Executive Summary

This event forms a part of a major piece of continuing work on Mental Health by Healthwatch West Berkshire, which has included three other Thinking Together events, our widely supported Rough Sleeper and Homelessness Report, close involvement with the Mental Health Action Group (MHAG) and playing a major role in a large Healthwatch Berkshire wide ‘Enter and View’ of Prospect Park Hospital.

There is a wide range of recommendations at the end of the report, which it is strongly advised that senior managers and commissioners in both health and social care review and consider.

Our recommendations are drawn largely from this event but have been influenced by the experiences developed from this work.

Summary of Key recommendations
(NB this is a snapshot of the recommendations)

- Senior managers and commissioners of Berkshire Clinical West Commissioning Group (BWCCG), Berkshire Healthcare NHS Foundation Trust (BHFT), Adult Social Care West Berkshire Council and The Health and Well Being Board are asked to view and consider the video on line showing the questions raised by service users and voluntary sector organisations. It raises some serious concerns about the quality of support offered by the crisis line and the team. It can be viewed at this link. This should be set alongside the issues raised in the crisis tree exercise. [http://www.healthwatchwestberks.org.uk/thinking-together-for-mental-health/](http://www.healthwatchwestberks.org.uk/thinking-together-for-mental-health/)

- Staff support was a key issue; both emotional and practical issues were raised.

- Relationships across sectors and in particular with the voluntary sector also came to the fore and some consideration must be given to how this is managed.

- Impact assessments should form an underpinning of all this work and all organisations are asked to produce an impact assessment showing the extent to which change has been implemented as a result of this work. These will form part of detailed report to be prepared by Healthwatch West Berkshire.
• It is clear that funding issues are underlying many of the issues raised during this event and previous events. The Mental Health Action Group (MHAG) and the Health and Well Being Board are asked to address this locally to understand the full impact on services.

• These events have shown how much the mental health service users appreciate being listened to actively and a way of keeping the open connection between Mental Health Service Users, the voluntary sector and statutory services should be identified.

• The Social Care Information Point is advised to review the database taking into account the suggestions by those attending this event.

• Healthwatch West Berkshire will be ensuring that organisations are held to account on implementing recommendations identified. They will develop and impact statement based on the reporting back from all the organisations to show how and where change has happened and publish it publicly.
Introduction

This was the Fourth Thinking Together event.

1. Arrangements for the event

Thinking Together was attended by 92 people. Of these 48 were service users/carers, 32 were professionals and 12 were volunteer helpers, there in that role only. It was agreed that the primary focus of the day would be on the voices of the service users. Just 20 minutes was given over to professional presentations, by SCIP and the BHFT Crisis team (this latter also generated questions from the audience which are outlined later).

There were three main activities during the event.

The Crisis Tree

All participants were asked to identify crises for themselves or for others and place them on a “crisis tree” which represented the degree of crisis that they assessed for their particular issue, from not very serious to moderately serious to extremely serious. Professionals and services users were differentiated by the colour of the post it-note they used.

Discussion groups

This was an opportunity for service users and professionals to really think about what is currently going on in mental health services and how what could/should be changed. It formed the bulk of the event and is the main focus of this report.

Presentations

There were two presentations, one about SCIP, which arose partly from the recommendations made by various groups during the last Thinking Together event and one about the Crisis team to provide context for the later discussions.
Crisis Tree

2. Crisis Tree (Appendix 1)
This asked professionals and service users to identify crisis at three levels. Less serious, moderately serious and very serious. Professionals and service users were given Post It notes and asked to make as many comments they wanted on their view of crisis and stick the Post Its on images of trees least serious at the bottom, most serious at the top. The two groups were differentiated by the colour of the Post Its they were using.

Least serious
There were not many comments at this level, not surprisingly as the two concepts, crisis and not serious, are not really aligned. It was well defined by a professional comment

“Changes in circumstance or adverse life event but have good support networks or solutions to help you through it.”

Moderately serious
It is interesting to note that some professionals identified their own experiences in this area. Several comments referred to causes of crisis being issues outside their control.

“Missing an important event due to situations out of my control.” (service user)

“Having loads of work on and deadlines to meet then all the IT breaking down.” (professional)

Lack of support was another issue mentioned several times.

“Feeling anxious and frightened and not knowing where to go for help.” (service user)

“Feeling hopeless or unsupported.” (professional)

Very serious
Feelings of a complete loss of control were significantly mentioned in this section.

“A sucker punch of anxiety which paralyses mentally and physically, needing someone to pull me out, but knowing/believing no-one can reach me.” (service user)
Suicidal thinking was also significantly mentioned. It was more mentioned by professionals than by service users.

“Suicidal - too in it to realise how bad I am.” (service user)

There were a couple mentions by service users of lack of confidence in CMHT throughout. However, this was not commonly mentioned but the discussion with the crisis lead from CMHT later suggested that there was some disillusion with services that needed to be voiced and these comments reflect that.

“CMHT have made me feel worse, Crisis team not helped even laughing at me when I say I’m taking my medication correctly.”

“Where the mental health services look you up and down and ignore you.”

In conclusion
The opinions of the service users and the service providers were quite well aligned. However, it would be helpful for professionals to review the comments at Appendix 1 with a view to considering how service users perceive crisis. Particularly as they are less likely to mention suicidal thought which may commonly be considered a trigger for hospital admission.
Where to go for Help

3. Discussion Groups

3.1 Where to go for help (Appendix 2)

Over 50 organisations were mentioned during this discussion. In addition, the importance of social situations and family were commonly mentioned, from visiting the pub to using social media.

This information would make a very good starting point for the further development of the SCIP database, it is probably the most comprehensive list anywhere, locally derived, from the knowledge and information of a wide range of people both in a professional capacity and in a personal capacity.
What should help look like?

4. What should help look like (Appendix 3)?

There were many suggestions about what help should look like produced by the groups. There were some strong themes across several of the groups, which can be divided into two broad areas: - How services are organised and how services behave.

How services are organised: - A single point of access is important to both service providers and service users. This is a recurring theme for service users in all areas of health and social care, not just mental health. It has been identified as a priority over many years, but despite this there is a perception that this is not the case at the moment.

Having a Plan is also important. There are continuing mentions of people being caught in between services, neither picking up their immediate needs. A plan is important to ensure this does not happen and so that families and service users understand what is happening and what the next steps will be.

How services behave: - Communication is a recurring theme mentioned throughout the event and always mentioned in this type of consultation. Continuing concerns are raised about out of hours support, lack of trust in having to call a Slough number out of hours only to find there is an answer phone, when a call out of hours is clearly seen as urgent by the caller. It relates strongly to the importance of a plan. A good plan should ensure that communications routes
are always clear and the nature of the support available is understood by the service user and provided by the services.

*Empathy and being non-judgmental* are both important in all walks of life. Several mentions were made, on the day, of situations where this was not the experience of the service user. Both are clearly valued by both service users and service providers but the undoubted values of the organisations are not being translated into delivery of these basic civilities from the point of view of the service providers. It is important to note that this should be a two-way process, treating those working for your benefit with respect is also important.
What Needs to Change

5. What needs to change (Appendix 4)?

During this session participants were asked to identify what needed to change to improve services from their point of view. They were then asked to make their own recommendations about the future. The original intention had been that the groups should be mixed for this session but in event this was not possible. This may have had a positive effect in that professional groups may have felt more able to address their own needs and some interesting and similar ideas were put forward from both professionals and service users.

![What Needs to Change Diagram]

**Effective listening:** This pinned down the mentions of communication in the previous session with more specific recommendations from the groups.

“Better listening to service users”

“Communicating the difficulties of running a crisis team”

“Better information for families”

“Better information for service users: what can be expected when”
Working cooperatively: - There were many mentions of the importance of working cooperatively, some direct some indirect. A strong message was the need to stop having a silo mentality - this was a message from both service users and professionals. Widely recognised as an issue.

“Services, voluntary and statutory working together” (professionals)

“More effective communication between professionals” (service users)

“Whoever you talk to takes you through the whole process” (service users)

Supported staff: - there was recognition on the part of both professional and service users that this would only move forward if staff were well supported. This applies to training, internal support, effective recruitment and emotional support.

“Empathy fatigue - support for staff” (professionals)

“Staff retention” (service users)

“Creative solutions - in relation to staff recruitment” (service users)

Honesty/transparency: - This referred to how service users and families are dealt with and was commented on by both service users and professionals. It was considering how people are informed about services available and the constraints on services and how people are supported through the system. It also referred to being more open about mental health.

“Transparency on the difficulties of running a crisis team” (professionals)

“Clarify and manage expectations” (professionals)

Encourage people to talk about issues- mental health more readily accepted” (service users)
**Attitude:** This was mainly a response by service users. They referred to behaviour and perceptions.

*“People’s perceptions and attitudes to mental health” (service users)*

*“Parent’s Voices need to be heard and respected” (professionals)*

**Further observations**

Funding and crisis care were mentioned throughout the comments. There is a clear underlying concern about lack of adequate funding and the quality of crisis care. Crisis care appears in the recommendations from the groups and is a concern carried forward from the discussions at the previous Talking Together event. In referring to crisis care there are mentions of problems for families, suggestions that the team should be reviewed and support to avert a crisis before it develops.
Participants’ recommendations

Based on their discussions participants made the following recommendations:

Group Two (professionals)
1. For staff - good quality supervision and training for a healthy staff/working environment
2. Stop silo working - services coming together to share knowledge and support

Group Three (professionals)
3. Communication/feedback/listening/reliable info
4. Communicate to rural areas
5. Stop empathy fatigue of staff through support

Group Four (service users)
6. Better info of what’s there - for families too
7. Continuity

Group Five (service users)
8. Better recruitment of staff - benefits/policies in place to retain staff
9. Less silo working
10. Change in public attitude

Group Six (service users)
11. Funding
12. Recruitment
13. Help is available before crisis

Group Seven (service users)
14. Sustainable support - to stop reaching crisis
15. More community connections

Group eight (service users)
16. Review and revamp of services in crisis
17. Funding/promotion (social media)

Group Nine (service users)
18. More action not apologies
19. Clarification of status of non-professionals

Group Ten (service users)
20. Understanding at the beginning
21. More clarity (diagnosis)

NB Group one (professionals) had dispersed between groups two and three
Presentations

6. Presentations

Social Care Information Point (SCIP) (Appendix 7)

It has been recognised that the current SCIP system is not working well for users. It is not phone friendly, users are unaware of its existence so it is mainly a resource for professionals. Aim is to make it more user friendly, a better public offer with better links and to ensure it is up to date which will depend a lot on the organisations feeding into it.

Crisis Team

There are seven teams across west of Berkshire and a street triage team which undertakes triage and assessment. It is mobile (but not an emergency service). It’s main aim is to keep people out of hospital. It can signpost to other services.

There are two parts to the crisis - assessment and triage of people at risk to themselves or others. They then work out what can be done. Home treatment teams, may go in 2-3 times a day, to help with medication. They also have psychiatrists and psychologists as part of the team.

Crisis is widely interpreted by people and they suffer from their name. They get calls from people in crisis which are not mental health, e.g. housing, drugs, relationships, but can’t help with those. Although they will try and signpost to the right support.

This presentation was followed by a range of questions most of which were very critical of the current provision particularly in relation to the provision of a crisis emergency line which was referred to as unavailable (all staff in a meeting), unresponsive (no call back within in hour), unhelpful and uncaring. These can be viewed at the following link

http://www.healthwatchwestberks.org.uk/thinking-together-for-mental-health/
Report Recommendations

7. Report Recommendations

These recommendations are drawn from the whole event.

For Health (Berkshire Clinical West Commissioning Group (BWCCG and Berkshire Healthcare NHS Foundation Trust (BHFT) and Social Care West Berkshire Council: -

- It is strongly recommended that the video on line showing the questions raised by service users and voluntary sector organisations is viewed and considered by senior managers within all organisations, both providers and commissioners. It raises some serious concerns about the quality of support offered by the crisis line and the team. It can be viewed at this link. Whilst it is clear these are individual responses it is important to note the strength of feeling expressed is likely to be representative of wider issues which need to be addressed.

  http://www.healthwatchwestberks.org.uk/thinking-together-for-mental-health/

- A review of how staff are supported is suggested, taking into consideration training needs, emotional impact of service delivery and ensuring effective delivery to clients.

- A resolution should be found to supporting those individuals who use the voluntary sector to support their approaches for formal assistance. Often this approach is not accepted by formal services but it is the only suitable route for the service user (refer back to the homeless report on this matter).

- Effective ways of working across sectors, statutory and voluntary for the continuing needs of service users need to be found to avoid silo working.

- Furthermore, silo working within and across statutory organisations must be addressed.

- The effective access to crisis cares should be considered and clear information made available about what is available and why. In this context the issues raised on the crisis tree should be reviewed.

- The limitations of service should be made clear to service users so that unrealistic expectations are not fostered in the community.

- In respect of individual service users, care plans should make clear the whole process so at any stage the service user knows where to turn for help and advice.
• There should be a full impact assessments by Berkshire West Clinical Commissioning Group (BWCCG and Berkshire Healthcare NHS Foundation Trust (BHFT) and Social Care West Berkshire Council of the of the changes made as result of this and previous Healthwatch reports on Thinking Together, to feed into an overarching impact report to be produced by Healthwatch. It is suggested that these should be produced in June 2019.

For Health and Well-being Board

• The board should make itself aware of all recommendations from this report.

• The board in particular should view and consider the strength of feeling revealed in the response to the presentation about critical care. The Board is asked to raise this as a discussion point for a future agenda item in light of this strength of feeling.

The comments can be viewed at the following link:
http://www.healthwatchwestberks.org.uk/thinking-together-for-mental-health/

For Mental Health Action Group (MHAG)/ Health and Well Being Board

• Funding issues should be addressed locally to understand the full impact on services.

• Reductions in funding should be identified and impact considered with a view to supporting statutory sector organisations in delivering effective services in a limited financial environment.

• Priorities should be clearly identified.

• Funding shortages should be challenged robustly at local level.

• A way of keeping the open connection between Mental Health Service Users, the voluntary sector and statutory services should be identified.

• There should be a full impact assessment by the MHAG of the changes made as result of this and previous Healthwatch reports on Thinking Together, to feed into an overarching impact report to be produced by Healthwatch. It is suggested that this should be produced in June 2019.

For the Social Care Information Point

• A wide range of organisations that support those with mental health issues was identified at the event. These should be included in the database where possible (a full list is at Appendix 2)
• The name of the service should be reconsidered, evidence from our last Thinking Together (November 2017) suggests that service users are unfamiliar with its existence and this may be in part because the title is very specific to social care even though the database includes a much wider range of groups.

For service users

• A wider recognition that statutory services are under considerable financial pressures. This can impact of staff in many ways, recognising their commitment and effort despite the pressures they work under and offering them respect is important for the morale of these staff.

For All

• Ways of ensuring open and public lines of communication are maintained

• Work on the perceived stigma of mental health - looking at joint approaches to combatting this.

For Healthwatch

• A complete review of the recommendations and findings from the four Thinking Together events should be made.

• In particular some further work with service user with experience of accessing the crisis team may be useful as there is strong evidence of service that is not working well for individuals. An online and face to face survey would be an effective way of doing this, perhaps using small focus groups.

• An impact statement should be developed from the reports produced as suggested.

• Planning should be taken forward for making sure that the outstanding actions are identified and ways of ensuring organisations are held to implementing recommendations are identified.
Next Steps

8. Next Steps

Future of Thinking Together

It is suggested that Healthwatch has proved the value of the Thinking Together events. It has also been proven that regular opportunities for groups of professionals and mental health service users to get together have been helpful. A lot of recommendations have been produced over the four events and it is important that these should now be consolidated and taken forward.

Healthwatch should now be focussing its energy in relation to mental health services to ensuring that recommendations, which have come out of these events, should be taken forward and not into arranging further Thinking Together events for Mental Health. MHAG could look at whether such events held perhaps on a biannual basis for mental health service users and health professionals to meet and talk as equals would be helpful.

Healthwatch could consider taking the Thinking Together model and applying it to other areas of health and social care. It has the advantage of allowing an open dialogue between Health and Social Care and service users and carers.
Appendices

9. Appendices

This describes the main points made by each group and their suggestions.

Detailed discussion notes for each topic are in the Appendices.

There were three discussions topics, which were discussed by every group, and at the end of the session all groups were asked to identify two recommendations that they would like to see for future development of services.
What is crisis to you?

More serious

Less serious
### Appendix 1 - Crisis Tree

<table>
<thead>
<tr>
<th>Level One Less Serious (service users)</th>
<th>Level One Less Serious (professionals)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Where the mental health services look you up and down and ignore you.</td>
<td>Changes in circumstance or adverse life event but have good support networks or solutions to help you through it.</td>
</tr>
<tr>
<td>Fell over in the snow</td>
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<tr>
<td>Falling off bike</td>
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<tr>
<td>Being so stressed I grind my teeth in my sleep and wake up with a headache</td>
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<tr>
<td>Basic Trigger - snappy, become irritated, my body closing down</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Level 2 (service users)</th>
<th>Level 2 (professionals)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Being on my own with no one to talk things over with.</td>
<td>Medication not working properly or running out.</td>
</tr>
<tr>
<td>Feeling out of control about the future - how to get a job when its competitive.</td>
<td>Feeling hopeless or unsupported.</td>
</tr>
<tr>
<td>Missing an important event due to situations out of my control.</td>
<td>Unable to cope with worrying thoughts or impact of the world around and not knowing how to cope.</td>
</tr>
<tr>
<td>Not doing well in something you’ve worked really hard for.</td>
<td>Unable to manage day-to-day activities without/ despite current help.</td>
</tr>
<tr>
<td>When a physical illness stops me from practising the self-care I need to stay mentally well. I start to skip and it all can quickly snowball to being overwhelmed.</td>
<td>Needs support</td>
</tr>
<tr>
<td>Loss of identity, loss of purpose, hopelessness, fear, isolation, confusion, anxiety.</td>
<td>Insomnia</td>
</tr>
<tr>
<td>Change in life style</td>
<td>The car breaking down and I haven’t got the money to fix it.</td>
</tr>
<tr>
<td>Feeling anxious and frightened and not knowing where to go for help.</td>
<td>Having loads of work on and deadlines to meet then all the IT breaking down.</td>
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<td></td>
<td>Finding out the CQC have quality concerns about the organisation I work for.</td>
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<td></td>
<td>When something unexpected happens that I can’t cope with.</td>
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<tr>
<td>Level 3 (service users)</td>
<td>Level 3 (professionals)</td>
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<td>---------------------------------------------------------------------------------------</td>
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<tr>
<td>Family member is ill.</td>
<td>Do staff receive dementia training?</td>
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<tr>
<td>When breathing is hard. Awaiting hospital appointments, a long time.</td>
<td>Acute, Anxiety</td>
</tr>
<tr>
<td>Death of a family member.</td>
<td>Self-harm</td>
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<tr>
<td>Care home provisions for elderly people with bipolar disorder</td>
<td>Support for the carers with people with dementia</td>
</tr>
<tr>
<td>I have suicidal thoughts going around my head. I am on a long waiting list for therapy. I need help now as awake most of the night, can’t function.</td>
<td>Attempted suicide</td>
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<td>Feeling down but nobody to talk to.</td>
<td>Having suicidal thoughts</td>
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<tr>
<td>Feeling unable to calm down.</td>
<td>Feeling isolated with no support.</td>
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<tr>
<td>Drug users in upstairs flat stole my keys. I need help to get locks changed as too frightened to go out and leave flat. I can’t afford a locksmith.</td>
<td>Friends stop calling</td>
</tr>
<tr>
<td>Hopelessness</td>
<td>Unable to cope with day to day life</td>
</tr>
<tr>
<td>A sucker punch of anxiety which paralyses mentally and physically, needing someone to pull me out, but knowing/believing no-one can reach me.</td>
<td>Reaching their limit</td>
</tr>
<tr>
<td>When I lose all capacity to think rationally, believe all the negative thoughts, run out of strength to fight, don’t see the light at the end of the tunnel.</td>
<td>Housing /Homelessness</td>
</tr>
<tr>
<td>Unseen health issues, mental health - a lot of people struggle to understand, mental health needs to be having more focus- how can you expect someone to cope if they can’t cope with their own mind.</td>
<td>Accessing benefits</td>
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<tr>
<td>People judging you</td>
<td>Running out of money, job insecurity</td>
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<td>Having no friends - loneliness, being unhappy about nothing</td>
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<td>Symptoms getting worse</td>
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<td>Mental Health</td>
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<td>Breakdown in family relationships</td>
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<td>No knowing who to talk to or where to go</td>
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<td></td>
<td>Feeling hopeless with thoughts of suicide</td>
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<td></td>
<td>A sense of being out of control</td>
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<td></td>
<td>Extreme feelings of not coping</td>
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<td></td>
<td>Breakdown in support network, leading to isolation</td>
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<tr>
<td>Feeling suicidal</td>
<td>Helplessness</td>
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<td>--------------------------------------------------------------------------------------------------------------------------------------------------------</td>
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<tr>
<td>Made to feel it’s my fault I’m ill, loss of control, feeling hopeless, unable to control emotions, cant for the want of trying, left vulnerable, becoming dependant on others, to easily lead, overwhelmed by everything, homelessness - hand in hand because of mental health, being medicated, no after care, feeling suicidal all the time, CMHT have made me feel worse, Crisis team not helped even laughing at me when I say I’m taking my medication correctly.</td>
<td>Full relapse in Mental Health for whatever reason</td>
</tr>
<tr>
<td>Crisis for me is unfair treatment discrimination from many organisations unable to buy food, clothes without going to foodbank etc. The system fat cat solicitors ripping me off no one seems to listen.</td>
<td>People high risk of self-injury/suicide, lack of support from mental health professionals i.e. Learning disabilities gets referred back to social services.</td>
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<tr>
<td>Worry about being homeless.</td>
<td>Any adverse life event that affects ability to cope with everyday life.</td>
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<tr>
<td>The feeling of not being able to control your emotions or the situation.</td>
<td>Eating disorders</td>
</tr>
<tr>
<td>Being deceived</td>
<td>Suicide</td>
</tr>
<tr>
<td>Suicidal - too in it to realise how bad I am</td>
<td>Perhaps feeling suicidal</td>
</tr>
<tr>
<td>Feeling suicidal</td>
<td>Person self-harming</td>
</tr>
<tr>
<td>Helplessness</td>
<td>When there is an imminent risk to life of oneself or others.</td>
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<tr>
<td>Full relapse in Mental Health for whatever reason</td>
<td>Death of a friend or family member</td>
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<td>People high risk of self-injury/suicide, lack of support from mental health professionals i.e. Learning disabilities gets referred back to social services.</td>
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<tr>
<td>Death of a friend or family member</td>
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</tbody>
</table>
Appendix 2 - Where to go for help?

Group One

Samaritans, GP’s, Family / Friends, Pub, Religious Leaders, Managers/Colleagues, Social Services, Police, Ambulance, CAB, Social Media, Community/ Neighbours, DWP, Carers Groups

Healthwatch, CRUSE


School, Hobbies, A & E, Young Carers Group, Help the Aged, Alzheimer’s Association

MP, Mind/Rethink, Mencap, British Legion, Library, Voluntary work, Helplines, Employer/line manager, Probation

Group Two (Professionals)

Community support / Faith, Family & Friends, GP (neutral), Support Group, Emergency Services, Talking Therapies, C.P.E

Group Three

GP, GP practice Staff, Family, partner, church, Samaritans, Village Agents, No-one I feel confident in, Not the Crisis Team, Lawyer, Mind Website, Social Media, Internet, Pets, Employer, Police, Friends who have had similar experiences, Private Therapist, Hobby Group e.g. (music), Third Sector Groups, What about night time?, Days like today

Discussed the need to support the supporters & provide information about how to respond to people in Crisis.

Group Four

GP, Talking Therapies, Mind Website, Friends & Family, SEAP, Social Clubs, Singing / choir

Dementia Helpline, bipolar association, CPN, Social Worker, Police, Carers association, Psychiatrists, sport in mind, Crisis Team (CPE), Mindfulness apps, Direct contacts (v. important), Volunteers - village agents, street pastors, Samaritans, friends in need, church, eight bells, other faith centres, Soup kitchen, loose ends, community furniture project, Fire service, housing associations.
Group Five
Time to talk, social worker, neighbours, Police, ambulance, friends, teachers, emergency services, GP, spiritualist, Family, CAB, Church, CAMHS, ELSA Teams, Eight Bells, Crisis, Open for Hope, Pharmacist, Stranger, Samaritans, Internet/online forums/website/apps, Lawyers, Health visitors, Recovery college, Talking therapies, Carer, Care co-ordinator, Peer supporter, Emotional Health academy,

Group Six
We don’t always know where to go for help, School, council (parent carer local offer)
GP, Friends & Family - telephone or talk face to face, Crisis - instant response, Samaritans
Healthwatch, SEAP, Patient Information Point, Voluntary sector - e.g. Eight Bells, Open for hope, Employer , Online support and search

Group Seven
School & welfare staff, Volunteer organisations, FRANK, Social Workers, Youth centre, O.T, A&E, Family & Friends, Internet/Social media, Religious Cultural Group, Sport in Mind, GP, CAB, CMHT Team (Com, Mental Health Team), CAMHS (Child Adolescent Mental Health), CPOE (Common Point of Entry), Support Groups, SPOT Team, Eight bells, Yewtree Lodge, Crisis House, Acute Unit.

Group Eight
Beachcroft (MH Unit at WBCH) - come to me twice a week
Adult ADHD Team, Reading (no treatment, unless not taking drugs) nothing more local for ADHD
Common Point of Entry, CMHT, Talking Therapies, hard to access CMHT - threaten suicide to get noticed
Samaritans - not just for crisis but general advice (referral to Beachcroft)
Police picked up and took to Prospect Park
If in crisis do some form of exercise - go to middle of nowhere & clear head.
But may self-harm and very draining. Risk can’t cope and do something stupid.
Need calm down e.g.: meditation technique someone mentioned it and looked into it - ways of coping
Meditation - on YouTube (sounds at particular frequencies to stimulate aspects of the brain)
Music/play piano

Don’t focus on negative thoughts, try to self-help (but accept help), wife gets respite care (go into a home), people make mistakes, may end up homeless - what help then?

**Group Nine**

Kathryn - Eight Bells, Julie / Night Shelter (my mentor), My daughter / Family can really help
Healthwatch, Samaritans, Shelter, SEAP, Soup Kitchen - signpost., How do you know where to go? Isolated / disabled
Can you go to the police station?
Salvation army when open - signpost
If no access to phone/transport
Local church, Local post office, Contact details can be difficult to access
Talking Therapies, Mistrust of services - sometimes not truthful, GP - but no time or experience, Probe accessing services if homeless, Loose ends - signpost
MEAM - A misleading title i.e.: work limited number

**Group Ten**

SEAP, 999, Prospect Park, Male Survivors Berkshire, Samaritans, Crisis Team, Family & Friends, Trust house, Foodbanks, MIND, Talking Therapies, GP’s, Eight Bells, Recovery in Mind, Nacro, CAB, CHMT, NELFT (New Dialogue First Service)
Appendix 3 - What should help look like?

**Group One**
Responsive
Timely, punctual, empathetic, empowering, supportive, being heard/understood/listened to
A plan, Assertive outreach, medication, single point of contact, containment

**Group Two**
Smooth transitions between services i.e.: children & adults, one point of contact who can help me to navigate services, No judgement, A clear pathway that adapts to my needs at the time, Someone who cares, Someone/a service who can help me even if I have other issues
(i.e.: learning disabilities, drugs/alcohol, housing), Someone who understands my needs, Don’t have to tell my story again & again
Someone who uses plain English, Empathy

**Group Three**
Proactive approach
Open dialogue (North London Foundation trust)
Consistency of care. Well trained, ownership of a problem by staff, communication between services, seamless services not one stopping and a long wait for another
Adequate staffing 24/7
Robust sign posting to alternative services
Empathetic - Respect non-judgemental
Feedback
Services should be safe for service users
Tailored services to individuals

**Group Four**
Immediate, Feedback to individuals & professionals giving feedback on experience, Empathetic
Taken seriously, Non-judgemental, Well trained staff, Accessible - knowing what services are available, Managing expectations, Personal/not machine, Keeping families updated / consent?
Ensuring good communication between agencies (joined up communication), Understanding where our ‘crisis’ fit, Referral to most appropriate services, Using appropriate / understandable language (acronyms), Appropriate action
Group 5

Listening - there when you need it, Empathy, actually doing, something - talking action
Tailored to the individual, Connecting, As empowering as it can be - everyone can do something to help themselves. Getting to the point where crisis happens less and less.

Group Six

Non-judgemental, Empathetic, Professional, Rapid, Consistent careworker/advocate who stays with you - SPOT - and you get the right help & support, Follow up on the onward referrals
Reduce having to repeat ‘yourself’ to different organisations.
Parent/child - issue with individuals over 18 needing to access treatment, information many agreement, what level @mental health act filled, primary ‘rethink’, information mainly between organisations

Group Seven

Better quality of communication
Consistency
Sharing of info with other professionals
Trustworthy
Approachable
Action - seeing things through to the end of the process
Easily accessible

Group Eight

Crisis team patronising
Should be good communication between professionals
People doing the communication should be experienced
Phoneline should be available 24hrs a day
There are 4 services
Samaritans, crisis team, suicide hotline, talking therapies
    - Can’t they provide 24hr cover
Eight Bells - v good

MEAM - ‘NOT MAKING EVERY ADULT COUNT’ Only take a limited number of people. Two much for one person to deal with, but professionals attend MEAM meetings and they do communicate & deal with cases. Empty dwelling managing orders. Landlords by passing requirements - should have to get people in, in 7 years, successful when used in other parts of the country.

1. 24 hr phone line
2. Co-produced service review of crisis service.
Group Nine

Not sure

I realise I need help when its almost too late

I need to build trust - people need to earn it

People offer to help but not sure how they can help

Personal to me/person in need - Tailored to them

Needs to take account of their situations i.e.: what’s happen to them at that time

Want to talk to someone who is approachable & will not discriminate.

Group Ten

Language / accents can be a barrier on the phone from the healthcare side, frustrating users, particularly the elderly

Listen to us

Understanding the persons needs

Feedback

Not to be turned away

Learn from previous experience

Preventative and act on it - work to help before crisis happens

Easier access and quicker action

More empathy

Community support is vital in helping support each other

One size doesn’t fit all, different approaches needed.
Appendix 4 - What needs to change?

Group Two
Clarify & manage expectations
More reassurance and follow through
Get different teams to meet up & get to know each other
Employers should support staff so they can support their clients better
Actually listen to what service users are telling us
Improve communication
Avoid silo mentality

Group Three
Communication :fearsome, listening, reliable information, communication to rural areas
Training - empathy
Prevention
Early Intervention
Funding Levels - use of resources
Empathy fatigue - support for staff
Rotate staff
Honestly / Transparency on the difficulties running a crisis team
Support for supporters of people
Safe drop in service/café
Service hub with professionals involved
Services voluntary and statutory working together
Crisis flat/house

Group Four
People’s perception & attitudes to mental health
Encourage people to talk about issues - mental health more readily (acceptance)
Improve mental resilience at a younger age
(blue book of sunshine, emotional health academy)
Better information of what’s available & for what issues - for families/referrer/individual
Have a single person to take you through the problem
Using feedback for continuous improvement
Empowering the person in Crisis
Group Five
Funding - more provision, training, recruiting more people, someone to talk to
More effective communication between professionals
Help available before Crisis point - not having to get really bad to get support
Better understanding from GP’s
Better after care support after crisis

Group Six
Better recruitment of staff
Staff retention
Creative solutions to attract staff
Better communication
Less silo working between organisations
More feedback from service users on service improvement
Ensuring that any public organisations is working in favour of service users
More transparency on how the mental health system is minded and whether there is enough on crisis, prevention etc.
Public attitude to mental health

Group Seven
Living as communities not as individuals - greater connections
Better information for service users: what can be expected & when. What is the process that should be followed
Having constant /sustainable support
Greater amount of co-production
Greater degree of knowledge amongst other professionals of the crisis services

Group Eight
co-production review of crisis - including all organisations not just the crisis team including Prospect Park, care homes
also NHS, police, voluntary sector etc.
stop generalisation - labelled as one things rather than whole person
GP’s not to just throw medication at people - investigate whole person
Whoever you talk to takes you throughout the process - continuity of care - each service doesn’t work in a silo, see you as ‘discharged and not their business anymore
Case manager to follow through including prevention, crisis other services
Could get ambulance to crisis care but then can’t get back, so unable to access services because of transport issues.

Make better use of west Berks community hospital, e.g. have crisis team there.

More funding

More publicity on social media about services & also the needs to promote fundraising

**Group Nine**

Action - not apologies

Stop bullying - more empathy from professionals

Stop discrimination - made to feel awkward like a shadow/not important

Parents’ voices need to be heard & respected

What defines a professional - status as carers /profs

How to work with volunteers / carers

**Group Ten**

Action putting things in place

Easier access to give feedback

Stop passing the buck

More service led (taking on board ideas - action taken)

Understanding the (rules/eligibility) at the beginning of each service used

Service users are listened to

Review of crisis team

What can the organisations change?

More community support - groups/ peer support

More staff who are better trained

People can be given too many labels/ diagnoses by different health care staff
Appendix 5 - Recommendations

These are the main recommendations of each group

Group Two

1. For staff - good quality supervision and training for a healthy staff/working environment
2. Stop silo working - services coming together to share knowledge and support

Group Three

3. Communication/feedback/listening/reliable info
4. Communicate to rural areas
5. Stop empathy fatigue of staff through support

Group Four

6. Better info of what’s there - for families too
7. Continuity

Group Five

8. Better recruitment of staff - benefits/policies in place to retain staff
9. Less silo working
10. Change in public attitude

Group Six

11. Funding
12. Recruitment
13. Help is available before crisis

Group Seven

14. Sustainable support - to stop reaching crisis
15. More community connections

Group Eight

16. Review and revamp of services in crisis
17. Funding/promotion (social media)

Group Nine

18. More action not apologies
19. Clarification of status of non-professionals

Group Ten

20. Understanding at the beginning
21. More clarity (diagnosis)
Appendix 6 - Crisis Presentation

Crisis Presentation

(With thanks for these contemporaneous notes to Dr Adrian Baker)

7 teams across west of Berkshire.
And street triage team.

Triage and assessment.

Mobile (but not an emergency service).

Main aim to keep people out of hospital. Can signpost to other services.

Two parts.

Crisis - assessment and triage. People at risk to themselves or others.

Then work out what can be done.

Home treatment teams, may go in 2-3 times a day, help with medication. And have psychiatrists and psychologists.

Suffer from name. Get calls from people in crisis but not mental health, e.g. housing, drugs, relationships, but can’t help with those. But will try and signpost.

Q. Do you liaise with other services, like ADHD? My experience is that there isn’t proper communication. Have to keep repeating things which makes things worse.

A. Do work closely especially with CMHT. In Newbury we are sited within CMHT team. Work closely with CPE.

Being asked to go over things an issue - it’s because each service does its own assessment. Accept do constantly get asked same questions.

Have 50-60 members of staff. Big team so can be issues with communications. We’re trying to smooth it out.
Q. 8 Bells. Been in post 8 years (?). Crisis team has continually let our members down. Someone phoned, told someone would get back, no response an hour later, slashed wrists. So rang and put through to Slough. Have had phone put down. Been told to ring back later. Lack of empathy of people responding to call.

Not seen an improvement to the service in 5 years.

I’ve accessed the team on behalf of others and found it incredibly stressed, and I don’t suffer from mental health issues. I have found people not wanting to contact the service.

Q. Was laughed at. Told was taking medication.
A. Have complaints procedure. Can’t stand here and answer ...

Q. Set up soup kitchen. Have phoned crisis Thursday evening, answer machine and phoned back Saturday.
No feedback.

When said was volunteer wasn’t taken seriously. Not listened to. Feel things not moved as they would be if had a professional qualification behind me. People don’t go to professional services because of mistrust.

Q. Contacted crisis team through CPE a few weeks ago for 28 year old son. Police were involved. He wouldn’t accept needed help. CPE bit brilliant. When spoke to Crisis Team, because he’s 28 years old couldn’t tell me anything. Later, had 15 min call, then spoke to me and said couldn’t do any more for him.

When discharged, go off record altogether?

A. Sometimes maybe discharged to GP care or to another service, if feel nothing can do, we can’t do anything.

Secondary mental health resources are very tight. It’s hard to fill vacancies.

Will try and look at that case.

AF - you said to me earlier, on the table, that you get one complaint a month and see 80 people a day. This feedback doesn’t accord with that. How to take this to help improve things so we don’t get these stories?
How do we pick up the common issues from them.

A. We are looking at our telephone service. We do have a high caseload and people move through it quickly. Services can’t always take people quickly. Perhaps write down common themes and me and AF look at it.

There is a carers’ group once a month.

Q. Need for support. But can’t get it if on drugs. But need that as a coping mechanism.

AF - why does the crisis service work for some people and not for others?
Appendix 7 - SCIP

Current version of West Berkshire Council’s adult social care information point (SCiP)
And new version