Scottish Intercollegiate Guidelines Network (SIGN) Consultation on Eating Disorders -See Me Response

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See Me is Scotland's national programme to end mental health stigma and discrimination. Our vision is to enable people who experience mental health problems to live fulfilled lives.

We are working to change negative behaviours towards mental health, by creating a movement for change, bringing people together all over Scotland who are all passionate about tackling stigma, to work as one. Currently we have nearly 10,000 people signed up, including supporters, volunteers and champions, who are leading the way in making real changes in communities across the country.

We want to change the culture around mental health so people feel confident enough to speak about how they are feeling and can ask for help if they need it, without the fear that they will be stigmatised and discriminated against. To do this we are targeting key settings where people face stigma and discrimination; in work, education, health and social care, and in their local communities.

Eating Disorder SIGN Guidelines – See Me Focus Group

Contributors: 5 young people aged 16-25 years

- Mixture of personal experience of eating disorders and personal experience of wider mental health conditions/CAMHS experience.

Conducted by Sara Preston on behalf of See Me, Consultant support staff and Beat Senior National Officer Scotland.

Process:

- Address and discuss stigma surround eating disorders for those affected
- Challenge each stigma point with ideas for overcoming and best practice guidance to overcome stigma/challenges
- Review of current draft questions – comments
- Identifying additional questions and areas for inclusion in guideline
- Winder comments and discussion on the guidance as a whole

Purpose: Review proposed draft questions in first stage of SIGN guideline consultation

- Questions appropriate?
- Additions and areas missed?
- Any omissions?
- Other comments on questions and guidelines in general?

Overview: Sections detailed more comprehensively below.

1. Current questions and comments
2. Prioritisation of guidance sections
3. New questions and areas to be covered
4. General comments

1. Current Questions and Comments

The group felt the all of the current questions listed were appropriate to be included and didn’t conclude any omissions. However, they did dissect and have comments on the way the questions and topic areas were phrased and structured [see below].

- Questions 1-2 and 4-5, why diagnoses were not used rather than ‘low weight’ and ‘normal/high weight’ eating disorders.
- They felt using diagnosis of Anorexia, Bulimia, Binge Eating/Emotional Over-eating disorder and EDNOS [eating disorder not otherwise specified] would be better to have distinct sections.
    - They felt this would mean that Binge Eating Disorder, Bulimia and EDNOS would receive the equivalent consideration and attention for best practice treatment that Anorexia receives/dominates [when Anorexia makes up approximately 10% of all those impacted] by eating disorders.
    - They did agree that within identifying the specific diagnoses – there should be recommendations and information that someone with Anorexia can be normal weight and equally someone with Bulimia can be underweight.
    - They were very passionate about not focusing on weight and weight loss and making this very clear within the guidelines [detailed further in other sections] – a key area they felt was missing within questions was only looking at a number on the scales and not considering % weight loss e.g. One young person identified that someone could lose a considerable amount of weight in a very short period of time due to destructive means and eating disorder behaviours, but be in a normal weight range so be deemed not in needing of treatment when in actuality their body is ‘starving’ and there mental health/relationship with food is incredibly poor.
        - In relation to this, the young people felt there should be distinct questions/sections relating to level of behaviours and psychological wellbeing – separate to weight e.g. n example given is that someone could be normal/over-weight range but be engaging in destructive purging at high levels which puts them at high risk.

2. Prioritisation of guidance sections

A key discussion point that came of the focus group – was young peoples’ thoughts and personal insights about prioritisation of guidance/recommendation topics.

- They felt that questions/sections about best practice guidance for psychological treatment, medical/physical interventions and pharmacological/medication should remain – but were very passionate in advocating a priority and tiered approach to this – being made clear in the guidance.
- As explanation – they felt that psychological understanding, intervention and treatment should be at the fore front and the primary action, recognising and highlighting that eating disorders are mental health illnesses [albeit there are often physical symptoms and complications], these are secondary to the psychological turmoil and diagnosable mental illness.
- As such – the young people identified that they would wish guidance to prioritise psychological intervention first, supported by medical/physical support considerations as needed, and then further looking at medication and pharmacological intervention as a positive supplementary to therapeutic input established. The young people were quite passionate about this staged nature of interventions, as most of the group expressed experiences of being prescribed medication upon first 10-minute appointment with GP without time or ability to discuss fully mental health challenges they were facing.

Who is the guidance targeted at – should there be distinct sections?
an interesting discussion point that arose from the young people – was *'Who is this guidance for?' 'Can it cover everyone?' 'Should it be divided up for different professionals?'* – which isn't considered in the current draft questions intended to look at/be explored.

Young people were very insightful in considering the different levels of expertise of professionals and different points of contact for an individual/patient impacted by an eating disorder.

As such they identified that there should be distinct sections and recommendations for the different levels of clinicians:

- GPs: Initial appointment best practise conduct, language and advice for early intervention, diagnosis, referral needs and how to refer.
- General MH Clinicians: How to best support ED patient, best practise advice for initial appointment and balancing medical/psychological support in conjunction with other professionals.
- ED Specialist Clinicians: Engaging in best practise therapeutic treatments whilst maintaining medical monitoring – as well as wider linking to associated organisations and establishing relevant co-support for co-morbid conditions and additional considerations relating to gender, sexuality and religious/cultural considerations e.g. Muslim individuals navigating treatment and Ramadan.

3. New questions and areas to be covered

Original points and questions that arose from discussion/questions young people deemed necessary to consider.

- **Wider transitions:** The young people were supportive of considering transition between CAMHS and adult services – as many had experience of this in different service and contests, with differing success, they felt this key to be included in best practise guidance.
    - In addition, they felt transition guidance should be considered more widely e.g. Inpatient to outpatient transitioning, transitioning from one geographical service to another and also raised that some service transitions from CAMHS to adult at 16 whereas others have more person centred flexibility to transition at 17/18 years old dependant on the needs of the individual.

- **NHS Service links:** The young people felt there should be best practise guidelines, information sharing and established links between ED services across the geography of Scotland – so that if a young person in treatment or in referral process, who is moving away from home to attend University, can receive top quality support and a smooth transition between services with open communication.

- **Early Intervention, triage of patients, guidance on referrals process and timelines:** Young people felt that getting help early was a key item missing from the current questions and intended guidance.
    - They spoke about the Scottish Government mission to ‘as once and get help fast’ yet felt this wasn’t being actioned in practise across all mental health conditions. The young people were most insightful in detailing they felt there should be a priority for early referral and there should be guidance provided to Gps with this and stronger communication links between GPs and specialist services. More so, their passion for triaging patients was to consider psychological torment and increased behaviours as priority over physical weight when triaging, whilst still recognising that at times crisis medical cases require immediate intervention.

- **Professional make up of services:** The young people talked about the differences in CAMHS services across the country and the make-up of specialist teams/clinicians within services. They felt there should be a best practise standard for what would be the ‘ideal eating disorders team’ – e.g. Psychologist, Psychiatrist, General Medical Doctor, Specialist Dietician, Occupational Therapist, CPN.

- **Information Provided to Young People:** Young people engaging in CAMHS/IP/OP treatment of various kinds including eating disorder treatment, were left out of conversations in relation to their treatment and did not receive any information about the treatment that “was going to be applied to them” – which overall created distrust and feelings of uncertainty, confusion as to what was going on and feeling left out.

  - Young people felt that it would be very beneficial for diagnosis, treatment programmes and expectations to be explained to them at the earliest point. They felt that this would be most helpful – but they acknowledged that in crisis or critical point of mental ill-health that this may not be taken in or digested at the first point of contact, but commented that they thought it would be a positive thing to address and they could reflect on later, to alleviate uncertainty and set a clear tone for therapeutic relationships moving forward.
  - Young people said they often experienced being excluded from conversations and felt more information – paraphrased/interpreted as ‘psycho-education’ would be helpful as part of treatment in the early stages.

- **Family intervention, support, empowerment and upskilling:** Young people had mixed experiences of family intervention and involvement relating to eating disorders and mental ill health.
  - Firstly, young people identified being excluded from conversations, information being provided to parents/carers/guardians when unnecessary and at times this being detrimental in their treatment path e.g. *“They said let’s get your Mum in to talk – when my Mum and family situation was one of the main issues contributing to my mental ill-health – so it just made it worse.”*
    - As such, young people felt there needed to be better awareness and consideration of the appropriateness and helpfulness of family interaction/involvement in young people’s treatment and the information shared [when not critical/necessary re: confidentiality].
  - On the flipside, the young people were very considered in recognising the distress to parents/carers/families when they are left out of aspects of treatment, and with eating disorders – are not supported or upskilled in how to continue treatment and recovery for their loved one out with formal NHS services e.g. How to deliver meal support [medicine delivery] when back in-home environment after inpatient treatment.
  - They felt more support and information would be helpful both for the parents/carers/family and the young person themselves.

- **Links with specialist services:**
  - <u>Autism Services:</u> High correlation between ASD and eating disorders but services are not linked up and treated/function in isolation – or eating disorder behaviours which align with ASD behaviours are treated as solely a symptom of ED to be solved, rather than in wider context.
  - <u>Diabetes Services:</u> Specific questions relate to treatment of diabulimia – but don’t detail best practise in linking with Diabetes services/training of diabetic nurses with regards to mental health and eating disorders, or best practise for ED practitioners in understanding the medical and

  psychological needs and potential complications for Type 1 diabetics with an eating disorder.
  - LGBTQi: Young people were enthusiastic to identify specific needs of LGBTQi individuals – where individuals face greater challenges in accessing treatment, lack of understanding and discrimination [in challenges identified as purely done to struggle with gender or sexuality and not interlinked or 2 separate entities] e.g. Gay cis identifying males experience a great deal of pressure within the gay community to fit a certain body ideal and 'categories' of preferable partner – such as *'twink' 'bear' 'beaver'* – [terms used by young people].
    - Transgender best practice advisement was a key talking point – with regards to extreme body dysphoria and mental health torment in being trapped in the incorrect body. This was especially highlighted with regards to Female to Male [FTM] transitioning – whereby restrictive eating can alleviate gender dysphoria and rapidly change body shape.
    - For example: Rapid weight loss in FTM individuals – can result in period loss, reduction in female fat deposits [creating a more flat and androgynous/male physique], reduction in breast size [reducing the need for binding] and development of lanugo on face and arms [lanugo is a stress response to starvation where downy hair grows as a means for the body to keep itself warm, which can be seen as positive for trans-men in initial development of facial hair prior to hormone treatment]. In addition, the consideration of hormone treatment on transitioning individuals and as the young people described 'a second puberty' links into eating disorders and causative factors for eating disorder development in non-trans individuals.

The young people also felt these links and education should be delivered and available, not just for clinicians but also education, youth and social care professionals – and there should be a 2-way link between NHS and wider specialist services and groups.

4. General comments

Young people were very considerate of the potential audience that may read and conduct practise based on the SIGN recommendations – and a key theme that came up time and time again through discussing the draft questions and sharing of experiences – was baseline information and best practise language to be used when interacting with patients.

- Young people felt it was inherently important to have baseline information relating to eating disorder diagnoses – signs and symptoms and developing patient relationship.
- Young people were very passionate in advocating for a best-practise and non-stigmatising/non-triggering bank of terms/language [in essence an eating

disorder dictionary] be created and approved – to advise clinicians at all levels.

- The young people strongly advocated this as not just an ED Clinician guideline – but something that could be best practise for primary care GP first interactions, teachers and other professionals – as first port of call and developing understanding and trust. They felt that understanding could determine to trajectory for their ongoing support/treatment/recovery/life.
- It was identified very critically, that when in a vulnerable eating disorder position [irrespective of diagnosis], wording and language is of paramount importance – in developing trust, not feeling triggered, feeling they are being taken seriously, and
- being hopeful for recovery.