Item 12 b Appendix 1

Cambridgeshire County Council Health Committee

Personality disorder Community Service/Complex Cases Service including Lifeworks

Consultation Response

1. Background and Introduction

This document sets out the response of the Cambridgeshire County Council Health Committee to the Cambridgeshire and Peterborough NHS Foundation Trust (CPFT) consultation: 'Personality Disorder Community Service/Complex Cases Service, including Lifeworks'.

The issue first came to the attention of the Council's Adults Wellbeing and Health Overview and Scrutiny Committee (AWHOSC) following representations made in March 2014 to Councillor Kilian Bourke, Chairman of the Committee, by local campaigners and the MP for Cambridge,. Cllr Bourke met with Aidan Thomas, Chief Executive, and Chess Denman, Medical Director CPFT, to discuss the situation, and spoke with officers from the Cambridgeshire and Peterborough Clinical Commissioning Group (the CCG). He also met with service users to understand how they had been consulted on the planned closure. He subsequently requested that CPFT delay the closure of the Lifeworks service to enable consultation with service users to take place.

The AWHOSC discussed the proposals and the issues arising from the closure of Lifeworks at its meeting on 1st April 2014, at which representatives of the service users who were occupying Lifeworks put forward their concerns.

At that meeting, the CCG's Mental Health Lead, John Ellis, confirmed that the need to make savings was not a key driver for this closure: if more money were available, the CCG would still intend to decommission the Lifeworks service.

The Committee set up a working group which discussed the proposed consultation process and terms of reference with CPFT and with the CCG. The working group also facilitated a meeting between representatives of the Lifeworks service users and CPFT.

The Health Committee, which took over responsibility for scrutiny of the NHS from the AWHOSC in May 2014, discussed the emerging proposals and consultation arrangements at its meeting on 29th May 2014. It set up a new working group to ensure a fair consultation process and co-ordinate a response.

Healthwatch Cambridgeshire participated in the AWHOSC and Health Committee working groups.

During the consultation process CPFT and the service users reached an agreement to end the occupation of Lifeworks at Tenison Road on the condition that CPFT commit to keep the service at Tenison Road operational for five

years, using its own resources. CPFT was however very clear that the consultation paper still stands.

2. Approach

Because the clinical evidence was cited as the key driver of the changes to the service, the working group sought to examine the available evidence base.

To this end we obtained advice from the County Council's Public Health team, led by Public Health Consultant Emma de Zoete, who cross-referenced the Trust's proposed pathway with existing National Institute for Clinical Excellence (NICE) guidance (CG 78 & CG77).

We subsequently discussed the proposals in detail with CPFT officers, and asked for further information on a range of issues.

We met with service users to better understand their concerns and how these related to the guidance.

3. Findings regarding consultation

The consultation process prior to the proposed closure of Lifeworks was seriously deficient, and out of line with NICE guidance and DH commissioning guidance for this patient group, which is clear that comprehensive consultation over a long period of time is necessary. It is also cause for concern that CPFT seemed to have a very limited comprehension of its duty to consult with both service users and the Local Authority Health Scrutiny Committee, prior to the difficulties it encountered. This suggests a lack of familiarity with both clinical guidance and correct process.

Both the tables and the proposed service model provided as part of the consultation exercise were of limited value in the absence of additional information that was not provided in the consultation paper. It has required extensive additional questioning of CPFT staff about each of the interventions put forward to achieve even a partial overview of what was proposed.

Recommendation 1
We recommend that CPFT urgently review its ability to effectively consult with service users and stakeholders and to communicate clinical information effectively, and to work with the CCG from an early stage where public consultation is required.

It is concerning that despite requests from the Committee, and efforts from officers of the Trust, CPFT has not yet been able to produce a clearly articulated pathway diagram which sets out the different patient journeys and timescales from referral to discharge in a transparent and accurate fashion, which patients, staff, carers and agencies can understand.

There were also clear inconsistencies in the consultation document about the estimated number of patients that would have access to the 18-month Mentalisation Based Therapy (MBT) programme.

Recommendation 2
We recommend that CPFT produce a clear pathway diagram as a matter of urgency to provide clear expectations for all concerned.

Recommendation 3
We recommend that CPFT review and publish their estimates of the numbers of patients that would access the different interventions, particularly in relation to the MBT programme.

4. Service monitoring and review

Service monitoring and review is particularly important in view of the lack of clarity around the numbers of patients receiving the different types of support, and the precise service specification. The new service model should enable much greater transparency and recording of treatments on the pathway, and full use should be made of this by CPFT and the CCG.

A service review point should be agreed as part of the response to the public consultation. There is a need to monitor access times in particular alongside outcome measures, particularly in relation to the 12-week and the 18-month MBT programmes. It is also important to monitor re-referrals to the pathway and use of the crisis team in considering the effectiveness of the new PD service.

Recommendation 4
We recommend that CPFT and the CCG as service commissioners monitor the new service very closely in the coming years, and agree a clear service review point. The review should include access times and outcome measures, as well as re-referrals and the use of the crisis team.

We call for the CCG to request as part of its contract monitoring processes that CPFT keep the PD service under close ongoing review, and report on progress on a regular basis, and that these reports are published.

5. Findings regarding the service proposals

Not a statutory service

Personality Disorder (PD) Services are non-statutory (i.e., it is not a legal requirement to provide specialist treatment for this condition), and some Mental Health providers do not offer any specialist service for this condition. Based on informal discussions, CPFT's service is considered to be about average. We recognise that this is not an insignificant level of investment given CPFT's low level of overall funding.

Lifeworks and peer-support

NICE guidance does not specifically describe or recommend a service like Lifeworks. However, this does not mean that Lifeworks is not effective, nor has CPFT suggested that this is the case. Service users themselves have spoken of its effectiveness for them personally.

Although NICE says little about peer-support, it does state that the role of specialist mental health services for services for Borderline PD should include the following: '*be able to provide and/or advise on social and psychological interventions, including access to peer support*" (p25); and '*should involve people with PD and families or carers in planning service developments, and in developing information about services. With appropriate training and support, people with PD may also provide services, such as training for professionals, education for service users and families or carers, and facilitating peer support groups*' (p26 CG 78).

An element of peer-support could accordingly be incorporated into the countywide service redesign, especially as a number of service users understand their condition and some have relevant qualifications. This would provide an opportunity for the service users, who are very passionate about the service, to put that passion to good use. User-led services, in conjunction with any support that can be provided by the recovery college, would be a beneficial addition to the service.

We are therefore pleased at the commitment to work with service users to develop a joint proposal for a longer-term service model that promotes recovery.

We also welcome the decision to provide a Lifeworks service in Cambridge for the next five years unless replaced by an agreed longer-term service model, in view of the issues raised by the occupation of the Lifeworks building.

Mentalisation-Based Therapy

The 18-month MBT treatment - the key psychological therapy the redesigned service will provide - is in line with NICE guidance, and should, based on current evidence, be effective at enabling some patients to recover their lives from their condition.

Only 30% of patients who are referred to the introductory 12-week MBT psycho-education treatment (MBT1) will subsequently receive the full 18-month MBT programme (MBT2). There is no specific evidence to demonstrate that a 12-week MBT course is effective as a standalone intervention. However CPFT informed us that the effectiveness of this intervention is undergoing trials.

Recommendation 5
We therefore recommend that CPFT closely monitor and evaluate the impact of the 12-week MBT course as a standalone intervention, feeding into and learning from the trials, and that a date is set for reviewing whether it is working, to ensure that it is an effective use of scarce resources. The evaluation should feed into building the evidence base in this area.

Equity of access across the county
We are pleased at the commitment to create improved equity of access to the service, although we note that, in part, the inequity that exists results from CPFT having closed down other Lifeworks centres around the county without public consultation.

Reducing the number of senior roles within the service and using these reductions to fund more frontline staff will increase capacity and allow more patients to be treated countywide than is presently the case. This will create greater equity of access, although it is not clear to us that there will be sufficient capacity to achieve the level of service set out in the consultation document.

Whilst we welcome the end to the sit-in and recognise that the decision to continue to provide Lifeworks from Tenison Road for 5 years was made in order to achieve this, this does create an unequal level of service across the county. This will be beneficial for Cambridge and the surrounding area, particularly as we have concerns about the lack of support for service users who have been discharged, and Lifeworks will help to fill this gap. However, we hope that some additional support can also be provided for discharged service users countywide, so that provision will be equal.

We do not wish to call for Lifeworks in exactly its previous form to be restored across the County, as guidance suggests that there are probably more effective and efficient ways of delivering this support that might incorporate elements of Lifeworks, peer-support, the recovery college, and the voluntary sector. The next section of our response provides more information on this view.

Recovery model and support for discharged service users

Although we consider the recovery model to provide a good starting point for thinking about personality disorders, we understand from our discussions with the Trust that, given the time-limited nature of the service and limited capacity, some service users who did not respond to the treatment would be less likely to receive the service repeatedly. Part of the rationale for the service change was precisely to avoid lifelong service dependency.

Whilst we accept this logic - the recovery model involves making tough decisions about how best to provide services, and this is part of its effectiveness - it nevertheless raises legitimate concerns that some people with high-level needs and conditions will, having been treated once or twice, find themselves “out of the loop”, as they will no longer be a priority for receiving services. Our concern is that these people could potentially be significantly worse off as a result of the new model, unless the recovery model is applied sensitively and they are given appropriate support either outside the pathway or as part of a redesigned pathway.

Therefore we are of the view that applying the recovery model sensitively to a personality disorder service means ensuring that there is an acceptable level of support available to discharged service users that provides them with a fallback option in the event of ongoing difficulties. This may enable these people to “stay recovered” for longer, and reduce their dependency on more labour-intensive services. It would also help to prevent GPs referring their patients straight back into the specialist PD service.

Given the importance of ensuring that there is proper ongoing support for discharged users, CPFT is also unclear about what actual support there will be. In response to a request for written clarification of the level and nature of

support that would be provided, "*it is not possible to say exactly what will be available as this will depend on the service user's needs, and what is available at the time, but in broad terms the kind of supports accessed include Independent/voluntary sector help where available (e.g. MIND, Richmond Fellowship), CPFT Recovery college East, employment, education.*" We are concerned that this response is too vague to provide assurance that discharged service users will have any ongoing support. In particular, we are very concerned that there may not be sufficient extra capacity in the voluntary sector to absorb significant additional pressures.

We understand that the current work being undertaken with the service users to co-design a modified pathway is partly intended to address similar concerns about discharged patients, and so we strongly support this work.

Recommendation 6
We therefore recommend that CPFT work closely with other organisations to ensure that discharged users have an appropriate level of support, and that they know what this is and how it can be accessed. We recommend that CPFT set out clearly what additional support is available at the earliest opportunity.

The future review of the service should include a detailed audit of discharged service users and the support that they are receiving

As a more general statement, we do not believe that the recovery model provides a simple service framework that can be lifted off the shelf and applied to every mental health condition in a straightforward way. It needs to have regard for the condition in question. It is not clear whether this thinking has taken place in the case of the proposed service redesign for PD services, although we are optimistic that it is now taking place in the discussions with service users.

6. Working with GPs

The working group consider that the success of the new service to a significant extent rests on the ability of GPs to diagnose and know when to refer patients. This would require them to be aware of the service and the pathways, particularly for new patients, and know both how to access it and when to refer, as well as having an awareness of the condition.

Discharge is a key area of concern. Getting the transition right when the patient is discharged is crucial, and the GP needs to be involved in this and know what support is available to their patient.

Recommendation 7
We therefore recommend that GPs are provided, as soon as possible, with factsheets about the new PD service. Information about the service should be put on the GP update training programme as soon as possible.

7. Crisis Support

Patient and GP access to timely support in a crisis out of hours was a key concern of councillors, as this has an impact on people with PD, particularly those who have been discharged from the pathway.

8. Partnership working

Effective partnership working between CPFT and other agencies to support people with PD is key to the provision of the service pathway. This includes, for example, housing providers, social care, the police, and more localised services in both the statutory and voluntary sectors.

Evidence that would show the true cost of PD patients to the wider health and social care system might help to make the case for greater investment across the system.

9. Funding

We are concerned about the level of resourcing for CPFT, particularly in view of the current disparity between the level of funding provided to acute hospitals through the payment by results system, and the level of funding for more preventive community based mental health services financed through block contracts.

10. Specific Assurances

We welcome the following specific assurances that we received from CPFT in response to concerns that we raised.

- GPs will have access to CPFT's crisis team.
- Anyone discharged will have three appointments over the course of a year.
- Fenland residents will not have to travel to another district to access higher-intensity interventions.
- 50% of service users would receive a 12 week psycho-education programme. The other 50% of service users would receive a six week psycho-education programme.
- No patient on the PD pathway would receive services for fewer than 6 months in total.

Councillor Kilian Bourke
Chairman, Health Committee
23rd July 2014