

Consultation Response Paper

Personality Disorder Community Service/Complex Cases Service, including Lifeworks

September 2014



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1. INTRODUCTION AND BACKGROUND

1.1. About This Document

This document is the formal response to the consultation which ended on the 14th July 2014. It provides a summary of feedback received, responds to these and describes the next steps.

1.2. Background

The consultation into services provided by CPFT for people with personality disorder commenced on the 2nd June 2014 and ran for 6 weeks, concluding on the 14th July. The consultation paper had been produced jointly with the Cambridgeshire Commissioning Group (CCG), with oversight provided by the Cambridgeshire County Council Health Committee working group. The paper has also been discussed at the Peterborough City Council Health Overview Group. HealthWatch in both Cambridgeshire and Peterborough have also been involved and provided support to the consultation process. CPFT extends its thanks to everyone involved.

Whilst this was not a public consultation, CPFT was keen to get feedback from as wide a group of stakeholders as possible. To that end we;

- Sent paper copies of the consultation paper and questionnaire to current and past service users of CPFT personality disorder services. They were also provided with a pre-paid/addressed envelope in which to return the questionnaire.
- Made copies available to the Complex Cases Friends and Family group.
- Made the paper and questionnaire accessible on the Trust's public facing website
- Made the questionnaire available electronically on 'Survey Monkey'.
- Set up a dedicated email address where responses and comments could be sent.
- Held focus groups across the county in order to broaden feedback and discussion about the proposals

In order to support the transparency of the process, all written responses, including queries raised at the Focus group events, have been scrutinised by a local councillor representative of the health committees from Peterborough and Cambridgeshire, HealthWatch and CCG.

The focus groups were arranged with the support of both HealthWatch in Cambridgeshire and Peterborough as follows:

- Cambridge – 20th June Meadows Community Centre
- Huntingdon – 27th June – Medway Centre
- Peterborough – 25th June – The Fleet Community Centre
- Wisbech – 3rd July – Rosmini Community Centre

The Trust would like to thank everyone who has taken the time to provide feedback.

It is important to note that the consultation relates to the CPFT specialist personality disorder service. People with personality disorder are frequently in contact with other CPFT teams and services (such as adult locality teams, CRHT etc.), and services provided by other organisations such as MIND, Richmond fellowship and primary care. Therefore the numbers of service users and staff referred to in the consultation relate only to the specialist PD team.

1.3 Joint Proposal Project Group

Since the consultation started and as part of the agreement reached to end the sit-in at Tenison Road, a joint project group has been formed. This has representatives from a wide range of stakeholders

including service users and carers, voluntary sector organisations and local authority commissioners. The aim of this is to undertake a co-designed proposal for further service development for people with personality disorder. Work is at an early stage, but the aim is to see if a joint model can be agreed by stakeholders, and if it can, develop a business case for submission to commissioners. It is recognised that obtaining funding in the current financial climate is going to be a challenge. Never-the-less the first step is to see if a joint proposal can be produced. This work should conclude in the autumn.

2. RESPONSES TO THE CONSULTATION

2.1 Who responded to the consultation?

In total 58 consultation questionnaires were received. Of these, 25 were submitted online via the survey monkey, 9 were emailed to the project mailbox and 24 arrived by post.

In addition to the completed questionnaires, written submissions were also received including a response from:

- some service users at Lifeworks supported by a petition with 3426 signatures and 965 online signatures
- Cambridgeshire County Council Health Committee
- Peterborough City Council Mental Health Lead
- A number of email responses were also received.

Overall, the majority of the respondents were from Cambridge City or South Cambridgeshire. This is perhaps unsurprising as the current service is focused in Cambridge, although efforts were made to disseminate information about the consultation in all parts of the county.

Number and proportion of respondents from Cambridgeshire & Peterborough LA districts

Cambridge City	South Cambs	East Cambs	Huntingdonshire	Fenland	Peterborough	Other
48%	30%	4%	8%	2%	6%	2%

Roughly half (53%) of the respondents were service users, carers or members of the public, and just under a third (29%) were NHS professionals.

In addition to the written responses, we held meetings in Cambridge, Peterborough and Huntingdon,

2.2 Feedback about the aims of the consultation

Respondents were asked whether the proposals helped to achieve the aims of the consultation:

To what extent do you think the proposals help to achieve the following aims?

	Negative impact	Neither positive nor negative	Positive impact
To use resources as efficiently as possible	45%	23%	32%
To meet the needs of patients across the whole area served by the Trust in an equitable way	32%	23%	45%
To provide services which are recognised as effective (i.e. there is evidence to prove that they are effective)	40%	27%	33%
To maximise the number of people who can be seen by the service	29%	19%	52%

To provide a service that supports recovery (see glossary at the end for what we mean by recovery)	39%	24%	37%
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There were differences between the responses from service users/public and professionals, as the following examples show. Overall the professionals were much more likely to think the proposals would have a positive impact:

To what extent do you think the proposals help to achieve the following aims?

	To use resources as efficiently as possible				
	Negative Impact	Neither	Positive impact	blank	Total
Health or Social Care Professionals	10%	10%	80%	0%	100%
Organisations	0%	29%	29%	43%	100%
Public	63%	22%	11%	4%	100%
Grand Total	41%	20%	30%	9%	100%

	To meet the needs of patients across the whole area served by the Trust in an equitable way				
	Negative Impact	Neither	Positive Impact	blank	
Health or Social Care Professionals	10%	0%	90%	0%	100%
Organisations	0%	29%	29%	43%	100% =101
Public	48%	19%	30%	4%	100% =101
Grand Total	32%	16%	43%	9%	100%

Some of the comments illustrate the different perceptions of efficiency and equity in the context of the PD service:

'It is clear that a greater number of clients, from a larger geographical area can receive a well thought out service from appropriately skilled staff.' (Health/social care professional)

'It might seem fairer to give more people a little but if it is not enough to produce change for anyone then no one is actually benefiting for the same expenditure. At least a few people were before.' (Service user, Cambridge City)

Not everyone agreed with the aims of the changes, and several people commented that there was not enough information or evidence to comment. The main concerns expressed were about:

- The closure of a service considered effective (lifeworks)
- The need for a lifelong service
- Limitations in the proposed provision, leaving people with unmet needs
- Lack of social support and individual approach.

2.3 The proposed changes

Overall, a quarter of respondents agreed with the proposals, 35% agreed with some aspects and 38% disagreed overall. Almost half of the respondents felt the proposed changes would have a negative effect on them. It was clear from the comments that many service users felt the changes would put their lives at risk:

'Losing Lifeworks will lead to my isolation; increase my depression and suicidal thoughts. I will feel I will have no purpose in life and no reason to get out of bed.' (Service user, Cambridge City)

'If the service changes, I feel this as a life or death situation.' (Service user, South Cambs)

Whilst there was support of the more focused therapeutic approach to treatment, overall there were concerns about the impact of the proposed changes. People expressed fear about the loss of regular social contact and a safety net. There was concern about people who might face discharge without being ready to move on and without clear understanding of resources available in the community to support them. Concerns were also expressed about:

- Loss of hope
- Loss of regular contact and a safety net
- Group therapy not suitable for everyone
- The service offer being too structured/rigid

In terms of mitigations and suggested alternatives, the following comments were made:

- Keep Lifeworks.
- 3 follow up appointments are pointless, need a stable social group.
- Fast track a re-referral and place with previous care co-ordinator.
- Offer one drop-in group a week.
- MIND proposal goes some way but more specialist input needed.
- Access to open clinic/crisis support.
- Lifelong support.
- Social forum, not just therapy.
- Involve SUs in service design.
- Support for family and friends at referral/assessment/ transition.
- Prompt response to emergency referral.

Health and social care professionals raised a number of questions regarding the proposed pathway

- Who is responsible for SOVA?
- Clarity needed for the social worker role
- PD triage from ARC
- Responsibility for care management at the end of the pathway; clarity on GP role
- More modern and effective
- It is too expert driven

These are addressed further in Section 3.

2.4 The two year pathway

One of the key changes proposed in the consultation paper was to offer a service of up to 2 years, with the aim of moving towards a client's independence and discharge from mental health services.

Only 15% of the members of the public agreed with the time-limited pathway. This contrasted with 80% of the health or social professionals:

	Which of the following statements do you agree with the most? “The personality disorder service should maintain regular contact with PD patients throughout their lives.” “The personality disorder service should support PD patients for a limited period of time until they are able to manage their symptoms themselves and get back in control of their lives.” Tick the one that most closely reflects your views			
	Limited period	Throughout	Unsure/can't say	Total
Health or Social Care Professional	80%	0%	20%	100%
Organisation	50%	25%	25%	100%
Public	15%	65%	19%	100%
Grand Total	35%	45%	20%	100%

3. SUMMARY OF MAIN THEMES AND RESPONSES

Feedback has been grouped under eight main themes. Where there are specific questions these have either been addressed under one of the eight headings or are responded to separately. So that anonymity is maintained individual feedback is not reported here, however as mentioned earlier, all individual responses have been independently read, and it is confirmed that this summary is a fair reflection of the points raised.

3.1 Need for lifelong support and stability. Concern about post-discharge support, access to crisis and the role of GP's and other organisations.

Many respondents emphasised that personality disorder is a lifelong condition and that periodically during their lives people may need more support. Being discharged and re-referred at these times was seen as problematic for the following reasons:

- Difficulty getting back in to the service, lack of assurance that support will be available, long waits seen as likely
- Seeking help is not easy
- Need for stability
- Need for support from specially trained staff

In its response, the Cambridgeshire County Council Health Committee working group expressed concern that having been through the pathway once or twice, some people with high-level needs may find they are no longer a priority for receiving services. The working group emphasised that the recovery model should be applied sensitively and that there should be appropriate support either outside the pathway or as part of a redesigned pathway.

Concern about the proposed time-limited service and the lack of support in a crisis for people outside the service were prominent themes among the consultation responses:

*‘BPD by its nature is good times and bad. Service users come and go, and come back again. They need to know that the net is always there for them. Stability in their unstable lives.’
(Service user, Cambridge City)*

‘The time limit is hugely stressful and I will miss the regular contact with my case manager. Although I do not see him very frequently, knowing I can help me get by. Often having support on call is enough for me, I really fall to pieces if I know it's not there....Suggestions: To be able

to fast track a re-referral and place them with their previous co-ordinator. To offer one drop in group a week' (Service user, Cambridge City)

'(Need) a service which is not time limited (we have this for life, there is no way it can be sorted in 2 years!). Someone or somewhere to go when in crisis with specially trained staff to deal with it.' (Service user, South Cambs)

'It is clearly aimed at "new entrants" to the service, i.e. emphasis on recovery model and maximum two years of service. This does not seem to reflect the reality for many with this lifelong illness and their movement into and out of the Service. For the small number but growing number of residents with treatment resistant personality disorder the treatment and support in the community is and will be about stability and continued access to help in times of crisis.' (Carer, South Cambs)

'The fear of being discharged before I am well is so great that it stops me being able to focus on getting better, this is just another thing that wants to give up on me if I am not good enough.' (Service user, Cambridge City)

'People like us are known for having difficulty asking for help, making us do this over and over again is cruel and frankly people like me just won't be able to manage it. We will just disappear, which may make your numbers look good but in reality will not serve us at all. Out of the 6 people in my group, all 6 have been 'pathwayed' out, before the consultation we were considered worth helping'. (Service user, Cambridge City)

'Personality disorders (PD) are usually long-term conditions that can fluctuate over time. Due to the tendency for long-term implications with PD, there needs to be a service for those with the most complex/severe and enduring needs.' (Member of the public, Cambridge City)

'Who will hold the risk when the time with the service comes to an end? Is this flexible?' (Health/social care professional)

Response

We recognise that moving to a more focused time limited pathway approach is for some existing service users and carers (particularly in Cambridge) a significant change, and has caused concerns. These were reinforced by the decision taken initially to close Lifeworks. The aim of the changes was to provide a specialist service across the Trust as equitably as possible, using available evidence and best practice.

The work that has been done over the last several months has helped raise the profile of personality disorder and the needs of people with mental health problems, and the current availability of services and funding. However it needs to be recognised that services across mental health, both NHS, voluntary sector and primary care are under severe pressure.

Response

For those service users who are discharged from the Trust services, it is important to note that a large part of the treatment approach will be to try and help the patient avoid or better manage crisis periods as far as possible. Care planning and discharge planning will include plans for dealing with the eventuality of a crisis or relapse. Once discharged from the CPFT, risk will be held by the GP, the service user and where appropriate their carer, and any other service involved.

For service users in contact with the PD community service - support will be defined within the care plan. Outside of normal hours this will be via out of hours GP service, A&E (there are mental health staff working out of A&Es who would have access to the persons records and care plan). They will also have access to CRHT (Crisis Resolution Home Treatment) teams either via the PD service or via GP referral out of hours).

'As regards to discharging from the service I would suggest a discharge to the GP with a plan is a good idea but leaves the client unsupported socially so I would think that we need the option for the client to keep contact with the third sector in a supportive role and to allow re-referral to ARC by workers in MH trained organisations such as MIND....Primary care will need some solid support for those clients who have completed therapy and are ready for discharge and this is when I would recommend a discharge case conference involving the key players.' (GP, Peterborough)

Response

GP mental health leads have been involved in the redesign of the adult community services. Each locality team psychiatrist is attached to a number of GP surgeries – and is forming effective working relationships. This supports GPs contacting 'their' locality consultant or the PDCS consultant psychiatrist directly for advice (also using CONFER – a secure messaging service). In addition the PDCS will be liaising with GPs specifically about the PD pathway – to help explain the pathway and also to discuss specific patients.

In addition the personality Disorder Community service duty team/crisis workers are available for advice to GPs regardless of whether the patient is current with the PD service or discharged.

'The proposed time limits on treatments in the consultation seem to be based on a misunderstanding of the evidence base. The document makes much about bringing in time-limited evidence based treatments, as though the evidence supports the time limit. It does not! The research trials have not looked at what effect the time limit on treatment might have, but simply compare one treatment with another. The trials have to specify a limit on the length of treatments to be compared, but that does not mean that length of treatment is particularly to be recommended. Indeed most trials, especially those on Personality Disorders, observe that patients still suffer from significant symptoms at the end and recommend longer periods. Recognising this, the NICE guidance does not recommend particular time limits and the commissioning guidance even recommends providing long-term interventions and support.' (Collective response from Lifeworks service users and supporters)

Response

We believe that the interventions described can be delivered within the two year pathway across the Trust. We would like to be able to do more for longer but this would require additional resources. In order to monitor the effectiveness of the interventions and time scales we will monitor and evaluate the impact and outcomes (see section 7). It is also important to stress that the two year timescale reflects the evidence base for psychological interventions where trials have shown that a period of two years is effective. We recognise that NICE guidance does not generally set a timescale for duration of contact.

'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 fall-back 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.' (Cambridgeshire County Council Health Committee).

Response

We recognise that PD can persist over many years, and that discharge can be stressful. In general terms discharge planning will start as early as possible – discharge should be no surprise, and should be planned with those involved, service user, carer, other services involved where relevant and GP. The discharge plan should set out what needs to be done in the event of deterioration, and how the person's care and support is to be 'stepped down' to less intensive support.

Recovery is about enabling people to live well even with their condition. Staff from the Recovery College are involved in the co-production work. As part of this, sessions explaining Recovery have

been and will be held. These have gone some way to provide helpful information about what Recovery is and what it is not. This needs to be an ongoing process to help alleviate any misunderstandings.

3.2 Need for social support interventions and opportunities to socialise

Many respondents highlighted the importance of social support interventions as part of the service offer. Some expected this to be provided via the NHS, others accepted that opportunities to socialise could be provided outside the NHS, in the community. There was significant concern about the loss of Lifeworks which enabled people in Cambridge to access this kind of support:

'Socialisation is also very important for people to share their experience and how they cope with their condition.' (Member of the public, Cambridge City)

'I do not react well to therapy so having social groups/recreations/cooking/walking etc helped me build important bonds with other patients and staff and be able to help me speak when in therapy I can not speak.' (Service user, South Cambs)

'The idea that the new pathway which involves coming in for therapy groups and then coming home with no socialisation or support frightens me.' (Service user, Cambridge City)

'The social aspect helps me to understand how to integrate with others as I tend to isolate myself at home. I find it very difficult to leave my house and Lifeworks has given me the courage to do this.' (Service user, South Cambs)

'It is evident that the proposed service model will not provide the level of social support that has been available previously...When in crisis, social support services can be a lifeline for those who really struggle. Even if an individual is self-reliant and functioning reasonably well (e.g. working, managing a home, tenancy etc.), when in crisis they may need a higher level of support which should be available to them at short noticeIt is true that some people with PD (or features of PD) may require short-term and/or non-frequent interventions and contact. But those with severe, enduring or complex PD should have regular contact with well co-ordinated NHS services that can meet their needs.' (Member of the public, Cambridge City)

'All we are asking for is an NHS day centre in Cambridge where we can go and socialise and feel safe and where there are staff to talk to when feeling bad. All the day centres and halfway houses have been closed in Cambridge and there is nothing left! Lifeworks is the last one!' (Service user, Cambridge City)

Response

The importance of socialising as a means of supporting a person's recovery is recognised. To aid this, making sure that full use is made of the existing services and supports already provided in the community by working more effectively with the voluntary sector is essential, and to that end work will be taken forward to strengthen joint working with in particular the voluntary sector.

In addition the joint proposal being developed will aim to bolster opportunities for accessing social contact.

The closure of day centres has taken place over a number of years, and has been in line with national and local policy. As previously described, in recent years only Cambridge had the Lifeworks service. The agreement to sustain Lifeworks in Cambridge for a period of 5 years was in response to finding agreement to end the sit-in. It is acknowledged by all that having a service in Cambridge that does not exist elsewhere is inequitable. Therefore the aim of the joint project is to try and develop an agreed model of service – building on the CPFT pathways and services provided by other service providers, which can seek funding to implement across Cambridgeshire and Peterborough.

During the consultation period there was considerable discussion about 'Recovery' and it was clear that there was a degree of misunderstanding about this a concept. Information has since been provided about this, but more needs to be done so that 'Recovery' is better understood.

Another strong theme has been the need for support to 'transition' or move between services and settings. This issue applies to other groups of service users as well as to people with personality disorder.

3.3 Greater equity welcomed but is the offer sufficient to meet needs?

One of the main aims of the service redesign was to provide a more equitable service across the county, as Complex Cases was very much focused in Cambridge. Many people welcomed this wider focus.

'This will do a great deal for Peterborough where I have a GP surgery...Overall a wonderful proposal which improves access across the county in an equitable way, uses evidence based therapies and is money spent well.' (GP, Peterborough)

'It is clear that a greater number of clients, from a larger geographical area can receive a well thought out service from appropriately skilled staff.' (Health/social care professional, South Cambs)

'I have spent the last 3 months liaising with locality teams around the Trust, and it is clear that there are many service users who are not currently getting specialist support for their personality disorder' (Health/social care professional, Cambridge City)

However, many current service users questioned whether a service that was too thinly spread was cost efficient. For many, the proposed service would leave unmet needs, for example:

- Insufficient MBT (concern about the timescales of interventions)
- Group therapy not appropriate for some, need for more 1:1 support
- Support to be available in people's homes
- Not enough psychotherapy provision
- Not enough social support
- 3 year pathway would be more effective
- Services not provided by sufficiently skilled staff

'NOT enough psychological therapy provided. All suitable service users should be offered an approach such as DBT or CAT, and not just when in crisis.' (Service user, Cambridge City)

'Are (the services) efficient if they only half treat a greater number, which could actually make things worse?' (Service user, Cambridge City)

Response

The importance of making sure that the specialist service is available Trust wide is acknowledged and understood. There was a view expressed of a reduction of service in Cambridge, where complex cases and specifically Lifeworks has been in existence for longest, but that elsewhere in the county that the proposals are an improvement on current provision, particularly in Fenland where to date there has been very limited access to specialist personality disorder services.

As mentioned previously, it is also important to note that this consultation was about the specialist PD pathway. People with personality disorder will also have contact with other CPFT services such as locality teams older people's services, CAMH teams and acute care services.

In terms of the issue about MBT being insufficient and not in line with NICE guidance for the duration of therapy – to be clear the 12 week course relates only to the psycho-education package (MBTi). This is not the same as MBT therapy which will be for 18 months as indicated by NICE

'Given the down banding of the staff employed by the service, it is likely that most treatments will be offered by band 5 staff. It is highly unlikely that band 5 staff would have the training, skills and experience to achieve an acceptable level of competence in individual psychological therapies.' (Collective response from Lifeworks service users and supporters).

Response

We are committed to all staff having the required training and expertise to deliver the interventions. In particular the 18 month MBT therapy will be delivered by a qualified therapist assisted by a co-facilitator who will have specific MBT training. It is important to note that staff are recruited not just of their technical skills, but also because of their interest and commitment to working with people with personality disorder.

'The talking therapy times appear to short for patients with long term complex mental health needs. The new service does see a lot more patients but if the treatments are not effective there is going to be a revolving door system where discharged patients are going to seek more treatment soon after their two years of treatment ends'. (Service user, Cambridge City)

Response

We believe that the approach described will be effective. As described elsewhere, we will monitor effectiveness of the pathway to see if any changes or modifications are needed. Getting feedback from service users and carers will be key in helping evaluate.

'Evidence based support - NICE guidelines clearly state that brief interventions of 3 months or less are not suitable for people with personality difficulties. It's unclear from this document whether some of the CBT input might be below this threshold. Our experience tells that it is not just insufficient but potentially dangerous to work with people in short term interventions - it can bring very challenging issues to the surface and undermine existing coping strategies, without time to explore, address or replace these. There is strong evidence for DBT but what is offered here is a kind of DBT lite, just the skills groups rather than the other components of one to one and out of hours contact with therapist which enable people to make use of the skills learned. The question not asked here is whether it is best to make a genuinely life changing difference through intensive treatment which significantly improves quality of life and reduces use of services for the rest of someone's life, for a few people or lower impact support which keeps people trapped in the difficulties of personality disorder and more likely to need ongoing support, but available to more people. (Service user-led organisation).'

Response as previously stated, in terms of the length of therapy MBT will be for 18 months as indicated by NICE. The team would like to be able to offer more psychological interventions to a larger number, but what has been estimated is what the team should be able to provide and sustain.

Response

The proposals were generally welcomed in areas other than Cambridge (due to the loss of Lifeworks), as in Fenland, Huntingdonshire and Peterborough, the new service enhances the range of interventions available building on what is already available from the locality teams and acute care service.

3.4 Service users need to be treated as individuals. Offer seems rigid and too medical-driven

Linked to the concerns about lack of social support, there was concern that the proposed service model was too rigid and medically driven. Others welcomed the therapeutic approach.

'This looks much more like a modern and effective PD service than the model that it replaces. In particular the extremely low numbers treated and the geographical limits were major flaws in the previous system. The numbers treated, and the emphasis on lower banding and use of groups is the right way to go in my view. My only criticism of the new model is that it looks expert focussed. While DBT and MBT both include some ideas of empowerment and patient led interventions, they tend to reinforce the 'I know what's wrong so do what I say if you want to get better' model. It would be useful to have some explicit indication of how the risk of the sometimes disempowering expert driven model might be mitigated e.g. patient involvement in oversight and planning, use of mentoring in group work etc.' (Health professional from other Trust)

'Overall, while the proposed pathway is clearly presented, and is rational, it appears to lack a 'whole person' approach. The pathway seems to opt for a good deal of service compartmentalization, which gives the impression that service users will be on the receiving end of 'having things done to them' on the basis of specific individual symptoms, rather than working from the basis of treating them as whole people experiencing a range of difficulties, and participating in their own recovery process; working on equal terms with clinicians wherever possible, and with their peers in group'. (The Group Therapy Centre)

'The idea that the new pathway which involves coming in for therapy groups and then coming home with no socialisation or support frightens me. This is an important part of my treatment at Lifeworks. The idea of a rigid regime is very off putting and does not feel welcoming.' (Service user, Cambridge City)

'It is good that a service will be available to a greater number of people but much of the proposals sound superficial, are concerned with numbers and so called measurable outcomes, rather than primarily viewing the service user as an individual. Service user, South Cambs)

'I agree that the PD service should be treatment driven. However, not everyone in the service is ready for intense treatment and they should be offered individual support until they are ready.' (Service user, Huntingdonshire)

Response

From the teams perspective the pathway is not seen as medically driven as it has a strong multi-professional structure that includes nursing, occupational therapy and psychology. The current PD pathway lead role is covered by a psychologist. In addition the crisis support is much strengthened and this will look to support the person and family experiencing a crisis from a number of perspectives not just from medical perspective.

More broadly we agree that empowerment is an essential part of the model and this is definitely the intention. The service user being central to the care and support and having control over their care is seen as core to the approach. Further, the staffing model includes Peer Support Workers (staff with lived experience of mental health problems) and support workers who's primary aim is to support service users link into and access community resources/facilities.

The team will aim to work collaboratively and in partnership with both the service user and carer, and as mentioned, fully recognises the importance of service user and carer empowerment and their role in being responsible and involved in their care. The service will monitor service user experience and have developed a questionnaire based on the guidance within the White paper 'no longer a diagnosis of exclusion'.

3.5 Consultation unsatisfactory, and information not clear.

There was dissatisfaction and resentment with the way the proposals had been communicated and also the extent to which the new pathway was being implemented.

'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.'
(Cambridgeshire County Council Health Committee)

'The insulting way the proposal to end the service was made has meant that service users have lost trust in staff and those responsible for running it.' (Service user, Cambridge City)
'There is much in the Consultation document that has already been, or is in the process of being, implemented. This undermines the whole purpose of the Consultation.' (Collective response from Lifeworks service users and supporters).

Response

As previously acknowledged, we agree that we should have done better initially with the plans for Lifeworks in Cambridge. Through the engagement work done via the consultation and agreement to end the sit-in, there is a much improved understanding by all involved on the perspectives and views held. The joint work being done to form a joint proposal is also helping strengthen this.

The consultation paper and the consultation process were agreed with the CCG with significant input from the Cambridgeshire health committee working group and Cambridgeshire HealthWatch prior to the consultation paper being published.

Aspects of the new pathway as defined in 2013 adult community service redesign have been implemented, this was because there are large numbers of people requiring a service and to have delayed implementation would have meant to deny access to any specialist service. It should be acknowledged, and staff commended in both the adult locality teams and PD specialist teams for the huge efforts made to maintain care and interventions as far as possible.

3.6 Service user participation in service design.

Linked to the quality of the consultation itself, there was also feedback about the involvement of service users in designing services.

'Include patients' opinions in the design of the service, we know best!' (Service user, South Cambs)

'Both the NICE guidelines and the commissioning guidelines recommend giving users some participation in the design of services and the choice of treatments. The commissioning guidelines even recommend therapeutic communities in which users have much of the responsibility for the running of the service. There is little in the proposal about how users will be involved in the service and the proposal to close Lifeworks would suggest this was not part of the vision underlying the proposals.' (Collective response from Lifeworks service users and supporters)

Response

We recognise that there should have been much better involvement of people affected by these changes early on. The work on co-production will hopefully redress some of the impact of this and build a more effective approach to service design and also in making difficult decisions about how to make best use of the limited resources available.

3.7 Review and evaluation of new pathway

Some respondents and the Cambridgeshire County Council Health Committee in particular, argued strongly for a robust review and evaluation of the new pathway:

'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.’ (Cambridgeshire County Council Health Committee)

It is worth noting however, that there may be different perceptions of effectiveness and measures of success:

‘But how do you measure success? This is critical to the whole concept of Payment by Results. You have to be able to quantify people coming into the system and people being discharged at the other end. But Lifeworks doesn’t work that way. ..Lifeworks enables many of them to have personal lives, to work, to socialise, and contribute to society, without the constant acute interventions, attendance at A&E and worse, which would undoubtedly otherwise occur. However, such a ‘result’ is very hard to quantify, which is why Lifeworks apparently does not fit the ‘payment by results’ pattern, and is being scrapped.’ (Collective response from Lifeworks service users and supporters)

Response

We agree that there should be regular review and monitoring of the service, involving partners in this, especially the CCG and local authorities. We are keen to explore the possibility of undertaking some research or service evaluation into the service model, including whatever design comes out of the co-production work. Part of the monitoring will aim to include impact on other health providers such as accident and emergency departments.

3.8 Funding for mental health services and recognition of longer term savings to the public purse. Impact on voluntary sector

In terms of cost-effectiveness, many respondents highlighted the need to consider this from a holistic perspective rather than just in the context of the PD service, recognising the potential impact on emergency services, the voluntary sector and other agencies:

‘Positive changes are being made but it is not enough. PD is still a diagnosis of exclusion and this is not acceptable. Vulnerable people are being let down by services due to funding. Too little community care causes more A&E visits and more inpatient stays which are both traumatic to the individual and expensive for the Trust.’ (Service user, Cambridge City)

‘I agree with the crisis support team/specialists being extended but feel that on going life long support is absolutely necessary for most people with BPD (including myself) and is more cost effective in the long run. MH services are woefully underfunded.’ (Service user, South Cambs)

‘Not having routine and expertise of the current service I fear i may use A&E and hospitals more than i have done since being in the service for 6 years.’ (Service user, South Cambs)

‘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.

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.’ (Cambridgeshire County Council Health Committee)

'If the additional cost of closing Lifeworks to the acute mental health budget, acute hospital care including A&E, police, social services etc. are taken into account, then surely it is a truly false economy?' (Collective response from Lifeworks service users and supporters)

'We are very concerned that there may not be sufficient extra capacity in the voluntary sector to absorb significant additional pressures'. (Cambridgeshire County Council Health Committee)

Response

We are also concerned about the level of funding provided to mental health in Cambridgeshire and Peterborough. Whilst we believe that the redesigned PD service allows CPFT to provide as good a service to the greatest number as possible, it is fair to say that mental health services (both NHS and voluntary sector) and GP services are under considerable strain. We will continue to work with partners especially commissioners to try and improve funding for mental health, and to find innovative ways of making best use of available funding.

Payment by results may provide a fairer funding mechanism but this is yet to be tested locally.

We are keen to see if a research or evaluation project could be established to look at the impact and possible cost savings the new pathway may have, and to see to what extent there are system wide savings and improvements in outcomes

3.9 Specific questions and responses

3.9.1 What is being done to support young people who may not have a diagnosis, but who are displaying characteristics or who appear to be at risk of a PD diagnosis in future?

Response

The service currently works and will continue to work on an individual case by case basis with CAMH teams and also with local authority 'looked after children' services. This normally involves the child's care team making contact with the specialist PD team prior to the child's 18th birthday, in order to plan the transition at 18 years of age. Referrals of this type are prioritised by the service.

More broadly there is a willingness to look at service development opportunities in the future.

In addition, staff from the personality disorder service have provided training to a voluntary sector organisation, and would be happy to be commissioned to provide more training.

3.9.2 Who is taking responsibility for Safeguarding of Vulnerable Adults in the PD pathway?

Response

Safeguarding responsibilities will follow existing agreed policies and procedures within CPFT.

3.9.3 Will clinicians be skilled to provide care packages?

Response

As previously described a key part of the pathway is to make sure that staff have sufficient skills and capacity to carry out the pathway interventions.

3.9.4 Who is diagnosing PD to enable people to come directly from ARC to the PD team?

Response

ARC work closely with CPFT teams to make sure that they triage effectively to make sure that the person gets to the right team when needed. The referral process will be one aspect monitored as the pathway is implemented.

3.9.5 What is the role of social workers and how does it fit with social worker role in locality teams?

Response

We were pleased that as part of the new service model, Cambridgeshire LA transferred resources to fund a specific social work post into the PD service. The post holder will work as a core member of the services providing expertise and support within the team.

3.9.6 Who is responsible for care management when patient transfers over from other team?**Response**

Service users with the specialist service will all be managed under the CPA (Care Programme Approach).

3.9.7 Who holds risk at the end of the PD pathway?**Response**

The management of risks will be part of the discharge plan. Responsibilities of those involved, including the GP will be clear at that point.

3.9.8 What is meant by "Huntingdon has limited access to the Cambridge service"?**Response**

This is largely a historical comment – reflecting that in the past some Huntingdon residents were able to access services in Cambridge. The now model should reduce significantly the need for this in the future.

3.9.9 Where will specialist personality disorder services be provided for service users in Huntingdon?**Response**

CPFT has a dedicated mental health community centre in Huntingdon (Newtown centre). Where additional space is needed the service will aim to find this.

3.9.10 How is the social work post funded?**Response**

The social work post is funded by Cambridgeshire County Council.

3.9.11 How will;

- the service link to current social work input and meet the Local Authority duties regarding assessment and care planning?
- the service work with PCC Target Operating Model and Customer Journey?
- the service work with PCC ASC and accommodation providers and employment services?
- the proposal aid the aspirations of the Crisis Concordat and preventing people accessing A&E or being detained on S136?

Response

The PD service and the Community Division will liaise with local authority officers to consider all of the above points. We anticipate that the PD service will work with local authorities in line with the approach used with other CPFT services and as agreed as part of the section 75 agreements.

3.9.12 How will this group access advocacy services?**Response**

Service users will access advocacy as per current arrangements. Information on advocacy will be routinely provided to service users.

3.9.13 How is this service interdependent with other services/organisations?

Response

The service recognises the importance of good joint working with other organisations. As noted, CPFT is just one organisation working with people with a diagnosis of PD. Regular meetings both at clinical and managerial level will aim to build on the existing joint working. Also, Voluntary sector organisations are involved in the production of the joint proposal.

3.9.14 Will the service achieve recovery outcomes?

- sustaining or improving personal relationships
- improved stability in social environment (housing, finances etc.)
- independent lifestyles, integrated in the community
- increase in time spent out of prison
- positive steps towards valued activity through work, education, employment preparation, recreation etc.
- improved self-management and self-determination

Response

Some of these will be reflected in PbR outcomes, others from useful areas to monitor as the service is implemented. The capacity of the service will affect the ability to influence these outcomes.

3.10 Specific assurances requested by the CCC Health Committee

3.10.1 That GPs will have access to CPFT's crisis team.

Response

As currently, GPs will have access to CRHTs and where needed, inpatient care.

3.10.2 Anyone discharged will have 3 appointments over the course of a year.

Response

The three appointments is part of the pathway post-discharge. The effectiveness of this intervention will be monitored.

3.10.3 Fenland residents will not have to travel to another district to access higher-intensity interventions.

Response

This question is about travel to access service. The PD team are currently exploring locations in Fenland that aims to keep travel to a minimum, but the rural nature of the Fenland patch means that travel, as in other localities is necessary for some users.

Fenland will receive the same level of access as the other areas.

3.10.4 50% of service users would receive a 12 week psycho-educational (MBTi) programme. The other 50% of service users would receive a 6 week psycho-educational programme.

Response

We confirm that all service users will be able to access psycho-educational programmes. The length of this will depend on what aspect of the service they are signposted to. The shortened programme will apply to those people accessing the largely occupational therapy element of the service. The longer 12 week psycho-educational programme will apply to those who are identified as going onto MBT therapy. Whilst the six week programme is seen as beneficial, if resources allowed the team would like to provide everyone with the same level of Psycho-educational therapy.

3.10.5 No patient on the PD pathway would receive services for fewer than 6 months in total.

Response

This would be in the case except where this is shorter by agreement or where the service users does not want to or is unable to continue with the service.

4. NEXT STEPS

We are very grateful for the time and effort people have made in providing feedback to this consultaion. We are particularly greatful to the Local Council Health Committee subgroups, HealthWatch in both Cambridgeshire and Peterborough, and CCG for their support with the consultaion process and in providing overview of it.

In terms of next steps;

4.1 The CPFT two year pathway as described will be rolled out across Peterborough and Cambridgeshire.

4.2 The CPFT service will be known as Personality Disorder Community Service

4.3 The project group overseeing the co-production of a joint proposal will continue to meet to as needed and if successful oversee implementation of the proposals. Once developed, the proposals will go to the CCG and local authorities for consideration. Other funding routes will also be considered. Lifeworks in Cambridge remains open as per the agreement reached.

4.4 The implementation of the new service will be monitored on a regular basis to evaluate impact and the importance of identifying opportunities for research or evaluation is understood. The monitoring arrangements will be formulated together with the CCG.

Appendix 1.

5. Summary of responses

Question 1. To what extent do you think the proposals help to achieve the following aims?

	Negative impact	Neither positive nor negative	Positive impact
To use resources as efficiently as possible	45%	23%	32%
To meet the needs of patients across the whole area served by the Trust in an equitable way	32%	23%	45%%
To provide services which are recognised as effective (i.e. there is evidence to prove that they are effective)	40%	27%	33%
To maximise the number of people who can be seen by the service	29%	19%	52%
To provide a service that supports recovery (see glossary at the end for what we mean by recovery)	39%	24%	37%

Question 2. Which of the following statements do you agree with the most?

The personality disorder service should maintain regular contact with PD patients throughout their lives.	The personality disorder service should support PD patients for a limited period of time until they are able to manage their symptoms themselves and get back in control of their lives.	Unsure / Can't say
53%	30%	17%

Question 3. To what extent do you agree with the Trust's proposals for the PD service?

Agree overall	Agree with some aspects	Disagree overall	Unsure
25%	35%	38%	2%

Question 4. In what way do you feel the proposed changes affect you?

Negative Impact	Neither Negative nor Positive	Positive impact	Unsure	Not Applicable to me
48%	2%	15%	17%	19%

Question 5. Which part of the county do you live in?

Cambridge City	South Cambs	East Cambs	Huntingdonshire	Fenland	Peterborough	Other
48%	30%	4%	8%	2%	6%	2%

Question 6. Are you currently a service user of CPFT or another mental health organisation?

Yes	No
53%	47%

Question 7. Do you currently work for or within the NHS?

Yes	No
29%	71%

Question 8. Are you:

Providing your own response	Providing a response for someone else
100%	0%

Question 9. Are you responding as:

A member of the public	A health or social care professional	On behalf of an organisation
61%	23%	16%

Question 10. Please tell us your age:

21-29	30-39	40-49	50-59	60-69	Rather not say
13%	31%	13%	21%	15%	8%

Question 11. Do you consider yourself to have a disability?

Yes	No	Rather not say
58%	40%	2%

If yes, do you have a:

	Yes	No
Physical Impairment	21%	79%
Sensory Impairment	7%	93%
Learning Disability	0%	100%
Mental Health Condition (Long Term)	60%	40%
Other Health Condition (Long Term)	16%	84%

Question 12. How would you describe your ethnic background?

Any other mixed background	Any other white background	Rather not say	White British	White Irish
2%	2%	11%	83%	2%

Question 13. Gender:

Male	Female	Rather not say
23%	63%	15%

Question 14. Do you now, or have you ever considered yourself to be transgender?

Yes	No	Rather not say
0%	78%	22%

Question 15. Religion or Beliefs:

Agnosticism	Atheism	Buddhism	Christianity	Pagan	Spiritualism	No Religion or Belief	Unsure	Rather not say
2%	11%	7%	37%	2%	2%	15%	2%	22%

Question 16. Sexual Orientation

Heterosexual	Bisexual	Gay man	Other	Rather not say
71%	2%	2%	2%	23%

Question 17. Are you currently providing support to a partner, child, relative, friend or neighbour who could not manage without your help and/or support?

Yes	No	Rather not say
30%	55%	15%

To what extent do you think the proposals help to achieve the following aims?

	To use resources as efficiently as possible				
	Negative Impact	Neither	Positive impact	blank	Total
Health or Social Care Professional	10%	10%	80%	0%	100%
Organisation	0%	29%	29%	43%	100%
Public	63%	22%	11%	4%	100%
Grand Total	41%	20%	30%	9%	100%

	To meet the needs of patients across the whole area served by the Trust in an equitable way				
	Negative Impact	Neither	Positive Impact	blank	Total
Health or Social Care Professional	10%	0%	90%	0%	100%
Organisation	0%	29%	29%	43%	100%
Public	48%	19%	30%	4%	100%
Grand Total	32%	16%	43%	9%	100%

	To provide services which are recognised as effective (i.e. there is evidence to prove that they are effective)				
	Negative Impact	Neither	Positive impact	blank	Grand Total
Health or Social Care Professional	10%	10%	80%	0%	100%
Organisation	14%	29%	29%	29%	100%
Public	44%	26%	15%	15%	100%
Grand Total	32%	23%	32%	14%	100%

	To maximise the number of people who can be seen by the service			
	Negative Impact	Neither	Positive Impact	Grand Total
Health or Social Care Professional	10%	10%	80%	100%
Organisation	0%	60%	40%	100%
Public	35%	19%	46%	100%
Grand Total	24%	22%	54%	100%

	To provide a service that supports recovery			
	Negative Impact	Neither	Positive impact	Total
Health or Social Care Professional	0%	20%	80%	100%
Organisation	0%	25%	75%	100%
Public	60%	24%	16%	100%
Grand Total	38%	23%	38%	100%

	To what extent do you agree with the Trust's proposals for the PD service?				
	Agree overall	Agree with some aspects	Disagree overall	Unsure	Total
Health or Social Care Professional	60%	40%	0%	0%	100%
Organisation	40%	40%	0%	20%	100%
Public	11%	33%	56%	0%	100%
Grand Total	26%	36%	36%	2%	100%

	In what way do you feel the proposed changes affect you?					
	Negative Impact	Neither negative nor positive	Not applicable to me	Positive impact	Unsure	Total
Health or Social Care	0%	10%	40%	30%	20%	100%

Professional						
Organisation	25%	0%	50%	0%	25%	100%
Public	63%	0%	11%	7%	19%	100%
Grand Total	44%	2%	22%	12%	20%	100%
	Which of the following statements do you agree with the most? “The personality disorder service should maintain regular contact with PD patients throughout their lives.” “The personality disorder service should support PD patients for a limited period of time until they are able to manage their symptoms themselves and get back in control of their lives.” Tick the one that most closely reflects your views					
	Limited period	Throughout	Unsure/can't say	Total		
Health or Social Care Professional	80%	0%	20%	100%		
Organisation	50%	25%	25%	100%		
Public	15%	65%	19%	100%		
Grand Total	35%	45%	20%	100%		

To what extent do you think the proposals help to achieve the following aims?

	To use resources as efficiently as possible				
	Negative Impact	Neither	Positive impact	blank	Total
Health or Social Care Professional	10%	10%	80%	0%	100%
Organisation	0%	29%	29%	43%	100%
Public	63%	22%	11%	4%	100%
Grand Total	41%	20%	30%	9%	100%

	To meet the needs of patients across the whole area served by the Trust in an equitable way				
	Negative Impact	Neither	Positive Impact	blank	
Health or Social Care Professional	10%	0%	90%	0%	100%
Organisation	0%	29%	29%	43%	100%
Public	48%	19%	30%	4%	100%
Grand Total	32%	16%	43%	9%	100%

	To provide services which are recognised as effective (i.e. there is evidence to prove that they are effective)				
	Negative Impact	Neither	Positive impact	blank	Grand Total
Health or Social Care Professional	10%	10%	80%	0%	100%
Organisation	14%	29%	29%	29%	100%
Public	44%	26%	15%	15%	100%
Grand Total	32%	23%	32%	14%	100%

	To maximise the number of people who can be seen by the service			
	Negative Impact	Neither	Positive Impact	Grand Total
Health or Social Care Professional	10%	10%	80%	100%
Organisation	0%	60%	40%	100%
Public	35%	19%	46%	100%
Grand Total	24%	22%	54%	100%

	To provide a service that supports recovery			
	Negative Impact	Neither	Positive impact	Total
Health or Social Care Professional	0%	20%	80%	100%
Organisation	0%	25%	75%	100%
Public	60%	24%	16%	100%
Grand Total	38%	23%	38%	100%

	To what extent do you agree with the Trust's proposals for the PD service?				
	Agree overall	Agree with some aspects	Disagree overall	Unsure	Total
Health or Social Care Professional	60%	40%	0%	0%	100%
Organisation	40%	40%	0%	20%	100%
Public	11%	33%	56%	0%	100%
Grand Total	26%	36%	36%	2%	100%

	In what way do you feel the proposed changes affect you?					
	Negative Impact	Neither negative nor positive	Not applicable to me	Positive impact	Unsure	Total
Health or Social Care Professional	0%	10%	40%	30%	20%	100%
Organisation	25%	0%	50%	0%	25%	100%
Public	63%	0%	11%	7%	19%	100%
Grand Total	44%	2%	22%	12%	20%	100%

	<p>Which of the following statements do you agree with the most?</p> <p>“The personality disorder service should maintain regular contact with PD patients throughout their lives.”</p> <p>“The personality disorder service should support PD patients for a limited period of time until they are able to manage their symptoms themselves and get back in control of their lives.”</p> <p>Tick the one that most closely reflects your views</p>			
	Limited period	Throughout	Unsure/can't say	Total
Health or Social Care Professional	80%	0%	20%	100%
Organisation	50%	25%	25%	100%
Public	15%	65%	19%	100%
Grand Total	35%	45%	20%	100%