specialised adolescent acute options, step-up/step down services and more. But the need for those is not served by closing the only service available that caters to the sufferers at the severe/complex end of the spectrum.

Whilst budgetary issues were a predominating concern across government services and the public service at that time, it was always emphasised by government representatives at every level that the termination of the service was <u>not due to</u> <u>financial constraints</u>. In fact the most recent online statement regarding the closure posted in November 2014 (http://health.qld.gov.au/news-alerts/news/141118-barrett-centre.asp) states clearly that "*the closure of BAC was not a cost-saving exercise*." So, that being the case, it would make sense to continue to provide that specific tier of care – otherwise not offered anywhere in the state – to ensure the full suite of adolescent treatment options are available and that every level of suffering across the spectrum of adolescent mental health issues is catered for.

As far as the provision of increased adolescent-targeted services within communities is concerned, it should be emphasised that no one opposing the moves to terminate the delivery of a Tier 3 service like the Barrett Centre has ever refuted that community-based care is the first port of call to be utilised whenever it can be effective. However, those types of services had already failed to achieve progress with the young people who came to the Barrett Centre - this is the reason that they were referred to Barrett. When issues are severe and complex, fortnightly or monthly psychiatrist appointments and access to a local Headspace unit can make no impact or not even be accessible by teenagers whose illness has deteriorated to the point where they are unable to leave their homes; are suicidal, violent and/or self-harming; and/or in a turbulent or challenging domestic situation. There must be an option for the cohort whose suffering is at the extreme end of the scale. To deny that is akin to denying specialist treatment for anyone afflicted with the most serious form of any illness. It would be unthinkable to terminate transplant surgery for sufferers of liver/kidney/heart disease so why should Queensland adolescents with severe mental health issues be totally denied access to a treatment that has proven to be effective for many in similar situations.

2) THE RECOMMENDATIONS OF THE EXPERT CLINICAL REFERENCE GROUP – DISREGARDED

The announcement of the formation of an Expert Clinical Reference Group (ECRG) to assess the need for the Barrett Centre or similar Tier 3 facility came after plans for the closure of the Centre were made public in November 2012. From that time, the key government spokespeople on the issue i.e. the Health Minister Lawrence Springborg, the Premier Campbell Newman, the Chief Executive of West Moreton Hospital and Health Service Lesley Dwyer, the Chair of the WMHHS Board Dr Mary Corbett all stated that there were no definite plans to close the Barrett Centre and that the future of the service was dependent on the recommendations of the ECRG. Based on experiences that highlighted that the affected group of young people have very specific needs and that even psychiatrists who only deal with adult patients or young people with less severe issues can be ignorant of the appropriate treatment for the severe/complex cohort, those within the Barrett community (families, staff etc.) were concerned about the backgrounds and understanding of those on this expert panel in

relation to this particular group of sufferers. So efforts were made to enquire about the expertise of those making up the ECRG. However, very little information was forthcoming, even to parents of young people at Barrett or on the waiting list for admission. The most comprehensive reply came from Dr Mary Corbett who said on 9 January 2013 (in response to an email I had sent to the Health Minister), "the expert clinical reference group consists of experience child and youth mental health *psychiatrists, nursing, allied health and education staff*[°]. Beyond that, identities would not be revealed. Frequent requests for the progress of the ECRG's operations were made but little information was given until after the announcement of the closure on 6 August 2013. Only then did a summary of the ECRG Report become available. (See Appendix 7.) The contents revealed that, amongst other stipulations, the ECRG had emphasised that "Inpatient extended treatment and rehabilitation care (Tier 3) is an essential service component" and that "Interim service provision if BAC closes and Tier 3 is not available is associated with risk". So, if the closure could not be prevented, then another Tier 3 service would need to be provided. As the 6 August announcement had included the news that the statewide governance around mental health extended treatment and rehabilitation for adolescents would be moving to Children's Health Queensland, the Barrett community along with allied professionals and community members sought to ensure that the ECRG recommendations were heeded by contacting Dr Peter Steer and his colleagues at CHQ as well as those they were already in communication with at WMHHS and other agencies. Not only had experiences over the preceding months – the lack of meaningful engagement with the community being a significant disappointment – begun to foster a lack of trust in the government's commitment to provide the right level of ongoing care, but the ECRG summary report included additional content that was a valid cause for concern i.e. alongside the expert panel's recommendations, additions made by a 'Planning Group' appeared in a number of cases to nullify the recommendations.

Recommendations Modified by Planning Group

There has been nothing to indicate the composition of the Planning Group whose modifications were noted on the ECRG report nor has there been any clarification on the purpose of this Group. If there was to be a Statewide Adolescent Extended Treatment and Rehabilitation Strategy Steering Group (SW AETRS) – as was set up immediately after the ECRG's work came to an end – what was the function of the Planning Group? And what qualifications and/or expertise did its members have to amend the recommendations of the ECRG? For that is what they did. The Planning Group's Recommendations were listed on the summary report alongside those of the ECRG. And although these comments annotated each ECRG recommendation as 'Accepted', the majority qualified that acceptance "with considerations". And because, in some cases, those considerations virtually quashed the initial recommendation, the Barrett community was deeply concerned about what services would be available following the closure. e.g.

ECRG RECOMMENDATION

A Tier 3 service should be prioritised to provide extended treatment and rehabilitation for adolescents with severe and persistent mental illness.

PLANNING GROUP RECOMMENDATION

Accept with the following considerations. Further work is needed to detail the service model for a Tier 3. Models involving a statewide, clinical bed-based service (such as the Barrett Adolescent Centre) are not considered contemporary within the National Mental Health Service Planning Framework (in draft). However, there are alternative bed-based models involving clinical and non-clinical service components (e.g., Y-PARC in Victoria) that can be

developed in Queensland to meet the requirement of this recommendation. Contestability reforms in Queensland may allow for this service component to be provider agnostic.

So, from 7 August 2013, many people sought to gain confirmation that a replacement Tier 3 service was part of future plans. (These efforts are particularly evidenced in Appendices 2, 4 and 5.) One of the best opportunities for a conclusive reassurance came at the meeting with representatives from WMHHS and CHQ on 30 August, where Dr Stephen Stathis responded to the direct question "*Will there be a Tier 3 service with onsite schooling?*" by saying that there would definitely be "*a Tier 3 service with access to schooling*", clarifying that it couldn't be determined whether the school would be onsite until a suitable location for the new centre was locked in – but that specialist school services would be in proximity to be accessed by the young patients resident at the Centre. However, public confirmation of a future Tier 3 service was never made by the Health Minister or by representatives of the West Moreton Hospital and Health Service irrespective of significant efforts to elicit that. (Hundreds of people contacted Lawrence Springborg through use of an online email form alone – Appendix 2 – and numerous others utilised other means, continuing to indicate the necessity of following the ECRG's recommendations until the government changed in February 2015.)

Parents tried numerous approaches to ensure that post-Barrett treatment options would be adequate. They had to apply considerable pressure to be allowed to make a presentation to the Statewide Adolescent Extended Treatment and Rehabilitation Strategy Steering Group (SW AETRS) on 4 November 2013 so that they could explain the circumstances of those that need an extended inpatient service with access to schooling. They were allocated half an hour to do so and so provided a written submission prior to the meeting during which they verbally summarised key issues during their allotted time. (An account of their contribution is in Appendix 6.) On 11 December 2013, a new model of care proposed by Children's Health Queensland was presented to Barrett parents and a summary was made available on the CHQ website (also in Appendix 6). This new model included a Tier 3 "Statewide Adolescent Inpatient Extended Treatment and Rehabilitation Service (new)" via a "Bed-based Unit" that "provides medium-term, intensive, hospital-based treatment and rehabilitation services in a secure, safe, structured environment for adolescents who have a level of acuity or risk requires inpatient admission; are unlikely to improve in the short term (i.e. weeks or months); require a therapeutic environment not provided by an inpatient unit."

Key Recommendations not followed

However, despite the clear statements from Children's Health Queensland in August and November of 2013, when the Barrett Centre closed in January 2014, there was no Tier 3 service for patients to transition to and no interim service to support them as a new facility was developed. Families knew that the young people were at risk even without the warning from the ECRG report (that "interim service provision if BAC closes and Tier 3 is not available is associated with risk"). Those in a position to fight for the best support that was available for the young people in their family had done all they could – but ultimately the services required did not exist. Those whose lives were already seriously compromised by dealing with a family member with severe/complex mental health issues now had a greater burden with the increased demands and stress of caring for teenagers in decline. All tried to make the best of the circumstances they were left with - but there was no treatment program available that would even consolidate the progress made at Barrett for young people for whom an extended inpatient service still had much to achieve in dealing with complex issues. (Those affected will be able to provide considerable evidence of the deterioration of transitioned patients.)

Then, in April 2014, more than three months after the Barrett Centre closed, the CHQ website was updated with a revised *Proposed Model of Care for Extended Treatment and Rehabilitation Services for Young People.* (Appendix 11). **There was no Tier 3 service now listed and all but a proposed day program could not be categorised even as Tier 2 services**. In addition, vast areas of regional Queensland were not included in the plans at all (so if the rationale for the change was to ensure greater access to services closer to home, even that didn't seem to be met).

More Comprehensive ECRG Report Accessed via RTI

Although efforts were continually made by Barrett parents to access the full ECRG report, it was never made available. However, when the ABC News division applied for documentation on the Barrett Centre closure through Right to Information, an RTI Release version was finally provided and made public on 7 November 2014 (see Appendix 7). The greater detail in the report only served to underline the vital need for an inpatient extended treatment and rehabilitation service component with an onsite school as well as the necessity to prioritise the needs of current and 'wait list' consumers of BAC and their families/carers stating that "*'wrap-around care' for each individual will be essential*" – key recommendations not undertaken, with the results by that time already tragically evident in the In reactions that only serve to add to the distress of the Barrett community, however, representations by those operating under the previous state government and by the now Opposition Leader Lawrence Springborg and Shadow Health Minister Mark

now Opposition Leader Lawrence Springborg and Shadow Health Minister Mark McArdle still continually state that all 7 recommendations of the ECRG were accepted and that the services offered and planned are contemporary options endorsed by experts. If a statement from Sharon Kelly, Executive Director, Mental Health and Specalised Services, WMHHS is true, then the responsibility for the service provision to the Barrett community – or lack thereof – lies with a number of government departments and agencies i.e.

The West Moreton Hospital and Health Board considered the documentation put forward by the Planning Group in May 2013 and all seven recommendations made by the Expert Clinical Reference Group (ECRG) with the additional comments from the planning group were accepted. Further key stakeholder consultation was then conducted with the Department of Health, the Queensland Mental Health Commissioner, the Department of Education Training and Employment, and Children's Health Queensland.

Sharon Kelly, 7 August 2013, to Alison Earls, copied to Lesley Dwyer and the Queensland Mental Health Commission

3) THE TIMELINE OF THE CLOSURE AND TRANSITION OF PATIENTS

The official announcement on the evening of 6 August 2013 of impending closure gave an "early 2014" deadline. As Lawrence Springborg was announcing this decision on ABC Radio, the parents/carers of Barrett patients were receiving phone calls from representatives of the WMHHS. Many Barrett parents were told that evening that the Centre would close by January 2014. It has never been explained why this timeframe existed and when some aspects of the closure were examined by an external review in October 2014 (see Appendix 12), it was found that "the closure date set an artificial/administrative deadline for transition". Even now, an active page on the Queensland Health website with a summary posted on the Barrett Centre in November 2014 states:

A taskforce was then formed incorporating members from the Department of Health, the West Moreton Hospital and Health Service and the Queensland Children's Hospital to transition BAC patients to more appropriate and clinically supported models of care. **The best deadline for this to occur was considered to be January 2014, as the Centre**

always closed during the Christmas holiday period so it was not sensible to re-open in the New Year for it to close shortly thereafter.

http://health.qld.gov.au/news-alerts/news/141118-barrett-centre.asp

If the needs of the patients and families were to be the priority as per ECRG recommendations, then surely the progress and readiness of individual patients as well as the availability of appropriate replacement services should have dictated the time of the closure of the Barrett Centre. While the wellbeing of patients was frequently stressed as important in public communication from the Minister and others throughout Queensland Health ... *e.g.*

our goal in West Moreton Hospital and Health Service continues to be to ensure that adolescents requiring mental health extended treatment and rehabilitation will receive the most appropriate care for their individual needs – Sharon Kelly, 7 August

Children's Health Queensland will provide the leadership for a new model for adolescent services. In the meantime the Barrett Adolescent Centre will continue to provide services until this model is operational. – Dr Mary Corbett, WMHHS Board Chair, 9 August

(More similar statements in Appendix 13.)

... there was never any indication through any action related to the closure that the timing was linked to patient readiness for transition. This was despite a direct assurance from the Chief Executive of West Moreton HHS when the closure was announced that the Barrett Centre would remain open until there was <u>a new agreed</u> model of care in operation and that transition plans for patients would be organised by careful and thorough collaboration between all stakeholders. i.e.

(In response to the question "Is there, or will there be, a timeline so that staff, patients and parents can essentially know what's going to happen to them and know how they'll be adjusted into the new model?') Look, we've been talking about early in 2014 but what I will say is we will continue to operate Barrett until at such time there is an agreed model and those models are up and running and that the transition plans for our current adolescents have been agreed with by their treating clinicians, the adolescent themselves and their carer and families. – Lesley Dwyer, 8 August, Radio 4ZZZ

However, in the weeks and months following the announcement, the processes underway for transition gave rise to serious concerns that that commitment was not going to be met. So when a concerned raised the issue of patient readiness with Lesley Dwyer, Sharon Kelly and Dr Stephen Stathis at the

meeting (details in Appendix 5) and it was confirmed that there was no flexibility in the early/January 2014 deadline, there was undisputable cause for alarm. The concerns were recorded in documentation presented to WMHHS, CHQ and the Health Minister on that day and also at the meeting with the Queensland Mental Health Commissioner on 11 September 2013 (also in App 5), where the key government agencies were asked directly:

Have there been rushed decisions and if so, why? Is the early 2014 deadline realistic? And perhaps most importantly, is there an option for the 'early 2014' closure to be delayed to allow the best solution to be worked out or is that decision irreversible? And if it cannot be changed, how can adequate facilities be developed within the next 5 months?

The implacability on the issue of the closure timing only served to cause more stress and induce more urgent warnings regarding the stability of patients and the increasing impossibility that appropriate transition processes would be able to be applied within the time allocated. However, although frequent well-founded concerns were raised between August 2013 and January 2014, every government response reaffirmed that the closure was set for early/January 2014 and would not be altered for any reason. Ironically, the regular reassurances regarding continuity of care and the availability of new services continued to be delivered – paradoxically alongside statements that indicated that readiness of replacement services would not align with the closure date. In the same seating of parliament (22 August 2013), in response to the Opposition Leader's tabling of the ECRG Report (and within minutes of each other), the following two statements were made:

... with regard to the expert panel and its recommendations and working with the Mental Health Commissioner, no decision will be made to close that facility until such time as we know that appropriate alternatives are in place, including alternatives which adequately ensure that young people with educational needs, as many of them are, can be supported in conjunction with Education Queensland. ... This is a decision which will be made some time in the early part of next year. ... I can assure the House that no-one will be disadvantaged by this decision. - Health Minister Lawrence Springborg

It is very clear that my department through the metropolitan region is establishing a working group to review and make recommendations on effective educational provisions to meet the needs of the new service model being investigated by Queensland Health. I am advised that Queensland Health advises that this model could take up to three years to develop and implement. – Education Minister John-PAUL Langbroek

So not only did contradictory statements cause confusion and uncertainty but the indication that new services would <u>not be available in time for the scheduled closure</u> generated significant anxiety in families of staff and further traumatised young sufferers of mental illness who were already dealing with severe levels of anguish and adversity. And as the date for closure moved closer, the fact that "*proposed*" service areas were still being revised in December 2013 when presented to parents as a <u>theoretical model that, even on paper, was only "*nearing completion*", operational services that would support young people with severe and complex issues were clearly a considerable way off, if they were ever to be made available at all.</u>

The impending lack of services, mixed messages and the pervading sense that any concerns or warnings from families, staff and the wider community were treated as irrelevant by all arms of government, though, were not the only factors in the ongoing destabilisation of the Barrett Community – a group of people for whom such uncertainty and the prospect of withdrawn treatment can have devastating consequences.

4) DETERIORATION AND TRAUMA AS A RESULT OF GOVERNMENT MISMANAGEMENT

Again, much evidence of the damage caused by the decision to close the Barrett Centre, the process of closure and the ensuing lack of adequate replacement services can be provided by many people beyond a bystander with no direct link to the Centre. I hope that these people will have the fortitude, support and opportunity to do so. In my experience, however, the very things that have led them to Barrett can also be the impediments that prevent them from speaking out on this issue. Young people and their families burdened by severe and complex mental health issues are rarely in a position to do anything other than put all their energies into getting through the next minute. And devoted practitioners who are motivated to work in an area of significant challenge wish to remain in employment that will allow them to continue to offer the support that they know can make a difference – particularly when there are few with a true understanding of the effective treatment and education strategies and the patients who have reached this depth of suffering will only begin to make progress when there is trust and stability in therapeutic relationships (qualities that have been lacking in the journey that brought them to their lowest point). However, there are

The

some general points that I can raise for assessment as to whether they might merit further investigation.

DAMAGING ACTION/INACTION AND BROKEN PROMISES

At the time that plans for closure were leaked, the Health Minister publicly countered that a decision was still pending but he – and any other government representative contacted – would not rule out a closure. From that time onwards, the patients and staff felt that their treatment and employment may be terminated within weeks and this caused an undue amount of stress for all attendees of the Centre. This is evidenced by an online posting made around November 2013 at the website

www.patientopinion.org.au – a public forum for discussion on Australian health services – by a Barrett Centre words

clearly describe the situation that has been recounted to me in numerous ways from other patients and staff.

It should be noted that it is very possible that

circumstances described align with However, even without direct identification, the posting is an indictment of the process of the closure as the negative effect it was having on patients and staff is clearly illustrated. The emails I received from one patient who made contact through the online petition also reflect the turbulent experience endured by patients. (See 'Unsolicited Emails ..." in Appendix 3.)

Once the closure was formally announced, the assertions that the timeline would be according to availability of new services and patient readiness to complete transition led only to greater uncertainty because the actions taking place in relation to Centre operations were in direct contraction of public statements. While the public heard the following:

Mr Springborg last month said no patients would be moved from the Barrett Centre until options were prepared for parents in early 2014. *"We expect to have the options available to people in early 2014 and the transition will start in the early part of 2014, as we build up services in the other parts of the state,"* he said. – reportage by Tony Moore, Brisbane Times, 12 September, 2014 http://www.brisbanetimes.com.au/queensland/centres-future-must-be-assured-opposition-20130912-2tn7c.html

... patients and parents were already experiencing decreased services and staff numbers amidst an atmosphere of pressure to meet a deadline.

Throughout the period between November 2012 and January 2014, along with the ongoing uncertainty, additional events placed even greater stress on the Barrett community, the most significant of these being the removal of Dr Trevor Sadler as Director of the Centre and the primary psychiatrist for a number of the patients. His absence and replacement with an unfamiliar clinician would have been seriously destabilising in itself. However, the process by which this occurred caused even more distress that could have been easily avoided. The events, from my experience and from information publicly accessible, transpired as follows:

<u>10 September 2013</u>: The Health Minister met with the Queensland Mental Health Commissioner, Dr Lesley van Schoubroeck.

<u>10 September 2013</u>: I was contacted by Dr Schoubroeck in the afternoon requesting that a meeting suggested by her and organised weeks prior be postponed. As the

of a Barrett patient who was scheduled to attend was uncontactable – already in transit from – Dr van Schoubroeck agreed to proceed

with the meeting but warned that names of all



Minister for Health

Date of Meeting	Name of Organisation/Person	Purpose of Meeting
10 September 2013	Lesley van Schoubroeck, Mental Health Commissioner, Date Shuttleworth, MP, Ministerial staff) Mental health issues
10 September 2013	Lesley van Schoubroeck, Mental Health Commissioner, Departmental and Ministerial staff	Regular gèneral diseussiens regarding mentat health

Note: These were the only meetings listed for Dr van Schoubroeck on Mr Springborg's diary during September.

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attendees would be passed on to the government. (Full detail in Appendix 5.)

10 September 2013: The carers of each Barrett patient were phoned that evening to

by the WMHHS representatives who spoke to parents). Parents/carers were in turmoil as they were unsure as to what could have caused Dr Sadler's removal and were deeply concerned for the welfare of the young people who had very positive connections with him as their treating clinician. They were informed that patients had been informed that Dr Sadler was on leave.

<u>11 September 2013</u>: The Mental Health Commissioner met with a

and me (with two Barrett education staff withdrawing because of apprehension – in lieu of Dr Sadler's removal – over the warnings of their names being reported to the government). When concerns were immediately raised with Dr van Schoubroeck about Dr Sadler's removal and the impact on patients, Dr van Schoubroeck indicated that she could not discuss the matter though she was aware of it and could confirm that the actions were necessary, but she said that she would pass on the concerns of the families. The were openly distressed about the impending closure and the frequent disruptive actions from WMHHS officials and above and they stated plainly that the histories of their young people and others that they had come to know well meant that there was genuine risk of suicide.

<u>12 September 2013</u>: The Health Minister, Lawrence Springborg, made the following statement on the floor of Queensland Parliament:

Following this, multiple news outlets ran stories, some of which misinterpreted the ambiguity of the Minister's words to allude to a possibility that the senior staff member stood aside was *involved* in the rather than questioned over governance issues of reporting incidents that had occurred between

Before these media reports were withdrawn when the outlets were made aware of the error, Barrett patients – at the Centre and on leave visiting family – had the opportunity to read them as well as other more accurate reportage of the removal of their Director and primary clinician. Many contacted their families/friends in considerable distress.

Representatives of a number of media outlets arrived at the Wacol site to gather imagery and information to enable them to provide more coverage. This caused further trauma to patients and staff and careful strategies had to be employed to ensure patient safety.

There can be no question as to the impact that this had on a community of people already under almost unbearable stress, to say nothing of the damage to the reputation of Dr Sadler, who I am sure records will show,

Dr Sadler's history and character continue to place him in the minds of his colleagues, patients and families as a man of great integrity and compassion. As a result, many parents expressed concerns about the genuine reason for his removal and the very public and ambiguously worded announcement thereof. Realistically, it is unlikely that there will ever be certainty on the motivation behind this chapter in the closure of the Barrett Centre. However, I believe that it should be considered as representative of the roles and behaviour of many parties directly connected to this issue and is worthy of consideration in this context.

It's important to note that although a looming deadline following months of uncertainty caused great anxiety, the damage already inflicted was compounded when plans for the transition of patients became the centre of more turbulence. Not only will most families be in a position to recount incidents relating to accelerated relocation to home or other care situations as well as lack of understanding of individual need requiring carer intervention etc. but a new divide between staff answerable to Queensland Health and those employed by Education Queensland appeared and grew. Prior to the threat of closure, one of the unique qualities of Barrett was the seamless collaboration of the multidisciplinary team. However, once the possibility of employment termination hung over Queensland Health employees, warnings about their interaction with teaching staff creating a threatening work environment which was not only challenging for all staff but had ramifications for the patients. Staff numbers decreased significantly and services were reduced. Continuity of care was dramatically affected by continual changes in personnel - something that is particularly disruptive with patients for whom stability and trust through familiarity are essential. And through it all, patients, families, staff and the wider community did all they could to make the increased risk and deterioration of patients' health known. And because all efforts went unheeded, feelings of abandonment were ominously compounded.

Ultimately, the most obvious and momentous impact from the process of the closure came as a result of the fact that there were not appropriate services for patients to transition to.

treatment and therapeutic access that they needed to ensure their safety and have any chance of progress, these young people – whose illness and resultant isolation had suspended important aspects of their social and emotional development and whose turbulent histories had never given them opportunities to have knowledge or skill in domestic duties, let alone sole responsibility for their daily needs – were expected to clean, cook and, in some cases, shop for themselves with all the obligations of an adult living alone. This would have been challenging for any 17 year old. But for those who had the emotional maturity of young children, it was unfathomably dangerous.

I know of no patient or family who has felt that their treatment or support services post-Barrett were adequate – but I have not had contact with or knowledge of every family. All of those that I know or know of, however, will indicate that what transpired during and following transition was detrimental to the young people and to themselves and that no adolescent was even able to consolidate the progress they had made at the Barrett Centre. The staff I know have communicated that to me as well. So, it is my contention that most, if not all, the patients suffered regression. It is a fact that

and several remain at risk of following their friends. And from what I've seen and heard since April 2014, I honestly believe that no person for whom Barrett meant something will ever truly recover from the damage that these losses have wrought. Families and communities have genuinely been devastated. And devoted teaching and healthcare staff have been left to struggle through bereavement, stress and abandonment of their own. (One of the teaching staff told me that, having had to take stress leave after ensuring that the students were as stable as could be managed following the

And this is particularly devastating when the relationships – developed through carefully structured learning experiences that are intrinsically informed by mental illness, turbulent pasts, true compassion, and dedicated patience – have a depth and intensity that even many therapeutic relationships don't.)

The information I have gathered – both theoretically and anecdotally since November 2012 – paints a picture where the duty of care to patients (consumers) and families (carers) was not simply neglected by a number of government officials and agencies but abused. And the obligations of an employer to vouchsafe the wellbeing of employees and of a service provider to ensure the best service possible have been similarly denigrated. Nothing can restore the lives lost or the permanent damage done to the psyches, emotions and health of many. But it is sincerely hoped that an inquiry will provide an opportunity for those who were not listened to to finally be heard and for those who refused to heed warnings to be shown to be responsible in some way for the avoidable harm that has been inflicted. Above all, though, it is vital that those who come to provide future services will utilise the knowledge and skills of true experts in any field of service provision – from dedicated professional staff with extensive backgrounds and contemporary practice in the specific area and from those with lived experience who have encountered programs, practitioners and environments that are both effective and ineffective. When few people understand, those that do must be the guides for those with the power and responsibility to provide assistance.

LACK OF UNDERSTANDING OF THE COHORT AND REQUIRED TREATMENT

One of the more significant problems encountered in the provision of services for this particular group – those affected by severe and complex adolescent mental health issues – is the obvious lack of understanding of who they are, what they deal with and what must be provided in order that they are given the best chance of improvement in their health and circumstances.

Conflicting comments from key government officials gave an indication that there was either a failure to comprehend the aspects of service provision or a selective use of information to justify decisions e.g.

"A spokesman for Health Minister Lawrence Springborg said the **average occupancy rate at the Barrett Centre was 43% of 15 beds**." – Queensland Times, 5 December 2012

"Well, basically what we have – the Barrett Youth Mental Health facility at the moment that has 15 beds. They're not always completely occupied. There's been times in the past where they haven't been ..." – Lawrence Springborg, 612 ABC Radio, 6 August 2013

"Certainly I have been approached by parents of adolescents using the facility, of adolescents who have used the facility and parents on the **waiting list** to use the facility." – Lesley Dwyer, Brisbane Times, 20 November 2012

"That's the whole point of this to leave no one who is currently a patient or resident there and those that are hopefully, you know, **on the list** so that they can have services closer to their own home..." – Lawrence Springborg, 612 ABC Radio, 6 August 2013

So, even those at the highest levels of the Health Department and WMHHS knew that there was an ongoing demand for the services of the Barrett Centre but, as mentioned earlier, still proliferated one of the reasons for its closure as the sub-50% occupancy statistic. The error in the application of adult metrics to this patient centred, flexible service aiming to transition patients back into the community compounds the perspective that the treatment offered by the Barrett Centre and required by this cohort is misunderstood by those who have a responsibility to have comprehensive understanding in this area.

But perhaps even more troubling is the lack of understanding for the young people themselves. Adolescents suffering severe and complex mental health issues are a unique group from whom methods and approaches that have proven effective with linked groups cannot simply be extrapolated or slightly adjusted. Treatment that is effective with severely afflicted adults is inappropriate for this group. Techniques that work with young children are equally unsuitable. Even young people who suffer from depression and for whom Headspace and fortnightly therapy achieve progress are very different from adolescents with ~

various combinations of developmental trauma, major psychiatric disorders and multiple comorbidities, high and fluctuating risk to self, major and pervasive functional disability, unstable accommodation options, learning disabilities, barriers to education and training, drug and alcohol misuse. –Beth Kotzé & Tania Skippen, 30 October 2014

As the investigators charged by the former Director General of Queensland Health to examine aspects of the closure/transition went on to state, "*this was a cohort in the main characterised by high, complex and enduring clinical and support needs.*"

When there are multiple challenges co-existing within one individual, the resultant behaviors, symptoms and outcomes are a unique concoction. Not simply a more extreme version of a sufferer of a clear single issue. And, at a basic level, it seems that this is one of the main characteristics that many within government have failed to understand.

This is clearly evidenced in a University of Queensland research report (selected pages in Appendix 13) where lack of understanding of the characteristics of the severe and complex adolescent cohort <u>even at the Senior Executive level of Queensland Health</u> is blatantly demonstrated. On 4 December 2012, a Senior Executive of Queensland Health – possibly with significant responsibility in the provision of mental healthcare services – gave information that led to the following published statement: *"Barrett Adolescent Service at Wolston Park is a long stay unit for troubled young people – with bad behaviour more than highly disturbed. It is going to be closed but it is not clear how it will be replaced."*

This reveals a critical ignorance of the severe and complex mental health issues of the Barrett Centre's patients. And in addition, despite public statements to the contrary at that time and until August 2013 stressing that there was no plan to close the centre and that the ECRG recommendations would determine the future of appropriate service provision, it appears to indicate that **Queensland Health continued to plan the closure even after** the November 2012 leak and denial. This would call into question any stated commitment to advice from the ECRG as well as compliance with policies of community engagement and consumer/carer collaboration.

In addition, the fact that the Queensland Mental Health Commissioner also fails categorically to comprehend the nature of severe and complex mental health issues in young people is extremely troubling. Even after having the Barrett community provide her with information and personal stories that include young people dealing with combinations of chronic depression, severe anxiety, diagnosed psychosis, Autistic Spectrum Disorder, poor impulse control, long-term social withdrawal, paranoia and feelings of self-loathing, Post Traumatic Stress disorder, ongoing incidents of self-harm, backgrounds of domestic turmoil or abuse, Eating Disorders, suicide attempts from an early age, Receptive Language Disorder, substance abuse, intense mood swings from infancy, Oppositional Defiant disorder, multiple learning difficulties, years of school refusal ... etc., the Mental Health Commissioner still responded to the question as to whether the Barrett Centre should have closed by saying:

You want young people to live as close to home as possible so as their mental illness is treated, they stay connected with family, with school, with their sporting friends, they watch telly with their mates on the weekend when they can – it's absolutely the right direction. ... you'll still have those intensive centres where people, young people can go for that short period of time when they are really ill but that absolute urge to get them home as soon as you can so they can have treatment at home or in a local centre is, has to be the only way you can go so those young people can look back when they're 30 and 40 and go 'yes, I am reconnected, I've been to school, I've been to uni, I've got a job'.

Lesley van Schoubroeck, ABC's 7:30 Report, 8 August 2014

Many young people suffering severe and complex mental health issues cannot leave their bedrooms, some have never had a friend in their lives, others are crippled by trauma or nightmarish thoughts or fear and anxiety so intense as to induce vomiting. These are not young people who have "sporting friends" or who "watch telly with their mates on the weekend". These are not adolescents who have "that short period of time when they are really ill". Their behaviour has been severely compromised for years often since infancy, their thoughts and emotions can be so impaired that contact with external reality has been lost. And if these young people don't receive the right treatment, many will never reach 30 or 40 – and those that do will not be able to look back on *school, uni* or *a job* but long periods of just trying to get through days and nights in the purgatory of their own minds. For someone in the role of Mental Health Commissioner – who has had people with lived experience explain the torture of severe and complex adolescent mental health issues – make these remarks publicly is akin to a senior representative of the Kidney Foundation denying the existence of end-stage kidney disease and suggesting oral medication is the right direction while approving of the termination of any access to treatment by dialysis or transplant.

To suffer with the severity and implications of the issues that the Barrett cohort and their families are faced with can be overwhelming. To have that suffering denied and the only treatment option withdrawn by those responsible for service provision can – and has – led to genuine despair.

5) LACK OF COMMUNICATION WITH KEY STAKEHOLDERS ABOUT THE CLOSURE AND TRANSITION DESPITE BEST EFFORTS OF THESE GROUPS TO PROVIDE INPUT

Despite repeated requests for meetings with the Health Minister and Director General, frequent phone calls and emails to the West Moreton HHS Executive and Board and specific concerns raised directly with Barrett staff (who were powerless to do anything outside the parameters of operation that they had been given by the aforementioned officials), the serious concerns of families and the courageous pleas of the young people themselves remained largely ignored from November 2012 until the change of government in February 2015. During the meeting with WMHHS and CHQ representatives on 30 August 2013 (detailed in Appendix 5), Lesley Dwyer and Sharon Kelly made a commitment to improve communication with families, acknowledging that it had been seriously lacking. This led to the addition of some email updates (though, possibly through administrative error, not all parents received these) to the already employed online factsheets (see Appendix 6). However the content of both unfortunately remained in the form of the broad statements being made by the Health Minister and others e.g.

No decisions will be made until all options for statewide model of care have been investigated by the expert clinical reference group - Fast Facts 4, March 2013

Following through with our commitment to ensure there is no gap to service delivery, West Moreton HHS will work with other service partners to provide transitional services for current BAC consumers and other eligible adolescents while the future services are being finalised. – Fast Facts 10, November 2013

Sweeping declarations are grossly inadequate when specifics on plans/dates/treatment programs etc. are required to assure the welfare of high-risk patients. But no details were provided through any public medium or carer group communication and there was no regular forum for individual case queries to be raised. When proactive parents pushed for answers, generalised reassurances were given with little recognition for the very real warnings regarding patient safety. In fact, a number of carers were made to feel as if they were overreacting or being unreasonable when, of all people in the community, these families have experienced so much that is extreme and, to many, unimaginable that they often have low expectations and a heightened tolerance for adversity. So when they indicate that a situation is of deep concern, their profound understanding of their own child's health and behaviour should warrant extra attention – not total disregard or even empty platitudes or a polite rebuff.

One or two parents who made the time and put in a great deal of effort continued to monitor things as best as they could – querying the absence of regular services (as staff numbers reduced, access to various therapeutic options e.g. psychology diminished) and future options. Were it not for the proactive approach and determination of someone like - a parent who has done as much as possible to represent the needs of all the families – I believe there would have been considerably less support for patients and families over the final year of operation of pushed for a holiday program when it was clearly not going to the Barrett Centre. be provided (without any advance notice) contacted WMHHS when situations for individual young people or several families were reaching crisis point and requested information when, too often, none was forthcoming. And without the insistence of the parents themselves, they would not have even had 30 minutes to present their case to the SW AETRS. To have been put in the position of having to repeatedly beg to be heard on vital issues or push for fundamental service provision things that should have been offered as a matter of course - is a burden that these

families should not have had to bear. The fact that the support that was provided was so insubstantial even after parents' desperate efforts would seem to fall far below the basic responsibilities that Queensland Health services are required to meet. The families themselves will obviously provide the best evidence in this regard but the accounts of meetings that I attended with families (Appendix 5) and statements by family members via the media and other public forums (Appendix 3 contains examples, including mp3 files of radio interviews) are included in this submission should they be useful.

It may also be of value to the Inquiry to note that, following the closure, there was minimal continuity of care from Queensland Health in relation to follow-up to determine if the new treatment options were adequate or how patients had coped / were coping with the transition. There was no ongoing support strategy, no appointed Queensland Health liaison for families to communicate with once the Wacol site was closed and absolutely no contact with former Barrett families when any of

When any group of mental health patients suffer the shock of the unexpected bereavement, it would seem standard practice to enquire as to their welfare. But considering that this was a group of teenagers between whom deep bonds have been formed as a result of years of social isolation and the impact of shared life-threatening health issues, even to a layperson it's clear that some kind of contact from the body charged with the provision of healthcare would be a rudimentary procedure. However, when there was no communication whatsoever from Queensland Health, let alone provision of grief counselling for adolescents, families, or the dedicated education staff, when a former Barrett therapist who has moved into the private sector volunteered her time to visit the school to hold a counselling session with students who wished to participate, I have heard anecdotally that she was subsequently threatened with de-regulation. If this is true, the operations of Queensland Health need serious examination.

6) QUEENSLAND MENTAL HEALTH COMMISSION – NOT AN INDEPENDENT BODY AND UNABLE TO ADVOCATE FOR THOSE AFFECTED BY THE BARRETT CENTRE CLOSURE

Throughout the period during which the Centre was under threat of closure, it has appeared that there is no one to advocate for these people, particularly within the oppressive environment of a time where funding cuts and public service employment reductions threatened. However, when the Queensland Mental Health Commission was established on 1 July 2013 and Dr Lesley van Schoubroeck took on the role of the inaugural commissioner, the Barrett community had hopes that the gravity of their circumstances might finally be represented to the government in terms that would elicit an appropriate modification to the closure and transition plans. This was not to be, unfortunately.

Initial concerns about the Commission's ability to make an impact came when the closure was announced. It did not seem logical that the government had come to a final decision on the termination of a service that was unavailable anywhere else in the state when the Commission's remit was to "prepare a whole-of-government strategic plan" for mental health service provision (*Queensland Mental Health Commission Act 2013 - Act No. 7 of 2013*) informed by input from the Queensland Mental Health and Drug Advisory Council (QMHDAC), positions on which were only advertised on the 20th of August 2013 with applications to close on the 30th of September. In addition, Dr van Schoubroeck had a pre-existing obligation for the month of August so was only available for a short period in July before resuming her role again in September. So how could a decision on the termination of a vital mental

health service be made before the Commissioner or the Council could provide input? Was the development of a future Statewide Adolescent Extended Treatment & Rehabilitation Plan not something that the Commission and the Council should have been intrinsically involved with? The QMHDAC's responsibility is to:

- drive reform to improve the mental health and wellbeing of all Queenslanders
- provide advice and guidance on mental health and substance misuse issues
- make recommendations about how the Commission fulfils its functions.

It will act as a champion for people living with mental health issues and/or substance misuse as well as their families, carers and support people and also seek out professional expertise. Consultation and liaison with community, government and industry will inform advice provided to the Commission. – <u>http://www.qmhc.qld.gov.au/qmhdac/</u>

So fears that a premature decision had been made following the 6 August closure announcement seemed not without foundation.

In addition, the legislation to set up the Commission seems to indicate that the new entity is not the independent body that is in operation in other states i.e.

			Quaensland M Part 2 Queans					
[s 8]								[8 12]
Div	ision	1	Establishment		13	Mir	niste	rial direction
9	Commissior		ssion represents the State	((1)		The commissioner is subject to the directions of the Minist n performing the commissioner's functions under this Act.	
-	(1)	1) The commission represents the State.				(2)		commissioner must comply with a direction given by the uster.
	(2)		miting subsection (1), the commission h ileges and immunities of the State.	as the		(3)	The	commission must include in its annual report details of—
Page	10		2013 A	ct No. 7			(a)	any direction given by the Minister under subsection (1) during the financial year to which the report relates; and
							(b)	action taken by the commissioner as a result of the direction.
					2013 A	ct No. 1	7	Page 13

Indeed, the Advisory Council also appears to be under the direction of the Minister of the day and the Commissioner (who is "*subject to the directions of the Minister*") i.e.

		Queensland Me Part 5 Queensland Mental H				
		[\$39]			[\$42]	
Divisi	ion 2	Membership	Div	ision	3 Conduct of business by council	
			42	Co	Conduct of business by council	
		hip ouncil consists of the number of persons appointed by inister that the Minister considers appropriate.		(1)	The council may conduct its business, including its meetings, in the way the chairperson of the council considers appropriate.	
2013 Act No. 7		Page 23		(2)	However, the chairperson must consult with the commissioner before deciding the way the council is to conduct its meetings.	
20101011017	110.7	. 1 890 20		(3)	The Minister may direct the council about the conduct of its business, including its meetings.	
				(4)	The commissioner is to attend all meetings of the council, unless excused by the chairperson.	
			2013	Act No. 1	7 Page 25	

So, how can either the Commission or the Advisory Council freely advocate to the Health Minister on behalf of those affected by mental health issues if they are directly answerable to that same Health Minister? Independence from government would seem to be an essential principle of a Mental Health Commission that is to successfully "bring together experience and professional expertise by partnering with the community, government, and industry across a range of areas" and through these partnerships, "find solutions and guide action to improve the systems that support people with, or at higher risk of, mental illness or substance misuse, as well as their families, carers, support persons, and the Queensland community." The people in need of representation to high levels of government/industry are those that find themselves outside the sphere of influence – powerless or vulnerable. A conduit *from* government *to* those people that simply reiterates the government position would seem of considerably less value than an independent liaison with an understanding of the sector and of community concerns that could bring parties together to achieve the best objectives through true collaboration.

Both the issues of QMHC/QMHDAC involvement in decisions regarding adolescent mental healthcare and the independence of those entities were raised frequently between August 2013 and January 2014 (see Appendix 5) with no response forthcoming from any government representative.

But beyond those concerns, the Barrett community still made considerable efforts to appeal to the Mental Health Commissioner for advocacy regarding the closure - in all aspects regarding timing, the transition process and replacement services. A detailed account is included in Appendix 5, the summation of which would be that Dr van Schoubroeck did not see herself in a position to do anything other than pass on family/carer concerns to Queensland Health and the Minister. She had not read the ECRG report (or the summary that had been released on 7 August 2013) by the 11 September meeting with Barrett representatives (although she had known of the report's existence since July (as indicated in the Hansard excerpt from Health Estimates on 24 July 2013 in Appendix 13) so could not discuss the recommendations made therein. And with the removal of Dr Sadler the day before causing families to fear for the already deeply distressed young people, her response to carers' pleas for assistance in negotiating for more time before the closure to allow for the readiness of replacement services and a proper transition process left little doubt that she would not undertake to assist with advocacy or support. If this is not the role of the Commissioner, then who can legitimise the input of patients, carers and wider community when it has been so unequivocally disregarded by government?

A body that represents government to the public but not vice versa is undertaking a role that can be fulfilled by those already in the employment of the public service – perhaps better, as representatives of departments have a greater depth of knowledge about specific services or programs. But an independent body that can facilitate collaboration and objectively elicit the best input of all stakeholders would be of significant value, an asset that has seemed to be lacking throughout the Barrett Centre closure.

When the realisation that this support did not exist with the QMHC, this was, for many Barrett families, confirmation that they truly had nowhere to turn.

7) NON-GOVERNMENT AGENCIES AND GROUPS WITH MENTAL HEALTH FOCUS

From November 2012, Barrett families and community advocates contacted a number of non-government agencies, some of whom sympathised but who could do nothing public for fear of jeopardising their funding; others who communicated the situation to their membership to allow individuals to take action should they choose to do so; and others who indicated that it was not in their mandate or capacity to advocate for maintaining or changing services. (See examples from Queensland Voice for Mental Health Inc, Queensland Alliance for Mental Health, etc. in Appendix 14.) Approaches were made to the Queensland branch of the Australian Medical Association, at that time headed by Dr Christian Rowan, who went on to run as an LNP candidate in 2015 state election, winning the seat of Moggill and to the Commission for Children, Young People and Child Guardian which ceased operation on 30 June 2014. Contact was also made with federal politicians and agencies operating at a national level but, understandably, responses indicated that *"the responsibility for the provision of acute mental health services, including those for young people, remains with the state and* *territory governments.*" (Jodie Thornton, Acting Director, Headspace and School-based Program Section, Dept, Health and Ageing – App 14.)

So, although some indicated sympathy and understanding, there was no group in a position to support the Barrett community in their efforts to have their concerns recognised and adequately responded to.

8) HEALTH DEPARTMENT DIRECTOR GENERAL'S REPORT INTO CLOSURE – WHAT WAS ITS PURPOSE WITH SUCH NARROW PARAMETERS?

Externally, it's not possible to know what prompted the then Director-General of Queensland Health, Ian Maynard, to order a report on the closure of the Barrett Centre in August 2014. The may have been the stimulus, the widespread media coverage that highlighted the tragedies or the calls for a Commission of Inquiry (including an online petition at http://www.abc.net.au/news/2014-08-08/parents-plead-for-re-think-on-adolescent-mental/5659678) may have been contributing factors. Whatever the motivation, the Director-General authorised a report in mid-August 2014 and a redacted summary version was made public on 5 November when ABC radio presenter, Rebecca Levingston, was given early access (prior to Barrett parents or anyone within the Barrett Community) and the opportunity to interview one of the professionals charged with investigating and reporting findings as well as Queensland Health representatives. In the 5 November interview, Dr Beth Kotzé, the co-author of the report, herself indicated the limitations of the investigation when she said "We did not look at the clinical decision-making and care post-transition." Kotzé and Skippen document further restrictions in the report itself i.e.

"Noting that transition is a process in which the communication and negotiations between the referring and receiving services are critical, this investigation was limited to review of the available documentation and interviews with key clinicians from BAC. Staff of receiving services were not interviewed and limited documentation was available from these services. Education Department staff associated with BAC were also not interviewed."

And in the ABC radio interview Dr Dr Kotzé also clarified that no patients or carers/parents been consulted in investigations. (Further detail on the report is in Appendix 12.)

So the parameters of the report would seem somewhat inadequate if the objective was to do anything other than report on the self-assessment of the Queensland Health employees responsible for the transition. This may raise more questions about Queensland Health and the motivations behind some of their practices, particularly in relation to the Barrett Centre and those affected by severe and complex adolescent mental health issues. Obviously, the Inquiry is the best process to determine if further examination is required.

9) INSIGHTS FROM THOSE AFFECTED

The young people who needed the Barrett Centre will always be a vital source of information on the closure. The fact that have had both the motivation and the opportunity to since they were moved on from the care that provided them with comprehensive support, security and opportunity sadly speaks volumes. Others will be unable to participate in an Inquiry as they are have again become crippled by their mental health issues and are severely restricted. Some are unable to leave their homes or the residential options that they exist within and others are hampered daily by extreme anxiety, depression and other debilitating symptoms. For so many, the struggle with their illness, their challenges, their circumstances and their histories requires energies they no longer have and the

conquest of hurdles too great to surmount. When not surrounded by daily expert support, just surviving another day is an accomplishment. All of these young people and their families are burdened by the ordeals they've already endured, the failures they've already experienced, the rejection and denial that has pushed them down repeatedly. So until the announcement of an Inquiry, I know it is accurate to say that many felt completely abandoned and almost totally hopeless.

It has taken a lot for some of them to speak out throughout the trauma of the closure. A few have been able to do so (links to media coverage and audio files in Appendix 3) but most are inhibited by their circumstances. The effort and courage of the carers and young people who have made contributions has been driven by pure desperation and, sadly, fuelled by grief.

But it is these people – the Barrett community ... parents, grandparents, teachers, nurses, therapists and particularly the young people themselves who have the truth about the impact of severe mental health issues on adolescents. About the treatment and support that can take despair to productive adult lives. And about the threat of closure of the centre that was their last chance to access that and the damage done by the process to make that closure a reality.

I hope that the Inquiry will hear some of their stories and give them a voice when they are able to speak, write or look back on their harrowing experiences. To provide them with some indication that they are worth listening to, that their experiences mean something is of great value. Because they have been made to feel just the opposite throughout the Barrett closure – on top of already feeling that they were lost causes in the eyes of the world before they arrived at the Wacol centre.

The adolescents have borne the brunt of more than two years of challenges added to those that already burdened them. But the families and the staff of the Centre too have suffered significantly – not only through seeing the young people they know and care for in decline. As people who have dedicated so much of their time and efforts to helping others, they deserve our best support – never the disdain and disregard that has been their punishment for caring for vulnerable teenagers. Parents have been made to feel unreasonable or melodramatic when they pressed for basic service provision for high-risk patients. Education and health staff have had their work environments reduced to a torturous place of intimidation and restriction (providing even greater challenges in providing a nurturing haven for their patients/students) and their dedication used to threaten their job security. That we have such people in our community committed to providing specialised support to these young people and their families is an asset – something we cannot spurn but should be nurturing, expanding and rewarding.

The crux of this to me, an outsider, is just that. We have people suffering severely and we have others with the skill, understanding and drive to alleviate that suffering. We must seize any opportunity to bring them together to achieve what's possible. To allow such potential to be lost will lead, as we've come to see, to genuine tragedy.

Other young people's mental health issues have become more difficult to manage, bringing increased anguish and burden to an already challenging daily existence for each individual – the young person and the significant people around them. And those still to be identified languish without the prospect of effective intervention and support. Nothing will rectify the most devastating damage that has been done – not only can three young lives not be restored but there are many scars too deep to ever heal. However, it is my hope, as I know it is that of those directly connected to the Barrett Centre, that this Inquiry will be the beginning of a new phase in the lives of this group of Queenslanders – the people who have suffered due to the loss of this vital service. That a time and opportunity has finally come when their experiences will be heard and validated, that they will be understood and supported and that their great achievements in the face of adversity will be acknowledged. And that they will be provided with what they need to ensure stability and to restore that potential for progress that has been buried since November 2012. And then, ultimately, that the foundation will be built for the provision of the best possible services for Queenslanders – now and in the future – who require/will require help with severe and complex adolescent mental health issues. Only if those goals are met, can we begin to counter the decline that was begun when the closure of the Barrett Centre became a possibility.

The time and energy spent by the Commission of Inquiry into the closure of the Barrett Centre will be invaluable and those affected and the broader community are extremely grateful to Justice Wilson and her team for their efforts in this regard, as well as to the current Queensland state government for instigating this procedure. It has long been said that we can judge a society by the way it treats its most vulnerable – it is hoped that the lessons that will be learned by the Barrett Inquiry will be ones that resonate to the extent that we can, in the future, be proud of Queensland for the heart it displays, the ethics that are at its foundation and the brainpower that it utilises for the benefit of many – in addition to the physical prowess and determination already celebrated in our sporting achievements.

Yours faithfully,

Alison Earls

cc: Dr Mark Lynch (Director, Research) Ms Catherine Muir (Counsel Assisting the Commissioner)