



Eating Disorders and Body Image Engagement Report

September 2018

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Executive Summary

NHS Hull Clinical Commissioning Group is re-procuring the community eating disorder service (adults) for Hull. To inform and support the procurement of this service, NHS Hull CCG has undertaken an engagement exercise to determine recent service users', and potential service users', experience and views about body image and the community eating disorders service to inform the service specification and service improvements.

The goals of this engagement work were to:

- Determine why potential users of service might not access eating disorder services.
- Listen to the experiences of existing service users to find out what aspects of service they value, and what areas they would like to see improvement.
- Find out what support may be required by carers and family members of those living with an eating disorder.

Two groups were targeted for this engagement; potential service users, and those who have experience of eating disorder services, this included carers and family members of those living with an eating disorder. The potential service users were engaged through social media and an online questionnaire; semi structure telephone interviews and a questionnaire were used to try and engage those who have experienced services.

The two facebook adverts promoting the potential service user questionnaire ran from 25th July to 5th August 2018. Both adverts were seen by a total of 53,132 people the highest social media reach Hull CCG has achieved through paid promotion on facebook.

388 people took part in this engagement exercise, 369 people completed the online questionnaire through facebook for potential service users, 3 service user telephone interviews were conducted, and 14 people completed the questionnaires aimed at service users, and their carers or family members.

A summary of the engagement findings can be seen below:

Increasing the number of people accessing eating disorder services

- Additional promotion of the available services is required as 60% of respondents stated they are not sure or don't know what services are available.
- If someone suspected a friend or family member had an eating disorder 99% of respondents would, or would consider, letting the person know they were there if needed for support, and 94% would, or would consider, talking to the individual about their concerns. 53% of respondents would hope that if someone close to them thought they may be exhibiting the first signs of an eating disorder that they would talk to them about it. It is clear that there is scope for a marketing campaign targeted at friends and family rather than the individual experiencing the eating disorder; highlighting the warning signs, what support is available, and how to support them.

Service Provision

- There is a need for clarity regarding the eating disorder pathway particularly for the early stages of the condition. The following clarification may be needed; who to refer to and how to manage, if people do not meet the referral criteria. This needs to be appropriately communicated to services that have a close operating relationship with the community eating disorder service, e.g. Primary Care, Let's Talk
- There should be choice built in to the eating disorder pathway, as people report benefitting from, and preferring, different modalities at different stages of their condition. Modalities that have been highlight include 1:1 sessions, group sessions and self-management with quality resources. All should be available at all stages of the pathway.
- There is a desire for online information and support, as well as a telephone helpline or drop in aspect to the service. This was referred to by both cohorts engaged, and should cover the full pathway, with particular emphasis on the early part of the pathway.

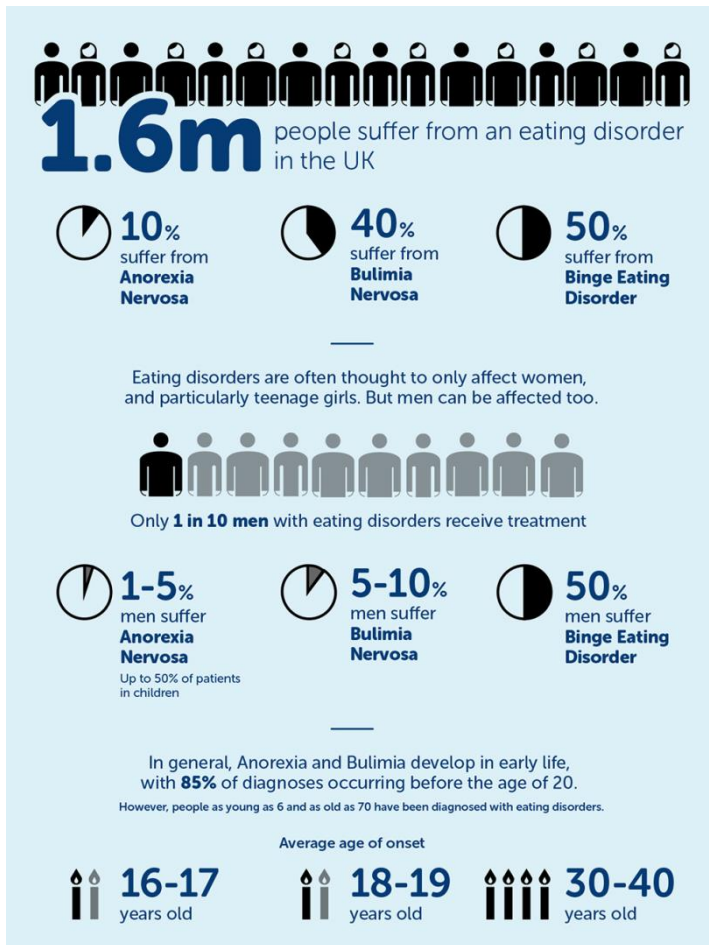
Other Findings

- Although location of service was discussed as part of the telephone interviews and the service user questionnaire there does not seem to be any definitive feeling regarding location. There was agreement that having the same location helped with confidence in the service, reduced anxiety, and helped build the therapeutic relationship.
- A need for confidence in the service and the resources used was highlighted by the service user engagement. Although service confidence may seem obvious, a high level of initial confidence seems to particularly influence how well and quickly the therapeutic relationship develops, and whether an individual will engage in services at all. Further work is recommended to ascertain what gives people confidence in eating disorder services before they have experienced it.

Any changes or improvements to service should be informed by patients and the public who are likely to use the services in question. Supplementary engagement work with service users is recommended.

Introduction

The community eating disorders service (adults) in Hull is a community based education, advice and support service; led by specialists in eating disorders. The contract for this service is due to expire in March 2019. To inform the procurement of this service, NHS Hull CCG has undertaken an engagement exercise to determine recent service users' and potential service users' experience and views about the service and eating disorders to inform the service specification and design.



Figures for the amount of people suffering from eating disorders vary hugely. Research carried out by BEAT, an eating disorders charity in the UK, estimates that more than 725,000 people in Britain suffer from an eating disorder, others put the number as high as 1.6 million. But as many sufferers do not seek help, it is likely the real number is even higher.

In the last financial year 2017-18, 145 people accessed the service. It is believed that eating disorder services are underutilised, but the reasons for this are unclear.

◀ **Diagram 1**
National statistics relating to people living with eating disorders¹.

¹ "Eating disorders and how to effectively treat them" *UK Addiction Treatment Centres*, <https://www.ukat.co.uk/eating-disorders/> Accessed 17 July 2018.

How We Have Listened

Methodology

The goals of this engagement programme are to:

- Determine why potential users of service might not access eating disorder services
- Listen to the experiences of existing service users to find out what aspects of service they value, and what areas they would like to see improvement.
- Find out what support may be required by carers and family members of those living with an eating disorder.

There were two distinct groups that we planned to engage with; current service users and potential users of service.

Potential users of service

There are concerns that the number of people currently accessing eating disorder services in Hull is lower than expected. Potential service users are a particularly difficult group of people to identify as they may not be aware, or have come to terms with the fact that, they have an eating disorder or are exhibiting the warning signs that could lead to an eating disorder.

Based on national and local figures the age range of service users is 16 – 40, however a separate service is commissioned for the under 18s. It is accepted that eating disorders effect women more than men, taking this into account the number of men accessing these services in Hull is lower than expected. The only other demographic group that are particularly susceptible to an eating disorder, bulimia in particular are homosexual men².

Due to the difficulty in identifying this cohort of potential service users, the demographics of this group and the sensitive nature of the subject matter, it was decided that a short online questionnaire be developed. The questionnaire covered the following areas; how people felt about the weight or body shape, what they would do if they thought someone close to them was exhibiting the warning signs of an eating disorder, what they would do if they were exhibiting the warning signs of an eating disorder, and how confident they felt about what services are available and how they would access them.

The questionnaire was shared, and promoted on facebook through targeted advertising. Two adverts were developed one using generic non gender specific imagery and one targeted at men, these can be seen in [appendix \(ii\)](#) on [page 15](#). Both adverts were also printed on business cards promoting the engagement exercise and distributed during Hull Pride to target homosexual men and the wider LGBT community.

² "Bulimia Nervosa" *UK Addiction Treatment Centres*
<https://www.ukat.co.uk/eating-disorders/> Accessed 17 July 2018.

Recent users of service

This is a difficult group of people to engage with, due to the sensitive nature of the services involved. As the existing service uses therapeutic group work and to the relatively small number of service users, it was felt that focus groups would be an appropriate way to engage with service users. Participants were recruited through the social media engagement and through invitations distributed by the eating disorder service and the local eating disorder charity Seed. Unfortunately due to logistical issues semi structured telephone interviews were used instead.

Following the interviews two short questionnaires were developed; one for service users and one for the carers and family members of those living with an eating disorder. These were distributed by the existing service and Seed.

Engagement Reach

388 people took part in this engagement exercise, 369 people completed the online questionnaire through facebook for potential service users, 3 service user interviews were conducted, and 14 people completed the questionnaires aimed at service users, and their carers or family members.

The two facebook adverts promoting the potential service user questionnaire ran from 25th July to 5th August 2018. Both adverts were seen by a total of 53,132 people the highest reach Hull CCG has achieved through paid promotion on facebook. This was particularly successful due to the organic reach, reach by people interacting with the posts, this accounted for almost a third of the overall reach (16,000 people). Both posts received a total of 93 comments. The social media reach can be seen in [appendix \(iii\) on page 15](#).

Due to the low uptake of service users giving their views, supplementary engagement and consultation work with service users is recommended.

Results

Chart 1

How respondents feel about their weight and body shape
(n=369)

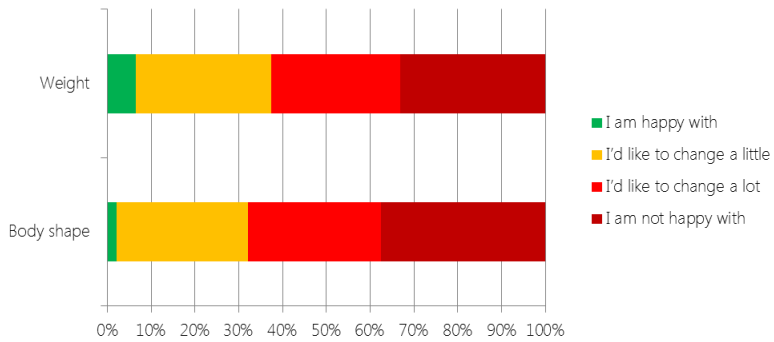


Chart 2

What action participants might take if someone who is close to them started to exhibit the warning signs of an eating disorder
(n=299)

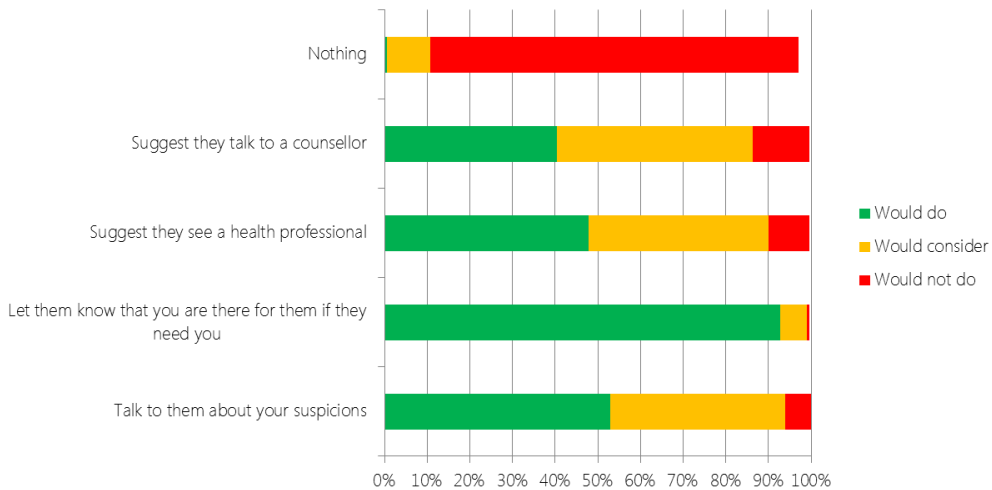
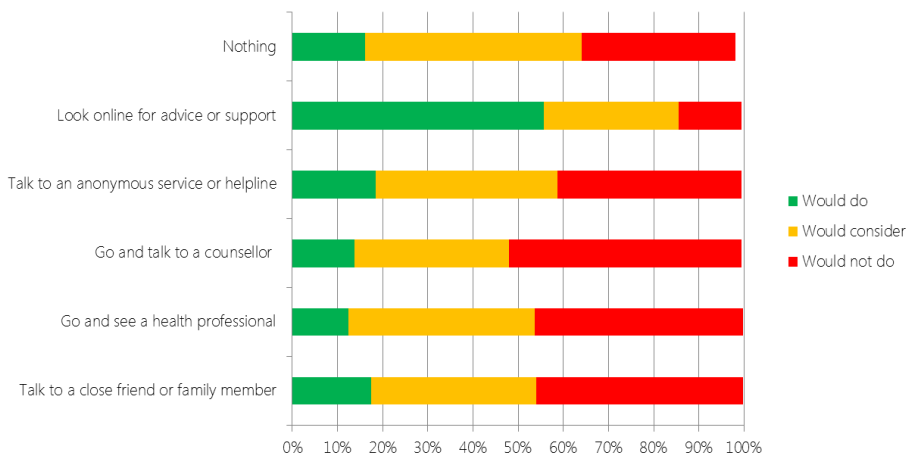


Chart 3

What action participants might take if they started to experience the first signs of an eating disorder
(n=298)



Potential Service Users

Chart 1 shows that between 60% and 70% of respondents have a negative or very negative view of their weight or body shape; with 90% of respondents wanting to make some change to their body shape or weight.

Charts 2 shows what action people would, and would not, take if someone close to them, exhibited the first signs of an eating disorder. If someone close to them started to show the first signs of an eating disorder, the majority of people would act by offering support themselves; 99% of respondents would (93%), or would consider (6%) letting the person know they were there if needed for support, and 94% would (52%) or would consider (40%) talking to the individual about their concerns. This is mirrored in chart 4, which shows that over half of respondents (53%) would hope that if someone close to them thought they may be exhibiting the first signs of an eating disorder that they would talk to them about it. With regards to accessing services 90% would (45%) or would consider (45%) recommending that the person close to them see a healthcare professional, whereas 85% would (40%) or would consider (45%) recommending they see a counsellor.

Chart 3 shows what action people would and would not take themselves, if they felt they were experiencing the early signs of an eating disorder. 85% would (55%) or would consider (30%) looking online for advice or support, accessing an anonymous service or helpline was the next most popular (59% would or would consider) followed by Talking to a friend or family member (54% would or would consider), 53% would go or consider going to a healthcare professional, and 47% to a counsellor. The least popular action was going to see a counsellor (51%).

Chart 5 shows that there is a lack of awareness about what services are available with 60% of respondents saying they are not sure (41.95%) or don't know (17.98%) what services are available. Just under a third know about some of the services, only 8.24% feeling confident about accessing services.

Chart 4
If you felt you were experiencing the first signs of an eating disorder, would you hope that someone close to you would notice and talk to you about their suspicions?
(n=286)

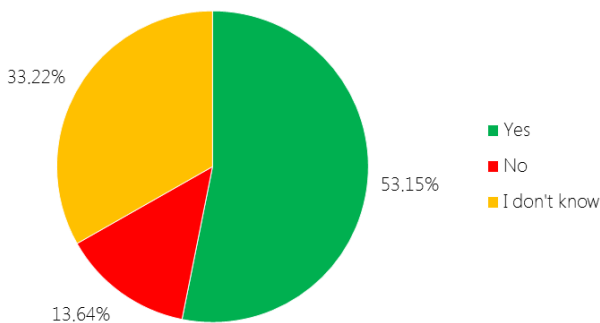
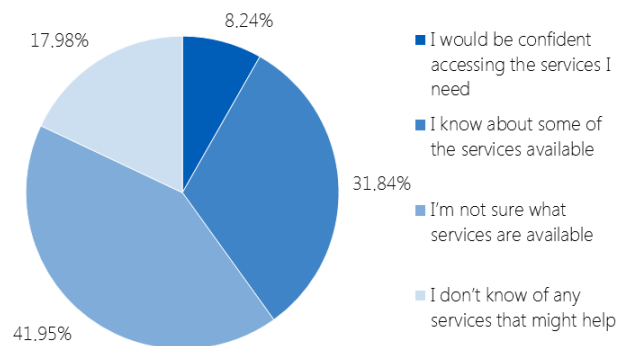


Chart 5
How confident would you feel that you know what support for eating disorders is available?
(n=267)



Service Users

Due to the low level of response from service users, and their family and carers, reporting a detailed analysis of the questionnaires is not appropriate. Emerging themes will be highlighted here and it is recommended that supplementary engagement work or co-production with service users is undertaken, building on these areas.

The people taking part in the semi structured interviews had quite different experiences over quite a long period of time. All ended up receiving support through different referral routes, one was initially referred to a dietician, and one to Let's Talk, the other went straight to Seed (local eating disorders charity). One thing that is clear from some of the comments in the questionnaire and the interviews is that there seems to be confusion on how to deal with the initial stages of an eating disorder. With one person saying they were not able to access eating disorder services "because they hadn't lost enough weight".

The semi structured interviews and the service user questions both indicate that there is no preference from group support or 1:1 support, and that it depends upon the individual, and what stage of their treatment and recovery they are at. It is clear that there is a desire to have "out of service" support i.e. telephone support or online support and information to complement the support they are receiving when they attend the service.

Confidence in the service was referred to a few times during the telephone interviews. Confidence in the service before attending seems to lead to the person being more engaged, one individual for part of their treatment plan was travelling to Leeds to a service that she had heard about; "I knew I was going and I knew what that meant and I knew it was absolutely going to help me". Conversely if someone accessed a service and something happens where their confidence in the service drops, it can mean they don't attend; not just that service but any service. The type of support, if it is a type that is not a good fit for the person, the quality of the resources, how the group work is facilitated can all greatly diminish confidence in the service.

Service users were asked about the location of services as part of the telephone interview and the online questionnaire, there wasn't any definitive feeling regarding geographical location; with people finding it equally easy and difficult to get to. However, having a single fixed location seemed to be preferred as it reduced anxiety as the place became more and more familiar. One of the individuals interviewed had confidence in a particular service in a particular location, having a peripatetic service may make building confidence in a service harder.

All participants seemed to have both positive and negative things to say about their experiences of services. Negative comments centred on difficulty in accessing support that they need, or the support in a format that works for them. Positive comments almost always centred on an individual practitioner or when people get into the "right" or preferred service or have the "right" or preferred support.

Conclusion

Increasing the number of people accessing eating disorder services

It is clear that the community eating disorder service (adults) would benefit from some promotion as 60% of respondents stated they are not sure or don't know what services are available. The content and mode of promotion should be carefully considered. A simple print media promotion of the service targeted at demographics more likely to experience eating disorders may not be effective; as 65% of respondents said that if they thought they were experiencing the warning signs of an eating disorder they would do (15%) or would consider doing (50%) nothing. 85% of respondents said they would (55%) or would consider (30%) looking online for help or support.

A marketing campaign aimed at people close to the person living with an eating disorder or exhibiting symptoms would be worth exploring. 99% of respondents stated that they would or would consider letting the person know that they are there for them, 94% would consider talking about their suspicions that the individual is exhibiting symptoms; this is validated by 53% of people would hope that a friend or family member would talk to them if they thought they were exhibiting symptoms. A campaign about the symptoms or early warning signs and where to go for help would be beneficial as 90% of respondents would recommend seeing a healthcare professional to someone close to them who was exhibiting warning signs of an eating disorder ([chart 2, page 8](#)).

Service provision

There is a need for clarity regarding the eating disorder pathway particularly for the early stages of the condition. The following clarification may be needed; who to refer to and how to manage, if people do not meet the referral criteria. This needs to be appropriately communicated to services that have a close operating relationship with the eating disorder service, e.g. Primary Care, Let's Talk. A pathway would be beneficial during periods of recovery and remission that are away from the service, as some service users have spoken about issues where they were unsure how to re-access support, some saying that they felt that they were discharged too early; a pathway would help manage expectation and support transition between different phases of support.

It is clear that a number of different modes of support should be available and various times throughout the eating disorder pathway, as there is no definitive preference for group support or 1:1 support. There should be choice built in to the eating disorder pathway, as people report benefitting from, and preferring, different modalities at different stages of their condition. Modalities that have been highlighted include 1:1 sessions, group sessions and self-management with quality resources. All should be available at all stages of the pathway. Based on the findings of this engagement work the initial contact to determine the intervention options available should be a 1:1 session.

There is a desire for online information and support, as well as an anonymous service aspect such as a telephone helpline. This was discussed by service users and would be the first port of call for family and friends, as well as potential service users. It is not clear if this would need to be developed or if the information or service already exists. The information should cover the full pathway from early warning

signs and symptoms, what to do if those signs and symptoms emerge, who to see and when and how to be referred. Particular emphasis should be on the early part of the pathway.

Other findings

The location of services was discussed as part of the telephone interviews and the service user questionnaire. There was some discussion about alternative venues e.g. existing health centres and gyms, but there does not seem to be any definitive feeling regarding location. Some respondents felt the current location was easy to get to, and others felt the opposite, there was not enough evidence to suggest that the service should be moved. There was agreement that having the same location throughout treatment would be beneficial for a number of reasons; it supports confidence in the service as location is often intrinsic to service perception, service users reported that having the same location reduced anxiety, and helped build the therapeutic relationship.

Although all health services require a level of confidence for user to access them, for this group of people the level of confidence seems to be high, participants seemed to have confidence in services they had not used based on the professionals working there or the reputation of the service. Lack of confidence in the service and the resources used was highlighted by one service user as the reason they stopped engaging with services. Although service confidence may seem obvious, a high level of initial confidence seems to play particular importance on how well and quickly the therapeutic relationship develops, and whether an individual will engage in services. Further work is recommended in what gives people confidence in eating disorder services before they have experienced it as this could improve service uptake and people maintaining their therapeutic intervention.

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Appendix (i)

Demographics of respondents

The information below shows the demographics of the respondents to the questionnaire. It is recommended that the Equality Impact Assessment for the extension of access to primary care is revisited in light of this information.

Distribution of respondent characteristics

Chart 6

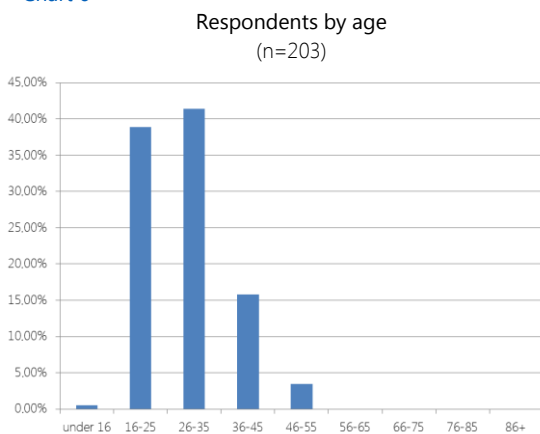


Chart 7

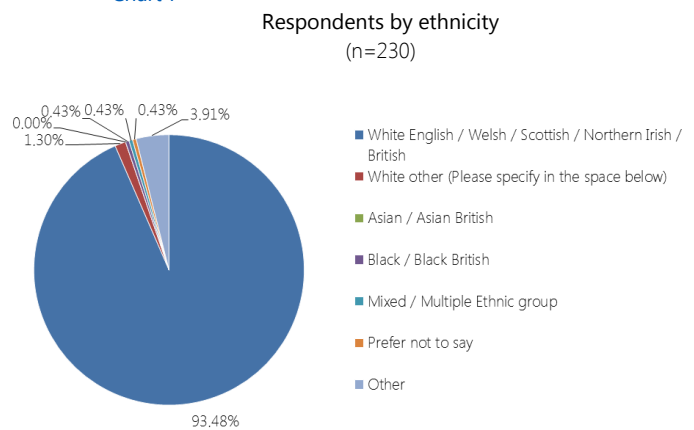


Chart 8

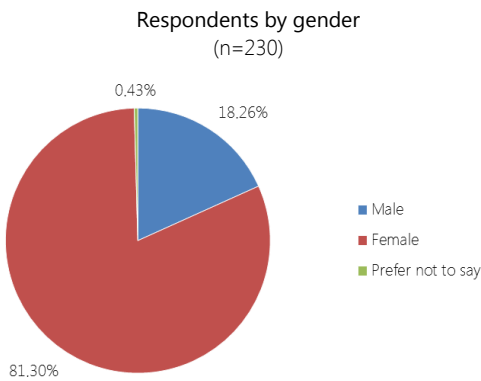


Chart 9

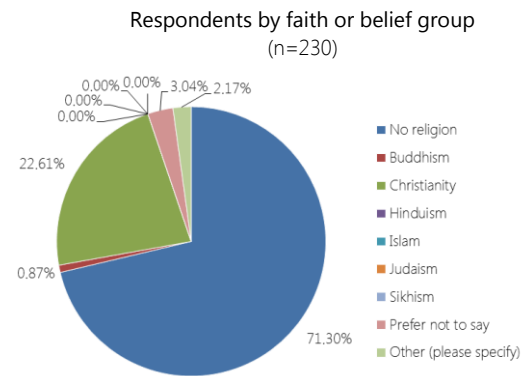
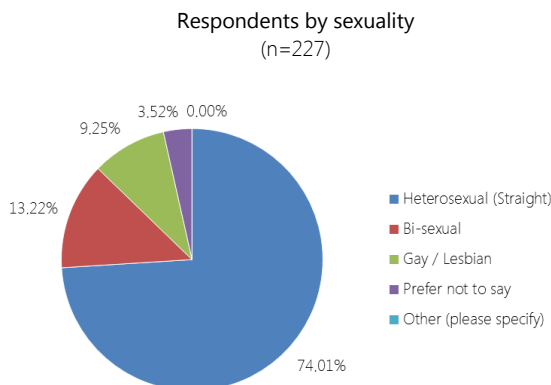
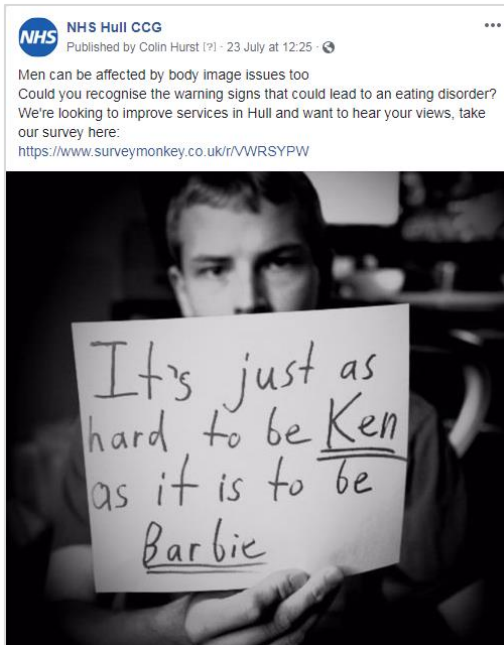


Chart 10



Appendix (ii) Facebook Adverts



Appendix (iii) Social Media Reach

Facebook Jul 25 - Aug 5

Posts: 2

Total estimated reach: 53,142

Reach Paid: 39,160[#]

Reach Organic: 16,869^{##}

Engagements: 3380^{###}

Reactions: 684

Link Clicks: 406

Shares: 158

Comments: 93

[#] Our reach is the total number of individual people we have contacted. Our paid reach is monitored to the individual and ensures that we have been seen by around 15,000 people.

^{##} Because organic reach is gained from people who like our page and from their friends and contacts, it's difficult to keep a running total and provide a definitive figure.

^{###} This is the total number of times people engaged with our posts (Shares, likes, link clicks, etc).

Appendix (iv)

Body Image Questionnaire



NHS Hull Clinical Commissioning Group (CCG) would like to hear your views on body image issues and eating disorders to help improve service in the future.

Completing the Questionnaire

Taking part in this questionnaire is voluntary and anonymous. For each question please tick the box that is closest to your views or closest to your experience.

If you have any questions about this questionnaire, or would like it in another language or format, please ring the Communications and Engagement Team for help on: 01482 344700.

What is NHS Hull Clinical Commissioning Group?

NHS Hull Clinical Commissioning Group (CCG) plans, funds and monitors the quality of NHS healthcare services for people who live and work in Hull.



1. How would you describe yourself? (please tick one option)

- I am happy with my body shape
- I'd like to change my body shape a little
- I'd like to change my body shape a lot
- I am not happy with my body shape

2. How would you describe yourself? (please tick one option)

- I am happy with my weight
- I'd like to change my weight a little
- I'd like to change my weight a lot
- I am not happy with my weight



These are some of the first signs of someone who is developing, or has, an eating disorder

□

About a friend:

3. If someone who is close to you started to show any of the above signs what would you do?

	Would do	Would consider	Would not do
Talk to them about your suspicions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Let them know that you are there for them if they need you	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Suggest they see a health professional	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Suggest they talk to a counsellor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Nothing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Something else (please specify)

About you:

4. If you felt you were experiencing some of the first signs as described above what would you do?

	Would do	Would consider	Would not do
Talk to a close friend or family member	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Go and see a health professional	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Go and talk to a counsellor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Talk to an anonymous service or helpline	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Look online for advice or support	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Nothing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

5. If you answered nothing or "would not do" to the above question, use the space below to tell us why



6. If you felt you were experiencing some of the signs described, would you hope that someone close to you would notice and talk to you about their suspicions?

- Yes
- No
- I don't know

7. If you answered no to the above question, use the space below to tell us why



8. If you or someone close to you started to show some of the first signs of an eating disorder would you feel confident that you know what support was available?

- I would be confident accessing the services I need
- I know about some of the services available
- I'm not sure what services are available
- I don't know of any services that might help

9. If you have any thoughts or comments about body image or eating disorders please use the space below to let us know



About you

We know that people from different age groups, ethnic groups, religions, and sexualities access healthcare in different ways, they have different health needs and sometimes have differing experiences of care.

By telling us a little about you, we can make sure that everyone has the opportunity to receive care in a way that is most appropriate to them.

If you don't want to answer any of the questions please select "Prefer not to say". Your responses to this section will be completely anonymous.

10. What is your postcode?

11. Which GP Practice are you registered with?

12. What is your year of birth?

Prefer not to say

e.g. 1990

13. Which of the following best describes your ethnic background?

White English / Welsh / Scottish / Northern Irish / British

White other (Please specify in the space below)

Asian / Asian British

Black / Black British

Mixed / Multiple Ethnic group

Prefer not to say

Other (please specify)

14. What is your religion, belief or faith?

No religion

Buddhism

Christianity

Hinduism

Islam

Judaism

Sikhism

Prefer not to say

Other (please specify)


15. What is your gender?

- Male
- Female
- Prefer not to say

Is there anything else about your gender you would like to tell us?

16. What is your sexual orientation?

- Heterosexual (Straight)
- Bi-sexual
- Gay / Lesbian
- Prefer not to say
- Other (please specify)



NHS
Hull
Clinical Commissioning Group

NHS Hull CCG would like to hear your views and experiences to help us improve healthcare in the city

17. If you would like to be involved in the future please select one of the following options:

- I would like to be more involved in this consultation
- I would like to give my views on other healthcare services
- I would not like to be involved any further



18. Thank you for agreeing to be involved in our future consultations and feedback, please enter your contact details below.

Name	<input type="text"/>
Email Address	<input type="text"/>
Phone Number	<input type="text"/>

To keep your survey response anonymous, this information will be separated before processing.

NHS Hull CCG will use this information to contact you with opportunities to give your views on the services it commissions.

Your information will not be shared with any other organisation or agency.

If you would like to change your mind and wouldn't like to be contacted please contact NHS Hull CCG Communications and Engagement Team:

Tel: 01482 344700

email: HULLCCG.contactus@nhs.net

If you would like more information about how we use your information please read our [privacy statement here](#)



Information and support

If you would like more information about eating disorders [please click here](#)

If you would like to talk to someone about eating disorders [please click here](#)