Cross Party Group on Eating Disorders Minutes

5 December 2023, 09:30 - 11:00 Microsoft Teams

In Attendance

- Sarah Murphy, MS
- Jo Whitfield, Beat
- Brandon Renard, Member Support Staff
- Sarah Tombs CTM UHB Eating Disorder Outreach Service
- Nia Holford, CTM UHB
- Tamsin Speight, NHS Executive
- Tracey Elizabeth, CTM UHB CAMHS
- Carole Philips
- Natalie Chetwynd, Hywel Dda UHB -Clinical Lead Tier 3 Eating Disorders

- Donna Mason, Mental Health Matters
- Martin Ball
- Rhys Hughes, Member Support Staff, Rhun ap Iorworth's Office
- Joshua Beynon, NHS Executive
- Emily Hearne, Member Support Staff, David Rees' Office
- Isabella Jurewicz, Cardiff and Vale UHB - CMHT

1. Welcome and apologies

Jo welcomed everyone to the meeting and explained that Sarah Murphy had been delayed in bad traffic and would join as soon as she can.

Apologies received from:

- Mike Hedges MS
- Rhun ap Iorworth MS
- David Rees MS
- Dewi Druce-Perkins, CTM UHB -Eating Disorder Outreach Service
- Emma Hagerty, Aneurin Bevan UHB
- Rebecca Bowen, Cardiff & Vale UHB
 - CAMHS
- Manon Lewis

2. Minutes from the last meeting

Minutes from the last meeting were agreed as accurate.

4. Beat campaigning updates

Jo gave an update on campaigning activities undertaken by Beat since the last CPG meeting in June.

Best Practice

Jo reported that that current focus is on the intensive outpatient element of the best practice campaign. Jo explained that the intensive outpatient campaign is a UK wide campaign that aims to ensure that everyone who needs it has access to intensive outpatient treatment including day and home treatment in their local community.

Beat has set up an advisory board of clinicians from across the UK who will advise on the development of the campaign. Beat are updating the literature view that was completed as part of the paper on intensive outpatient treatment published in 2019. A half-day virtual workshop on this issue is being run on the 12 December.

Calories on Menus

Jo reported that in July Beat co-hosted with the Royal College of Psychiatrists and the Royal College of Nursing, a drop-in session for MSs where they shared concerns about the Welsh Government's plans for calorie labelling on menus in Wales. The event was well attended by MSs with about 50% of all MSs attending.

The event followed an announcement from the Deputy Minister for Mental Health, that the Welsh Government would be pausing it's plans to introduce mandatory Calorie labelling on Menus until the outcome of research being undertaken into the impact such legislation has had in England on people with eating disorders.

Beat, the RCPsych and RCNursing will continue to work with the Welsh Government to share the voice of experts by experience and keep the impact of this potential legislation on the political agenda.

2018 Welsh eating disorder service review implementation

Jo reported that Beat had recently delivered an open letter to the Deputy Minister for Mental Health reminding them of the findings in Beat's 3 Years On report. The report found that progress made to achieve the vision outlined in the 2018 review has been slow and uneven, continuing the postcode lottery that people face when seeking support in Wales.

The letter was co-signed by nearly 400 people from Wales calling for urgent action. Jo reported that many of the people who signed the letter shared their experiences of receiving treatment in Wales and while some of this feedback was encouraging, much of the feedback was disappointing and concerning. Beat are awaiting a response from the Deputy Minister.

5. National Eating Disorders Clinical Lead update

Tamsin Speight delivered a presentation on the work she's been undertaking since starting the Clinical Lead role in April.

Tamsin explained that when she came into post the NHS Executive was newly established and that a considerable part of her role to date has involved working with colleagues to establish a full Mental Health team. As of the end of November Tamsin is full time in the role rather than the original two days a week, and works alongside a Programme Manager and Project Officer.

The purpose of the NHS Executive is to provide strong leadership and strategic direction enabling, supporting, and directing the NHS in Wales to transform clinical services in line with national priorities and standards.

The NHS Executive receives an annual mandate from Welsh Government. For eating disorders, this year's remit is to improve early intervention and achieving the 4-week waiting time for assessment and treatment. Tamsin explained that a key part of her role is to support health boards to deliver this mandate. Therefore, Tamsin's focus this year has been on early intervention models and thinking about how Wales can achieve a unified early intervention approach, to address the variations in service provision that patients currently experience across Wales.

The eating disorder workstream within the executive works closely alongside other mental health work streams such as Perinatal, CAMHS and Adult Mental Health.

The work of the eating disorder workstream is informed by various policy drivers including the Together for Mental Health strategy, Talk to me too and Healthier Wales.

The Executive's role within the strategic programme is to drive improvements in:

- Quality & Safety
- Deliver better and more equitable outcomes, access and experience
- Reduce service variation
- Improve mental health within the population
- Act as an interface between Welsh Government, Policy and service delivery and provide direction and support to NHS Wales organisations.

The work is guided by the National Clinical Framework. The first clinical implementation network meeting was held in September and the next meeting will be in January.

Tamsin noted that the original eating disorder framework for Wales did not include definitions for Binge Eating Disorder or ARFID. There has been an increase in both presentations, and this has put a huge amount of pressure on eating disorder services in Wales. Tamsin is awaiting clarification on the latest eating disorder definitions and whether they will include Binge Eating Disorder and ARFID.

Tamsin re-iterated that the current focus is on early intervention and achieving a unified model for Wales. It's being treated as a priority because it's part of the Welsh Government Mandate, it featured at the core of the 2018 Welsh Eating Disorder Service Review, it's also found in RCPsych quality standards, NICE guidelines, Beat's 3 Years On report, and in HB priorities. Tamsin reported that significant improvements are being seen across Wales, where people can access services earlier. Tamsin and her team are currently mapping the services to understand service variation and help to develop a

unified model across Wales. The team is also trying to develop an understanding of referral pathways and criteria, services workforce and waiting times. The team is working with a data analyst to think about how to consistently gather this information to give a better understanding of the challenges faced by Health Boards.

Isabella (Chair of ED faculty of RCPsych) asked about the issue of eating disorder inpatient beds in Wales and what plans are in place to address this? Tamsin responded by saying that this is a key area that will need to be addressed as a priority after early intervention. A focus on early intervention will prevent people from becoming more unwell down the line. Tamsin acknowledged that even with early intervention there will be some people who will need inpatient treatment, and the focus should be on looking at intensive outpatient treatment. Tamsin noted that there are some good models of this already happening in Wales, and Tamsin and her team are currently mapping this and looking at how it could be rolled out nationally.

Isabella noted that the issue of inpatient interventions in Wales will remain unresolved as long as Wales doesn't have a Wales based inpatient unit and that a decision about such a unit has been under discussion for 15 years or more.

Update from Sarah Murphy

Jo Welcomed Sarah Murphy to the meeting.

Sarah noted the significance that Tamsin's role is now full time and that there is also a team supporting the programme. Sarah thanked Tamsin for all the work undertaken since she came to post in April.

Sarah, spoke of her recent visit to the CAMHS team in CTMUHB and the work that they have undertaken on tackling early intervention. Sarah also spoke of the transformational work that's been undertaken in the Ty Llidiard adolescent inpatient unit in Bridgend.

Sarah spoke also about the debate that took place in the Senedd on the introduction of mandatory calories on menus. There was significant cross party support during the debate for **not** introducing calories on menus, and Sarah noted how members spoke about the impact introducing such measures would have on people with eating disorders. This engagement helped the outcome of the debate which was for the WG to pause plans to introduce mandatory Calorie labelling on Menus in Wales until the outcome of research being undertaken into the impact such legislation has had in England on people with eating disorders. Sarah paid tribute to the people with lived experience who took part in the government's consultation on this and the campaigning in this area undertaken by Beat, RCPsych and RCNursing.

Sarah noted that Lyn Neagle, the Deputy Minister for MH is keen to attend a future CPG

meeting. Sarah also noted that it's her understanding that the WG is looking at a solution for adult in patient beds within Wales in Ebbw Vale and just over the boarder of North Wales, in the Wirral, which, if comes to pass, will be a real step forward for people affected by eating disorders in Wales. Sarah acknowledged that inpatient beds is one part of a much wider solution needed in Wales, and noted the importance of prevention and early intervention work along with the continued development of intensive outpatient support. Sarah thanked everyone involved in the various programmes of service improvement work.

6. Mental Health Matters, SORTED peer support group overview

Donna Mason gave the group an overview of the peer support group she runs for people in Bridgend called SortED. The group runs both online and face to face in Bridgend. The online group has people who attend from across the UK and the face-to-face group tends to attract people who live in Bridgend and South Wales. The SortED group is the only face to face support group in Wales. People who attend the group don't need a formal diagnosis of an eating disorder. SORTED offers an opportunity to meet people who may be in a similar situation in a safe and confidential space. People support each other by sharing experiences, thoughts, successes and problems or by simply listening.

The face to face group runs on Wednesday evenings 6pm at the MH Matters office in Bridgend, and the online group runs on a Tuesday from 6pm - 7pm. There is also an online carers group for anyone caring for a family member or friend with an eating disorder.

For more information visit the MH Matters Website: https://www.mhmwales.org.uk/Sorted.htm

Sarah spoke of her experience of visiting Mental Health Matters shortly after she was elected and how welcoming and supportive the team at MHM are. Sarah spoke about how she attributes her own recovery journey to Donna and MHM.

Sarah noted that during the pandemic, CTMUHB allocated some funding to MHM so that they could continue to run the service and that this time Donna had around 50 people engaged with the support she was providing.

Sarah asked Donna how the support is currently funded and how it integrates with the ED service at CTMUHB?

Donna explained that it's been challenging due to the loss of links with the T2 service and lack of funding. Donna stressed that MHM would like to re-establish links with the T2 service and work closely with them.

Nia Holford who has recently joined CTMUHB to re-establish the tier 2 service explained

that the new T2 service has only just opened its doors. Nia is keen to meet with Donna to discuss how they could work together, signposting to MHM and develop a plan for the future.

7. Eating disorder awareness week 2024

Jo confirmed that ED Awareness week will take place from the 26 February - 3 March 2024. This year the week will shine a light on Avoidant Restrictive Food Intake Disorder (ARFID). Sarah confirmed that she will try to secure a debate during the ED awareness week.

The group agreed that the next meeting of the CPG could take place during EDAW. Sarah agreed to invite Lyn Neagle, Deputy Minister for Mental Health to the next CPG meeting. Jo asked group members to let her know if there are any other thoughts and suggestions as to anything else the group would like to do during the week.

Further Senedd Updates

Sarah explained that James Evans MS is putting together a member's bill about mental health and noted that there will be a debate on the 13th December which Sarah will be taking part in.

Sarah referred back to the open letter sent to the Deputy Minister for Mental Health and noted that once a response is received a copy will be circulated to CPG members.

Sarah once again expressed her thanks to everyone involved in the work being undertaken in Wales to improve eating disorder services and noted that it's very positive that eating disorders are getting the profile and attention they deserve.

Review of Actions

- Nia and Donna to report back to CPG following their meeting.
- Sarah to work towards securing a debate in the Sendedd during ED Awareness Week
- Aim to hold next CPG meeting during ED Awareness Week and for the Deputy Minister for Mental Health to be in attendance. (Sarah / Jo)
- Once received, circulate Deputy Minster's response to open letter. (Jo)

Date of next meeting: TBC