



## “Listening to our communities”

*From people and their carers, who use mental health services*

December 2013 – February 2014

### Final Report

#### \*\*\*\*\*ABSTRACT\*\*\*\*\*

This document draws together the key findings, priority areas and actions raised by local mental health service users, based on a set of listening events.

This report includes detailed feedback from partners to the thirteen key findings that were shared with them. These include East Sussex County Council and Sussex Partnership NHS Trust who have the statutory responsibilities for these services.

This will help Healthwatch East Sussex and our partners consider priorities for further work.

July 2014

## 1. EXECUTIVE SUMMARY

In order to create meaningful priorities for the Healthwatch East Sussex (HWES) work stream it was felt that a “back to basics” approach to researching what the key issues and priorities might be might be useful. The following report describes the process; its potential limitations but also the key findings that emerged from the five listening events held across the county. ESCV is grateful for the open and honest way that all parties have engaged with us in this process.

From the thirteen key findings some useful commentary and feedback has been received from our statutory partners which is set out below. Further work can then be drawn from the findings and will be explored in more detail with partners as to how to move them forward.

## 2. CONTEXT & BACKGROUND TO THE STUDY

### 2.1 The research

In December 2013 East Sussex Community Voice (ESCV), in its Healthwatch East Sussex (HWES) role, commissioned Age UK East Sussex (AUKES) to deliver five listening events for users of mental health services in East Sussex. The aim of the short piece of commissioned work, was to gather a snapshot of current concerns; as heard from mental health service users, their carers, members of the public as well as organisations working with them. This was not to detract from the existing structures for user and carer engagement such as the Mental Health Advisory Groups (East and West) which enable a range of user-led organisations and carers to meet with service commissioners.<sup>1</sup>

The aim was also to identify what might be current concerns that Healthwatch East Sussex (HWES) as the new Health and Social Care Consumer Champion, should focus on. These were to be matched against, and provide context to, the historical set of concerns that HWES was passed by the Local Involvement Network (LINK Legacy – March 2013) namely:

- Prisoner health
- BME mental health<sup>2</sup>
- Services for people with Learning Disabilities
- Young people accessing Child & Adolescent Mental Health Services (CAMHS)<sup>3</sup>
- Improving Access to Psychological Therapies (IAPT)
- Dementia services<sup>4</sup>

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<sup>1</sup> MHAG East and MHAG West currently meet three times a year each and feed issues through to the Mental Health Partnership Board.

<sup>2</sup> A separate consultation activity was carried out with mental health service users who do not have English as first language to explore some of their concerns and issues. Some of their comments have been drawn into this report. This was run in conjunction with ESCC Race Equality in Mental Health Service (REMHS) officer

<sup>3</sup> Although one or two carers of young people with LD raised some issues at the listening events this area may merit a separate piece of work.

This report is a summary of the thirteen key findings, priority areas and actions that were provided to ESCV and subsequently to local partners to consider. They will be used when setting future work programme priorities. This final report draws in the feedback from our voluntary and statutory sector partners under the relative priority headings. ESCV is grateful for all the considered and detailed responses and comments received from our partners. This final report will be shared back widely for comment and consideration.

## 3. STRUCTURE OF THE RESEARCH

### 3.1 Promoting the sessions

The aim was to recruit 8-10 participants for each event across the five areas within the county. Clients and carers were able to register via telephone, minicom, e-mail or by post (freepost return). The project aimed to recruit clients who have rarely or never attended service user events. An incentive in the form of a £10 Boots shopping voucher and lunch was offered. The registration form asked for any special requirements, including transport in order to ensure true access to the events. An A4 poster was produced which was emailed to 48 organisations across the county. A4 flyers were also delivered to town halls, CABs, GP surgeries, in each of the five localities. Participants were invited to speak to or email the co-ordinator to register an interest in attending or to seek further information. AUKES received 63 responses to the emails and posters. Participants registered via telephone calls, emails and personal recommendations from other organisations, health and care providers.

### 3.2 The Facilitator

AUKES invited an experienced facilitator who was known to the organisation. David Holland has a nine year track record of hosting and facilitating reference groups and focus groups for older people and disabled people in East London.

### 3.3 Structure of the focus groups

The focus groups followed best practice for such consultation events for involving mental health service users in research<sup>5</sup> Although the research was not instigated or controlled by the service users themselves as might be preferred it was open to all whether service user, carer or organisation. It was as accessible as possible<sup>6</sup>, a reward was offered and support was available if people felt that it was too intense for

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<sup>4</sup> One of the carers present raised some issues around support for people with dementia. Other work will be ongoing in this area

<sup>5</sup> Service User Research group for England SURGE (Nov 2006) Louise Morgan *Brief Guide to Involving Mental Health Users in Research* page 5 -6.

NSUN (April 2014) *Mental Healthwatch Handbook: Improving mental health in your community*

<sup>6</sup> A separate session was set up for people who required interpretation support to explore some of the issues they face. This was run in conjunction with ESCC Race Equality and Mental Health Service (REMHS). Some of this session focussed on access to interpretation services. A separate report on this topic is due soon.

them and they wished to withdraw. At one session a POHWER advocate was present.

The process was described thus:

*The Co-ordinator was there to meet and greet participants and was in attendance for the duration of all events so that participants could get reassurance from her, if required. This was needed on one occasion with a participant becoming emotionally distressed during the event. The Co-ordinator was able to take the participant to a quiet area until he felt well enough to go home.*

*After the first event, it became clear that due to the sensitivity and complexity of the discussions, an optimum number was for 6-8 people for events with a two hour timescale. This is something that may need to be taken into consideration for any future events with a longer time allowance being required for larger groups with this complex a subject.*

*A total of thirty people actually attended with eleven ‘no shows’ across the five events with. An attempt was made to contact all of the people who failed to attend, with messages being left where possible. One person then booked to attend a different event. Of these thirty people, 28 completed the demographic information and feedback forms whilst 2 people declined to do so.*

*Two hour meetings of the groups were held in January and February 2014 in Lewes, Eastbourne, Hastings, Battle and Crowborough.*

*Each discussion was introduced with a brief reference to the declared goals of East Sussex Mental Health services, including the following statement that services aim:*

*“...to support people according to their personal choices and levels of needs into social, cultural, spiritual, health, educational, voluntary and employment opportunities.*

*Promote social inclusion and recovery approaches, enabling the development (or reestablishment) of valuable social networks, social capital and coping strategies to enable people to recover, maintain their mental health, and live their life as independently as possible.”<sup>7</sup>*

*Participants were invited to consider whether the services they had received met this standard and more generally what was good about their experience and what was not. As an icebreaker, each session began with members pairing to introduce themselves to each other and say something about their experience of mental health services. Each ‘listener’ then introduced their partner to the group.*

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<sup>7</sup> From the introduction to the Sussex Clinical Commissioning Groups and East Sussex County Council ASC (Nov 2013) *Mental Health Directory of Community Support*.

*Consideration was given as to whether to use this or similar techniques to explore particular issues, but on the whole, the groups were too small for this to be productive and participants proved not only willing, but in general eager, to share their experiences with other members of the whole group.*

*Some saw themselves as survivors of the mental health system and felt a sense of pride in their achievement in coming to terms with their conditions and reinventing themselves on this basis. Others felt angry at the treatment they had received (from employers for example) and resentful at what they felt was inadequate support or treatment.*

### 3.4 Questions asked

*Group discussion was structured to explore five issues, with ample space for participants to raise other concerns, outside this framework. The issues were explored in differing degrees of depth, depending on the experiences of the clients and inevitably some group discussions yielded richer results than others.*

- 1) How did you get involved with services? How easy was it – what was the response time?*
- 2) Were staff attitudes helpful?  
Were you treated in a way in which your dignity was respected?*
- 3) If you were prescribed medication, were you given any or enough information about it?  
Were you offered access to a talking therapy (such as CBT)?  
If so, how easy was it to get it?*
- 4) If you had a crisis – when you needed help quickly – how easy was it for you to get help and why?  
What did you think of the help you got?  
Were enough staff available and was there continuity of care – did you deal with the same person?*
- 5) Were other members of your family involved in your care? And did they get any support? If so, what did you/they think about it?*

*A brief summary was drawn up from each session. In some cases the opening discussion on access to services led to a wide-ranging disclosure in which many other issues were explored. Clients are not personally identified. Where a serious issue which might merit further investigation was raised, Age UK East Sussex can identify individuals, if clinical or other intervention appears to be an urgent matter, provided the clients themselves give permission to be identified. All clients were*

*promised anonymity in the report and asked to respect the confidence of other participants.<sup>8</sup>*

## 4. KEY FINDINGS WITH FEEDBACK

### 4.1 Validity of evidence gathered

Clearly there were not enough people involved in the listening events to constitute a representative survey. However the mix of experiences over age groups, dispersed geographically over the area, was enough for significant issues to emerge which were shared by enough participants to warrant closer examination and action.

From the five listening events the thirteen key findings below were drawn out by the research authors. These were those that received most comment or concern. The researchers noted that:

*.. it is recognised that there is likely to be a tendency for those volunteering to take part in discussions to do so because of dissatisfaction which they want to air. There are, however, enough themes raised repeatedly and individual incidents which should give proper occasion for concern to provide relatively rich evidence on which to base at least tentative conclusions<sup>9</sup>..*

Not all comments were negative and there were observations that care and services had improved more recently. For example:

“The participant spoke positively about careful care planning meetings, not uncommonly lasting two hours and of exceptional sensitivity”

“Another member in the group felt that attitudes in the service had markedly improved over time. They felt that their personal dignity had been respected by therapists in the recent period”

“Another participant felt that they had been treated respectfully and that treatment was person-centred; that they were offered choice and control and helped to be as independent as possible”

“Some participants had very long term experience of services and echoed the views of participants in the earlier groups on the improvement of mental health services over the time they had been in contact with them”.

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<sup>8</sup> Description of sessions taken from AUKES report <sup>8</sup> David Holland (Facilitator) Nonie Harris (Co-ordinator) February 2014 ‘Listening to Our Communities’ Focus Groups of Mental Health Service Users and Carers’ Report for Age UK East Sussex in fulfilment of commission from Healthwatch East Sussex (unpublished)

<sup>9</sup> David Holland (Facilitator) Nonie Harris (Co-ordinator) February 2014 ‘Listening to Our Communities’ Focus Groups of Mental Health Service Users and Carers’ Report for Age UK East Sussex in fulfilment of commission from Healthwatch East Sussex (unpublished)



## 4.2 Considerations around confidentiality

The decision was made to present the findings as a set of standalone thirteen comments in order to protect individual focus group participants. This decision was made in discussion with AgeUK ES following the production of the full report of the focus groups. As participants had been offered confidentiality in the focus groups this had allowed participants to feel able to freely and honestly share some of their own experiences. AgeUK ES provided the full feedback notes (without names) to HWES so that any particular issue that they feel ought to be investigated or escalated further can be actioned.

HWES, following its confidentiality policy, only allows the sharing of personal and identifiable data under certain circumstances. Refer to the *Privacy Statement* on the HWES website for in what circumstances confidential information might be disclosed<sup>10</sup> Therefore the content of the focus group discussions have not been shared; as to do this could have presented the risk of inadvertent identification, including if someone mentions a third party in conversation.

Promises of anonymity and confidentiality can present problems for the sharing of the research findings; but at the same time can be a useful factor towards encouraging research participants to feel able to share their experiences. These issues are discussed in Rose Wiles et al (University of Southampton 2006) *Anonymity and Confidentiality*<sup>11</sup> and a balance need to be found to ensure the research is worth carrying out.

An attempt was made to rewrite the full report and anonymise the comments in order to make the report more available but due to the low number of participants it was felt that this would still potentially allow for their identification.

## 4.3 Recommendations emerging from the research

ESCV had also asked for Age UK ES to identify three priority areas they felt were most important. This proved difficult as each of the thirteen key findings were felt to have importance in their own right. However they did identify three areas that they felt were especially noteworthy and these can all be found within the thirteen key findings.

1. A review of the capacity of psychiatric consultants should be considered, with a view to ensuring greater continuity of care and treatment tailored to the evolving needs of individual patients over time.
2. An annual review of patients with a history of mental health issues should be initiated as normal practice by GPs and steps should be taken to ensure that GPs are well informed of community services and their quality.
3. A review of support services for carers should be undertaken aimed at ensuring that systems are in place to ensure that carers are aware of support

<sup>10</sup> <http://www.healthwatcheastSussex.co.uk/privacy-policy/#.U8KyilEVG1k>

<sup>11</sup> Rose Wiles, Graham Crow, Sue Heath and Vikki Charles paper presented to the ESRC Research Methods festival, University of Oxford 2006. Document source <http://www.tandfonline.com/doi/abs/10.1080/13645570701622231?src=recsys#.U8KsY7EVG1k>

services and that they exist in a form which those who need them can draw upon at need.

## 5. FINDINGS AND FEEDBACK

### 5.1 Testing the findings

The initial findings were shared with a group of service users, carers and people working in mental health at a workshop at the University of Brighton School of Health Sciences 15th annual mental health conference 9 April 2014. They were asked if they felt that the thirteen comments collected resonated with their own experiences and also if there were any that stood out as issues.

The following comments were noted on flip chart paper. They are not assigned to anyone and are not set out in any priority order.

#### Waiting times:

- Agree that waiting times are a real problem and can be months. This is damaging to people who are really suffering.

#### Regarding the Mental Healthline:

- People feel fobbed off by the phone call, not really given help or access to treatment, more a listening ear.
- People can only have a limited time talking on the phone to the service and then it is curtailed.
- People weren't sure if the Mental Healthline would activate 999 if it was needed.
- People can't get through to general mental health services by phone in the day as lines are often engaged. East Sussex users are not able to use the Mental Healthline but West Sussex ones can during the day, why?

#### The issue about third party referral:

- This referred to someone who was a neighbour of someone in the group and the neighbour was clearly unwell but no one would do anything about it. Is the only recourse to call the Police? If so what can they do?

#### Complex needs:

- Some people don't fit easily into one service. How can they be supported?

#### Access to medication:

- Many people need advice on their medications from a psychiatrist and if they don't get it may in the end stop taking it because of this.

### 5.2 Feedback from our Partners

The thirteen findings were circulated widely to the HWES Advisory Group. We received the following from a member of Health Overview Scrutiny Committee (HOSC)



*I was very interested to read the Report "Listening to our Communities". As a psychotherapist working with clients suffering from mental distress I can only commend the view that it should be treated on a par with physical pain, and waiting times should reflect that.*

*Communication at all levels would seem to be key, as service users, carers and professionals all need to be appraised of all the relevant information available in order to maximise the chance of getting the best outcome. This would obviously be facilitated by a systematic approach to joined up services, which must be getting easier with all the media that are now available.*

*Lastly I can only agree that there needs to be a clear protocol for referrals for urgent care by third parties as spending the night in a police cell is hardly ideal for someone suffering a mental breakdown.*

## 5.2 Detailed feedback

Taking all thirteen concerns in turn together the feedback that has been received from partners has been added under each heading. However it is worth noting that ESCC felt that many of the concerns were known to them or were possibly historic and were already being addressed. There therefore may be further work required to dig more deeply into some of the comments. Or it may be a case of getting clear messages over to service users as to recent progress in these areas.

Sussex partnership NHS Trust provided responses to all of the areas apart from the question about access to benefits advice. These are set out below.

### 1. Access to psychiatrists

There was widespread concern about the adequacy of interviews with psychiatrists. With some very honourable exceptions, service users far too often expressed frustration during appointments with consultants, who had not had time to even glance through the patient's notes.

This was compounded by a lack of continuity. One participant said, "...in four years I've never seen the same psychiatrist twice".

Participants raised concerns of the patterns of adapting practices to the convenience of the provider, rather than the user for the benefit of whom the service exists.

Individuals acknowledged it is sometimes necessary to reschedule appointments. However they felt it seems very inflexible not to have a provision, when the result is that the patient loses one or more of a series of appointments, without alternative dates offered.

ESCC	Sussex Partnership NHS Trust
We would want to understand better	Sussex Partnership welcomes feedback

<p>how ‘typical’ this is, as opposed to frustrating when it does happen. We hope that a more detailed report would make this clearer.</p> <p>If this is a typical experience then we would want to take it up with Sussex Partnership as a clinical relationship/operational issue.</p> <p>Commissioners support continuity so far as practicable as it enhances outcomes.</p>	<p>and it is regrettable to hear that some people who use our service have experienced lack of continuity in seeing the same practitioner. In some cases people will be seen by trainee Doctors who will generally be on 6 month placements. As a teaching trust we do provide placements for trainee Doctors who are mentored by the local Consultant who will over see the care and treatment that they provide.</p> <p>It is also regrettable to hear that some people experienced rescheduling of appointments on a number of occasions. The trust acknowledge that we have made some changes to how we deliver services and this did have an impact on some scheduled appointments in addition we made some changes to up grading venues, which had some impact on clinical space during the building works.</p> <p>As mentioned the trust welcome feedback and want to hear the public’s feedback. We use this feedback as an opportunity for learning and improving on how we deliver services. It is regrettable to read that some consultations have not been to the standard that the trust would expect of their staff. As an action this feedback will be raised regarding quality of experience from consultant consultations with the Medical Director.</p>
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## 2. Self-funders

There is a gap in the patient/carer understanding, for self-funding clients in residential care, and what support is available from adult social care.

Participants felt that it cannot be fair that self-funders and their carers receive no advice or support.

ESCC	Sussex Partnership NHS Trust
<p>The Adult Social Care (ASC) teams do offer support and advice to self-funders. The Fair Access to Care Services (FACS) criteria are used to identify those whose needs make them eligible for Social Care funding. FACS is not a barrier to advice for self-funders.</p> <p>There are very few self-funders with Working Age Mental Health teams.</p> <p>Older People Mental Health Teams sign-post self-funding clients to other services and will allocate a worker to self-funding clients if the situation indicates that is what is required. The Service Placement Team also provides a service for self-funding clients. Social Care Direct (<a href="mailto:socialcaredirect@eastsussex.gov.uk">socialcaredirect@eastsussex.gov.uk</a> / 0345 60 80 191 / Text: 0779 7878 111) can provide advice to self-funding clients about an independent service can offer advice around residential care. The Social Care Direct service is widely publicised.</p> <p>The support to carers is the same for carers of people funded by the Council and those who are self-funding. Carers of clients who are care managed by Sussex Partnership NHS Foundation Trust should have the same access to Carers support as clients of Adult Social Care. There is a joint Carers meeting reporting to the Partnership Board to ensure this happens.</p> <p>Carers of self-funders are entitled to a carers assessment and support in their own right including Carers Personal Budget, emergency respite and respite for healthcare appointments. A wide range of carers' services available to</p>	<p>This response needs to be answered via Adult Social Care.</p>

all carers are commissioned across the county including information, advice, casework, advocacy, counselling, emotional support and carer respite provided by volunteers.

My Care My Home also offers information and advice to self-funders – see [www.mycaremyhome.co.uk](http://www.mycaremyhome.co.uk)

Information for carers is published at [www.eastsussex.gov.uk/socialcare/aboutus/leaflets/carers.htm](http://www.eastsussex.gov.uk/socialcare/aboutus/leaflets/carers.htm)

### 3. Waiting times

Waiting times for access to services: periods of six months and more were repeatedly mentioned by participants.

They felt it is reasonable that a patient suffering from mental distress should be treated similarly to someone in physical pain. It is most undesirable for there to be long waits to access services.

ESCC	Sussex Partnership NHS Trust
<p>That experience is not reflected in current performance data. Latest available performance data (for the period 01/10/2013 – 31/12/2014):</p> <p><b><u>EASTBOURNE, HAILSHAM AND SEAFORD CCG</u></b></p> <p><b>Primary Care - Health In Mind</b></p> <ul style="list-style-type: none"> <li>- 100% of urgent referrals contacted within 5 working days</li> <li>- 100% of routine referrals contacted within 20 working days</li> </ul> <p><b>Secondary Care - Assessment and Treatment</b></p> <ul style="list-style-type: none"> <li>- 100% of urgent referrals received a response within 4 hours (Year To Date)</li> <li>- 96% of referrals were assessed within 4 weeks (Feb 2014)</li> <li>- 100% of referrals started treatment within 18 weeks (Feb 2014)</li> <li>- 94% of long term clients were re-assessed within 7 days of a further</li> </ul>	<p>Sussex Partnership has agreed time frames to respond to referrals. These are 4 hours if the GP considers that the need is a mental health emergency, and for routine referrals 28 days.</p> <p>We respond to people who have previously been known to the trust within the last 2 years within 7 days of referral. We are also introducing another response time of 5 days for priority referrals.</p> <p>Sussex Partnership within East Sussex has a very good response time meeting the agreed performances with very few breaches within the response indicators set by our commissioners. These reports are provided to the CCG on a monthly basis.</p>

<p>referral (YTD)</p> <p><b><u>HASTINGS AND ROTHER CCG</u></b>  <b>Primary Care - Health In Mind</b></p> <ul style="list-style-type: none"> <li>- 100% of urgent referrals contacted within 5 working days</li> <li>- 100% of routine referrals contacted within 20 working days</li> </ul> <p><b>Secondary Care - Assessment and Treatment</b></p> <ul style="list-style-type: none"> <li>- 100% of urgent referrals received a response within 4 hours (YTD)</li> <li>- 99% of referrals were assessed within 4 weeks (Feb 2014)</li> <li>- 100% of referrals started treatment within 18 weeks (Feb 2014)</li> <li>- 97% of long term clients were re-assessed within 7 days of a further referral (YTD)</li> </ul> <p><b><u>HIGH WEALD LEWES HAVENS CCG</u></b>  <b>Primary Care - Health In Mind</b></p> <ul style="list-style-type: none"> <li>- 100% of urgent referrals contacted within 5 working days</li> <li>- 100% of routine referrals contacted within 20 working days</li> </ul> <p><b>Secondary Care - Assessment and Treatment</b></p> <ul style="list-style-type: none"> <li>- 100% of urgent referrals received a response within 4 hours (YTD)</li> <li>- 98% of referrals were assessed within 4 weeks (Feb 2014)</li> <li>- 100% of referrals started treatment within 18 weeks (Feb 2014)</li> <li>- 98% of long term clients were re-assessed within 7 days of a further referral (YTD)</li> </ul> <p>Data for secondary care is reported for all ages. Primary care is reported for adults only.</p>	
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#### 4. Support for carers

Participants indicated that systematic support for carers across all areas of the service is essential. Some carers spoke positively of support arrangements, i.e. from

Care for the Carers. However it was suggested that awareness of the availability of such support, seemed alarmingly low amongst the carers who took part in groups.

In addition, for carers in work who needed support to stay in work, some indications emerged of significant gaps in the availability of peer support groups meeting outside working hours.

ESCC	Sussex Partnership NHS Trust
<p>The Carers Breaks Dementia Engagement Team provide carers assessments and carers personal budgets to self-funding clients. This group particularly welcomes the carers assessment and the sign posting and link up to local services that comes with the CBDET's involvement.</p> <p>Referrals to the CBDET now come from across Adult Social Care and from the Sussex Partnership NHS Foundation Trust.</p> <p>All voluntary sector organisations need to have an awareness of support and services available to carers. E-learning “Carer Aware” is available to assist with this.  <a href="http://www.eastsussex.gov.uk/socialcare/providers/training/careraaware.htm">http://www.eastsussex.gov.uk/socialcare/providers/training/careraaware.htm</a></p> <p>During Carers Week 2014 there were over 50 information events held across the county to raise awareness and reach those carers not linked in to services.</p> <p>Through the 2014 Commissioning Grants Prospectus specific services to support carers into and/or remain in employment and education have been commissioned.</p> <p>Additionally, all commissioned services are expected to be able to meet the needs of working carers including out of hours information, advice and peer support</p>	<p>Within East Sussex we have begun to implement the Triangle of Care which is a model of including carers at the heart of care planning. The intention is to seek Carer views and acknowledge their perspective throughout the assessment and treatment process. We have begun to roll this programme out within in patients settings and are now moving to implement roll out in the community.</p> <p>In addition we work closing with carers and direct them to Adult Social Care who have a statutory duty to complete carer's assessments and have funds for some aspects of carers support. In addition to Triangle of Care we have a number of interventions for carers of people with dementia – recovery college course for couples, carers groups (caring and coping and dementia and us).</p> <p>We are providing training to staff on working with carers and families for people with psychosis and dementia. Importantly, we are working with Alzheimer's Society and carers to develop a carers' pathway.</p>

## 5. Regular review of medication

Participants indicated that a failure to regularly review the appropriateness of medication should be regarded as a serious systemic failure, in particular for a patient who lacks mental capacity.

This issue may be particularly relevant to patients in residential care, but surely must apply with equal importance to patients discharged by mental health services to the care of their GP.

Examples also emerged of a medication regime only being reviewed and changed when a crisis had prompted the attention of a consultant.

Monitoring of care home establishments should include interviews with family members on their experience wherever possible as normal procedure.

ESCC	Sussex Partnership NHS Trust
<p>A comprehensive care plan is a quality requirement for managing serious mental illness in primary care. The 2014/15 Quality Outcomes Framework for primary care includes the following relevant measures for mental health:</p> <ul style="list-style-type: none"> <li>- MH001: The contractor establishes and maintains a register of patients with schizophrenia, bipolar affective disorder and other psychoses and other patients on lithium therapy</li> <li>- MH002: The percentage of patients with schizophrenia, bipolar affective disorder and other psychoses who have a comprehensive care plan documented in the record, in the preceding 12 months, agreed between individuals, their family and/or carers as appropriate.</li> </ul> <p>The Adult Social Care Quality Monitoring Team (QMT) is responsible for monitoring the contract compliance of current care managed contracts and acting as a key interface for Safeguarding and Complaints activity. When QMT visits care homes we interview clients. If they are unable to be</p>	<p>The regular review of medication is important. It is the prescriber who is the person responsible for reviewing medication. However in some cases a psychiatrist initiates treatment and then delegates the on going management of this treatment to the GP.</p> <p>Some mental health prescriptions are prescribed for long term conditions, and don't necessarily need change in dose for a number of years unless there has been a clinical reason that requires some changes to psychotropic treatments plans.</p> <p>The trust has asked all Doctors to support their patients to have a better understanding of their medication and treatment plans. In addition we are providing written information to help provide more detail to support patient's knowledge.</p>



interviewed because of their medical condition we contact their closest relative and go through the questions with them.

To some degree families do provide feedback about care homes through the annual review process of funded placements. Individual reviews of clients do include the views of relatives/carers if the client wants this, or if they lack capacity and this would be seen as in their best interest.

For self-funding clients there would be less opportunity for this kind of input and to generally let other organisations know their views. Families would be able to contact the Care Quality Commission, the Residential Care Homes Association or East Sussex County Council.

## 6. Shortages of in-patient beds

There were several references to shortages of local mental health beds for acute patients. These resulted in placements out of county, isolating the patient from family support and increasing the stress on carers. Attendees indicated this to be highly important and possibly a key resource issue.

This topic has been raised at the Mental Health Partnership Board also.

ESCC	Sussex Partnership NHS Trust
East Sussex County Council's public health department will complete a needs assessment during 2014/15. The needs assessment will review demand for mental health treatment and the capacity of the acute mental health service. It is expected that the needs assessment will be published in Autumn 2014. All needs assessments are published on the Joint Strategic Needs Assessment website, <a href="http://www.eastsussexjsna.org.uk">www.eastsussexjsna.org.uk</a>	<p>There are periods of times when demand out weighs local capacity. However we are please to report within East Sussex this is not very often and when it does it is for brief periods of time.</p> <p>On the occasions that this has occurred we approach our neighbouring areas within Sussex Partnership and ask for support, and will bring the person back locally at the first available opportunity.</p> <p>We acknowledge that this is not ideal</p>

	and work hard to ensure that we have local beds because we acknowledge that importance of receiving care close to home.
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## 7. Access to benefits advice

Participants queried the role of benefit services and their responsibilities to people with serious mental health conditions. This is one of a number of issues that may require further evidence and insight gathering.

ESCC	Sussex Partnership NHS Trust
East Sussex has coordinated the ‘Welfare Reform’ project across East Sussex. The project has trained hundreds of front line staff and produces regular briefings about how benefits are changing. The council sends briefings to all mental health staff. <a href="http://www.eastsussex.gov.uk/community/benefits/practitioners">www.eastsussex.gov.uk/community/benefits/practitioners</a>	[No specific response submitted]

## 8. Complex needs

Two examples emerged in which services, (learning disabilities and dementia care), were described as serious mental health conditions, rather than ones where intermittent specialist interventions may need to be integrated with ongoing community support. These could be examples of service structures not being adapted to complex needs.

ESCC	Sussex Partnership NHS Trust
All mental health services adopt a ‘stepped care’ approach. It is not possible to comment further without more information about which services specifically are being referred to.	We agree that not all cases would be considered as serious mental health conditions and that in some complex cases brief interventions from specialist mental health services are needed.  Sussex Partnership provides support for people who have a learning disability within mainstream adult services following the guidelines of Department of Health reasonable adjustment for people with Autism and Learning disabilities. This includes adapting interventions in accordance to needs of

	<p>individuals in relation to the disability.</p> <p>There maybe occasions when adult mental health services within Sussex Partnership will work in partnership with colleagues in the learning disability service to support the mental health needs of the individual.</p> <p>As far as dementia is concerned once a diagnosis is confirmed there may be initial treatment offered and the individual may not need regular direct contact with mental health services as their GP may continue to monitor their needs.</p> <p>In some cases there may be some social care needs which may be part of a plan to support the person in managing daily living to support their independence for as long as possible.</p> <p>However in some cases the dementia is very complex and the person may have a high level of need which would be managed as a complex mental health organic condition.</p>
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## 9. Managing medications

None of the participants felt they had received advice on the possible impact of drug therapies.

They acknowledge there are difficulties in explaining the costs and benefits; especially to patients who are distressed or confused. However they still felt this issue has significant links to both informed consent and to promoting patients' self-management of their conditions.

In prescriptions for physical complaints, a briefing would now be considered normal as appropriate to the patient's capacity. Participants felt this should form part of the treatment process for mental health conditions.

ESCC	Sussex Partnership NHS Trust
We would want to understand better	The trust acknowledges this feedback

<p>how ‘typical’ this is, as opposed to frustrating when it does happen. We hope that a more detailed report would make this clearer.</p> <p>If this is a typical experience then we would want to take it up with Sussex Partnership as a clinical relationship/operational issue.</p> <p>Commissioners see open information exchange as an essential component to effective therapeutic relationships and would encourage this including for example leaflets on treatment options and medication explaining the potential benefits and risk of unwanted effects.</p>	<p>and takes this very seriously. Our senior clinical medical director has taken assertive action on this very topic in collaboration with our lead pharmacist.</p> <p>There is now available easy read information on medication that is likely to be prescribed and Doctors are required to have a conversation with the person to explain in detail the costs and benefits of treatment which is also recorded in clinical notes as evidence that this has taken place.</p> <p>We have also provided leaflets in waiting areas and prompts for people to ask for information about treatment options as part of their consultation.</p>
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## 10. Access to notes of meetings

Participants were concerned that a failure to provide reports on meetings and assessments to patients, undermines their ability to manage their own conditions in partnership with professionals.

Examples included confused patients having difficulties in understanding and remembering what they are told during consultations. Provision of a written record was felt to be highly desirable. This issue has links to the constructive support of carers and family members

ESCC	Sussex Partnership NHS Trust
<p>This finding seems likely to relate to the care provided to people with dementia. Dementia Advisors will (if required) spend time with a patient and/or their carer to explain the diagnosis, likely progress, medication and so on.</p> <p>Finding 2.10 seems to ask for a written record to be produced so that ‘confused’ people have got something they can refer back to. If a client is at that stage in the dementia journey it is unlikely that a written record will be of significant use. If no carer is involved it is likely that</p>	<p>We agree everyone should receive copies of communication regarding treatment plans and it is our aim to provide everyone with a copy of correspondence relating to their care plan.</p> <p>Unless someone specifically requests to opt out of receiving correspondence we will as a matter of custom and practice send copies to the person directly.</p>

<p>Adult Social Care or Secondary Care Mental Health services will be and there will be some form of communication from these services to the person.</p> <p>If these agencies are not involved we would hope that a referral to these agencies would be made</p>	
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## 11. Third party referrals

Protocols on referrals for urgent care made by third parties seemed unclear.

How can people instigate support from mental health services for someone who is clearly unwell living in the community short of calling the Police?

ESCC	Sussex Partnership NHS Trust
<p>Clients (or a carer or other ‘third party’ acting on their behalf) should contact their GP, rather than Sussex Police. The NHS 111 service also provides this advice.</p> <p>The NHS Choices website <a href="http://www.nhs.uk">www.nhs.uk</a> also provides this advice.</p> <p>The Healthwatch website also provides this advice on its mental health page <a href="http://www.healthwatcheastsussex.co.uk/mental-health-care/">http://www.healthwatcheastsussex.co.uk/mental-health-care/</a></p> <p>There are NHS walk-in centres in Hastings and Eastbourne.</p> <p>We are responsible for protecting vulnerable adults from abuse. Information about protecting vulnerable adults is here: <a href="http://www.eastsussex.gov.uk/socialcare/worried/report">www.eastsussex.gov.uk/socialcare/worried/report</a></p>	<p>People who are known to our service as part of a care plan will have a contingency plan to follow in crisis and this may include contacting Sussex mental health line out of working hours for direction and support in managing the crisis.</p> <p>To manage mental health emergencies, the person can ring up the local Assessment and Treatment service and speak to a practitioner on duty for advice. In addition for someone who is completely unknown we do have a 4 hour response time for mental health emergencies and a GP would need to see the person to make this request, based on their clinical assessment.</p>

## 12. Signposting to further support

A supported accommodation manager highlighted that clients have few examples of psychiatrists’ signposting to other services.

It was also suggested that doctors tended to be sceptical of community activities provided by the voluntary sector and have a low awareness of them.

A number of participants found it difficult to navigate a wide variety of organisations to meet their needs. Given the emphasis on recovery and activities in the community, they felt there is a need for a systematic approach to joining up services. This included clinicians and service users being aware of other support available in the community. Ideas included creating bespoke information for patients through “social prescribing” or “journey mapping”.

HWES will be working with other information providers to explore the implications of the Care Act provision around access to information and advice.

ESCC	Sussex Partnership NHS Trust
<p>Many clients are ‘signposted’ to lots of other services as part of their care plan. It may be a psychiatrist, the client’s care coordinator or another professional involved in their care who advises the client about additional services, or formally refers them.</p> <p>East Sussex County Council and the local NHS have produced the mental health services directory of community support, provided to all mental health staff and GP practices and published at <a href="http://www.eastsussex.gov.uk/socialcare/healthadvice/mentalhealth">www.eastsussex.gov.uk/socialcare/healthadvice/mentalhealth</a>.</p> <p>Information in the directory will be linked to the DXS information system used by GPs across East Sussex from July 2014.</p> <p>The Healthwatch website includes a link to the directory on its mental health page. The directory is freely available to anyone who might benefit from it. The online version of the directory will be updated during 2014/15.</p> <p>Sussex Partnership NHS Foundation Trust and the providers of our five wellbeing centres, Southdown Housing and Together, are working together on a shared plan to promote these services to help as many people as possible learn more about the services they provide.</p>	<p>Whilst it may be true that some doctors have somewhat limited awareness about certain elements of third sector provision, we do value of third sector.</p> <p>Within Sussex Partnership we have a web based tool called the (ROCK) Recovery Orientated Tool Kit, which peer support workers keep updated. This has a number of domains that offers individuals and practitioners signposting to a variety of resources to support individuals on their recovery journey.</p> <p>This is available on our public website. Staff are actively involved and proactively promoting and encouraging third sector activities.</p>

## 13. Out of hours or crisis support

The appropriateness of responses to mental health crisis out of hours services requires closer monitoring, e.g. general issue of the availability of services at the weekend. Feedback suggests that only the Mental Health line, the Samaritans, and/or A&E appeared to be available. Sometimes people in crisis need a safe place to go to recover, as described in a recent MIND report on access to crisis care<sup>12</sup>

The role of the Mental Health line has also been raised at the Mental Health Partnership Board as it requires input from the Clinical Commissioning Groups (CCGs) who may or may not commission the line. This is provided differently in the East and West Sussex parts of the Sussex Partnership NHS Trust

ESCC	Sussex Partnership NHS Trust
<p>The Crisis Home Treatment service is available 24 hours a day, 7 days a week. The service is required to respond within 4 hours.</p> <p>The service works closely with the psychiatric liaison teams at Conquest Hospital and Eastbourne District General Hospital.</p>	<p>Sussex Partnership have a crisis and home treatment service which is commissioned to support people who may otherwise require inpatient care. As part of the role of the service they also support people in the transition of leaving hospital. This service is available by professional referral and GPs do access this directly.</p> <p>The Sussex mental health line is also available and can be accessed directly by any person in need of speaking to someone with specialist mental health expertise.</p>

## 6. RECOMMENDATIONS

From the feedback the following emerge as possible areas of further work:

1. Further work may be required to explore the distance between people's reported experiences of waiting times and the actuality of services meeting their targets. A look at people's expectations and how waiting times are communicated might be worthwhile.
2. Further work may be required around how communication is managed with patients around their medication, treatment options and interviews with psychiatrists. Medication issues can be difficult if a person wishes to contest

<sup>12</sup> MIND (Nov 2012) *Mental health and crisis care: commissioning excellence. A briefing for CCGs*  
[www.mind.org.uk/crisiscare](http://www.mind.org.uk/crisiscare)



what they have been prescribed or is being treated under a community treatment order.

3. Explore with partners the implication of the Care Act provisions around information and advice in relation to people with mental health problems, their carers and people working with them .
4. More clarity possibly required around access to crisis care and the role of the Mental Health line. Are there clear messages about how individuals can refer themselves for support in a crisis and also how the general public, neighbours, friends etc can raise concerns about someone's state of mental health?