Making Involvement Matter in Essex

NORTH ESSEX

COMMUNITY SERVICES REVIEW

SERVICE USER AND CARER

FOCUS GROUPS

FINAL REPORT

CONTENTS

Background

A review of community mental health services in North Essex is being undertaken by a steering group which includes representatives from commissioning and provider organisations. The group adopted an 'appreciative inquiry' methodology as they felt it was the most appropriate medium for the evaluation.

> **"Appreciative Inquiry is a** form of action research that attempts to create new theories/ideas/images that aide in the developmental change of a system (Cooperrider & Srivastva, 1987.) The key data collection innovation of appreciative inquiry is the collection of people's stories of something at its best…. These stories are collectively discussed in order to create new, generative ideas or images that aid in the developmental change of the collectivity discussing them."
>
> Bushe, Gervase, "Five Theories of Change Embedded in Appreciative Inquiry," presented at the 18th Annual World Congress of Organization Development, 1998.
> http://appreciativeinquiry.case.edu/intro/definition.cfm

As part of the first stage of their inquiry members of the steering group sought information from a number of stakeholders - a literature search produced data on policy and approaches used in other areas and consultations took place with staff and clinicians working in the services. Making Involvement Matter in Essex (MIME) was asked to seek the views of service users and carers who had experience of using North Essex community services, as key stakeholders, on behalf of the steering group to complement the information gathering already undertaken.

As a result, two members of the MIME team, who both have experience of using services and undertaking research from a service user perspective attended a meeting of the steering group on 8th April 2010 to discuss the brief. Following discussions with the steering group it was agreed that MIME would facilitate 2 focus groups to elicit information/stories drawn from participants' experience of using Community Mental Health Teams (CMHTs) in North Essex. In view of the geographical area to be covered it was decided to hold the groups in Witham on 26th April and Epping on 7th May.

Recruitment and Publicity

The steering group arranged for publicity (see Appendix A) regarding the groups to be distributed via the CMHTs in North Essex and MIME advertised the events both through its Newsletter and via the networks it had developed with provider organisations when recruiting members.

We were fortunate to secure the attendance of 22 individuals at Witham and 13 at Epping. Therefore 2 focus groups were held at each venue. Very few participants reported seeing the publicity in their local CMHTs but that may have been due to the time frame as service users and carers attend CMHTs for appointments with varying frequency. An advertisement in the MIME Newsletter and flyers sent to voluntary sector providers were more successful. We were particularly pleased that 2 groups of service users organised mini buses to get themselves to the events and that seldom heard groups were represented by participants from:

- Black and minority ethnic groups
- Dual diagnosis – Mental Health/Learning Disability services
- Supported housing services
- Forensic services

The publicity for the groups specified direct experience of using a CMHT either in the present or the past and when booking participants were again asked if they met the criteria. All the participants confirmed that they did although we are unable to confirm the accuracy of that information.

Information was prepared and sent to participants through the post prior to the events (see Appendix B) although we were unable to ensure delivery for a few individuals who booked close to the time of the event and did not have internet access.

Process

MIME's approach in facilitating groups is rooted in valuing the unique resource provided by experts by experience. To enable us to draw on that knowledge base and with the aim of demonstrating a commitment to genuine involvement we asked open questions in order to allow participants to frame the parameters of the discussion rather than using detailed predefined questions which may give the impression that facilitators are attempting to influence the data collected. The questions were devised in consultation with service user members of the MIME team.

35 individuals took part in the consultation (for ethnicity and gender see Appendix D) and 1 person who was not able to attend submitted comments in writing. The majority of participants belong to other communities of mental health service users and were able to draw on the experiences of their peers as well as their own individual experience in contributions to discussions.

COMMUNITIES OF USERS

PARTICIPANTS

DATA
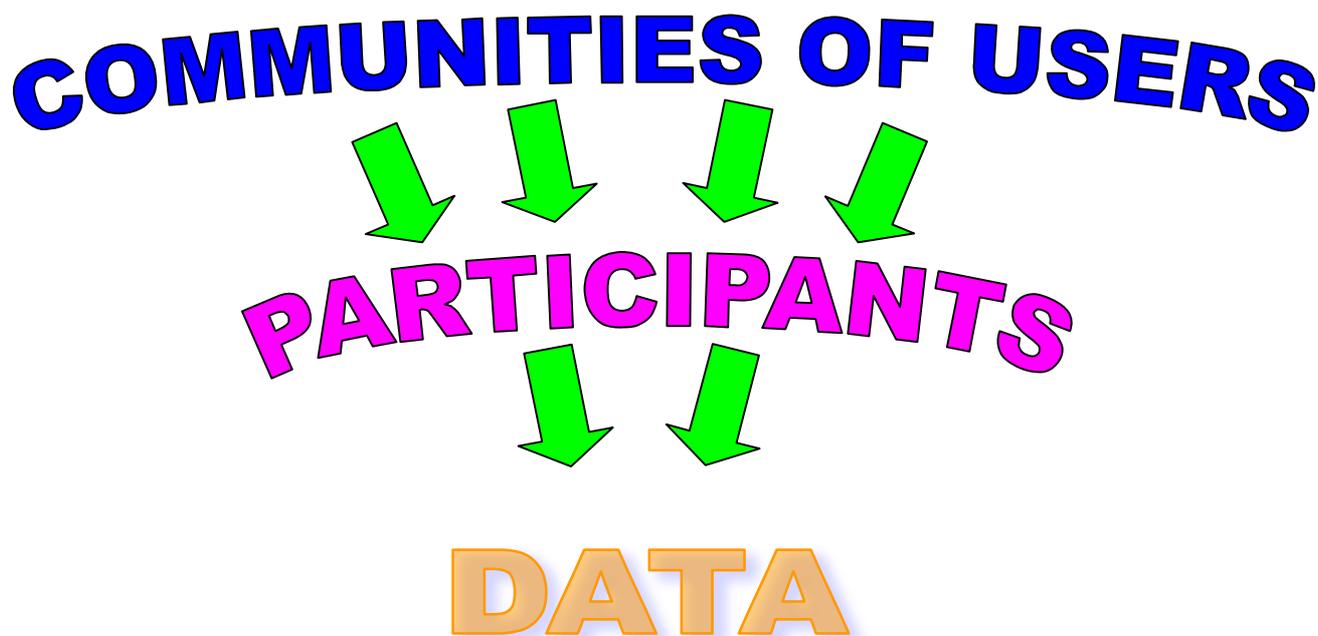
In order to enable the genuine participation of all those who attended we provided opportunities for individuals to write comments down as well as take part in discussions.

Both meetings commenced with lunch with the aim of creating a relaxed atmosphere and participants were split into two groups at each event to better facilitate discussions.

A brief introduction explained

- The purpose of the meeting,
- The stages of the review and the context in which the consultation was taking place
- How information would be fed back to participants (see evaluation below for more details)

We asked the following questions:

1. Thinking about your experience of using a Community Mental Health Team

    a) What do you think works well
    b) What do you think could have been better

2. If you were putting together a Community Mental Health Service

    a) What sort of services would it provide
    b) What skills would the staff need

A short break was provided between each of the discussions. The rational for using the word team in the first question and service in the second was that we wished to capture people's experience of using current provision, which is organised predominantly in team structures but also to encourage thinking outside the box for the future which may see reconfigurations with new pathways.

We would suggest that examining people's stories about their past experience can give powerful indicators of aspects they value and facilitate discussion of creative suggestions on how to address problematic areas. In this way, we hoped that a picture could begin to emerge of dynamic and innovative reconfigurations which were then available to inform the 'dream' sessions which we held in the second stage of the group discussions.

Collection and Analysis

In addition to their skills in running groups, the facilitators and note takers for all 4 groups had experience of using services, which we have found in previous groups helps to build trust and generate a safe space which enables open communication. Note takers concentrate on capturing as much as possible of what is said (see Appendix C). Then analysis can take place when all the notes are completed. Participants are given the opportunity to view the comments and clarify if they wish. In this instance we received no amendments. Individual comments are sorted and collated as themes begin to emerge.

When sorting and identifying themes the comments from each group were listed according to where the events took place in order to enable the identification of any potential differences in geographical areas. Participants at the event in Witham were predominantly but not exclusively from NE and Mid Essex PCT catchment areas and those in Epping were predominantly from West Essex.

Summary of Main Issues

> **<u>Some</u> of the themes that participants felt were important when considering how to develop high quality community services:**
>
> - The need for **consistency** and **reliability**
> - Widening access to a **variety of talking therapies** for individuals who use specialist mental health services as well as those who get support through their GP
> - The importance of providing **information** in a variety of formats about conditions, treatments and services to assist service users and carers in self help activities
> - The value of **social support** and opportunities for people with mental health problems to get involved in **peer support**
> - Enhanced **communication** both in terms of listening to service users and carers but also improving communication between teams
> - Offering more **training** to staff at all levels from a service user perspective and **increasing the numbers of staff who have personal experience of mental ill health** in order to facilitate understanding and delivery of a recovery based service
> - Improving **access** in terms of times and places where services are offered – **many people would prefer to access support through enhanced GP services rather than traditional CMHTs** but only if GPs can be offered further training in mental health which includes the service user perspective
> - The vital importance of a **good quality crisis service** which is an integral part of a community service
> - Information and support for **carers**
>
> These ideas emerged from discussions about what was valued and what participants felt would benefit from improvement in existing services as well as the 'dream sessions'.

Post It Notes were provided for those who did not feel able to say something in the group or wished to emphasise a point. The comments below came from Witham as participants at Epping did not take up the opportunity to write things down:

1 point you really want the commissioner to hear:

'Crisis Team' (2)   'More experienced staff for crisis team'
'Home calls'
'Don't let the psychiatric department dismiss occult, spiritual or religious issues'
'A drop-in centre with proper facilities where mental health people can meet & also get help & advice'
'More continuity of care (in all areas)'
'Continuity of care i.e. only seeing a few people regularly rather than what seems like a new person each visit'
'Why, because I am 70 years old that I am discharged and put on the forgotten list, thank you'

Comments taken from Evaluation Sheets

Witham	Epping
What do you think was the most important issue to come out of today?	
• 'Changes to improve community mental health' • 'Working together' • 'Meeting with service users from different parts of the trust, particularly when they have similar issues' • 'The post code lottery of services' (3 respondents) • 'Nothing' * • 'Users need more involvement' • 'Helpful for questions that I have asked' • 'A chance to have a say' • 'Everybody should be looked after as an individual. Services should be catered to different needs, age group – sex (M/F) and also religious interests' • 'Issues raised of continuity of care – also that a proper follow up after discharges from hospital by a social worker or other – CPN?' • 'Lot having some problems' • 'Consistency' • 'Still a lot to be done across the board – home visit a must for some	• 'Be able to express and hear feedback' • 'How to improve' • 'Listening to everybody's opinions and views' • 'Listening to everyone's points on mental health and what could be improved' • 'Time for change and services to communicate with each other better' • 'Early intervention rather than hospital admission after crisis' • 'Need for user led involvement at all levels of service development and service provision' • 'Meeting other service users in other situations' • 'Meeting different people in similar situations' • 'Information from other service users'

people' ***** One or two participants at Witham questioned whether it was worth contributing as they felt in the past their views had been ignored	

General Comments	
	• 'Nacro's helpful, • 'Mind is good, Harlow walk-in centre not so good' • 'More social groups and counselling, crafts, art, poetry, music recycling clothes making budget food which is healthy'

Anything you would like to add which wasn't discussed in the meeting:	
• 'The fact that people are not really sure that the people who make the decisions are guaranteed to take any notice what we say – just like they always have done' • 'Discharge against medical advice – if hospitalisation isn't helping then surely medical advice should be against it' • 'To go on courses put on by mental health service – if you get over level 2 NVQ you can't go on them' • 'Group meetings so we understand each other better' • 'I would like a discussion on psychiatric treatment in the hospitals'	• No (5 forms) • 'What facilities are on offer in the future'

| **Please indicate any follow up you would find useful**	
	• 'How information is used and how information improves services' • 'Any future meetings and "get togethers" for opinions of different people' • 'A leaflet or newsletter on what will change' • 'Finding out about services and groups that are available locally' • 'What is happening with our feedback' • 'Dissenting viewpoints should be highlighted' as well

Discussion of Emerging Themes

In choosing 'Appreciative Inquiry' as its methodology, the steering group had shown a commitment to undertaking a review which values that which is good in existing services and attempts to identify that which is not delivering quality and value for money in order to develop a new and innovative service specification which is in line with best policy guidance and draws on the views of clinicians and people who use services and carers.

The focus groups were designed to give some indication of the latter and we would suggest have given clear signals of the issues which are important to service users and carers. Similar themes emerged in comments around what service users and carers found helpful and less so in existing services and emerged again in thoughts about the future. The consultations also highlighted the obvious point that different people want different things from a community mental health service.

In order to illustrate our findings we would like to introduce you to the following people (they are composites made up from participants and the names chosen have no connection to any individual participants):
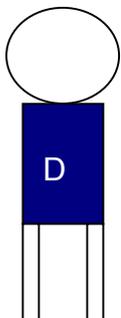
With apologies for lack of artistic flair and anatomical accuracy
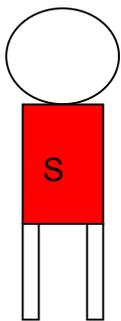
Sam has just been discharged from hospital following a first episode of a psychotic illness
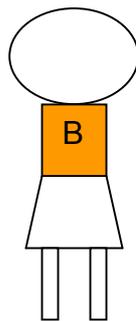
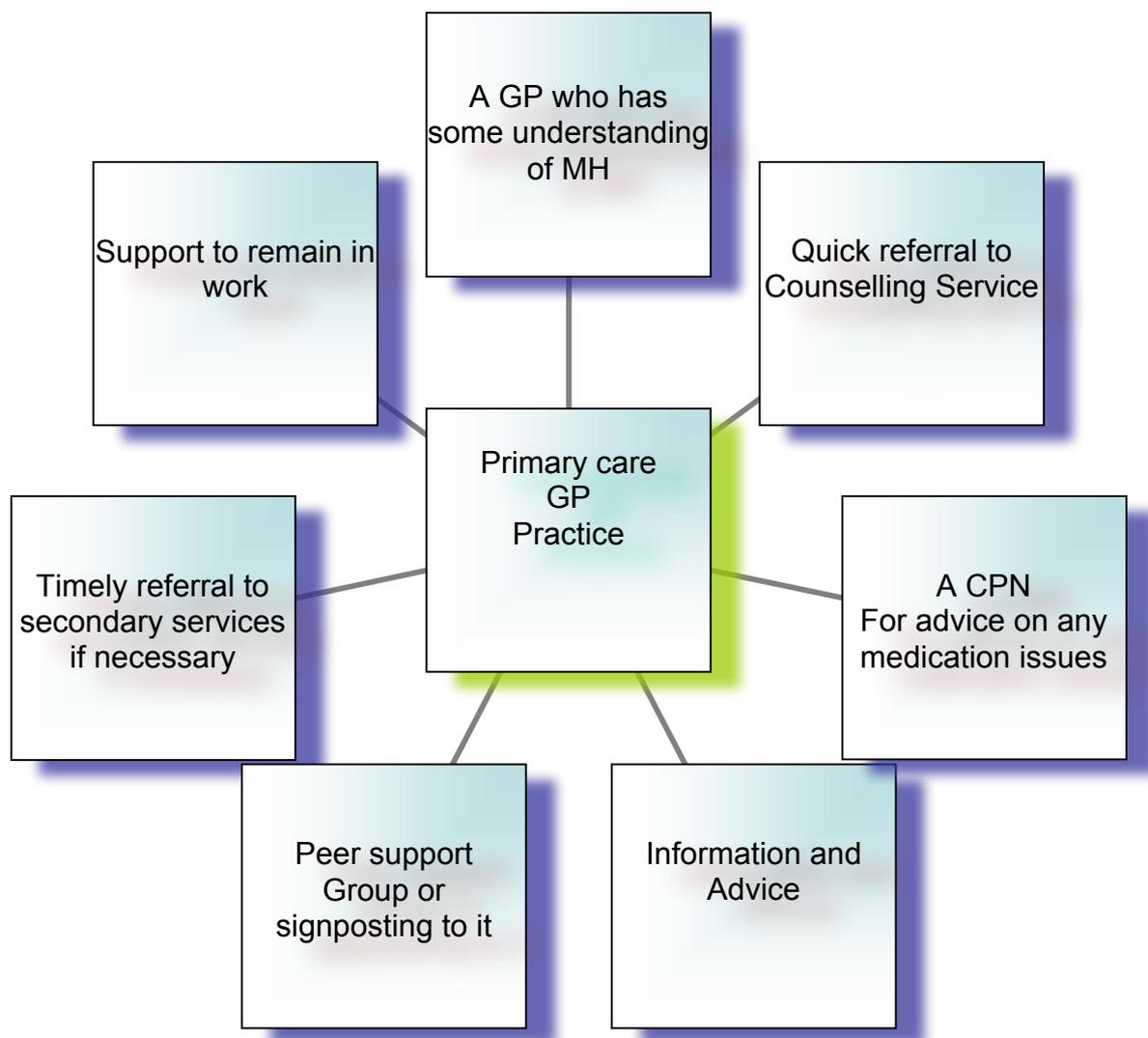**B**arbara is working but has been to see her GP with symptoms of severe depression & anxiety

David has been using mental health services for many years and experiences sudden changes in mood which can be severe enough to warrant intensive support either in hospital or the community
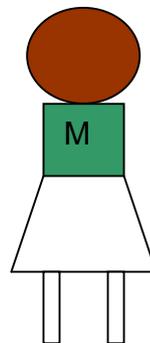
Mary cares for her son who has a diagnosis of schizophrenia

What does Barbara expect?

Primary care GP Practice

- A GP who has some understanding of MH
- Support to remain in work
- Quick referral to Counselling Service
- Timely referral to secondary services if necessary
- A CPN For advice on any medication issues
- Peer support Group or signposting to it
- Information and Advice

Many people with symptoms of a mental health condition seek help initially from their GP. They want to know that the person they see has some knowledge of mental health issues and/or can call upon specialist advice without having to make costly and time consuming referrals to secondary services.

Service users want information and advice on the symptoms they are experiencing and choices of treatment with many preferring to try some form of talking therapy before resorting to medication. Choices of group and 1:1 have been suggested. They are open to advice on self help and look for sign posting to sources of reliable information. Should they decide with their GP that medication is appropriate they would look for support with side effects etc in the same service, perhaps from a community based psychiatric nurse (CPN).

Basing CPNs, therapists, social workers and peer support workers in GP practices is a possible solution to the problems highlighted by service users around communication problems between services/agencies and may be cost effective as it reduces the need for specialist buildings. One way forward in areas of sparser populations might be to attach

staff who might traditionally have worked in specialist buildings to clusters of GP practices where they could spend time in different areas on different days. They would also be a ready source of support to GPs who are less familiar with mental health conditions, which many participants highlighted as an area of concern*. They might also help to reduce the number of inappropriate referrals to secondary services which are not only expensive but also can delay the beginning of treatment with all that means in terms of additional distress and increasing difficulty in symptom reduction.

As Barbara is working she has some IT skills and participants in other consultations have shown that they would welcome information and support in a variety of ways including web based formats.

* This may have assumed added importance following the publication of the Government's White Paper – 'Liberating the NHS'. Participants' experiences show that where GPs have an empathic understanding and a good awareness of mental health issues it is valued highly but the majority of participants when referring to experiences in their local practices talk of poor listening skills and lack of knowledge, which they often attribute to training deficiencies and lack of time.

What does Mary expect?

Carers concerns centre around support for the person they care for and for themselves. They want general information about the condition of the person they care for, the treatment options that may be offered and advice on how they might make a positive contribution to the care of the service user. They are often anxious to share their personal knowledge of the service user with professionals and be treated as a respected partner in the care offered.

However, both carers and service users in this and other consultations undertaken by MIME have consistently emphasised that it should be the service user's choice on how much they are involved.

Support for carers is a complex issue in mental health. While many service users are happy to have their carers fully involved in care planning a significant number are not. But this should not mean that carers are then left to their own devices. Carers report that they need information and support regardless of whether their cared for person is happy for them to be fully involved.

Offering a listening ear and reliable information can go some way towards meeting their needs – hence the suggestion in the data that carers need Befrienders as well as service users. Some carers have told us that they find peer support groups helpful, others who are heavily involved in caring prefer telephone/web based support as they may not feel they can spare time away from a vulnerable friend or relative. One carer in this consultation suggested scheduling group activities for carers and service users at the same time so both are free to attend. For those who are struggling to care for individuals who are very unwell respite care can provide a much needed break.

Joint information sessions for carers and service users for physical health issues have been successful in many areas and the steering group may wish to consider a similar service for mental health as the need for reliable information on both conditions and services available is consistently cited as crucial by both groups. Participants in this and other consultations have suggested participation by existing service users and carers in sessions for those who are newly diagnosed would be valuable.

Working with carers requires sensitivity. Even where the relationship between service user and carer seems very close it is good practice to offer both the opportunity for time to speak to professionals on their own as a matter of course. Both may have concerns they wish to discuss with professionals but be reluctant to voice them in front of the other for a variety of reasons. Merely asking if either wants to talk on their own in the middle of a joint interview may not be sufficient as each may not wish to give the other the idea that they are not being open or have a hidden agenda.

Our carer, Mary, may also have additional concerns as her family come from an ethnic minority group and she will wish to be offered services which are culturally sensitive. Liaison with a Community Development Worker service may be a useful way for professionals to ensure that the service they offer is appropriate. A Chinese service user at Witham was particularly insistent that services need to be responsive to individuals' cultural needs, intergenerational and gender differences.

What does David expect?

David may have been supported by CMHTs for many years and have experience of using hospital/residential services and statutory and voluntary sector provision in the community. Most of the people who came to our consultation drew on their experience of using those services to make suggestions.
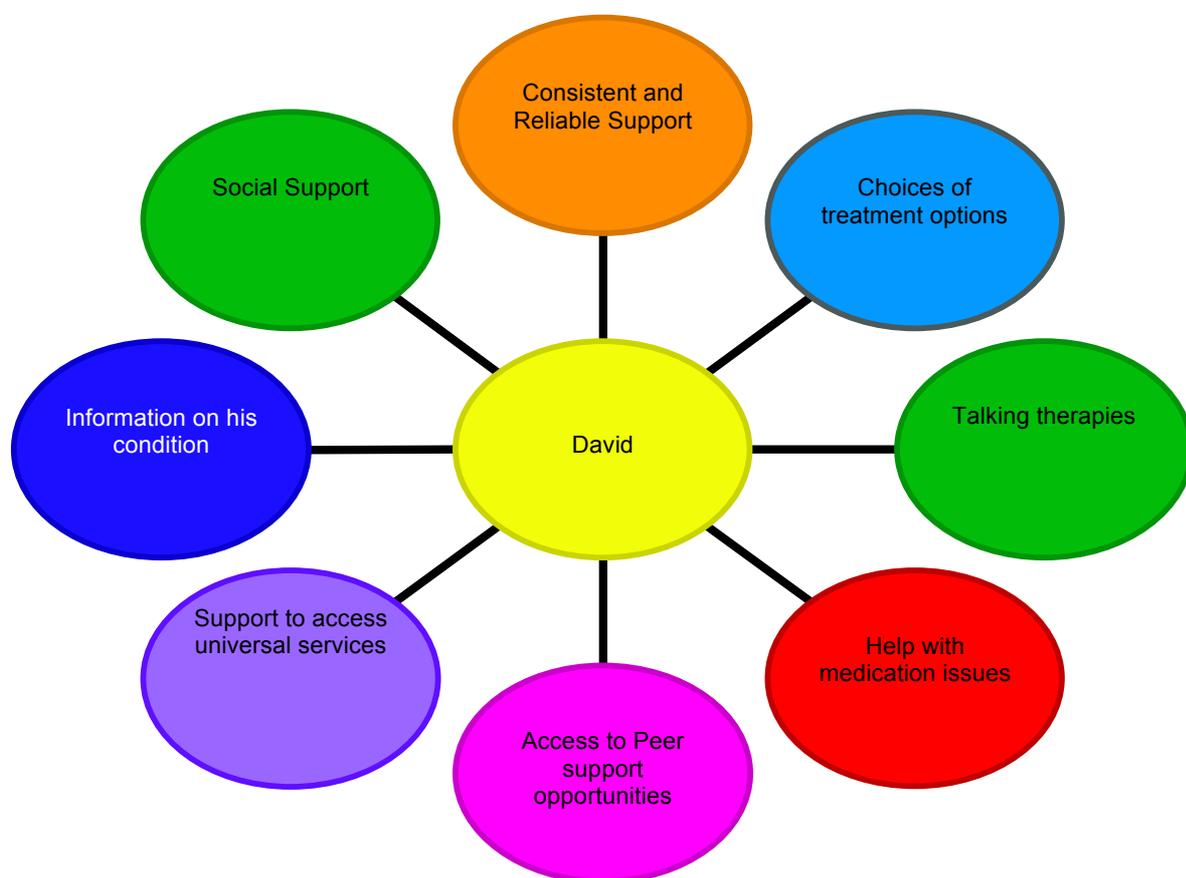
Underpinned by a

Reliable Crisis Resolution and Home Treatment Service

When asked to reflect on their experience of using existing services, David's peers consistently highlighted the importance of knowing that if they experienced a crisis there was someone there to help. Unfortunately all too often they gave examples of the existing service not meeting expectations.

Many participants in this and other consultations undertaken by MIME have said that they would prefer to access ongoing support for their mental health issues in the community in a generic service and most have mentioned either a GP practice or one of the new walk in clinics. The advantages they suggest are:

- It's close to home which is an important consideration, particularly in rural areas

- They feel it is less stigmatising
- Their physical health needs can be addressed in the same service where they can have holistic assessments which address the needs of the whole person more easily (there is some evidence to suggest that the physical health needs of service users with mental health conditions are not always addressed adequately)

David and his peers also unfailingly call for improved communication at the inter-agency/team and interpersonal level, as the comments in Appendix C show, and stress the importance of improved training for all staff in listening skills. They advocate including administrative staff in this as they are often the people they meet initially or when they are distressed and seeking additional support. They also highlight the importance of involving service users in professional training and increasing the number of people with lived experience who are employed in mental health services as the best way to enhance the delivery of recovery based services.

Service users value the quality of support they are able to give and receive from each other and therefore would consider opportunities for and signposting to peer support as an essential component of any community service. At the same time they are open to policy initiatives which encourage the use of universal services but would stress the importance of being given adequate support and information to make the transition.

Discussions in the groups revealed that many service users value social support more highly than medical interventions when considering quality of life issues rather than just symptom control. Although they are open to support to access activities in the community, past experience of stigma has led many to value the acceptance and empathy they received from peers in drop-in centres. The steering group may be tempted to dismiss requests to reinstate drop-ins as irrelevant but it may be useful to consider how opportunities for peer support might be provided as part of a revised service specification as a way of addressing a need which many service users would assert is not being met at present.

In this way what can at first look like a disappointing attempt to return to outmoded methods of service delivery, can be seen as a useful indicator of ways to move towards consensus with stakeholders on future planning.

Finally, the new government's avowed intention to get people off benefits and back into work makes the comments around training and support to regain employment relevant.

What can Sam expect?

Sam and his peers may have benefited from improvements in early intervention services but still be in need of appropriate further support in the community. We found that younger participants who had used services for much less time than David were anxious to avoid hospital and looked for and valued good quality support in the community when they experienced further crises.

They are more open to accessing universal services and more averse to being confined to specialist mental health services. Many said they did not wish to be constantly reminded of their mental health condition nor be defined by it. Although it was not raised in these focus groups the use of chat rooms and web forums has been highlighted as helpful in other consultations particularly by younger participants.

They share an interest with peers who have used services for longer in finding meaningful activities to engage in during the day and are scornful of outdated occupational therapy groups which fail to stimulate interest or offer useful new skills.

They were more likely to highlight the value of volunteering, training and support for re-entry to employment as a valuable component of the service they wanted. In groups, some showed that they had the potential to develop as peer advocates for service reconfigurations which supported recovery based working. But they were also empathic towards the anxieties of peers who had seen many service changes in the past and were still mourning the loss of services they valued.

Conclusion

We would suggest that all the comments detailed above are viewed as useful indicators of how service users and carers will judge future recommendations for service reconfigurations. An initial scanning of some comments might tempt members of the steering group to view any negative views expressed as disappointing in the context of their methodology and to dismiss others as irrelevant in addressing the specific questions that the steering group is hoping to answer.

However, we would argue that all the comments are useful if they are carefully analysed. With regard to the comments in Appendix C that are not specific to this inquiry for example, we would argue that service users and carers often tend to have a holistic view of the support they receive and either actively choose not to or are unable to look at its component parts separately. This can be seen as a strength but can also create frustration on the part of practioners who have chosen or been constrained to review or consult only on a specific service.

However, from a holistic viewpoint there is value in considering comments such as those which relate to work traditionally undertaken by Crisis Teams as service users consider the quality and availability of support they may require when experiencing a deterioration in symptoms as a crucial component of community services.

The balance of comments regarding the service provided by Crisis Teams in this and every consultation we have facilitated is overwhelmingly negative. The one positive comment made by a Carer in Epping was so far outside most participants' experience that it was greeted almost with disbelief.   However, the service she described was one which others would like to see in a new service but perhaps delivered as part of a single service

rather than a separate team. They felt it would be advantageous to have the service delivered by professionals who knew them and there would be less opportunity for sending people backwards and forwards until one team eventually takes action.

Comments which arose around early intervention for all mental health conditions and suggestions on work that could be done with young people can also be seen as part of this holistic view and appear to fit with both the aims of New Horizons and World Class Commissioning. But we appreciate that commissioners are also working with the legacy of the National Service Framework which tended to focus on team development like Crisis Resolution Home Treatment and Early Intervention in Psychosis.

In the past it has been argued that negative comments are not useful as they relate to past experience and service user 'complaints' should be ignored in the context of planning for the future. We would argue that complaints can often give indications of the value service users place on certain skills and types of support and should not be dismissed because they are not framed in optimistic concrete suggestions for future planning.

The most obvious example is the continuing complaints around day service reconfigurations, which may have been an important contributing factor to the angry outbursts which occurred at the beginning of the Witham event. Faced with what seems an irrelevant attempt to go over old ground it would be easy to dismiss the comments as a waste of time. But careful listening even in difficult circumstances can uncover useful indicators which are helpful in terms of future planning.

Service users at the events were quick to raise the spectre of disappointing consultations they had engaged in with previous user involvement initiatives where their views were given but they never received feedback on how they might have been used to inform decision making.

With that in view, we hope that this report provides a useful contribution to the work of the steering group but would emphasise that MIME is committed to keeping participants informed. We therefore look forward to an opportunity to discuss our results and receive feedback which we can use to both improve the way we work and pass on to participants in order to demonstrate that the groups were **not** 'a waste of time'.

Evaluation and Lessons Learned - Witham

We were extremely pleased that 22 people attended – many of them had not previously participated in involvement activities. It was a diverse group in terms of gender and age although some groups were under represented e.g. younger people and people from BME communities. We were also delighted that almost everyone was able to contribute to discussions verbally and we gave people the opportunity to write things down if they were not able to talk in the group and to send in notes if they were unable to attend. We were also able to assist 2 participants who were unable to read or write.

One participant in particular was extremely anxious on arrival, unable to make eye contact or help herself to refreshments and we were asked by her support workers to ensure that she sat with a facilitator at all times and was accompanied if she needed to leave the room. With a great deal of support and encouragement she was able to express her views in the group and when we were seeing her back to her transport she smiled and said 'I feel important.'

In spite of an inauspicious start (see below) a useful discussion took place which enabled service users and carers to express their views and give clear messages about their present experience and indicators of their hopes for future services. Many of the ideas expressed mirrored views from previous activities MIME has facilitated.

At a previous consultation service users had said they felt that commissioners should be there 'to hear what we have to say'. Subsequently commissioner involvement in two training sessions had been valued by the majority of participants but had also been a focus of disruption for some service users who were angry at their perceived loss of services.

As a consequence the MIME team have mixed feelings about the involvement of commissioners in consultation events. On the one hand, we acknowledge that commissioners naturally wish to take part in consultations and agree that service users and carers are entitled to feel that commissioners are listening to their views and attendance at meetings is one way to demonstrate that. On the other hand their presence can present challenges in terms of maintaining the focus on the primary purpose of the meeting especially when time is limited as participants can feel that they need to seize what they perceive as a rare opportunity to bring complaints and issues of concern to commissioners' notice.

On this occasion the commissioner's presence may have been a trigger for angry outbursts by some participants. Very similar views and anecdotal evidence were expressed at the JSNA consultation but without the accompaniment of similar behaviour. On that occasion a commissioner was not present. It will be for commissioners to reflect on these issues and come to their own conclusions. We are well aware that consulting successfully is a complex undertaking and the occasional expression of anger in a meeting may be the price we pay for genuine involvement.

An additional factor that may have contributed to the tense atmosphere was that the most vociferous participants asserted that they had previous unsatisfactory experiences of user involvement initiatives where they expressed their views but never received feedback.

We split the group into 2 smaller focus groups for discussions following the introduction but some participants felt that holding both groups of 11 people in the same room made it very noisy and difficult to hear and one person said that although the group had been split into

2 groups of 11 – this was still too big for him and suggested that a group of 5 to 6 participants would be easier for him to handle.

Further consideration needs to be given as to how we might continue to consult as widely as possible but also manage the anxieties of participants – some of whom may be quite unwell. It is possible that participants would have found the larger groups easier to deal with had it not been for the anger expressed at the beginning of the meeting. Also had we more space and additional team members we could usefully have split into 3 groups.

Some participants were pleased to hear that the commissioner would get back to them with advice on how and where to complain when initial complaints are not dealt with by provider organisations to the satisfaction of the person making the complaint. This was a welcome initiative as the issue has come up at every event we have organised and has been passed on to commissioners previously.

As a result of reflecting on the Witham event the following actions were agreed for the Epping consultation:

- Increase the number of MIME staff attending
- Give a much briefer introduction

    a) Emphasising the importance commissioners attach to involving service users at the information gathering stage.
    b) Explaining that the steering group are also gathering information from policy documents, staff and other areas of the country
    c) Outlining further opportunities to participate in next stage
    d) Reminding participants that the aim of the consultation is to improve services in the future
    e) Stressing the importance of maintaining a focus on the task in hand but giving advance notice of further wider consultations where service users will be offered the opportunity to discuss and comment on services generally in order to pre-empt any attempt to divert the focus of the meeting towards a discussion of 'complaints'

Evaluation and Lessons Learned – Epping

13 people attended and we were particularly pleased that some service users from a NACRO supported housing project were able to attend and a person with a dual diagnosis (MH/LD) - both represent seldom heard groups. Following on from the lessons learned at the Witham meeting, a few changes were made to the format:

- More staff were available which made it easier to maintain a focus on the task
- The partnership coordinator did the introduction as it was felt that on the previous occasion the commissioner's role in introducing the event may have given some people the opportunity to open up a wider discussion which made it difficult for others to focus on the task in hand once discussions started
- However, it was clear that participants' valued the fact that a commissioner was there to hear what they had to say

The atmosphere at the event was much more relaxed and less confrontational than the consultation in Witham. In addition to the actions taken above there may have been other factors which contributed to a more relaxed debate:

- The venue (larger with better acoustics) and lunch (both quality and quantity) were better
- The number of participants was smaller
- There did not seem to be the same level of distress attributed to previous service reconfigurations
- Some of the participants had previous experience of attending involvement activities within the services they used so they were familiar with the process
- There seemed to be slightly more positive comments about the services in West Essex than we had about NE and Mid Essex

The topics which came up in discussions were on the whole broadly similar to those which arose in Witham. However, it was noticeable that some time was spent in one group on issues which were not considered as important by participants at Witham – such as medication. This could mean that it was a particular issue for this group or that a specific supplementary question was asked which was not used in the other groups.

This is an issue we will review with facilitators in feedback and it may be useful to have a general discussion on this within our team as we would not wish to flag something up as an important issue when participants only spoke about it because they were prompted to do so.

One issue which came up at this event for the first time related to volunteers - one service user suggested that the statutory sector should learn from the voluntary sector and use volunteers to widen the scope of the services they can provide and even went so far as to suggest that CMHTs could link with providers of counselling training to offer placements to students in order to improve the availability of counselling without incurring extra costs. Both ideas were welcomed by his peers.

A carer at this event talked in extremely positive terms of the services she had managed to access for her cared for person which appeared to surprise other participants. The fact that she appeared to be a very articulate, white, middle class woman may have some bearing on the services she managed to secure.

APPENDIX A – FLYER

Anglia Ruskin University

Making Involvement Matter in Essex

NORTH ESSEX COMMUNITY SERVICES REVIEW
Service User and Carer Focus Groups
26th April – Witham - 12.00 – 3.30pm
7th May – Epping - 12.00 – 3.30pm

All services are reviewed on a regular basis to assess whether they are meeting the needs of the people who use them. MIME has been asked to facilitate some focus groups for service users and carers as part of the current review.

If you use a Community Mental Health Team (CMHT) your views are important. Come and tell us what you think works well and what can be improved. We will tell you about the review and how you will hear about the result.

The groups will start with lunch so we can get to know each other. We can pay your travel expenses on the day and there will be a thank you gift of £15.

Don't be left out – contact us today for more details and to book a place:

☎: 0845 196 4131 – we will be happy to call you back

💻: involvement@anglia.ac.uk

▤: MIME, Anglia Ruskin University, William Harvey Building, Chelmsford Campus,   Bishop Hall Lane, Chelmsford, CM1 1SQ

APPENDIX B – PRE EVENT INFORMATION
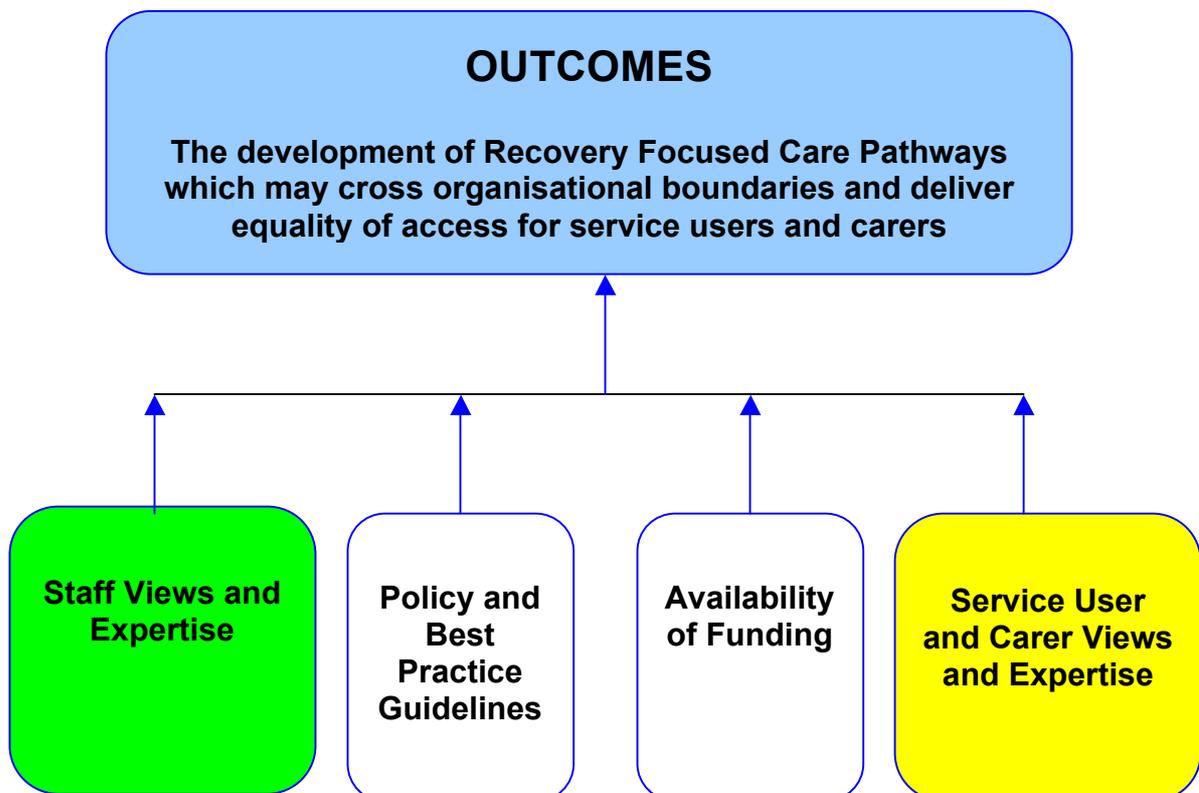
Making Involvement Matter in Essex

Community Services Review

Service User and Carer Focus Groups

Date	Venue	Time
26th April	Room A, 8 Collingwood Road, Witham, CM8 2TT	12.00 – 3.30pm
7th May	Epping Hall, St Johns Road, Epping, Essex CM16 5JU	12.00 – 3.30pm

Mental Health Commissioners in North Essex are looking at Community Services and in particular the services provided by existing Community Mental Health Teams (CMHTs). The Review aims to develop proposals for an improved service which is informed by current policy and best practice guidelines.

An integral part of the review is the parallel process of consulting with both front line staff and people who use services in order to provide the best possible outcomes.

OUTCOMES

The development of Recovery Focused Care Pathways which may cross organisational boundaries and deliver equality of access for service users and carers

Staff Views and Expertise

Policy and Best Practice Guidelines

Availability of Funding

Service User and Carer Views and Expertise

Stages of the Review

Stage 1 - Information Gathering

This stage enables the team to bring together the information which will inform the decisions they make. It includes:

- A review of current policy guidance, any relevant research findings and information about how other organisations are providing a service (Literature Review)
- Looking at what is provided currently via monitoring information
- Expert consultations – practitioners and service users and carers

Stage 2 - Developing Proposals

Drawing on the information provided in the first stage, the Review Steering Group will put together some draft findings.

Stage 3 - Vision Workshop

Meeting to provide the opportunity for all stakeholders to discuss the draft findings and develop proposals for improved service provision

Stage 4 - Options Paper

Following the Vision Workshop and utilising the ideas generated in discussions, the Steering Group will produce an options paper which will be circulated to stakeholders for comments

The advantages of undertaking the review in this way are that

- It provides an opportunity for all the stakeholders to share their expertise
- It identifies relevant information which helps to inform decision making
- It enables stakeholders to have joint ownership of the proposals

Initial Information emerging from the information gathering stage shows that CMHT's do not offer the same service across North Essex. There are differences in terms of:

- the skill mix of staff – the different types of worker in the teams
- caseloads – numbers and complexity – the number of people they work with and the issues they have
- talking therapies available
- funding – how much they receive which affects what services they can provide
- criteria for access – how people are referred to CMHT's and who can be referred
- the way they manage access to specialist services such as Assertive Outreach, Early Intervention in Psychosis and Crisis Resolution Home Treatment

In addition there is little robust evidence of outcomes – what they achieve.

**FRAMEWORK FOR SERVICE USER AND CARER
FOCUS GROUP DISCUSSIONS**

Making Involvement Matter in Essex (MIME) has been asked to facilitate two focus groups to seek your views on the CMHTs you have used. We thought you might find it helpful to think about the following questions before coming to the meeting and if you wish you can make notes to remind yourself of the most important points you wish to get over.

Thinking about your experience of using a Community Mental Health Team	
What do you think works well?	What do you think could have been better?

If you were putting together a Community Mental Health Service	
What sort of services would it provide?	What skills would the staff need?

On the Day

- When you arrive you will be given a **form to claim your expenses** and a monitoring form. We have to provide statistics on the number of people who attend – you do not have to put your name on this form. We realise that some of you may not like filling in forms but there will be plenty of people there to help if you do not wish to complete the form yourself

- We will then have **lunch**

- After lunch we will **explain the review** and **your part in it.**

- Then we will split up into smaller groups and discuss the questions on the previous page. **The people who will facilitate the discussions are also service users**

- As well as the questions we have suggested, there will be time allowed for you to share any other thoughts you might have about CMHTs

- We will also provide large post it notes so that you can write down the most important point you want to tell Commissioners or anything you have not been able to say in the discussion

- At the end of the meeting we will explain **what happens next** and ask you how you think the meeting went

- We hope that you will be able to tell us at the end of the meeting **what you think is the most important point that you wish Commissioners to hear**

- Before you leave you will receive your expenses and thank you gift (£15)

We know that filling in forms is often the least favourite part of a meeting but we genuinely want to learn from you how we can improve what we do so we will be grateful for any feedback you can give us.

We look forward to seeing you on the day and hope that you will enjoy the meeting!

APPENDIX C – NOTES OF GROUPS

Experience of Existing Services

Thinking about your experience of using a Community Mental Health Team – what do you think works well?

The issues which came up fell into the following broad themes:

Witham	Epping
• Consistency • Choices • Medication • Relationship • Talking therapies • Buildings/Location • Carers • General	• Consistency • Reliability • Response in time of heightened need • Communication • Talking therapies • Buildings • Carers support • General

The order of the above has no particular significance. Some comments are verbatim (in inverted commas) – others summarised.

Comments and Themes

Witham	Epping
Consistency	
• 'Regular contact with the same CPN fortnightly' • 'Seeing my support worker every week' • 'Having a named worker to see'	• Consistency, I had a steady person there all of the time • If I have one constant in the team it really helps • It helps if more than one worker on the CMHT gets to know the patient, not just passing on information about them at team meetings, but really getting to know them • 'I had the same worker for 5 years which was really good'
Reliability	
	• I found them all right – they're in it for the long term – they give you time • They hang on to you – until they are sure you are ok – 'she won't let go' until I am able to cope well

Relationship and Communication

• 'I had 2 CPNs – this was more than a job for them – it was a vocation. They have really been a lifeline.' • Helps me 'when they take a personal interest in you'	• I feel I can talk to the CMHT and they won't judge me, but will help me, that's how I want them to be • It helps having CMHTs because often friends and family do not understand how you feel

Talking Therapies

• One person valued the psychotherapy she had in the past and is getting again following deterioration in mood.	• Talking therapies do help – it helps to solve problems and helps you to be independent. Group or 1:1 sessions can be therapeutic

Choices

• 'My psychiatrist gives me options which I like…'	

Carers Support

	• Carers morning is good – food, advice and discussion

Buildings/Location

• 'Everything is in the same building' • 'Having a water machine is good' • 'Having a room to talk in and not a broom cupboard'	• Having music in the waiting area was a good distraction when I was waiting to see the doctor as it is always an • anxious time when having a review

Medication

• 'My CPN is good – makes sure I take my medication etc' • It's good 'when they get the medication right'	

General

• 'A lot of people have moved on' • 'Having appointments different days and different times' • 'The information you get by word of mouth by other service users is the best guide to a CMHT'	• There are lots of services in CMHT – smoking cessation, Employ-ability, CBT • They are good when they have knowledge of local services e.g. bridgebuilders, voluntary groups

Response in Time of Heightened Need

	• 'I think the CMHTs are brilliant – in an emergency I can ring up and talk to someone. We've been using the service for 20 years with no problem' (carer) • 'When you need hospital they do

	everything they can to get you in'
	• If you really need to go into hospital they will find you a bed even if it meant going into Sutton Manor. If someone really needs help they put themselves out
	• I need the CMHT because I need someone to monitor if I am coping or not as I don't always know if I'm not well

Thinking about your experience of using a Community Mental Health Team – what do you think could have been better?

The issues which came up fell into the following broad themes:

Witham	Epping
• Lack of consistency and reliability • Poor communication • Access • Lack of information • Lack of response in times of increased need/risk • Poor access to talking therapies • Carers issues	• Lack of consistency and reliability • Poor communication • Lack of information • Lack of response in times of increased need/risk • Lack of support around medication issues

Comments and Themes

Witham	Epping
Lack of consistency and reliability	
• 'There is a post code lottery' • 'No consistency of service' • 'No continuity of care when staff leave – you're left without a CPN for ages' • 'A lot of people don't turn up for their appointments'	• Don't like 'constantly changing staff' • 'Kept promising a CPA and it didn't happen' • I had a support worker for 3 or 4 days a week then it was reduced to less days then they left, it felt like a kick in the teeth, I had put all my confidence into this person • When I kept seeing someone different they all had different ideas and suggestions, its confusing plus it causes more anxiety • I hate having to change staff • It's the same with doctors they are constantly changing because of their

	• rotation • It is important how a change of worker is managed, we do understand that sometimes it cannot be avoided

Poor Communication

• 'Some staff make you feel they are just going through the motions' • 'An understanding by admin staff that you are not at your best and likely to act unexpectedly' • 'They promise to ring you back and then don't' • 'They ask why you missed an appointment and you didn't know you had one'	• One participant who also has a learning disability said 'I couldn't understand a word the psychiatrist said' 'he knew I had a learning disability' • Poor communication • Sometimes I didn't know what was happening or who was coming, I needed more information • Links with GPs and CMHTs are not always that good, sometimes the two might link better and then physical health and mental health are both treated together and linked up. Physical health problems can have a significant impact on your mental health • CMHTs should be referring to other CMHTs out of area • Doctors talk in jargon – they need to speak in 'plain English' • Admin/reception staff should be more understanding and informed , they are difficult people and are 'unsympathetic' and 'jobs worth'' in their attitude • 'Sometimes I think they pick the wrong person for the job'

Access

• 'I don't like having to go to the CMHT all the time – I'd like home visits sometimes' • 'After I've come out of hospital I don't want to go anywhere that reminds me of it' • 'My psychiatrist says now I am 70 I can't use services anymore – I don't understand - what am I supposed to do – I'm left with no support and I'm not well'	

Lack of information

• 'There's not enough information on what is available in the way of groups' • 'You're not told anything' • 'They don't explain why they are making decisions' • 'There is not enough information' • 'People don't know about direct payments – there needs to be a clear pathway' • 'Staff need to give you an idea of how they are going to help you' • Not given 'a knowledge of what else goes on in CMHT like what groups do or what else goes on – an introduction to other staff members (and who they are) that you are likely to come into contact with'	• If you don't know what's available you need to push and push – when you are unwell you are less capable of sorting things out • Lack of information from CMHT on what's available

Lack of response in times of increased need/risk

• 'When you are ill you need help fast but you don't get it' • 'If you have a condition which comes and goes you should be able to fast track back into services instead of having to wait ages for help' • 'When I'm not well I stop answering the phone and going to appointments – nobody checks up on me and I can't ask for help' • 'When your behaviour changes staff should check up – people are left – its dangerous' • 'It's useless asking if people are suicidal – when you feel like that you don't want to say especially if you have been sectioned in the past' – staff should be able to read the signs	• I need the CMHT to help prevent me going into crisis, I need help at the right time, sometimes they are too late intervening • Dovercourt only does support over the phone they don't do home visits

Poor Access to Talking Therapies

• One person said they felt guilty they were getting psychotherapy because so few can access it • 'Psychotherapy might be available but the waiting time is far too long' and when you get it – it's for too short a time – you just get to trust the person and it stops	

Lack of support around medication issues

	- There's not always enough CPNs to go round. I was put on the wrong meds – if they had been monitored properly I wouldn't have become so unwell - Getting used to medication is not easy – need more understanding around that - When medication is changed you can really feel quite vulnerable - He came off on his own – lost 7 stone – but we are doing a lot more than we used to - I always fight to stay off medication, the CMHT could help with that - There should be a range of medication options and these should be explained, but the staff don't always have the skills to discuss this, they don't always understand the medication themselves so are afraid to discuss it with you - More work on insight into my issues would help me with compliance - There should be more open discussion around medication with SU and CMHT, and GPs. SU's should be told where they can research to find out more but in a safe way to understanding medication without being frightened. As leaflets in medication packs can be scary when you read what you might get – one SU said medication to help depression said you might get depression, so this can scare you/put you off from taking. It seemed that services are scared to talk to SU's about medication. - There should be more positive risk taking for us to have medication breaks. Medication breaks and changes in medication should not be based on the team having staff to increase support and visits but what is best for me - I've never been told anything about my medication - I believe there would be less non compliance if medication was explained properly

	Nicola said we now have more pharmacists in the trust which should help
Carers Issues	
• 'Not enough support and information for carers and family members' • 'I didn't like my last care coordinator – he didn't talk to me – he only spoke to my mum not me. But I like my new one he speaks to me on my own'. • The comment above provoked a general discussion in the group which felt quite strongly that carers should only be involved if the service user gives permission	

Future Services

If you were putting together a Community Mental Health <u>Service</u> what sort of services would it provide?

The suggestions which came up fell into the following broad themes:

Witham	Epping
• Access/hours • Consistency and reliability • Flexibility and transparency • Good communication • Choices of talking therapies • Other therapies • Peer support • Ethos • Support for employment	• Access • User led/focussed • Flexible & transparent • Good communication • Early/Timely Intervention • Volunteers • Talking therapies • Complimentary therapies • Social support • Carers • Advocacy/legal issues

Comments and Themes

Access & Early/Timely Intervention	
• 'In an ideal world we would have a 24 hour system although this is not likely, but we do need more than a Monday to Friday 9 – 5 service' • A few wanted access 24 hrs a day even if some of it was telephone only but others just wanted longer opening hours • 'A team approach not individual – so always covered' • Don't use 'out of hours services – if you had your own group they would know what/who you are' • 'One dedicated member of staff per day for emergency/crisis' • Many wanted the option of home visits – 'I don't want to go anywhere near the hospital – too many bad memories' • Many wanted choices – 'being able to go and see someone, or talk to someone (on phone) or home visit' - 'There should be somewhere you can go or they would come to you' • We have the Crystal Centre (65+) where the CMHT are 'on the spot'	• 'Easy accessibility in its broadest sense' • Quick referral process and early intervention teams for all first onset • There should be easier access to support and counselling before secondary services are brought in – including peer support and self help • Quick referral times are key and quick access to services before a crisis occurs

• Some preferred access to specialist help within their GP surgeries but felt their GP didn't know enough about mental health and they would like to access support 'they could rely on … like a CPN in the doctor's' • 'A 14-16 hour contact service – if not an open service manned by someone who at least knows who you are' • 'Negotiation on appointment days and times'	
User Led and User Focused	
	• When services are more user led • Advice on how to set up user led groups • Peer support workers • I would like to see more service users as support workers, qualified or not, they understand what you are going through • SU suggested having a 'Circle of Support' like Learning Disabilities Model. You say who is in your Circle and they can then contact services on your behalf when you are unwell – might be family or friends (especially as family might be one of the problems). The circle also meet to discuss with you what care you need/want and these meetings can be with services on certain occasions. • Getting rid of labels
Flexible and Transparent	
• 'It would be very flexible' • 'Loneliness is a problem for some – need more support' • 'Thought needs to be given to people who need extra support' • 'Services which take into account people's individual needs in terms of age, gender, culture etc' • If a member of staff and client has a personality clash, they should be able to change without blame attached. You should know what you are getting/entitled to	• I would like there to be clear decisions and the service user told what they are

Good Communication

• 'Punctuality or an automatic notification as to amount of delay'	• Automatic sign posting system • Links between the AOT, CMHT and crisis team to make the service more seamless • Physical and mental health teams should work together • Teams to communicate with each other like assertive outreach. • How do you make seamless link so do not have to wait months before say talking therapy.

Consistency and Reliability

• 'Consistency and reliability' are vital – life can be like a 'bouncy castle' – people will go 'up and down' • 'Seeing the same person/Dr/psychiatrist each time'	

Choices of Talking Therapies

• 'Choices of talking therapies' in terms of 'types of therapy and group or 1:1 because we're all different'	• Access to a variety of talking therapies • Link up with training courses for counsellors and offer placements then people would have more access to talking therapies

Complimentary/Other Therapies

• One person didn't like the focus on 'counselling' – he would prefer something to take his mind off his problems – some sort of group activity like a type of occupational therapy or a 'distraction' • A few people would like support to access social activities in a group with peers 'because then we can be ourselves' and don't have to worry about stigma • 'I would like more places to go' • Could set up own group to go out together	• More access to courses like art appreciation, assertiveness training • Relaxation • I would like to see more complimentary therapies being offered, and for staff to understand that they do help – meditation, massage and relaxation. Maybe staff training about complimentary therapies so they do understand how they help • I would like to see them using animals for therapy which has a good evidence base to say that they help people with emotional distress • W Essex has no arts or music therapist so it would be good to offer this as an option in the future • CMHT to link in to community groups or activities. • Walking group would be good. • Support if feel anxious about going to a group, or activity, therefore could to

	have someone take you – like a befriender.
	• Pets as therapy – pets are used in many different fields and would be good to use in mental health.
	• Allotments and physical activities are also good for helping depression

Peer Support	
• A group room with comforts so peers can talk to peers 'like the German system' – they would then need less staff. The German way of doing things – there is a group room which is open 24hrs with coffee and tea available. You can talk with your peers, and there is always one member of staff present. You can ring them, and they would come out to you if you were at home and not feeling able to go in. There are only 4 beds, but they do not believe in 'in patients'. In the 2yrs I was there, I only saw 1 person admitted. There is always somebody there for you. You see your key worker twice a week.	
• 'There should be a member of staff who has 'been there themselves'	

Social Support	
	• Social clubs something to do every day 7 days a week
	• Groups for sport, gardening etc – option of MH specific or a universal service – different people want different things
	• Social groups are very important – more important than the medical side – but not like the ones that are 'dumping grounds' – bingo is not very stimulating
	• Stimulating activities – not 'card making for kids'
	• Something on every day of the week – people to talk to and meet – even weekends
	• More activities that are coordinated in groups, and support to attend community activities
	• Good to be in a group with other service users where you're not

	judged
Ethos	
• 'A service you feel part of – not just the problem' • 'An introduction board so you know who is who and what they do or are responsible for' • This is a place where I know I will be treated with respect and where I feel like an equal partner in my care.	
Volunteers	
	• Use volunteers • Work with volunteer bureau to give placements for volunteers – works in 3rd sector why not in statutory
Support to maintain or regain employment	
• Needs to be 'realistic' • There needs to be an understanding that 'employment is not for everyone' • Most people preferred to access employment support from an agency 'that specialises in the field'	
Carers	
	• Carers need Befrienders and regular respite should be written in to the care plan • There should be a care plan for both the service user and the carer • Carers should be there but only if the person agrees • Carer said 'service users should have time on their own' but 'the carer needs time too' • Carers need Befrienders too – carers groups are not much benefit because it means you have to leave the cared for person on their own – you could hold groups for service users and carers at the same time • More open communication is needed with the family
Advocacy/legal issues	
	• We should have 'the right to advocacy' • More understanding about the legal system for CMHT staff. They don't understand the courts system if you have committed an offence when ill and also more information about mental health law

If you were putting together a Community Mental Health <u>Service</u> what sort of people would it employ and what skills would they need

The suggestions which came up fell into the following broad themes:

Witham	Epping
• People and roles • Communication skills • Knowledge • Qualities • Willingness to take responsibility and act	• Communication skills • Attitude and Behaviour • Importance of training

Comments and Themes

Witham	Epping
People and roles	
• 'The staff team should be made up of people from very different fields of mental health' • 'Maybe a student mental health nurse could meet you at reception and make an assessment – but could call on more experienced staff if/when needed' • 'Still need receptionists'	
Qualities, Attitudes and Behaviour	
• 'Common sense' • 'There should be a level of honesty – good or bad news'	• Non judgemental • Treat service users and carers with consideration and respect • The admin/receptionist should be understanding and informed • Need to treat the person as an individual
Knowledge and Importance of Training	
• 'Give sound advice' • 'Be able to provide information that is up to date' • 'Be able to deal with all age groups/illnesses' and recognise they may have different needs • 'Have experience of different fields of mental health, or be able to contact staff to help' • 'IT skills' • 'Flexibility to recommend other staff/services and ability to access	• Trained and understanding staff that are client focused • MH Awareness training for admin staff would make them more understanding and better able to do their jobs • Training for all staff by service users

them for their clients' good – not just signposting'	

Communication Skills	
• 'Good communication skills' • Being able to listen – 'good listening skills' • 'Listening skills' • Have the ability/be willing to believe what the client says without question, regarding how they feel • 'The time and resources to use the skills they have trained in/for to their best ability and not just to pitch in as jack of all trades and muddle through' • 'The matching of skills to people's problems taking into account personality traits' • 'Willing to build a relationship and share a bit of themselves so you don't feel like a freak – not really personal stuff but if you say you like gardening for example and they do too – it would be nice if they said' – it would help to build trust and make me feel 'normal'. Some professionals' insistence on maintaining distance was perceived as unhelpful. Service users understand about boundaries and maintaining staff privacy but experience professional distance as a lack of empathy. • 'They need to understand that when you are shouting and swearing you're not being abusive'. 'It's not personal – you're desperate and no-one is listening'. This comment was supported by several members of the group and may be related to other comments about 'feeling punished'. It was suggested that staff need high quality listening skills, the ability to empathise and remain calm.	• Listening skills • Must be a good listener • Good communicators • Empathy • Ability to put points across in a nice easy manner

Willingness to take responsibility and act	
• Take action – there and then	

Other Issues

In addition to answering the specific questions above, where time allowed facilitators asked participants for comments which had been highlighted by individual members of the steering group:

Have you anything you would like to say about Assessments?(Witham)

- I had arranged for a friend to come with me to the assessment, then it was moved forward by 2hrs, and my friend couldn't come
- My social worker advised me to go on my own in case I wanted to discuss something personal that I didn't want my family to hear
- Quite a few people came with me – there were 8 people there including my husband
- My mum can be quite a demanding person. I didn't take her with me
- I always have an advocate

CMHT Staff – do they all provide the same service?(Witham)

This question raised a derisory laugh and a resounding 'no' from almost every member of the Witham group when it was discussed. But there was some support for the view that staff have different training and skills and therefore they should be allowed to do the job they have been trained to do rather than being asked to undertake roles they weren't trained to fulfil and that would result in an improved service for service users and carers.

In addition, participants also wanted to raise topics that were important to them even though they were outside the strict focus of the meeting. As these topics seemed to be shared by several participants and with the aim of allowing people to 'feel heard' so that they could then address the main topics some time was given to the following issues:

Witham	Epping
• Positive comments not related to CMHTs • Service provided by the Crisis Team and risk management • Issues related to psychiatrists • Consequences of reconfiguration of day services • Service user involvement • General comments/complaints	• Positive comments not related to CMHTs • Service provided by the crisis team • Psychiatrists and GPs • Voluntary/independent sector services • Advocacy • Stigma • General

Comments and Themes:

Witham	Epping
Positive Comments not related to CMHTs	
• When I came out of hospital I went to a 'halfway house' – this was good when I was there.	• When I used the Assertive Outreach Team they did lots of activities like going to the gym and using other

• 'Oxford Road is good (this is a house). You are allocated a key worker and they are responsible for you' • Swan Housing provides floating support for me. I have a key worker who has been assigned to me. I had a lot of debt and she has sorted that out for me. She came to see me once a week • When I was first diagnosed with severe depression I saw a social worker at Thorogood Road. I was sent to the crisis team they spoke with me and asked lots of questions. I felt a bit better after speaking with someone outside the family. I've never had anyone follow-up and I see my psychiatrist every 3 months • 'The Tillingham Centre is good'	community projects, they really helped me build my confidence • 'The consultant sent me to a day hospital (Abberton) which was a lot better than a ward'

Service provided by the Crisis Team and risk management

• The service is 'hit and miss' – social worker wanted the crisis team to come out but I felt worse afterwards. Different people came out each time – a bad experience overrides everything else • 'The crisis team didn't treat me very well; I felt I was being punished' • 'I felt let down' • There were several accounts of inappropriate advice over the phone – 'told me to overdose on medication' – when I was suicidal 'she said - well if you want to take the tablets its up to you' • On a Wednesday I was high and referred to the Home Treatment team but by the evening had still not seen anyone • 'I got nothing after a suicide attempt – you still have to wait' • There should be better communication between teams. If someone is in crisis and no-one in their team is available you shouldn't have to go away with no help. • If someone is in trouble they need contact within a short time – 'a 2-3 day wait is not acceptable'	• We've used the crisis team from Harlow – they came down the same day (carer) • The crisis team often gave conflicting information to the CMHT and their information was bad. The crisis team attitude was patronising. I have had problems with Harlow crisis team I would rather be an inpatient than use them, I have had better support from advocacy than the crisis team they made me feel like I was an inconvenience • 2 service users had used crisis teams and found them helpful (Not in Harlow) • The model and idea of the crisis team is good but the Harlow Team are unapproachable and patronising

• Some mature patients (over 65) have been waiting for six months to be seen and are still waiting – this is not acceptable • Where the crisis team never had the resources or manpower you get a 'skewed service' • This is not treatment but punishment	

Psychiatrists and GPs

• 'I moved from London to live here. When I left London I was given a letter explaining I would need weekly visits, injections etc'… the psychiatrist 'tore up the letter and put it into the bin' • Psychiatrists are not good at 'house keeping', at my CPA when I was asking for extra support all I got was 4-5 minutes • When I left Peter Bruff – the staff said no I wasn't ready, but the psychiatrist said yes – and I was to phone the crisis team • Psychiatrists seem to be 'married to pills – divorced from skills' • The rooms are too small and not friendly. They should expect people to attend that are supporting the client. It feels like the consultant decides how many people will be in the room	• When I had a consultant psychiatrist he monitored me regularly and got the meds right • After 6 months they change your psychiatrist • I feel with some new doctors I can be pre-judged and they need more than to just read a file • Services need to work together more. GP and psychiatrist should talk to each other, especially if you have a condition your GP understands and your psychiatrist doesn't but the condition affects your mental health – eg peri-menapausal • I had a good GP – he gave me good advice – understands meds etc – I go to work now • GP doesn't know what's going on • GP surgeries are notoriously bad at sending people on courses • Training for GPs so they know when to refer • Some GPs can be good on mental health but it does vary • With most GPs the information they have on offer is about medication • There needs to be more information from GPs about what is available in the community like support from voluntary sector or self help groups

Reconfiguration of Day Services

• Oak House (MIND) closed last September, and there have been a lot more problems since then. Dorson House has also 'gone' • It was alleged that 3 people have already taken their own lives since the closing of Oak House • The issue has been created since the	

'safety net' has been removed. People are in limbo after being discharged from statutory services • Someone should have looked at what was there and what the impact of having the safety net removed would cause. There should have been contingency plans. We were told that younger people don't use 'drop in'. They should have talked to people using the services. People were remaining well because of the safety net. • It was alleged that an approach was made to the papers and there was a write up – then the papers were 'gagged' • Commissioners need to recognise that service users are communities as well as individuals • Main stream society doesn't welcome us • There were some strong advocates for drop-ins where people can get information and support or sign posting to it	
Service User Involvement	
• Service users have to be involved in the consulting process from start to finish including having voting rights when they make their decisions • 'Nothing about us without us' • 'This is a waste of time' – they don't listen	• There should be training for all staff by service users
Voluntary/Independent Sector Services	
	• Mind services have been slimmed down. • Harlow Mind are supposed to be finding M a befriender but someone told me they had been waiting 2 years • Employ-ability are wonderful – found my son a job for 5 hours a week – he works on a conservation area. We didn't have to wait very long for an appointment - slow steps • Service users need to use whatever comes along

	• No good having a group with nothing to do – its boring • Need transport to get to services • When one service user was homeless they used NACRO and found them very good
Advocacy	
	• 'When I have an appointment I can't get an advocate' – they are never available. I ask for an advocate to come with me in advance and they can't • Lack of advocacy available – people often lose confidence – should be available to everyone • 'Advocates won't come on their own – other staff do' • But some service users felt the advocacy services of SAFE were good
Stigma	
	• Stigma is just as bad within services as in the general community. 'I feel quite strongly that the NHS and voluntary sector don't employ people with mental health problems because they are frightened they'll go off sick'. 'I would like to see less discrimination in the job market' • Although I do need help it is sometimes hard to admit because of the stigma, and the fear of being hospitalised, I am scared that because of my mental health problems I will be seen as being stupid • Stigma of using services can be an issue, especially how people react to you when they know you are under the mental health system

General comments/complaints

- Its just me and the psychiatrist, I only see him/her every six months
- I was discharged from hospital (Peter Bruff) without being there – I was told over the phone
- I was referred to pathfinders twice – I've heard nothing, although I've tried to ring back
- I've not had one call from the Trust in 3yrs
- 'I was due to see a social worker but nobody came. Instead staff from the supported housing project came to see me twice and it wasn't even their job'
- The commissioner said they were looking at how services are provided in other areas but she only mentioned this part of the country – they should look further - 'I used to live in Newcastle and the CMHTs there are fantastic' When asked in what way he replied in terms of 'consistency and the kind of people they are – really listening….' Going the extra mile.

- I have been in the mental health system for some time and I think the services are more outward looking now, they help you pick up connections to other organisations
- I don't want to be written off, sometimes I feel that services have written me off
- With having depression and anxiety I find it hard to do anything and I have no confidence or motivation
- Often statutory services are so stretched they don't know what is going on in community

APPENDIX D – MONITORING
Witham

Gender			S U / C				Ethnicity			
M	F	N/S	Service User	Carer	Both	N/S	White British	Chinese	Asian/Asian British/Indian	N/S
10	10	2	19	1	1	1	18	1	1	2

Epping

Gender			S U / C				Ethnicity			
M	F	N/S	Service User	Carer	Both	N/S	White British	Chinese	Black or Black British/African	N/S
5	8	0	11	1	1	0	12	0	1	0