RECOVERY AND OUTCOMES GROUP
EAST OF ENGLAND REGION
19th September 2014

Meeting Faciliator:

Ian Callaghan, National Service User Lead, My Shared Pathway ianmcallaghan@me.com

Regional Leads:

Gayle Woodcock gayle.woodcock@huntercombe.com

Welcome and Introduction

We were warmly welcomed and everyone introduced themselves.

National Updates:

Minutes of the last meeting

These were reviewed and there were no questions.

Please ensure copies are printed off and given to service users who do not have their own email address.

National Updates:

Feedback from the Steering Group

The Recovery and Outcomes Steering Group meets every quarter in Birmingham following the nine Recovery and Outcomes Groups around the country. The meeting is attended by all the Regional Leads together with some service users. The Regional Lead for East of England is Gayle Woodcock gayle.woodcock@huntercombe.com

Would like to have a service user representative for the East of England area.

Please let Ian or Gayle know if you are interested. Next meeting 9th October in Birmingham.

As well as reviewing the regional Groups and planning for future ones, there are several sub-groups.

Main Messages and DVD

The 'Main Messages' sub-group, led by Sally Gendle and supported by Cygnet Healthcare, has just produced a 'Main Messages about My Shared Pathway' document, which aims to introduce the

principles of My Shared Pathway and how it might be incorporated into Care Planning and CPA processes. The document may be downloaded at:

http://www.cygnethealth.co.uk/service-users/my-shared-pathway.html

We have also produced a 'Key Messages about My Shared Pathway' leaflet and poster aimed more at service users and these are attached with these minutes.

Action: Ian to circulate the leaflet and poster with the minutes.

In addition, Cygnet have sponsored the production of a second My Shared Pathway DVD introducing the main elements of My Shared Pathway. It is 30 minutes long and can be viewed in the same place on the Cygnet website or viewed and downloaded at:

http://vimeo.com/cygnethealthcare/mysharedpathway

Please do feel free to download and copy both the Main Messages document and the DVD as many times as you would like.

Other sub-groups

Another sub-group called 'Looking After My Future', aims to bring together people interested in developing resources for service users moving out of hospital.

Action: If you are interested in joining the 'Looking After My Future' group, please let me know.

We are still hoping to restart the work with the MoJ and explore doing an evaluation of My Shared Pathway but this is currently on hold.

The next meeting of the Steering Group is on Thursday 22nd January 2015.

Clinical Reference Groups and Commissioning

There are 3 Clinical Reference Groups (High/Medium Secure, Low Secure and the Forensic Pathway Group). These groups advise NHS England on what services to commission and consist of clinicians, commissioners and Patient and Public Engagement (PPE) representatives. Ian and two other service users from other regions are PPE reps on the High/Medium and Low Secure CRGs.

The Recovery and Outcomes Groups are always on the agenda for the High/Medium CRG and are a stakeholder, so our views are well represented.

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The CRG listened to the feedback from the Recovery and Outcomes Groups about what service users would like to see as next years CQUINs (the Commissioning for Quality and Innovation quality improvement scheme) and two of our suggestions have been included. These are 'Collaborative Risk Assessment' and 'Supporting Carer Involvement'.

Some of the other CQUINs include improving Physical Healthcare, the Friends and Family Test, Quality Dashboard and Pre-admission formulation, i.e. improving communication with service users prior to admission.

Action: Please let Ian know if there are any issues you would like raising at the CRG or with commissioners.

Rethink Mental Illness

Rethink Mental Illness are now undertaking the secure care work of the Innovation Network, which include improving care planning and CPA, collaborative risk assessment and management, and peer support. These interventions will all be evaluated over the course of the next two years and there will be updates during that time. South Staffordshire and Shropshire are participating in the Network.

Rethink Mental Illness are also planning a big piece of work In secure care that aims to give service users a better voice in improving services by collecting life stories from service users. The Head of Campaigns, Lara Carmona, recently sent this message to all the Recovery and Outcomes Groups:

"Rethink Mental Illness is preparing a massive piece of work to transform secure care. We know that not enough is being done to improve the voice of people using services in secure care settings. We want to change that.

We are very interested in your involvement in our project and we would like to know how we might best work with you."

We will be hearing more about this work at future meetings.

Action: Please let Ian know if you would like to be involved in the Rethink Mental Illness campaign.

Quality and Outcomes Group

There is a national group looking at more clearly defining outcomes and outcome measures and how they might be linked to care packages and their cost. This has links with My Shared Pathway and the electronic outcomes tool being developed by Partnerships in Care. The outputs from the afternoon

interactive workshop at the National Recovery and Outcomes Conference will be fed directly into this work.

National Recovery and Outcomes Conference – 16th July 2014

The first National Recovery and Outcomes Conference took place on 16th July at the National Motorcycle Museum in Birmingham and was a great success! With over 100 service users from around the country and 300 delegates altogether, there's already been great feedback. We used electronic voting pads to get instant feedback throughout the day from the service users and this proved very popular!

We were delighted to have been able to have support from Partnerships in Care and NHS England, whose Head of Public Voice, Olivia Butterworth co-hosted the morning session with Ian Callaghan. We had great presentations by Geraldine Strathdee, the National Clinical Director for Mental Health, who is a very inspiring supporter of secure care. We also heard from Geoff Shepherd, the Recovery Lead from the Centre for Mental Health and ImROC about their project looking at recovery in secure care.

We also had two inspiring presentations by winners of this year's National Service User Awards: one from Cygnet Kewstoke about the MAAP: My Awareness and Action Plan that has been developed to improve the understanding of patients and where they are in their recovery; and the other from Millfields Unit in East London about their innovative Personality Disorder Training Course. Many people said these really were the highlight of the day!

In the afternoon, following a warm up session dancing to 'Happy', there was an interactive workshop about how to make outcomes and outcome measures more relevant and meaningful for service users. Feedback from the day will help inform the national Quality and Outcomes work currently being undertaken by the Care Pathways and Packages Project, who very kindly provided the funding for the conference.

Following a great presentation from Quazi Haque and Liz Allen about 'PathNav' the Pathway Navigation System being developed by Partnerships in Care, we had the results from the afternoon's interactive workshops. These will all soon be available in a report about the conference that will also have all the results from all the voting pad sessions, together with feedback and evaluations from the day.

National Service User Awards 2015

The next National Service User Awards take place on Wednesday 11th March 2015 and the nominations are now open and close on 31st October.

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Nomination forms can be downloaded and all the details about the Awards can be found on the new Awards website at:

www.nsua.org

It would be great to have some finalists and winners from the East of England area next year!

Presentation:

'Restricted Items Project'

Ian welcomed a trainee forensic psychiatrist from East London Trust to give a presentation and lead a discussion about the 'Restricted Items Project'. She is drawing up some guidelines for better ways to assess potentially 'restricted' items and is keen to hear the views of service users and staff. She first gave a presentation about the project and then opened it up to questions.

Action: Ian to circulate the presentation with the minutes.

There was then a discussion about 'What are the most frustrating items?', 'What items should be better controlled?' and 'How should it be decided?'

What are the most frustrating items?

- Internet access, ipods, mobile phones, cameras, recording devices, Playstation 4, USB sticks
- Energy drinks
- Legal highs
- Loose tobacco
- Staff having things when patients can't – e.g. chewing gum, lucozade, cigarettes
- Over 18 films
- Not having proper plates, cups and glasses
- Religious items, e.g. rosaries, crosses, prayer mats
- Incense and essential oils – possibly have somewhere outside to light them?
- Own bedding
- Plastic bottles and cans
- Pringles
- Glue, scissors
- Drink cans
- Plastic bags – but peer support workers give out canvas ones

- No food from home visits
- Alcohol mouthwash
- Alcoholic meals
- Cotton wool buds
- Nail varnish remover

What items should be controlled better?

- Playstation 4, internet – should be person specific, supervised, blocks on sites
- Staff to be consistent with 'search policy'
- Cutlery
- Glass watches
- Razors
- Items in glass
- Alcohol on area and home leave
- Energy drinks – individual care plans?
- 'Healthy food' – dictating what can and can't be bought from the hospital shop

How should it be decided?

- Visitors to be made aware of prohibited items
- To be able to see RC report asking for things for patients regarding MoJ
- Test the items out with patients and staff
- Information clearly displayed and all parties concerned informed
- Collaborative discussion with service users/relatives/staff
- Individual risk assessment, care plans, person-specific, regular reviews and checks
- More discussion in ward rounds
- Joint meetings with service users and staff to discuss issues
- Agreed via care plans – agreements signed by MDT and patients so all know and agree what can be used/how/where

Discussion Groups – 'Collaborative Risk Assessment'

As part of this year's CQUIN (Commissioning for Quality and Innovation) scheme, services are being asked to improve the involvement of service users in their risk assessment and safety management. Ian gave a presentation developed by Ruth Hasley and her team at Cygnet Hospital Kewstoke. For further information on the presentation please contact ruthhasley@cygnethealth.co.uk

Action: Ian to circulate the presentation with the minutes.

This theme was then discussed in small groups in answer to the questions: 'Why should service users be involved in their risk assessments?', 'What is difficult about doing this?', 'How can these difficulties be overcome?' Jane again collated feedback, which included:

Why should service users be involved in their risk assessments?

- So patients are able to have their say so no misunderstandings
- To feel involved – it's our life!
- No miscommunications so the right risks are put in place and so patients can understand the reason for restrictions
- To know what you have to change
- Empowerment and increase skills
- Knowing what is required to get into the community
- 'No decision about me without me'
- Service users know their life better
- Come up with solutions that suit them best
- Staff can learn from patients
- Improves relationships
- More likely to be successful if involved
- Because it's about you
- So it builds self-esteem
- It helps staff to understand us better
- Feeling heard

What is difficult about doing this?

- My ability to retain information and what the MDT is speaking about
- Disagreements could cause incidents
- Not having capacity or the right mental state
- Could break down relationships
- No insight in the beginning?
- No mutual agreements
- Time
- Facing up to the root causes of our behaviour
- Lack of knowledge of risk assessment tools

- Some tools, e.g. HCR-20 are difficult to understand
- May not be offered to be involved in HCR-20
- Putting it into practice
- When unwell talking about risk is difficult
- The patient might not be honest
- Seeing history repeatedly
- Accuracy
- Being reminded about past – can be upsetting for patients and families
- Exposing reality

How can these difficulties be overcome?

- Sit down with staff and have the documents explained to you
- Good communication and regular 1:1
- Confidentiality and therapeutic rooms
- Being able to stay in CPA the whole length
- Plans for if things go wrong
- Training – staff and patients
- One to ones with psychologists
- Staff attitudes
- Staff that know you to be doing it with you
- Step-by-step as the patient is ready
- Open to negotiation
- Holding out the prospect of going back to the community
- Easier version of HCR-20 to help steer the patient until they're able to complete the full one
- Building up trust
- Agreeing to be honest with each other
- Being able to change inaccuracies
- Talk about things that may upset us when we're ready
- More education and support for our families
- Seek advice/education/support to help understanding
- Group activities

Any other business

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One of the service users told us about some information about Peer Support and read out the following statement:

Statement to encourage the appointment of Peer Support Workers

Ex patients with mental illness now recovered and willing to help those still suffering the effects of that illness.

- Have experience of mental illness and recovery. Lived experience who can keep life beyond illness alive.
- Give hope and support to patients, emotional and practical support in reciprocal relationships.
- Share stories of pathway to recovery and encouraging recovery in intractable instances.
- Change attitude of staff towards ore empathy bridging the 'them and us' divide.
- Be under supervision offering support and making sure the worker himself is supported to keep well.
- The difference peer workers make not only to those they support but also to the whole organisation.
- Assist people to plan their own recovery contributing to maintaining safety.
- Influence recovery focused practice within the team.
- Work under the same degree of confidentiality that clinical staff observe.

Training courses available:

- Cambridgeshire and Peterborough – 4 weeks full time with role plays; reflective diary and mid and final exam. Details at sharon.gilfoyle@cpft.nhs.uk
- Central and NW London – 10 day level 4 within 6 months of appointment. Details at debbie.lane-stott@nhs.net
- Nottinghamshire – 11 day course

Date of Next Meetings:

Thursday 5th March

Thank You:

We would like to thank their team for organising the meeting and the catering team for a superb lunch – thanks for going out for more!

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