

Co-producing the future of User Forums, peer support & Mental Health Action Groups

Initial scoping report

March 2018



Context

One in four adults experiences a mental health problem in any given year. People in all walks of life can be affected and at any point in their lives, including new mothers, children, teenagers, adults and older people. This could mean that at any time 380,000 living in Kent could be experiencing a mental health problem.

Mental Health User Forums, local Mental Health Action Groups (MHAGs) and a county wide MHAG are designed to be a key part of how the voice of people experiencing mental health problems is heard within the mental health system.

These forums, sit within a wider context of other mechanisms for sharing User Voice, examples are patient experience groups, voluntary sector, carers group, User reps', CCG listening posts, PALS and In patient groups to name a few.

Engaging Kent have been asked to support a process of co-designing a future for Mental Health User Forums and MHAGs to ensure that the voices of people with mental health problems are appropriately heard within the wider mental health system. We have visited or talked with organisations facilitating Forums and MHAGs as well as other stakeholders to explore their thoughts, ideas and concerns about the current way the User forums and MHAGs work. We have also reviewed the MHAG survey in which 89 people responded, 31% of whom were service users and 88% had attended a MHAG meeting, (West Kent Mind Nov 2017).

What is this co-production aiming to achieve?

We propose that this co-production process, over the next 10 months, facilitates stakeholders to explore, define and develop solutions to the questions raised in this report. The overall objective is to build strong and sustainable mechanisms to ensure user voice contributes meaningfully across the mental health system.

Stakeholders in the process are;

- Service users attending User Forums, peer support and Mental Health Action Groups
- Carers attending User Forums, peer support and Mental Health Action Groups
- People using mental health services that are not currently connected to User Forums, peer support and Mental Health Action Groups
- Carers that are not currently connected to User Forums, peer support and Mental Health Action Groups
- Commissioners
- Providers of mental health services, both primary and secondary
- Wider voluntary sector supporting people living in Kent, recognising mental health is not in isolation of other parts of someone's life

This report captures a range of questions raised by stakeholders and we propose they form the framework for facilitated discussions in the coming months. There are some challenging questions to address and we know that some of these discussions could be 'heated' but we believe that honest open discussions will enable a consensus view to be reached and each concluded discussion will detail a bit of the jigsaw, so that we will be able to reach an end point of agreeing how things should work in the future.

Questions raised by stakeholders

What is the purpose of the User Forums and MHAGs?

The User Forums and peer support activities are felt to be an important method of creating a safe, non-judgemental supportive environment to facilitate people giving feedback on services.

The MHAGS in Kent state that their purpose is to provide mental health information, support and expertise across Kent.

They aim to:

- Make positive change
- Make links and network
- Improve services
- Inform commissioners and providers of mental health services
- Combat stigma and discrimination
- Campaign

Feedback from stakeholders and the recent survey, confirm that networking and information sharing is highly valued and effective and ‘spin offs’ have developed in some areas to offer focused professional networking sessions to build further on the value of networking.

However, if the MHAG meetings are not attended by providers, discussions cannot be meaningful or issues resolved and as a result meetings can ‘just turn into a networking opportunity’.

Some Stakeholders have commented that ‘different people want different things’. Some people felt that the objectives of the meetings were not always clear resulting in ‘unframed discussions’. ‘meetings without objectives can be demoralising’ and some people reportedly had stopped attending MHAGs.

What is the governance of the MHAGS?

- If West Kent Mind do ‘Co-ordination’ and Healthwatch do ‘Facilitation’, where is the leadership?
- If service users are representative of other services users should this be a properly structured and supported role?
- Chairing the MHAG meetings is so important and can be very challenging, could more training and support be offered to Chairs?
- How do you manage performance of Chairs?
- What training could there be for Chairs to understand their role and the responsibility of service user involvement?
- Should MHAGs be facilitated rather than Chaired? What might the difference look like?
- Should there be equal numbers of Service Users, Professionals and Carers?
- How do MHAGs and User Forums link with those using primary care MH services?

Influencing change or holding to account?

- Previous iterations of MHAGs have had scrutiny function. Does scrutiny conflict with the principles of co-production?

- How do the User Forums and the MHAGs link with national issues such as campaigning for parity of esteem, anti stigma etc?
- Is scrutiny something that should sit as a separate function?
- Are the MHAGs for Action or Information sharing?
- Should MHAGs change their name focusing on the networking/ hub values of people coming together?
- Should local and county MHAG develop a set of wider annual priorities at local level, informed by user voice evidence and service changes, which can then come together under county as a Kent annual plan.
- Some actions need a bit of resourcing, could planning things help organisations make resources available?
- Some wider service user issues, such as transport, benefits and loneliness, not just affect people with MH problems. Can't we look at these wider issues too?
- MHAGs have 'business like jargon', could the meeting be split into two halves, the first session facilitated debate and the second half business-like.
- Do MHAGs need to be business like, aren't there other meetings for business to happen? Sometimes they don't feel very service user friendly.
- Could questions be submitted in advance of the MHAGs, so that people have opportunity to prepare a response?
- How can we make sure the MHAGs generate a strong 'bottom up' culture to challenge what feels like a 'top down' approach?
- Do we need to offer training and support to service users to 'level the playing field' in these meetings?

How effectively is the User Voice being gathered and heard?

There is little dissent from the view that MHAGs need to find ways to hear more service user's voices, from across the whole spectrum of people using mental health services, in terms of accessibility, equality, and from all mental health services, both primary and secondary, specialist led to service user led.

Gathering User Voice

The User forums and peer led activities are felt to be an important method of creating a safe, non-judgemental supportive environment to facilitate people giving feedback on services. Peer support as a one to one support process is essential to enable some people to find their voice but there was equally a sense that need to reach 'hidden voices' beyond the grant funded user forums and join up with other user forums.

- What expectation is there on the peer led activities and user forums to facilitate service users to attend the local MHAG? Is this skewing the user voice that reaches the MHAGs?
- How should we define peer support? What makes good peer support? How does this fit with Live Well?
- How can user forums develop a richer culture of creating peer supports to engage people to find their voice?
- Is there a need to ensure service users and carers have opportunity to raise separate voices? Is it right that they come together at the MHAGs?

A commonly held view is that service users shouldn't need to come to a peer support group or user forum in order to find their voice and have it added to other voices. Many ideas were suggested about ways people can be engaged:

- Outreach projects, going to local café's/pubs, local public spaces, GPs, IAPT including out of hours etc

- Some organisations invest grant funds in outreach activities/ patient councils
- Close working with community mental health teams/ STR workers
- Private Facebook pages
- Events with incentives, lunch etc

How and where should user voice be heard?

- How can MHAGs ensure that's service user voice is heard by providers and at the right time and the right place to have the best impact?
- What are the right channels to take things to providers? The route there and the feedback route are equally important.
- Should we have separate pathways/ processes for voicing complaints, evidencing lack of service provision, raising individual issues and generating collective views to influence providers and commissioners?
- How can we weave User Voice into a meaningful way of working all the time?
- Do MHAGs need to be clear about what can be dealt with at local levels direct with services, what issues should be escalated to locality MHAGS and what needs to be addressed at county level?
- Could we develop Service User Voice reps like the ESTHER model to enable greater use of user voice to generate composite stories to illustrate issues/ themes rather than focus on individual's person journey?
- If user voice is heard at a ward meeting or patient groups and issues resolved locally, should the issues raised be recorded and shared to build a bigger picture of issues across the system?
- How have recent 'listening' events worked?

How does User voice have the greatest impact?

- There are real personal benefits of face to face access to providers and this has made a difference to individual's issues being addressed, but this doesn't scale up for service users not in the room. How can MHAGs ensure that all service users benefit from MHAGs equally?
- How do MHAGs ensure a system approach not focus on individual issues?
- Quality standards for user voice, how do we measure what good looks like for User voice?

How do the User forums and MHAGs fit into the bigger picture?

Mental health services are taking service user led approaches such as recovery and self management more seriously, there is a recognition that physical health and mental health need parity of esteem and that collaboration of professionals and service users is at the heart of this culture change. The user forums, peer support activities and MHAGs need to understand how they add value to these principles.

As well as cultural fit, there is the need to explore the myriad of meetings that take place across Kent, to understanding again how the user forums, peer support activities and MHAGs can add value to and benefit from greater connectivity.

Cultural questions

- Culture of services is now more focused on positive outcomes, maintaining wellbeing and recovery. How could the user forums, peer support activities and MHAGs be part of this?
- How can people see user forums, peer support activities and MHAGs as part of their recovery?

- Do MHAGs need to move from problem stating to problem solving?
- What can MHAGs do to facilitate a healthier conversation with commissioners and providers, moving more towards genuine co-production?
- How should MHAGs balance dual role of direct action and making service shortcomings known alongside building better relationships and working better together?
- How can MHAGs get ‘the weight’ and respect to chase and get responses from agreed actions? Often frustration that there is no resolution and issues go round the system.

Strategic questions

- What are the strategic links with STP?
- Should the forums have a role in being ‘critical friend’ to emerging MH strategies?
- With the whole mental health service model moving toward recovery, primary care and secondary care - where would MHAGs best sit?
- How do MHAGs balance the experiences and understanding of people who have used mental health services for a long time and those that are newer to the system?
- Do issues sometimes get escalated to the county MHAG just because its there, when sometimes it’s not the best option?
How can MHAGS make sure that the right people are in the room for the right discussions?

What will a good forum for User Voice look like?

There was a common view that a framework of common approaches is needed to ensure forums and action groups are working in a similar fashion and have similar quality measures.

Thoughts about what elements would be in place in a good forum were:

- Clear rationale for escalation to a local MHAG or onwards to the County MHAG rather than direct feedback to a provider at the point of hearing the issue.
- A clear set of expectations for the services users whose voices are being raised
- A system of capturing all issues raised, be it local level, local MHAG or County MHAG, to create an evidence base of issues for county wide comparison/ themes.
- A behaviour charter for meetings and a way to follow up breaches to this charter.
- They are well Chaired / facilitated.
- There is a constructive collaborative relationship with Commissioners and Providers
- There is balance and diversity in who’s voices are heard
- They raise system issues rather than individual issues
- There is a constructive collaborative relationship with Live Well
- Balance of who is heard
- There is aspiration and evidence of effort in engagement beyond people in the room
- They are more outcome focused
- They make use of alternative technologies to enable people to contribute.
- There is clear monitoring and reporting clarity to build reputational reassurances that they are good.

How is current funding used?

The majority of the current grant funding is used to cover; staff costs, room hire, travel expense, a peer support activity budget, some outreach projects, phones/laptops and often an allocation towards overheads costs.

The grant from KCC gives organisations credibility and enables match funding.

In addition, activities around the user forums, peer support and MHAGs are subsidised with in kind and opportunity costs.

- A budget for service user expenses would enable all forum related expenses to be claimed from one place and to support more innovate mechanisms for peer support / user voice.
- Current funding arrangements require clarity. Chairs are required to Chair meetings, organise working groups, attend follow up meetings and support in following up issues raised. Sometimes this is at the cost of other activities.

Working together

Without exception all the organisations providing user forums, peer support and MHAGs would like the ability to share ideas, knowledge, contacts and approaches.

The idea of a Co-production charter across all the stakeholders was welcomed.