**Assessing the Need for RED HOUSE: Normative, Expressed, Comparative, and Felt Need**

An extensive needs assessment has been conducted for **RED HOUSE.** This includes detailed epidemiological data, statistical analysis and qualitative information, covering local, state, national and international levels.It also covers all 4 dimensions of need, being: normative need, expressed need, comparative need, and felt need. The full needs assessment is available on request. The following is an excerpt from the analysis of local (Brisbane-wide) Felt Needs. It includes invaluable anecdotal evidence from patients struggling within the current system.

**Local "Felt Needs" Assessment**

Felt needs were assessed through face-to-face consultation with consumers (both 1:1 interviews and group forums); individual psychiatrists, psychologists, and GPs with a special interest in eating disorders; staff and patients at New Farm Clinic; and entities belonging to the (QLD) State-wide Eating Disorders Network (RBWH, EDOS, EDA, Isis). All of these groups and individuals were in agreement that the current system of service delivery for eating disorders in QLD requires improvement. Importantly, there was a strongly perceived divide between the public and private sectors with regards to quality and accessibility of treatment. **RED HOUSE** will be instrumental in linking the two sectors, creating greater accessibility and equity.

Firstly, 5 women with chronic and intractable eating disorders, all of whom have struggled with an eating disorder for over 20 years, and all of whom receive outpatient psychiatric treatment, were conferred with separately. All of these women indicated a strong level of interest in the concept of **RED HOUSE** in terms of what they felt it could offer them, and its role in filling an imperative, though previously unidentified or ignored gap in treatment for eating disorders. These patients, and their psychiatrists, expressed frustration at the lack of appropriate treatment options available to chronic patients in particular. The vast majority of those who do not die of such chronic and intractable eating disorders either drop out of treatment altogether, or undergo decades of intensive outpatient psychiatric treatment without remission or recovery.

An in-depth Cochrane review (Hay, Bacaltchuk, Byrnes, Claudino, Ekmejian, & Yong, 2008) revealed that only 5 small trials specifically concerning adult cases have been conducted on the efficacy of outpatient psychotherapy. The study compared various forms of psychotherapy and while the authors found that subjects who received no treatment deteriorated, they found that for those who continued treatment there was no sufficient evidence to suggest that any particular form of out-patient therapy was more efficacious than another. Fairburn (2005) found similar results in his comparison of various psychotherapies, with none proving particularly effective for chronic anorexia. The 4 psychiatrists consulted for this needs analysis all agreed that a well planned, professionally run residential environment, where nutritional and behavioural rehabilitation is supported, would compliment and greatly enhance the psychiatric treatment that they were providing to these patients.

The responses of those suffering chronic eating disorders (all with anorexia nervosa binge-purge subtype) indicated that outpatient psychiatric treatment has not significantly improved their (subjective) quality-of-life, particularly in relation to feelings of isolation and loneliness, and their ability to control their disordered eating behaviours. All subjects expressed a desire for and more practical, day-to-day support in addition to their weekly or fortnightly outpatient appointments, especially since psychiatric outpatient treatment is designed to address the patient’s psycho-emotional issues, not food/eating related behavioural challenges. These patients had all endured more than 3 admissions to New Farm Clinic between 1992 and 2006, with length of stays ranging between 3 weeks and 7 months, and expressed that although it was of little benefit they felt desperate for help and had no other accommodative treatment option. Perhaps the most important point is that these subjects are still alive. This, as the above studies suggest, may be indicative that some form of therapy is better than none; however, it also suggests that outpatient therapy is not enough to enable these women to progress, and ultimately, recover. Just as a chronic alcoholic requires an environment that will not enable them to drink in order to overcome their illness, those with chronic eating disorders require an environment that will not enable engagement in their disorderly eating behaviours. While these two illnesses entail many differences, in both cases the sufferer must be removed from the environment in which the illness has control, until such time that they are strong enough to control the illness. **RED HOUSE** has been specially designed to provide such an environment.

**Results of Royal Brisbane & Women’s Hospital (RBWH) and New Farm Clinic Surveys**

Following a half-hour briefing about the concept, purpose, structure and operational model of **RED HOUSE**, patients from the RBWH and New Farm Clinic eating disorder units were surveyed. These two cohorts were selected due to the fact that these are the only two specialised eating disorder units in QLD, and **RED HOUSE** will operate specifically in conjunction with these two hospitals. Furthermore, with one unit being private and one being public, together they represent patients from both sectors. Since the primary objectives of **RED HOUSE** include shortening hospital stays and providing a more suitable alternative for chronic sufferers who have been ‘stuck’ in the “revolving door” of hospital for many years, these cohorts provide the best possible representation of patients that will be referred to **RED HOUSE**.

**NOTE:** During the collection of this data one participant sadly, and unnecessarily, lost her treacherous, long and hard fought battle against anorexia nervosa. This highlights the urgency for improved services. One life lost is one life too many.

**Quantitative Data Summary**

Quantitative data collected from the patients involved in the survey revealed most patients have had multiple lengthy admissions to hospital, indicating an inability to recover without multiple relapses under current hospital inpatient programs. All patients received outpatient and/or day-patient follow-up care upon discharge which also failed in preventing relapse for any of the participating patients. The high number of recurrent hospitalisations and/or duration of illness experienced by all of these patients indicate a chronic course, deeming them primary contenders for the **RED HOUSE** program.

**Qualitative Data**

The following qualitative data comprises written anecdotal responses, provided by the above patients, following a briefing on the concept of **RED HOUSE.** For reasons unexplained, private patients from New Farm Clinic were more open to providing information on their personal experiences than those from the RBWH.

**Patient 1 NFC:**

“There is a definite need for community-based support in the forms of residential treatment and day-patient programs following discharge from inpatient treatment (e.g. RED HOUSE). Since there are only 15 ED beds in QLD you have to be really underweight or cutting yourself badly to be accepted into an inpatient program. This just encourages people to get sicker and more self-destructive so they can get help. It would be so great to have a place to go that recognises that you can be really struggling even if you are not desperately underweight. This would prevent me from feeling like I had to get sicker and sicker just to get the help I need. I have had this illness for 25 years and hospital just doesn’t work for people like me. All they do is feed you up and send you back to the same old behaviours and problem-filled life. It’s not long before you then undo all that weight gain and end up back in hospital. It’s just a revolving door. I think RED HOUSE sounds awesome. It would benefit so many people like me. Why hasn’t the Government thought of this? I guess because it’s a mental health issue and we are always last on their priority list. We always get the dregs of the funding, and thus, the fewest service options and lowest quality care. It’s about time that changed”.

**Patient 2 NFC:**

“I live alone – I hide in the house – I cook heaps of food to binge on every single day - I do not let people into my house – I follow a strict routine – I hoard food – I can be as OCD as I want... When you have an eating disorder for a number of years the current hospital treatment (e.g. gain 1kg per week until you reach a BMI of 20) DOES NOT WORK! No-one seems to understand. I would commit suicide if I was made to reach a BMI of 20... Every day I realise how much I’m wasting my life away, but no-one seems to understand that the smallest, seemingly insignificant change is mammoth to me. I want help to make lifestyle changes that can be done slowly, incorporated into my life to make it better, and maintained; not just to gain weight and go home to the same dysfunctional life.”

**Patient 3 NFC:**

“I definitely agree that there is an undeniable need for a transitional service like RED HOUSE in QLD. When treated in psych wards so much emphasis is placed on weight gain and eating just to reach weekly weight gain targets, and once you reach your healthy BMI you are sent back to ‘real life’ with little or no support during meal times and it is scary and overwhelming and so hard to keep up the same routine as in hospital. If there could be a more gradual transition as RED HOUSE proposes with its residential, 3-day/week and 1-day/week programs I believe the possibility of recovery would be much greater. This integrated transitional care is definitely needed.”

**Patient 4 NFC:**

“I live alone. Isolation supports the eating disorder to remain present in my life... RED HOUSE provides a fantastic step-down for adults to leave hospital and normalise eating and exercise patterns. When patients are discharged from hospital at a healthy weight and have not been allowed to exercise at all they need a formalised ‘return to home program’ and ‘living and eating skills program’. If a patient has reached a healthy weight in hospital they still need the support from [a place like] RED HOUSE to acquire these skills. Thank you.”

**Patient 5 NFC:**

“Living alone can be very difficult as I feel I have no accountability to anyone. My eating disorder has control 24/7 and there is no-one to curb behaviours. I do not see myself maintaining the weight gain or eating I have done in hospital when I go home”.

**Patient 3 RBWH:**

“It’s hard going back home after hospital because my eating disorder behaviours come back. I think RED HOUSE sounds great because sufferers need a place where they can overcome the behaviours rather than just gain weight like in hospital. It would be great to have a place where sufferers can trust people to help them because they want to be there. In hospital you are usually there because you are told you have to be, so you don’t really want help because all they want to do is make you gain weight and so you just learn new bad behaviours from others. Being taught how to maintain a happy lifestyle on your own before you go home would be great.”

**Patient 4 RBWH:**

“Home is a very hostile environment when I am very unwell. I can’t eat adequately, I have very little support and I spend a lot of time alone. I will definitely not be maintaining this eating and weight gain when I go home. When I am discharged from the hospital and I’m still not well enough to study or work and tend to get very isolated and bored and then I resort to my eating disorder behaviours in order to cope and then of course ending up back in hospital. A “halfway house” is a fantastic idea. I think it should include enjoyable social outings so people can start to have a more normal life. You start to forget that there is a life outside of hospital. I really hope this comes about as it’s a wonderful idea.

**Patient 5 RBWH:**

“RED HOUSE sounds like it would be really helpful. Having a daily routine with individual sessions and group activities would be excellent. Support in establishing a personal meal plan and feeling like you are not on your own with the eating disorder would also be great. Having this help in a less clinical environment than hospital would be a big advantage. It would help you have a more normal lifestyle while transitioning back to work or study. Hospital is an ideal environment for comparing yourself to others and competing to be the sickest. There is a competitive eating environment where no-one wants to eat more than anyone else and so you have poor role models at the table. In the past I attended outpatient treatment in Melbourne initially at ‘Footprints of Angels’ and then at ‘The Oak House’ but this was expensive and only available to people with higher incomes. There were also time constraints on the length of attendance so if you didn’t get better in that time you were left on your own to get sicker again. Plus, some counsellors were inexperienced and unqualified.

A separate group of women suffering from Anorexia Nervosa (some with binge-purge subtype), all of whom live in Brisbane, except Emma who lives in NZ, expressed their desperation regarding the inadequacy (access, quality, effectiveness) of current service provision for people with eating disorders. The following statements were posted on an eating disorder support group Facebook page and have been included here with the permission of each individual:

**Conversation from October 29, 2013 - Demonstrates the lack of accessibility to services, the continued breach of human rights, and the immense suffering and helplessness.**

**Danni:** “I can't stand this ED anymore. After being taken to hospital last week because of my safety and health I was told by the hospital I wasn't sick enough to be there because I'm not at a BMI of 14, and I didn't fit all their ‘criteria’… It's made things way worse now with the Eating Disorder… I just can't take it any more. I am so ashamed I just want to die… struggling and don't know what to do.”

**Emma:** “I understand you 100% and just two nights ago I had the same "I am so sick of this I'd rather be dead" breakdown, and then spend yesterday having crying fits. It’s hell… I was so upset, so sick of my stupid head. Basically Sunday evening was spent praying I wouldn't wake up the next morning. I don't really know how to help - just know that your [sic] not the only one who has days where they really feel they can't deal with it. Xx.”

**Fiona:** “Danni, I'm so sorry you are struggling so much. I’m angry on your behalf at the system that has failed again. It is crazy that we have to be a low enough weight/BMI to get help - it's like telling someone with a small cancer to come back when it has spread. I wish they gave you the support you needed… unfortunately I haven't found that magic wand I've been looking for for so long yet, but I can listen and I care. I do relate… it seems like every single day at some point, I find myself wishing I was dead, just to get this over with, because life with this Eating Disorder is so fricken [sic] endless and I can't take it any more.”

**Danni:** “thanks Fi. The system sucks big time, it's like they don't care and just want people to suffer and get sicker. Another friend of mine was sent to the hospital by the same doctor 3 times now and they just kept turning her away because she wasn’t “sick enough”. It's just appalling.

**Emma:** “Danni, I fully agree, the system is dangerously screwed up... it's nowhere near even minimally adequate.”

**Fiona:** “In addition to not having enough services and people missing out, I wish they would expose how cruel a lot if treatment can be. That’s got to change… it’s just damaging people further, not helping them.”

**Olivia:** “On the topic of hospitalisation - I think it is so ridiculous that a low, deathly weight is a requirement. Anyone should be able to have help available if they need it. It's the eating disorder habits that destroy people and ruin their lives, not the weight as such. People's state of mind shouldn't be judged by their body - that's not how it works with any other mental illness, so why should it with anorexia? If it's debilitating you, preventing you from "living", causing you nothing but utter torture, surely you should be allowed to get help? Or are we supposed to just put up with it, like we do?”

**Danni:** “It’s so true Liv. It's absolutely crap. I’m now too scared to go back the RBWH if my doctor sends me there because of them just sending me away last time. Leaving me to just talk to people over the phone and seclude myself. I've really had enough. I'm tired of it all. I don’t see a tomorrow.”