Full report

Virtually Anorexic – Where's the harm?
A research study on the risks of pro-anorexia websites

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Executive summary

This research by Dr. Emma Bond at UCS, funded by Nominet Trust, investigated the risks from the increasing number of pro-anorexia websites online. The study examined 126 pro-eating disorder websites and online communities and found that the sites promote a disordered view of perfection in relation to body image which normalises an ultrathin/emaciated body. There is often extreme or dangerous dieting advice given which promote harmful behaviours. The sites reinforce an eating disordered self-identity and bullying is frequent. There is an increasing availability of pro-eating disorder forums and blogs but the nature of the sites varies according to the type of online space. The risks vary according to the type of content and the frequency of visits and young people who have low levels of self-esteem or are lacking in self-confidence are especially vulnerable. For people with an eating disorder there is a problematic relationship between feeling isolated from family and friends and finding support in online environments which makes treatment and recovery complex. The research concludes that health professionals, educators and parents need to be aware of Pro-Anorexia sites and the risks they may pose but it is important not to unnecessarily advertise their existence to children and young people. Educational strategies aimed at children and young people should emphasise the importance of critical thinking around visual images in relation to the wider context of harmful content online.

This report reinforces the importance of educating people to be safe, confident and competent users of digital technologies. In particular it highlights how challenging, but vital, this task is to ensure we best support the significant number of people with eating disorders. It's easy to highlight the benefits of online communities for supporting people through shared experiences when looking at communities such as Beatbullying's Cybermentors (http://www.cybermentors.org.uk/) or Youthnet's TheSite (http://www.thesite.org/) but this report highlights how online communities can reinforce messages and behaviours which can increase the risks faced by those accessing them. Supporting people to become critical users of digital technology is central to the work of Nominet Trust and it's a responsibility that lies across sectors and professional and family roles. As part of this, supporting people to develop their critical understanding of, and behaviours within social networks is vital.

This report follows a comprehensive study into a challenging area and I hope that is useful to ensure we can build the most appropriate digital, and non-digital support for people with eating disorders.

Dan Sutch
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Table of contents:

1. Introduction and Context

1.1.   This document outlines the main findings from the research study 'Virtually anorexic: Where's the harm?' which Dr. Emma Bond, Senior Lecturer in the department of Applied Social Sciences at University Campus Suffolk undertook between January –June 2012 in partnership with Beat[1] and Childnet international.[2] The study was funded by Nominet Trust.[3] The research aimed to gain knowledge and understanding of pro-anorexia sites and online communities and to provide a review of the risks in relation to young people's use of pro-anorexia (pro-ana) and pro-eating disorder (pro-ED) sites.

1.2.   This study is significant as health related sites and discussion forums enable people all over the world to communicate on a particular topic or shared interest.[4] However, there is a lack of evidence-based online health information related to eating disorders which places adolescents and their families at risk of obtaining inadequate information regarding the clinical characteristics and treatment options available.[5]

1.3.   This study does not only focus on risks to adolescents. According to Mind (the leading mental health charity for England and Wales), 1 in 100 women aged between 15 and 30 in the UK suffer from anorexia and recent reports show some girls as young as five years of age have weight concerns, and think about going on a diet. Anorexia Nervosa (AN) is most likely to strike during the mid-teenage years and it affects approximately 1 in 150 fifteen-year-old females, and 1 in 1000 fifteen-year-old males.[6]

1.4.   There are increasing concerns over the number and availability of pro-ana and pro-ED sites on the Internet yet little is known about why people use them, what they use them for and whether or not they are contributing to either the anorexic condition or the pro-ana phenomenon. It is well acknowledged that people use new media technologies for both risk management and risk-taking behaviours to achieve identity as individuals and as members of cultural groups in both offline and online environments.

1.5.   Whilst there have been other studies which consider pro-ED websites, this study looked specifically at risks in relation to these sites. It did not, however, seek to adopt a medical perspective in relation to both understanding eating disorders (EDs) and the risks associated with them. Due to ethical considerations this research considered the availability and content of online pro-ED websites, communities and Weblogs publically available. It did not endeavour to discuss the experience of using these sites nor being part of the ED community online. It is argued that it is essential to gain a deeper understanding of why people use these sites, how they use them and their thoughts and feelings about them. This is one of the recommendations of the report and some suggestions for further research are made.

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1 Beat provides helplines, online support and a network of UK-wide self-help groups to help adults and young people in the UK beat their eating disorders see http://www.b-eat.co.uk/

2 Childnet International is a non-profit organization working with others to "help make the Internet a great and safe place for children" see http://www.childnet.com/

3 Nominet Trust was established in January 2008 by Nominet, one of the world's largest Internet registries, which maintains the .uk register of domain names. As part of Nominet's public purpose, Nominet Trust was set up to fund internet-based projects that make a positive difference to the lives of disadvantaged and vulnerable people see http://www.nominettrust.org.uk/

4 Tierney, S. (2006) The Dangers and Draw of Online Communication: Pro-Anorexia Websites and their Implications for users, Practitioners, and Researchers. In *Eating Disorders 14: 181-190*.

5 Smith, A. T. and McGowan, K. A. (2011: 36) Quality of Eating Disorders Websites: What Adolescents and Their Families Need to Know. In *Journal of Child and Adolescent Psychiatric Nursing Vol. 24 PP 33-37.*

6 The Royal College of Psychiatrists [online] http://www.rcpsych.ac.uk/mentalhealthinfoforall/problems/eatingdisorders/eatingdisorders.aspx

1.6. This research project is an Internet-based exploratory study which aimed to improve knowledge and understanding of pro-ana websites and online communities. It considered perceptions of risk from a variety of perspectives and notions of self-identity in relation to pro-ana online environments. The research examined how the sites offer tips and advice, support and other information and an 'embodied' social space for people with eating diorders.

1.7. The research gathered detailed empirical evidence using existing literature and collected data online. Both quantitative and qualitative data were analysed, including text and images gathered from selected, publically available pro-ana websites, blogs and online forums. The relationship between the users' perceptions of risk as discussed online, self-identity and online environments was examined in order to gain knowledge and understanding of the range, uses and content of these sites.

1.8. Due to the ethical complexities of researching online environments and reporting findings specifically in relation to EDs (as outlined above), for the purposes of this research only webspaces which were not password protected were included in the study.

1.9. An objective of this study was to consider a research framework for an in-depth participant-centred virtual ethnography for researching pro-ana environments online which takes into account the complicated ethical issues raised by research of this type and in this subject area. This is one of the recommendations of this report. Further research would facilitate a more detailed understanding of the views and experiences of the online ED community and their families and the adoption of participant centred in-depth analysis of the social phenomena described in this report is a recommendation of this report. A detailed emancipatory research project with this oppressed and often stigmatised group would access knowledge that the study presented here is unable to offer and allow previously excluded voices to be heard.

1.10. Although pro-ana sites are different from other social networking sites such as Facebook, the discussion of the 'body' and the 'self' in virtual environments can also potentially have distinct positive implications in relation to wellbeing, peer networks and identify formation. Whilst there are risks and dangers related to pro-ED websites which this report highlights it should nevertheless be noted that that these environments also offer potential benefits to people with EDs and their families that may be drawn upon and adopted in the construction of positive virtual environments by pro-recovery organizations.

1.11. The values and principles of high quality social research online have underpinned this study throughout and this research has been conducted in line with the principles set out by the Singapore Statement on Research Integrity[7] and is reported in a way that is respectful to the community it has investigated and considers the reporting guidelines outlined by Beat.[8]

1.12. Funded by Nominet Trust and in partnership with Beat and Childnet International, this study aims to raise awareness of the potential risks associated with pro-ana sites and online environments for vulnerable young people through wide-ranging dissemination activities and further discussions with academics, policymakers and practitioners.

1.13. Overall the study provides a comprehensive and detailed account of online pro-ana environments that are openly accessible through a basic search engine such as Google. The data obtained from the research details the content of websites and online forums and includes both quantitative and qualitative verbatim data and associated documents such as photographs, images and video which were systematically analysed into categories –

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7 Singapore Statement on Research Integrity available to download from: http://www.singaporestatement.org/

8 Beat [online]*Media reporting guidelines* available from http://www.b-eat.co.uk/about-beat/media-centre/media-guidelines/

Perfection; Performance; Protection and Paradoxes. The categories are discussed in this report in order to present the range of identified risks in relation to these sites and online forums. These findings are considered in relation to the existing literature on eating disordered people and online environments.

2. Methodology

Review existing literature	Develop ethical framework	Online research	Review of content from selected websites and online forums
Review of existing literature in relation to anorexia and Pro-Ana websites and compile literatature review	Review academic and professional guidelines on ethical research online	Systematic online search for websites obtained by typing "pro-anorexia" into popular search engine	Systematic review of websites, documenting URL; type of online space; archiving and bookmark of online spaces
Identify key issues and ascertain research appraoches and knowledge to date	Consult with BEAT on reporting guidleines	Select websites that satisfy criteria for study: Pro-ED; recently updated and openly accessible (i.e. not password protected)	Detailed analysis of online content, tagging with key words and organizing both quantiative and qualitative data

2.1. Literature review

The research commenced with a thorough literature search using academic research databases. The review considered current professional and academic literature from a variety of perspectives (medical; psychological; sociological; feminist and media/cultural) on pro-ED websites and identified the key issues to date. The research thus built upon existing conceptual frameworks of anorexia and pro-anorexia in order to analyse the content of the websites and online environments in relation to what is already known about the condition and the pro-ana/ED community online.

Key issues identified from the literature review:

Diversity:	ED facts:	Pro-ED:	Internet:	Pro-ED online:	Concerns:	Ambiguities:
Various different spaces onlne	Prevalence	Anti-recovery	Online space	Transient	Triggering	Loving and loathing ED
Diversity of audience	Tended to be young and female	Wanted ED	Information sharing opporunities	Varied type and content	Promotes dangerous dieting behaviours	Not wanting ED but not wanting recovery
Different research approaches	Linked to other mental health issues	Sought to mantain illness	Anonymity	Thinspo; tips and tricks	Normalises disorder	Self-identity versus ED identity
Different academic perspectives	Lacked support/socially isolated	ED associated with feeling good	Increasing ease of access	Varied frequency of visits	Competative environment	Belonging online versus belonging offline

2.2. Ethical considerations

2.2.1. Although there is no single comprehensive ethical framework for undertaking this type of research the study used both the British Sociological Association (BSA) and the British Psychological Society's (BPS) guidelines for online research in order to ensure that ethical standards were adhered to and ethical issues considered throughout. The project was subject to full ethical approval from the UCS Ethics committee and complied with UCS ethical guidelines. The research study was not interactive (i.e. it did not make contact with users nor make any posts). This was a small scale exploratory study and was conducted using content analysis only.

2.2.2. In this research report careful considerations have been made with regard to presenting the data. According to the BPS:

> "Researchers should avoid using quotes that are traceable to an individual's posting via a search engine unless the participant has fully understood and consented to this. Instead, they could consider the use of composite 'characters' for analysis, and the paraphrasing of quotes, if this is consistent with the research design. Specifically, the address of the website or discussion forum from which any data is gathered should not be published alongside any analysis of communication sourced from that same site. The pseudonyms used by posters to communication forums should be treated with the same ethical respect as a researcher would treat a person's real name."[9]

Issues of confidentiality and anonymity have, therefore, applied throughout. Names of websites and contributors are not included in this report all direct quotes and screen casts from websites and chat rooms have been put through Wordle.™[10]

2.2.3. Furthermore, The BPS guidelines[11] state that: "In many current Internet Mediated Research (IMR) research paradigms, the participant is likely to be unidentifiable and uncontactable by the researcher. In planning research, therefore, investigators must consider whether they are likely to encounter problems, and what course of action will be adopted if they do". To this end if the research had identified a concern in relation to a young person's (under 16) wellbeing (for example a post stating that they felt suicidal) the appropriate organization e.g. CEOP would have been contacted with the details of the posting to be appropriately investigated.

2.2.4. The BPS[12] suggests that unless consent has been sought, observation of public behaviour needs to take place only where people would 'reasonably expect to be observed by strangers'. In order to comply with this no password protected websites or forums were included in this study; only those that were easily accessible and in the public domain were accessed.

2.2.5. It is, however, noteworthy that the review of the literature revealed somewhat contradictory practice in relation to the ethical considerations associated with online research of pro-ED websites. Some studies have undertaken covert observational and interactive ethnographic research in pro-ana communities whilst others document that they merely 'lurked'. Some previous research has included password protected communities, chat rooms and forums whilst other research endeavours have declared this inappropriate and ethically unacceptable. Different research approaches entail differing ethical viewpoints. The BPS suggest that there are ten issues which should be fundamental considerations when researching in online

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9 British Psychological Society (2007) *Conducting Research on the Internet: Guidelines for Ethical Practice in Psychological Research Online* [online] available from http://www.bps.org.uk/publications/policy-guidelines/research-guidelines-policy-documents/research-guidelines-policy-documents/

10 Wordle™ is an online tool for generating "word clouds" from text that you provide. The clouds give greater prominence to words that appear more frequently in the source

11 British Psychological Society op.cit.

12 ibid.

environments: "verifying identity; public/private space; informed consent; levels of control; withdrawal; debriefing; deception; monitoring; protection of participants and researchers and data protection."[13]

2.3.   Reporting guidelines

2.3.1. Words and pictures matter and there are some terms, phrases and images that can inadvertently adversely impact on someone affected by an eating disorder. Although an eating disorder cannot develop through copying what another person does – a person with an eating disorder can be influenced by the disordered behaviour of others which can be particularly dangerous. No images (other than one a simple search on Google images) have, therefore, been included in this report.

2.3.2. Competitiveness, perfectionism, control and low self-esteem comprise the key personality traits that raise the risk for individuals with eating disorders. People with eating disorders judge themselves very harshly and are constantly comparing themselves negatively with others. They typically feel they are not ill enough to deserve treatment and help – even when they are very seriously ill indeed. Their dangerously distorted body image can convince them they are grossly overweight when in reality they are emaciated. This distortion only affects their perception of their own body – they are able to accurately judge when others are underweight or ill. People with eating disorders speak about being 'triggered' – how their eating disorder behaviour and negative mental state can be stimulated, encouraged or reinforced by certain words, images or situations. Treatment and therapy can help people to identify, recognise and manage these triggers, but they remain a high risk to the individual. Beat provides specific advice and guidance on the reporting of Eating Disorders. This report follows this guidance and any press coverage of this research is requested to follow the guidelines set out by Beat available to download from Beat http://www.b-eat.co.uk/about-beat/media-centre/media-guidelines/[14].

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13 ibid.

14 Beat [online]*Media reporting guidelines* available from http://www.b-eat.co.uk/about-beat/media-centre/media-guidelines/

2.3.3. Everyone is different, but there are some common features of the media reporting of eating disorders that people affected would find problematic:

Specific weights	Any mention of the lowest weight a person attained is unhelpful. The competitive nature of eating disordered thinking would mean such a number would become a target to aim for. The self-critical aspect would make someone judge themselves harshly if they didn't get that 'low' – they can't have been really ill, or not a 'proper' anorexic if their own weight was higher than that reported in the media.
Amounts eaten	Similarly, mention of specifically small amounts eaten e.g. 'lived on half an apple a day' would act as an encouragement to restrict or purge.
Images	Images, especially photographs of certain emaciated body parts are triggering – ribcages, concave stomachs, collar bones, sternums and spines. Tops of arms that are shown as the same circumference as wrists, or thighs the size of knees are also unhelpful.

2.3.4. More general points to consider avoiding are inaccuracies such as referring to an eating disorder as the 'slimmer's disease' or as a phase, fad, or some celebrity copycat. Calling someone an anorexia or bulimia victim is not helpful, neither is adding 'orexia' as a suffix to create a trivial association. Examples are 'brideorexia' for women dieting to fit a particular wedding dress or 'tanorexia' for someone constantly using sunbeds because they believe they look thinner with a tanned skin. Referring to someone as 'flirting with an eating disorder' or having a 'touch of anorexia' is unhelpful as it can trivialise the condition.

2.4. Researching Online Environments

This study uses 'text' to 'refer to data derived from 'words and/or images' which have become recorded without the intervention of a researcher' and the advantages of collecting data in this way are outlined below[15]:

Richness	Close analysis of written texts reveals presentational subtleties and skills
Relevance and effect	Texts influence how we see the world and the people in it and how we act – think of advertisements and CVs!
Naturally occurring	Texts document what participants are actually doing in the world – without being dependent on being asked by researchers
Availability	Texts are usually readily accessible and not always dependent on access or ethical constraints. Because they may be quickly gathered, they encourage us to begin early data analysis

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15 See Silverman, D. (2011: 229-230) *Interpreting Qualitative data* (4th Edn.) London: Sage

2.4.1. This study does not claim that the data drawn from the content of these online spaces is a true depiction of people's lives (just as interview data/observations and questionnaire responses do not represent the reality of lived experiences) but that these online spaces do offer rich examples of "naturally occurring data which vividly represent how people represent their activities and experiences."[16]

2.4.2. The findings are presented as a true record of events in order to understand the pro-ana online culture and community. The study achieved numerical outcomes through analytical categories and narrative analysis to present the stories found there.[17] Furthermore, the careful analysis of images, which are central to the visual in post modernity[18], used pre-existing visual representations.[19]

2.4.3. "Culture became a crucial means by which many social scientists understood social processes, social identities, and social change and conflict."[20] This analysis adopts a cultural approach in that it considers social processes, social identities, social changes (in relation to online environments) and conflict.

2.5. Sample selection

2.5.1. A total of 126 websites and blogs were considered in the research study. All the sites were non-password protected and found through a simple strategy of typing "pro-anorexia"; "pro-ana" or "pro-ED" into Google or through a link from a site found in the original Google search. The rationale behind the sampling strategy was to find sites available through a basic search and, therefore, easily accessible to young people without requiring technical expertise (rather than by using a more technically complex route).

2.5.2. Inclusion and exclusion criteria were initially employed in order to exclude sites which were pro-recovery (including pro-recovery sites not run by professional/medical organizations). Only those sites that were openly anti-recovery and pro-ED were included. For ethical reasons any sites which required access via a password were also excluded. Some sites did, however, have a disclaimer (see section 4.9.) which had to be acknowledged before entering the site. These sites were included in the sample as neither registration nor a password was required.

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16 ibid

17 ibid

18 See Rose,G. (2012) *Visual methodologies* London: Sage

19 Pink, S. (2007) *Doing Visual Ethnography* London: Sage

20 Rose op.cit. (1-2)

Sample of online spaces considered after inclusion and exclusion criteria applied:

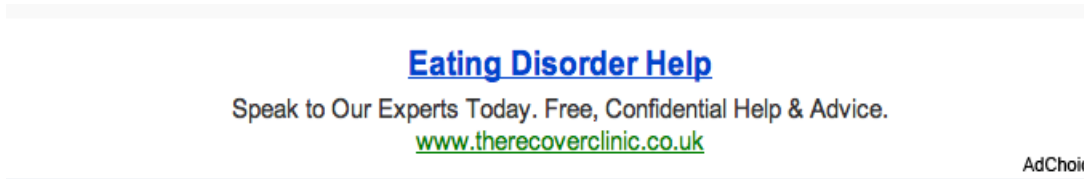|	Found on search for "pro-anorexia" and viewed	Pro-ana content	Recently updated	Password protected	Included in analysis
Multi-page complex website (CWS)	98	56	30	12	18
Individual Image based site (IIS)	129	97	45	9	36
Individual blog (IB)	145	130	76	29	47
Multi-page basic website (BWS)	72	66	32	7	25
Total:	444	349	183	57	126

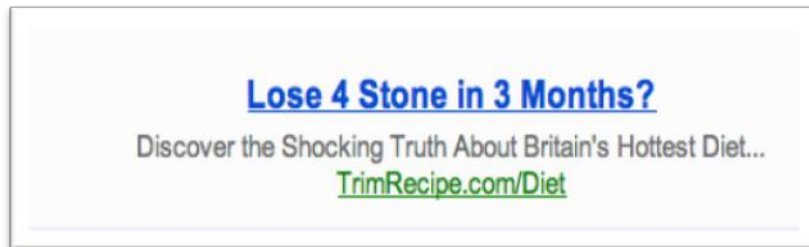**Pie chart to illustrate the proportion of online spaces analysed in the study:**
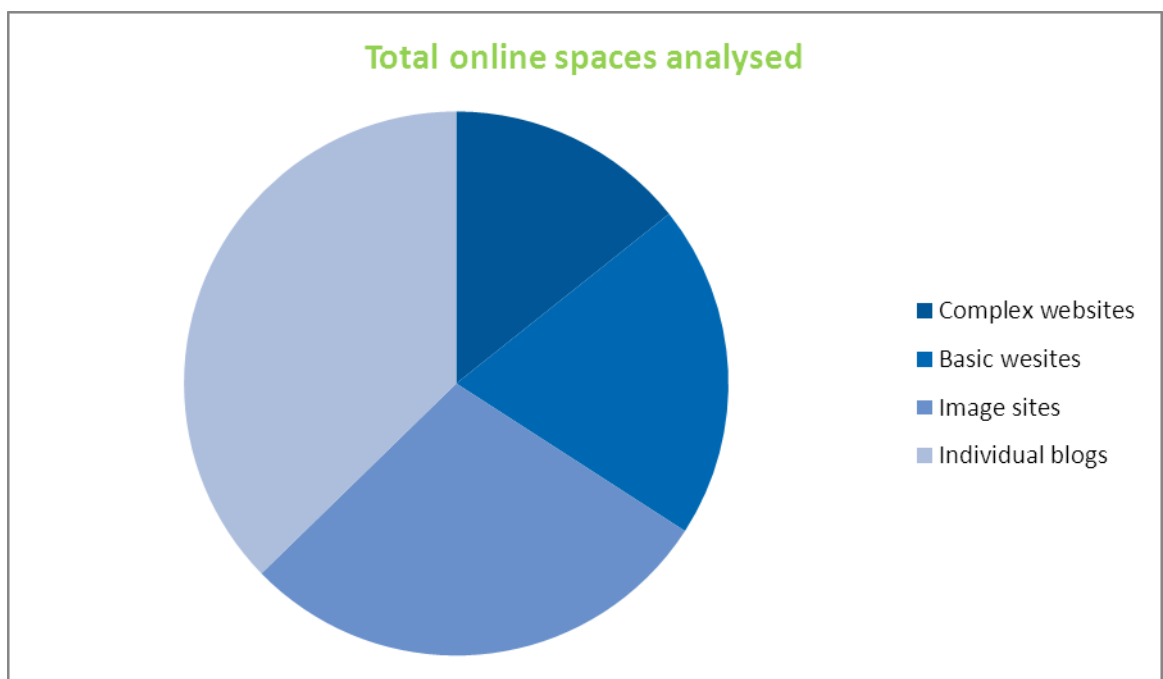
2.5.3. The online sample was saved and systematically categorised using an online bookmarking tool that saved the specific URLs of each website or Blog visited. As these sites can be unreliable, using this resource enabled quick identification of any site that had been recently closed down. Another advantage of the storing URLs, which remained persistent when the site was returned to, allowed aspects of the text to be highlighted and notes to be attached to the webpage throughout the analysis.[21] The addition of research-generated keyword tags, the uploading of images and the facility to categorise data made this an ideal tool to collect, analyse and store the online data.

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21 See http://www.diigo.com/

2.5.4. On a more reflexive note it was interesting that through the data collection process the bookmarking site being used had clearly the profiled the content of the sites saved during the research process for targeted advertising as the following link appeared at the top of the collection:

Eating Disorder Help

Speak to Our Experts Today. Free, Confidential Help & Advice.
www.therecoverclinic.co.uk

AdChoic

When clicked the advertisement lead straight to recovery help, advice and a treatment clinic. The advertisements of the researcher's personal Facebook profile also changed to offer diets; slimming pills and other weight loss solutions and this was a noteworthy development in the research process. The book-marked collection was identified as seeking information on anorexia, especially pro-anorexia and positively targeted with recovery advertisements and links for pro-recovery support. However, ironically the ambiguity associated with this topic[22] is also reflected in the advertisement which appeared at base the bookmarking page - one for diet and weight loss:

Lose 4 Stone in 3 Months?

Discover the Shocking Truth About Britain's Hottest Diet...
TrimRecipe.com/Diet

2.5.5. Once selected the sites were carefully analysed and with consideration given to key concepts identified in the literature review a coding frame was developed. An initial sample was analysed in relation to the coding frame, existing theories and literature in order to ascertain viability. Both contextual and conceptual codes were used. Contextual codes provided background information, for example, the type of website, when it was last updated, how many pages it had and what functions it offered (chat, images, text, dietary information, creeds etc.) and conceptual codes provided information about the nature and categories of content. This process was repeated with all the websites selected until no new relevant concepts emerged and theoretical saturation was reached.[23]

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22 See section 5.4.1.

23 See Strauss, A. and Corbin, J. (1998) *Basics of Qualitative Research: Grounded Theory Procedures and Technique (2nd Edn.)* London: Sage.

2.6. Acronyms used in the report

ED	Eating disorder
AN	Anorexia Nervosa
Ana	Anorexia
Mia	Bulimia
Pro-ana	Pro-anorexia
Pro-mia	Pro-Bulimia
BED	Binge Eating Disorder
EDNOS	Eating disorder not otherwise specified
UGC	User Generated Content
EM	Explanatory model

3. Understanding ED and pro-ED

3.1.   This review is not intended to be a medical account of the disease, but in order to understand the pro-ana, pro-mia and pro-ED communities under discussion it is important to clarify the use of terminology in order to understand contemporary concerns in relation to these online environments and the attractiveness to those that use them.

3.2.   Anorexia nervosa (AN) "is associated with long-term physical and psychological disability due to its chronic course and acute medical complications"[24] and displays little difference in males and females although male onset tends to be later.[25]

3.3.   Anorexia is a disorder (or illness) which stems from low self-esteem and an inability to cope safely with worries and problems and involves lowering food intake by skipping meals and cutting down the types and amounts of food eaten; some people over-exercise as well.[26]

3.4.   Bulimia is also a disorder linked with self-esteem, emotional problems and stress. People may constantly think about calories, dieting and ways of getting rid of the food they have eaten. Bulimia is more common than anorexia, but is more of a hidden illness, because people with bulimia usually remain an average or just over average body weight. People with bulimia may become involved in a cycle of eating a very large amount of food, making themselves sick, cutting down or starving for a few days or trying to find other ways to make up for the food they have eaten. Some people will not vomit but will take laxatives: both behaviours may be described as 'purging' by medical professionals but taking laxatives is particularly dangerous physically.[27]

3.5.   Binge Eating Disorder (BED) and Compulsive Overeating involve eating large amounts of food in a short period of time (perhaps not at a normal mealtime) and feeling a lack of control during these binges, but unlike someone with bulimia nervosa, people do not try to expel the food.[28]

3.6.   Eating disorders labelled 'not otherwise specified' (EDNOS) are very complex which means that there can be variations in the typical signs and symptoms and that not all of the signs and symptoms will apply to all people. There are many people that are diagnosed with EDNOS. These are disorders where people have some but not all of the diagnostic signs for anorexia or bulimia; they may also be diagnosed with a 'partial syndrome' eating disorder.[29]

3.7.   People with an eating disorder are also like to suffer from other mental health issues and frequently also suffer from depression or social anxiety.[30] This is significant to this study of online environments as research has found positive relationships between depressive mood and risk behaviours and that those found to be high in depressive mood were more likely to go online to communicate.[31]

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24 Dimitropoulos, G.; Klopfer, K.; Lazar, L. and Schacter, R. (2009: 350) Caring for a Sibling with Anorexia Nervosa: A Qualitative Study. In *European Eating Disorders Review 17 pp. 250-365.*

25 Crisp, A. (2006) Anorexia nervosa in Males: Similarities and Difference to Anorexia Nervosa. In Females   *In European Eating Disorders Review 14 pp 163-167.*

26 Beat *Types of eating disorders* [online] available from http://www.b-eat.co.uk/get-help/about-eating-disorders/types-of-eating-disorder1/

27 ibid.

28 ibid.

29 ibid.

30 Juarascio, A. S.; Shaoib, A. and Timko, C. A. (2010) Pro-Eating Disorder Communities on Social Networking Sites: A Content Analysis. *In Eating Disorders Vol. 18 pp. 393-407.*

31 Hwang, J. M.; Cheong, P. H. and Freely, T.H. Being young and feeling blue in Taiwan: examining adolescent depressive mood and online and offline activities. *In New Media and Society Vol. 11 (7) pp. 1101-1121.*

3.8. In a study of 150 respondents[32] who had visited a pro-ana site 84% had an eating disorder; 46% also experienced problems with self-harm; 37% anxiety and panic attacks; 24% depression and 24% another type of social difficulty. Thus there are many negative effects on physical health; psychological well-being and social interaction of the individual and on others around them and people often feel misunderstood and isolated.[33]

3.9. Conflict within families about how best to support a family member with an ED is common and these disagreements can limit the family's ability overall to help.[34] People with eating disorders often lack social support [35] and this need for social support, combined with technological developments which allow new online communities to develop quickly with little financial cost, has led to the plethora of pro-ED websites, online forums and communities now online.

3.10. A 'pro-eating' disorder is "a willingness to accept that an individual has an eating disorder without seeking to encourage that individual to find treatment, and may imply an aim to motivate or enable continuation of disordered eating behaviour."[36] 'Pro-ana' relates to individuals who adopt an anti-recovery approach in regard to eating disorders.[37]

3.11. From a grounded theory analysis of virtual ethnographic research in pro-anorexia chat rooms and forums, the pro-anorexia model (below) illustrates how people who use pro-anorexia websites "actually 'want' their anorexia because of the positive perception that they have towards it."[38]

The pro-anorexia model developed by Williams and Reid (2007):
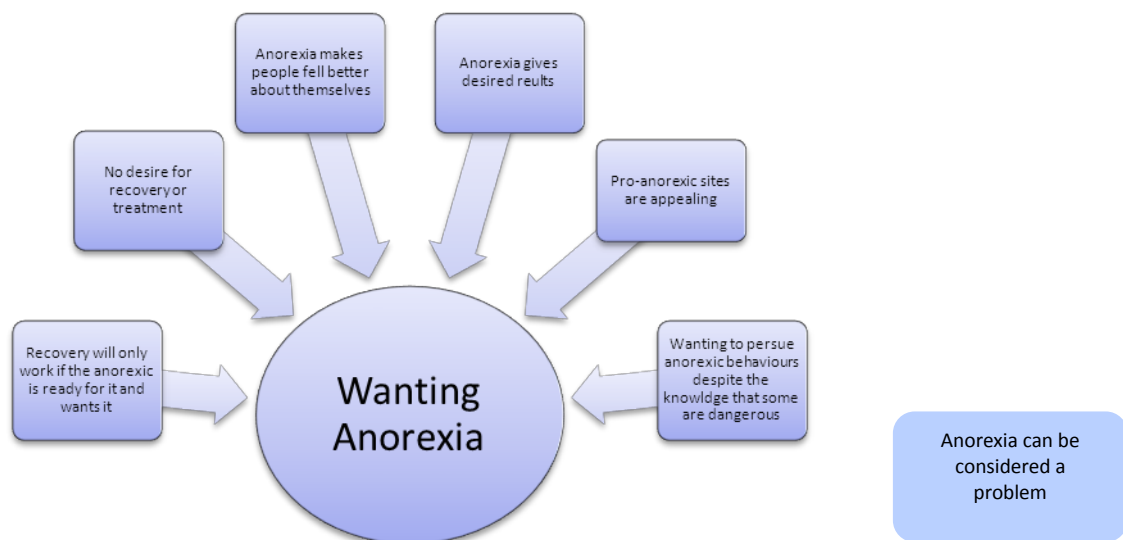
3.12. A "pro-eating disorder Website is a collection of Internet pages, all assessed through a domain name or IP address, that deliver content about eating disorder such as anorexia and

32 Csipke, E. and Horne, O. (2007) pro-Eating Disorder Websites: Users' Opinions. In European Eating Disorders Review 15 pp 196-206.

33 Williams, S. and Reid, M. (2010: 552) Understanding the experience of ambivalence in anorexia nervosa: the maintainer's perspective. In Psychology and Health Vol. 25. No. 5 pp. 551-567.

34 Dimitropoulos et al., op. cit.

35 Tiller, J.M.; Sloane, G.; Schmidt, U. and Troop, N. (1997) Social Support in patients with anorexia nervosa and bulimia nervosa. In International Journal of eating Disorders Vol. 21 31-38.

36 Csipke and Horne (2007: 197) op. cit.

37 Tierney, S. (2006) The Dangers and Draw of Online Communication: Pro-Anorexia Websites and their Implications for users, Practitioners, and Researchers. In Eating Disorders 14: 181-190.

38 Williams and Reid (2010: 553) op.cit.

bulimia. This content can be conveyed through text, images, or audio, and it encourages knowledge, attitudes, and behaviours to achieve terribly low body weights."[39]

3.13. The Internet has provided a space for marginalised and stigmatised groups to meet, share and exchange information and it is through both medicalization and stigmatization that participants of the pro-ana movement become marginalized and seek others who share their beliefs to find effective support and actively visit and maintain pro-ana websites, weblogs and personal pages.[40]

3.14. "There are a number of factors that might explain why "extreme" communities form on the Internet. The majority communicate through text-based mediums, such as email lists, newsgroups or web-based bulletin boards that provide users with visual anonymity"[41]. Online anonymous environments, therefore, allow people to express views about their disorder that would be judged negatively in other surroundings. 'Pro-sites' for those with positive beliefs about a stigmatised behaviour exist for other behaviours also such as drug use, self-harm and suicide.[42] Thus "cyberspace has emerged as a critical context for the construction of alternative identities and narratives relating to eating disorders. In recent years, an array of anorexic narratives has been published on the internet presenting the intimate everyday experiences and nuances of living with an eating disorder."[43]

4. Research Findings

4.1. Pro-ana websites are hypermedia environments – they are a diverse and often eclectic mix of text, weblinks, film and image some of which are user generated and others are taken from other media and embedded in the website or Blog. The term 'convergence' describes the spread of contemporary visual culture, the multiple ways media content is accessed and the merge between more corporate media and ever increasing participatory culture.[44] The pro-ana/ED phenomena online reflects this paradigm shift.

4.2. To consider risk in terms of a passive audience viewing harmful content would be a too simplistic analysis of the complexity that is both performed and experienced in these diverse online environments. Thus risk is not from the technology but from a complex interplay between people with an eating disorders, digital convergence and increasing hypermedia environments facilitated through unmediated virtual spaces.

4.3. The type of virtual environment within which the sites are hosted is also important to understanding the content and nature of use of various online spaces. Not all pro-ED websites are the same, an assertion that is borne out by the different types of websites and online communities that were observed and recorded. Some websites are multi-paged, highly sophisticated with a complex array of content and multiple affordances[45] – complex multi-page webites (CWS). Other websites, although comprising of several pages were far more basic by design and in terms of content (BWS); hundreds of social networking sites and

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39 Borzekowski, D. L. G.; Schenk, S.; Wilson, J. L. and Peebles, R. (2010: 1526) e-Ana and e-Mia: A Content Analysis of Pro-eating disorder Websites. *In American Journal of Public Health 100 8 pp. 1526-1534.*

40 Haas, S. M.; Irr, M. E.; Jennings, N. A. and Wagner, L. M. (2011) 'Communicating Thin: A grounded model of online negative support groups in the pro-anorexia movement'. In *New Media and Society Vol. 13 no 1 pp 40-57.*

41 Bell, V. (2007: 451) Online information, extreme communities and internet therapy: is the internet good for our mental health? In *Journal of Mental Health Vol. 16 no 4 pp 445-457.*

42 Williams and Reid op. cit.

43 Rich, E. (2006: 295) anorexic dis(connection): managing anorexia as an illness and an identity. *In Sociology of Health and Illness Vol. 28. No. 3 pp 234-305.*

44 Jenkins, H. (2008) *Convergence Culture: Where Old and New Media Collide* New York: New York University press.

45 See Hutchby, I. (2001). Technologies, Texts and Affordances. In *Sociology, 35(2), 441-456*

individualised weblogs (IB) and more image based sites hosted, for example, on YouTube or Tumblr.

4.4.   The popularity of social networking sites which have captured common communication and self–identity discourse is reflected in the number of pro-ana groups on social networking sites and these sites are more focused on social aspects like interaction and social support rather than on specific content relating to an eating disorder which is more common on Internet based websites.[46]

4.5   The initial search for this study found that many websites, although still in existence, had not been updated for a few years, nearly 40% had not been updated for a few months but others were highly active and updated regularly sometimes several times per day. Thus there is a diversity in the currency of the pro-ED websites but there was clear evidence of websites shutting down, or being shut down but ISPs, and then setting up elsewhere under a different name but with similar, sometimes identical content.

4.6   ''The pro-ana community is substantial''[47] and the rise of the popularity of the Internet and new media has played a significant part in providing easier access to information on how to diet, stay thin and maintain an eating disorder. The pro-ED community is thus described as a "phenomenon that has constructed itself by gradually increasing numbers of websites and their members into a community of practice" and there are estimated to be between 400-500 pro-ED websites available online.[48]

4.7   These figures are, however, unreliable as the sites are transient and nomadic by nature as they often get shut down either by ISPs or by the creators themselves but then emerge elsewhere under different name. As a result researching this rapidly changing technological environment is challenging. Many URLs outlined in previous studies had disappeared when the field-work for this study took place.

4.8   As discussed above (4.5.3) some sites were very complex, had hundreds of users and different pages for different functions and topics. The more complex multi-pages sites were well ordered, very well organized and up-to-date claiming sometimes over 2,600 members at the time of the research fieldwork. According to website statistics there had been 1,580 topics under discussion on some sites in different chatrooms across nearly 15,000 posts. In total many websites had over 25 different online areas to explore and each had several webpages and additional chat facilities and forums. These complex sites have an international following and are active for 24 hours a day due their global appeal. They offer a new members forum; a forum to talk about different types of eating disorders; a chat room for members who were pro-recovery (which included clear text based instructions requesting users did not post anything that could be considered triggering) and forums for discussions about family issues. There were others for discussions and advice on traumas, for example, relating to abuse. The opportunity to find an 'anabuddy' - an online friend, for support and advice was provided by other chat rooms where users could exchange email or contact details to communicate with each other away from the more public forum environments. A large proportion of the sites is dedicated to 'thinspo' (see perfection in section 5.1), photographs and aspects specifically to competitions and dieting challenges. Many websites also had forums for discussing issues related to self-harm (this was usually

46 Juarascio et al. op. cit.

47 Harshbarger, J. L.; Ahlers-Schmidt, C. R.; Mayans, L.; Mayans, D. And Hawkins, J. H. (2009: 369) pro-Anorexia Websites: What a Clinician Should Know. In *International Journal Eating Disorders Vol. 42 pp. 367-370.*

48 Giles, D. (2006: 464) Constructing identities in cyberspace: The case of eating disorders. In *British Journal of Social Psychology vol. 45 pp. 463-477*
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clearly indicated) and also pages dedicated to fashion; media, music and literature as well as art, poems, health and beauty and links to other pro-ED websites. The seemingly specific pro-ED focus of the sites was sitting in amongst more mundane and seemingly everyday discussions to be found on many other websites and chat forums. It is important to contextualise these sites and their use in the understanding of users' everyday lives.

4.9.　　The sites varied in their tone and content in relation to be pro-ED. The sample included more moderate pro-ED sites, very openly Pro sites and some uncompromising pro-ED sites (which all tend to be run by those with eating disorders themselves). 32 of the 126 sites sampled included a warning/disclaimer on the front page:

> *Welcome to [name of site]*
> *This is a pro ana website. It is not anti recovery but if you are recovering from an eating disorder then you should leave now. This website has content which maybe triggering. If you do not have an eating disorder please leave now. If you do not agree with pro ana then please leave now.*
> *This website acknowledges that there are different views on pro ana but this website believes pro ana is for the support of people who have eating disorders but are not yet ready to recover. That is what this website is for.*

4.10.　　The Internet has provided a space for marginalised and stigmatised groups to meet, share and exchange information. It is through both medicalization and stigmatization that participants of the pro-ana movement become marginalized and seek others who share their beliefs to find effective support and through actively visiting and maintaining pro-ana websites, weblogs and personal pages.[49] The prevalence of first time use is also of concern.

4.11.　　Highlighted by a study in the Netherlands (with the cooperation of one of the largest weblog providers), the incidence of first time visits (as denoted by the absence of cookies) to pro-ana sites in one year (1st October 2006- 30th September 2007) was 537,964.[50]

4.12.　　Online anonymous environments allow people to express views about their disorder that might be judged negatively in other surroundings and many different 'Pro-sites' for those with positive beliefs about a stigmatised behaviour exist for other behaviours such as drug use, self-harm and suicide.[51] The 2011 EU Kids online report highlighted that 21% 11-16 year olds in their research had been exposed to one or more types of potentially harmful user generated content: hate (12%), pro-anorexia (10%); self-harm (7%), drug-taking (7%) and/or suicide (5%).[52]

4.13.　　The age at which people visit pro-ED sites is, therefore, an increasing concern. As mentioned 10% of 9-16 year olds in the EU Kids online study had visited a pro-anorexia website,[53] the majority of users of pro-ana sites are young and female but they are also used by boys and young men.[54] One Belgian study of 711 secondary school children found that 12.6% of girls and 5.9% of boys had visited pro-ana websites.[55]

49 Haas et al. op.cit.

50 Martijn, C.; Smeets, E.; jansen, A.; Hoemans, N.; Schoemaker, C.; (2009) Don't Get the message: The Effect of a warning Text before Visiting a Proanorexia Website. In *International Journal Eating Disorders Vol 42: pp 139-145.*

51 Williams and Reid op. cit.

52 Livingstone, S.; Haddon, L.; Görzig, A. and Ólafsson, K. (2011) *EU Kids online Final report* available online from www.eukidsonline.net
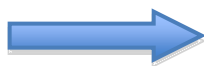
53 ibid.

54 Csipke and Horne op. cit.

55 Custers, K. and Van den Bulck, J. (2009) Viewership of Pro-Anorexia Websits in Seenth, Ninth and Eleventh Graders. In *European Eating Disorders Review Vol. 17 pp. 214-219.*

4.14.   A significant number of sites are actually created by girls under 18 years old.[56] However, it should be noted that "in media use research it is not uncommon to find rapid changes in behaviour between generations. Younger cohorts are likely to embrace new technologies at a higher level than those who went before them."[57]Setting up and maintaining a website or Blog requires a basic level of digital skills and many children in primary schools are able to master web design and management.

4.15.   Users of pro-ana websites score higher on a desire for thinness, perfectionism and Body Mass Index (BMI) and in positive attitudes towards pro-ana websites.[58] EDs are often actually seen as positive by those who have them[59] and it is often suggested that pro-ana or pro-ED websites claim that AN is not a disease but a choice of lifestyle.

4.16.   The relationship between an eating disorder and lifestyle choice is explored in much of the published literature on the subject and it is perhaps helpful to consider that 'lifestyle' does not necessarily imply a notion of choice; "rather, it is a lifestyle in the sense of a 'way of life' that pervades every aspect of the person's thought, perception and action."[60]

4.17.   The content on the sites considered in this study varied enormously and consisted of text and image based content, user generated content and content taken from other sources. The type and format of the online space (i.e. Website; Blog; social network) clearly influenced the nature and format of the content of the sites. It is perhaps also worth noting that it is the availability and accessibility of some of the more harmful content, in terms of both text and image that are of current concern, and the focus of contemporary academic debate.

4.18.   The risk in relation to these online spaces is understood, therefore, as a relationship between the accessibility and availability of these sites, the frequency of the visits, the nature and content and of the site and vulnerability and/or the resilience of the user.

Risks identified in relation to pro-ED websites:
- increasing accessibility and availability of pro-ED websites, online forums and blogs;
- the nature and content of sites varies according to type of online space;
- risk varies according type of content and frequency of visits;
- risk varies according to vulnerability of user.

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56 Norris, M. L.; Boydell, K. M.; Pinhas, L. and Katzman, D.K. (2006) Ana and the Internet: A review of Pro-Anorexia Websites. In *International Journal of Eating Disorders vol. 39: 6 pp 443-447.*
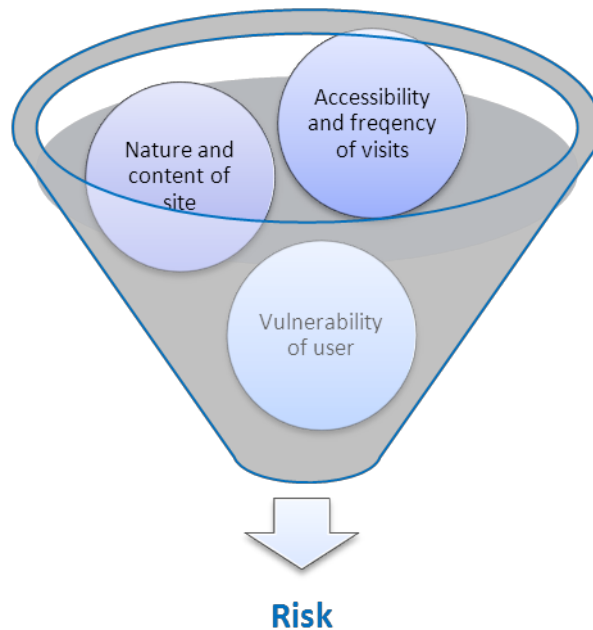
57 Custers and Van den Bulck op.cit.

58 ibid

59 (Williams and Reid op. cit.

60 Csipke and Horne op.cit.

The risk relationship:


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        Accessibility
        and freqency
        of visits
  Nature and
  content of
  site
        Vulnerability
        of user
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Risk

5. Key themes

Four main themes emerged from the analysis of the online data drawn from 126 pro-ED websites and online spaces. All the websites included in the study were carefully documented, analysed and coded. The initial coding was then grouped further and relationships between the categories analysed and commented on. Overall the data falls into four key themes.

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Perfection  >  Performance  >  Protection  >  Paradoxes
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5.1. Perfection

5.1.1. Perfection appears here as a category of risk. The phrase "starving for perfection" is a popular tag line on pro-ED websites and it is in the pursuit of perfection that the risk actually lies. The perfect body is a social and a cultural construction and the concept of perfection was the most dominant theme to emerge from the data analysis of the pro-ED online environments. Images of 'perfect' bodies especially celebrity bodies aimed at inspiring weight loss appeared alongside discussions and advice on how to achieve a perfect body dominated the sites considered.

5.1.2. It is not that the sites claim that anorexia or bulimia are glamorous and desirable lifestyle choices, but the "prevailing mood of these sites seems to be 'yes these are diseases which are dangerous to your physical and mental health, but bearing that in mind here is the inspiration to carry on if you want to, or feel you have to.'"[61] This inspiration, seen in the form of images and known as 'thinspiration', are images of often beautiful, often fairy-like, very thin bodies, but also 'reverse-thinspiration' with pictures of people with obesity.

5.1.3. In the pro-ED community perfection is thinness. The viewing of and striving for thinness underpins the pro-ED culture. The thinspiration content of these sites is well documented elsewhere[62] and owing to careful consideration of the reporting guidelines outlined by Beat actual images from the websites which could be considered triggering are not included for illustration in this report.

5.1.4. Thinspiration images of celebrities are originally published online elsewhere, of course, and had been copied from other media sources. There is a considerable discourse of concern in relation to the media construction of thinness in general as exemplified by recent government and policy initiatives. However, "in a media saturated culture, the argument that long term exposure can help shape the world views of particular sections of the audience is one that merits consideration, however, the EXTENT to which the media contribute to the personal identity remains unclear and is subject to continuing academic debate….the media do not, by their very definition, provide pure experience of the world but channel our experience of it in particular ways."[63]

5.1.5. The pro-ana websites contained page upon page of thinspiration featuring celebrities, for example, Keira Knightley, Victoria Beckham, Geri Halliwell, Mary-Kate and Ashley Olsen (to name but a few) looking very glamorous, slim, with bones clearly defined in the image. The majority were not dissimilar to the glossy fashion magazines available in the high street. A skim through Vogue, Tatler, Harpers or Cosmopolitan in a local newsagent would generate a similar range of images in relation to the featured celebrities and fashion models.

5.1.6. "Naturalistic and experimental research repeatedly finds that the media, in the form of magazines, television and film, play a significant role in negatively influencing body image and eating for many individuals."[64] What is more significant here is the particular audience viewing the images in this pro-ana environment.

5.1.7. "The social is thus perhaps the most important modality for understanding the audiencing of images. In part this is a question of the different social practices that structure the viewing of particular images in particular places. Visual images are always practiced in particular ways, and different practices are often associated with different kinds of images in different kinds of spaces."[65]

61 LIpczynska, S. (2007: 546) Discovering the Cult of Ana and Mia: A review of pro-anorexia websites. In *Journal of Metal Health Vol 16 No. 4 pp 545-548.*

62 Borzekowski et al. op cit.

63 Jade, D. (2009) The Media and eating disorders National Centre For Eating Disorders [online] available from http://www.eating-disorders.org.uk/media-and-eating-disorders.html

64 Bardone-Cone, A. M. and Cass, K, M. (2006: 256) Investigating the Impact of Pro-Anorexia Websites: A Pilot Study. In *European Eating Disorders Review 14 pp 256-262.*

65 Rose op.cit. (31)

5.1.8. It is thus the vulnerability of this specific audience that is significant rather than the images of themselves. Often accompanied by text entries either from the site author/editor or from a viewer, images would attract comments, for example, under a photographic image of Keira Knightly was written:

"She is so beautiful and she is so thin. I want to look just like her....".

5.1.9. The thinspiration section of websites and entries on individual Blog and social network sites, though, were not always celebrity model based. Many images were User Generated Content (UGC) – images of community members themselves, which were often copied across many different forums, sites and online spaces. Similar or even the same images were copied across from one site to another and often appeared many times. Whilst specific images are not included in this report for ethical reasons and the reporting guidelines outlined by Beat, the Google screen shot below illustrates the type and variety of thinspo available just through Google images:
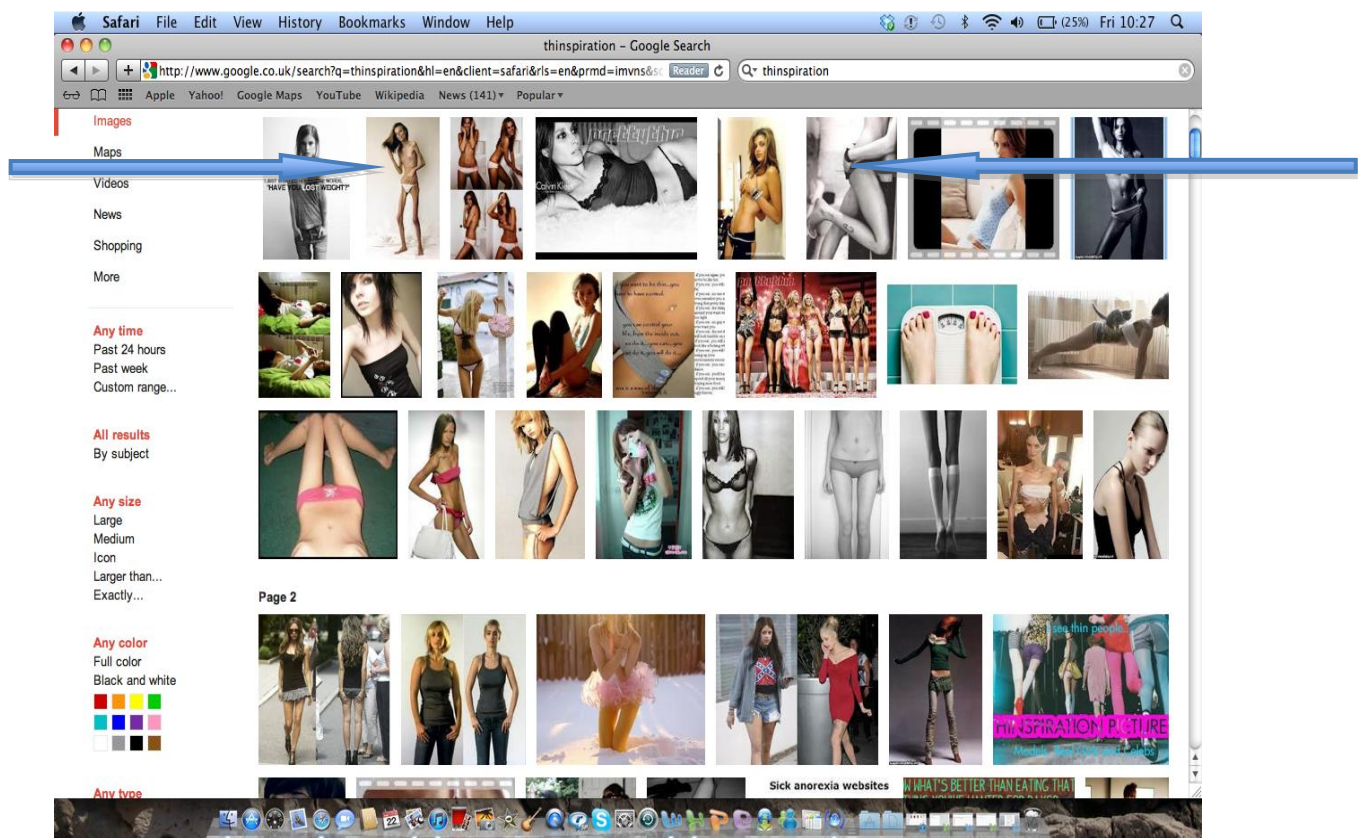
5.1.10. The range of images depicted above is illustrative of the diversity of images found on pro-ana sites. Some depict emaciated, almost skeletal bodies, some are highly sexualised (as illustrated by arrows) some are of celebrities or fashion models and others are UGC from pro-ana forums. Often only certain body parts are shown in the image – the idea of perfection associated with having a gap at the top of thighs or in the display of bony parts of

the body. Whilst very few celebrity photographs were of the celebrity looking unkempt, dishevelled or emaciated to the point of skeletal, some of the UGC images, were of extremely thin, emaciated and skeletal bodies, frequently in a state of undress showing collar bones, hip bones, tops of tights and knees as well as elbows, backbones and ribs.

5.1.11. Frequently the images also had comments from the site author referring to BMI or a certain weight. One image tagged 'emaciated' was accompanied by text claiming that the subject intended to lose another 15 lbs. Research suggests that the viewing of these images has a negative impact on mood and self-esteem and participants reported feeling low when they visited sites and felt worse about their body image as a result which overall discouraged them from seeking recovery.[66]

5.1.12. These thinspiration images were also a prominent feature of the more linear Blog and image sharing sites such as Tumblr and Youtube where they had been clipped together to form a moving montage of thinness. The images on personal blogs and less complex spaces often attracted comments both positive and negative from other users of the sites. It is this interactive contact and conduct that also forms the basis of the risk analysis in relation to these sites but for different reasons.

5.1.13. It is the normalising tendencies of extreme behaviours in online environments that compounds the risk of viewing the images and striving to be underweight is deemed not only as normative but as a signal as success.[67] Competition to become a better anorexic is prevalent on these sites.[68] "Not only is anorexia viewed as a lifestyle choice, but those who embrace it are praised for the desirable qualities involved in being a 'successful' anorexic: control over oneself, self-discipline and the denial of pleasure and nourishment."[69]

5.1.14. Current concerns in relation to viewing these images are, therefore, not just in relation to those with an ED as there is strong evidence that exposure to pro-anorexia websites has immediate and negative effects on young women: "regarding behavioural expectations, pro-anorexia website viewers [women without a history of an ED] reported that viewing the website made them more likely to exercise and think about their weight in the near future (today or tomorrow) than if they had not seen the website."[70] Even modest exposure to pro-ED websites can encourage significant changes in calorie consumption and increased disordered eating behaviours[71]. Caution, however, needs to be exercised in that the pro-ana community should not be viewed as a "universally coherent standpoint."[72]

5.1.15. It is also the sexualised nature of many of the images has caused concern. Young women have reported being targeted for 'Skinny porn". According to reports porn agencies' websites "sign up new clients and advertise images, films and escort-type services, such as body worshipping, fantasy role play and private photography sessions, for those "hooked on skinnies". Some of this porn is free to access while other "professional" agencies charge a monthly membership fee for regularly updated sexually explicit images and videos of emaciated women. Agencies also host anorexia porn on YouTube and advertise on anorexia pornography forums .[73]

66 Higbed, L. and Fox, J. R. E. (2010) Illness perceptions in anorexia nervosa: A qualitative investigation. In *British Journal of Clinical Psychology Vol. 49. pp 307-325.*

67 Borzekowski et al. op.cit. (1532)

68 see also Rich op.cit.

69 Csipke and Horne op.cit. (197)

70 Bardone-Cone and Cass op.cit. (544)

71 Jett, S.; LaPorte, D. J. and Wanchisn, J. (2010) Impact of Exposure to Pro-Eating Disorder Websites on Eating behaviour in College Women. In *European Eating Disorders Review Vol. 18 pp. 410-416.*

72 Giles op.cit. (464).

73 Hobbs, N. (2011) 'Anorexic women targeted by 'super-skinny' porn websites' in *The Guardian, Wednesday 6 April 2011*

5.1.16. In order to achieve 'perfection', sites offer advice on how to lose weight and further weight loss. The majority of these tips and tricks discuss weight control, calorie content of food and how to calculate a BMI. Much of this content is available elsewhere on mainstream weight loss/diet websites, magazines and health/exercise media. However, it is clear from the research to date that the use of unregulated information could lead to serious consequences for individuals with an ED.[74] In pursuit of perfection many anorexics are prepared to starve themselves in order to carry on losing weight. The harsh regimes which include advice on purging, taking diet pills and laxatives and diets recommending minimal calorie consumption together with harsh exercise regimes outlined on some sites would be considered extreme to say the least.

5.1.17. The idea of 'disordered perfection' appears very popular and again is a common phrase on the sites. There is evidence to suggest that there is recognition that the ideal or idea of perfection when living with an eating disorder is 'disordered'. In striving to achieve perfection the users of the sites perform their achievements through online documentation of images and text. One blog described it as "warped perception" – that even when they had lost weight when they looked in the mirror they did not see perfection and that they still felt fat even though they reached their goal weight. In pursuit of perfection they then further reduced their goal weight to an even lower target:

> *"I've now reached under my goal weight!!!! :) Yippee!!!! Now for a new lower goal weight!"*

5.1.18. The advice on how to control weight and continue weight loss is given through promoting certain behaviours from exercise, restricting diet and purging. This quote from a website has been put through Wordle™ (an online tool for generating "word clouds" from text). The clouds give greater prominence to words that appear more frequently and the identity of the source is protected in the presentation of the report:

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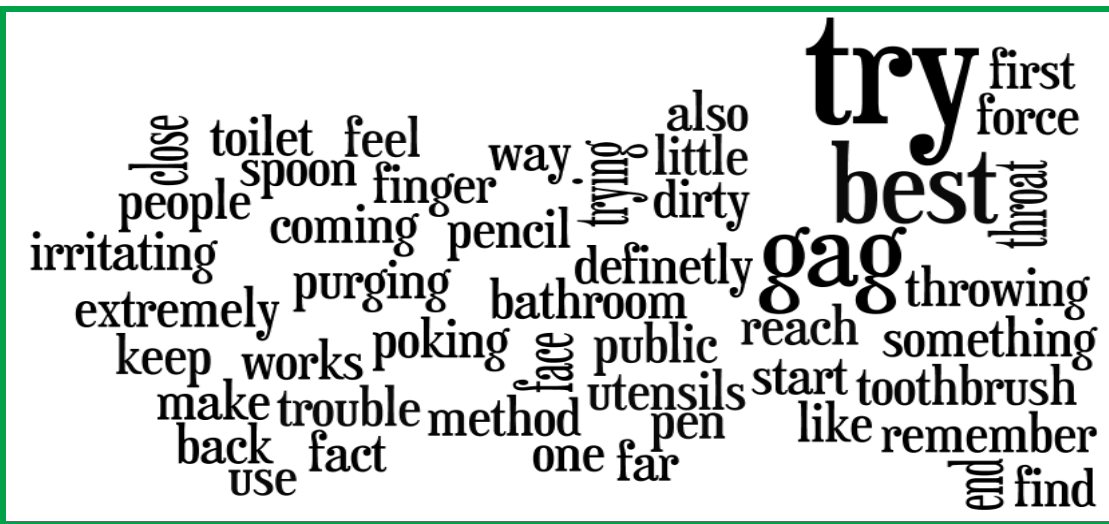
[74] see for example Harshbarger, J. L.; Ahlers-Schmidt, C. R.; Mayans, L.; Mayans, D. And Hawkins, J. H. (2009) pro-Anorexia Websites: What a Clinician Should Know. In *International Journal Eating Disorders Vol. 42 pp. 367-370.*

5.1.19. Much of the advice about diets includes most mainstream popular diets such as weightwatchers, Atkins; Cabbage soup and F plan diets, for example, with the strengths and limitations for each detailed. Other diets are more severe including the Ana Boot camp or ABC diet which:

> *"lasts for 50 days. It has a different amount of calories allocated for each day and the diet also includes fasts on some days. It is based on the idea that by changing the calorie consumption eat day you keep your metabolism guessing so that it doesn't slow down".* [some words substituted].

5.1.20. The calorie consumption recommended per day varies but tends not to exceed 400-500 calories per day and often the recommended intake is less. According to the NHS (online) an average man needs around 2,500 calories a day to stay healthy and for an average woman, that figure is around 2,000 calories a day.[75] The health risks of following these diets in the long term are well documented.

5.1.21. One website author advocates their own diet which advises minimal intake of food, lots of water and diet soda, plenty of cigarettes, coffee and diet pills. Thus concerns based on the ideas around disordered perfection consider the viewing of 'perfection' as not a normal/average weight body but a 'thin' body still striving to lose more weight. The 'thin' body becomes normalised in these environments and perfection becomes an ever shifting goal.

5.1.22. Nearly 90% of the sites analysed contained thinspiration material and over 80% contained overt information on personally engaging in pro-eating disordered behaviour (nb the sites were included in the research sample on this basis). Research suggests that "the content featured on these sites could lead to immediate and life-threatening problems."[76] Striving to be thin is of paramount importance in users' lives, recording details of various attempts undertaken in order to reach a desired weight goal but, whilst users appear to understand the damaging nature of certain activities, this does not restrict their efforts or even dangerous behaviours to lose weight.[77]

Risks identified:

- Seeking a disordered view of perfection
- Normalising of ultra thin body image
- Exposure to extreme or dangerous dieting advice or behaviours
- Low self-esteem and lacking in self-confidence

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75 NHS Anorexia Nervosa [online] available from http://www.nhs.uk/Conditions/Anorexia-nervosa/Pages/Introduction.aspx

76 Borzekowski et al. op.cit. (1531)

77 Tierney op.cit.

5.2. Performing

5.2.1. The concept of performing illustrates how users of pro-ED sites perform their self-identity and indeed their ED or ana identity in online environments. Performance refers to activities of an individual before a set of observers and suggests that everyone is playing a role.[78] The Internet, as a technology offers different affordances[79] and this section examines the interactions between the users and the different online spaces in the pro-ED communities. Interaction is defined as "the reciprocal influence of individuals upon one another's actions in performance, and may be defined as all the activity of a given participant on a given occasion which serves to influence in any way any of the other participants."[80] It is these interactions whether between the individual and web space content or between the individuals and others, which are discussed here, and considered in relation to risk and pro-ED web spaces.

5.2.2. One of the needs to the thin stems from having a low self-esteem[81] and these sites allow stigmatised or socially isolated individuals to share experiences anonymously in a "rich tapestry of identity work."[82] There are a plethora of asynchronous blogs and online dairies that claim to be pro-ana. Some are more text based in a diary format held on popular Blog sites and others are more image based with still images that are popular on photo sharing websites and moving/film image on sites such as Youtube.

5.2.3. These more personal, individualised spaces reflect how "cyberspace has emerged as a critical context for the construction of alternative identities and narratives relating to eating disorders. In recent years, an array of anorexic narratives has been published on the Internet presenting the intimate everyday experiences and nuances of living with an eating disorder."[83]

5.2.4. The personalised narratives performed in virtual environments are often hyperlinked to each other in a recommended or 'I am following' list and frequently have images and quotes from text replicated and re-blogged from each other's sites. The pro-ED community online is, therefore, understood as a "phenomenon that has constructed itself by gradually increasing numbers of websites and their members into a community of practice."[84]

5.2.5. The importance of understanding the role of the image as a digital artefact underpins the analysis presented here. The role of sign vehicles and artefacts in presenting the image of self and wanting to portray certain desired characteristics is highly significant in these environments and the sharing of content is linked to self-identity and to belonging to a cultural, social or gendered group.[85]

5.2.6. One individual image-based blog incorporated over 360 separate images, all black and white, some were clips from films, some still images of celebrities, others were drawings, doodles, images of the owner but the overall site was carefully and meticulously constructed – an

78 Drawn from Goffman, E. (1959) *The Presentation of Self in Everyday Life* Doubleday: Garden City, New York.

79 Hutchby, I. (2001) 'Technologies, Texts and Affordances'. In *Sociology Vol. 35 No. 2 pp. 441-456.*

80 Goffman op. cit. (26)

81 Karpowicz, E.; Skärsäter, I. and Nevonen, L. (2009) Self-esteem in patients treated for anorexia nervosa. In *International Journal of Mental Health Nursing Vol. 18. Pp. 318-325.*

82 Giles op.cit.

83 Rich op.cit.

84 Giles op.cit. (464)

85 Goffman op.cit.

artwork in itself. This site, together with 27% of the overall sample similarly presented, also contained images of self-harm, and images linked to depression and suicide.

5.2.1. In addition to using images nearly all of the more Blog based sites had detailed calorie consumption information often on a day-to-day basis. Exactly what an individual had consumed and how many calories each item consumed contained is posted in meticulous detail together with reflections of the bloggers' consumption habits. Whilst everyday life is taken up trying to avoid food most Blogs reflect a preoccupation with food in that the bloggers think about food constantly and obsessively. Feelings of success and achievement associated with excessively low calories intakes or on completing a day or two's fasting compete with harsh, self-punishing reactions to eating more than in the previously decided upon diet. These negative, punitive feelings were frequently associated with other reflections related to self-harm and self-loathing.

5.2.2. Thus the users of the sites obtain and maintain an identity of a successful 'ana' or a failing 'ana' in detailing their diet activities which are used as identity markers or cues online proving that they are a 'worthy' ana.

5.2.3. The blogs, chat rooms and online forums all detail everyday human experiences and responses to life events not just in relation to anorexia but also family or friends, relationships or work/school experiences. Dealing with doctors and the medical professional appear frequently here together with discussions of feelings of low self-worth/self-esteem or feeling good because weight loss has been achieved.

5.2.4. Alongside the images and diet based talk many blogs are highly self-analytical and assume quasi-religious connotations of the confessional which are also reflected in the content and postings of a large number of websites. The sites frequently contained 'letters to ana'; ana creeds and poems reflecting of the thoughts and views of the authors. Due to maintaining the anonymity of the author the poem depicted below has been pasted into Wordle™.
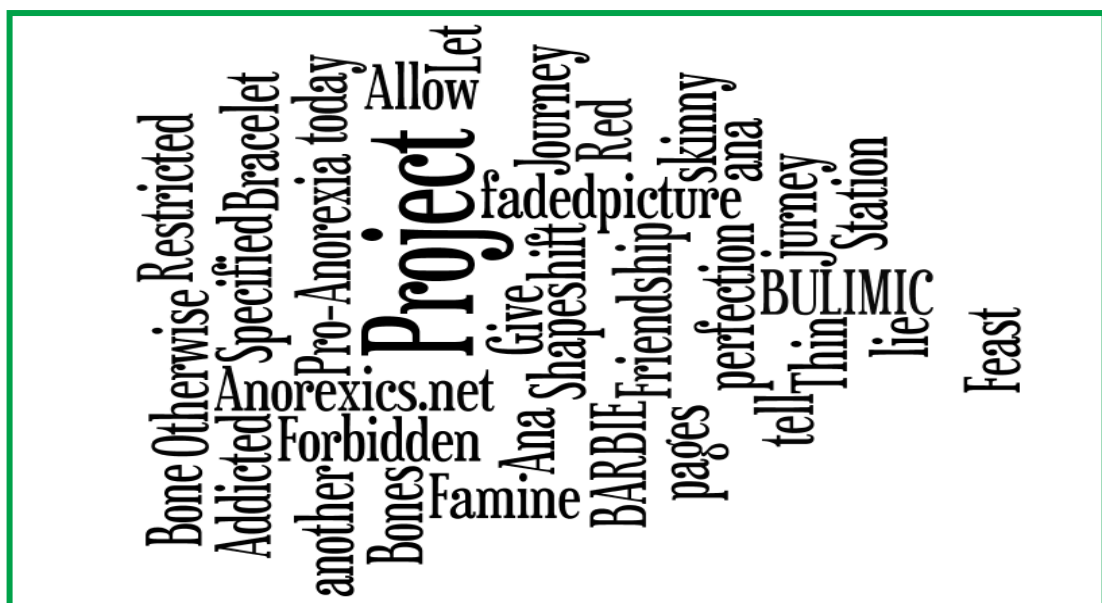
5.2.5. The letters and creeds to ana have a religious like quality to them and many are beautifully illustrated with drawings and other art work. The use of these religious metaphors and the

religious or spiritual nature of the sites abound with creeds or letters to ana and also goddess like analogies in relation to ana or to the creator of the site.[86]
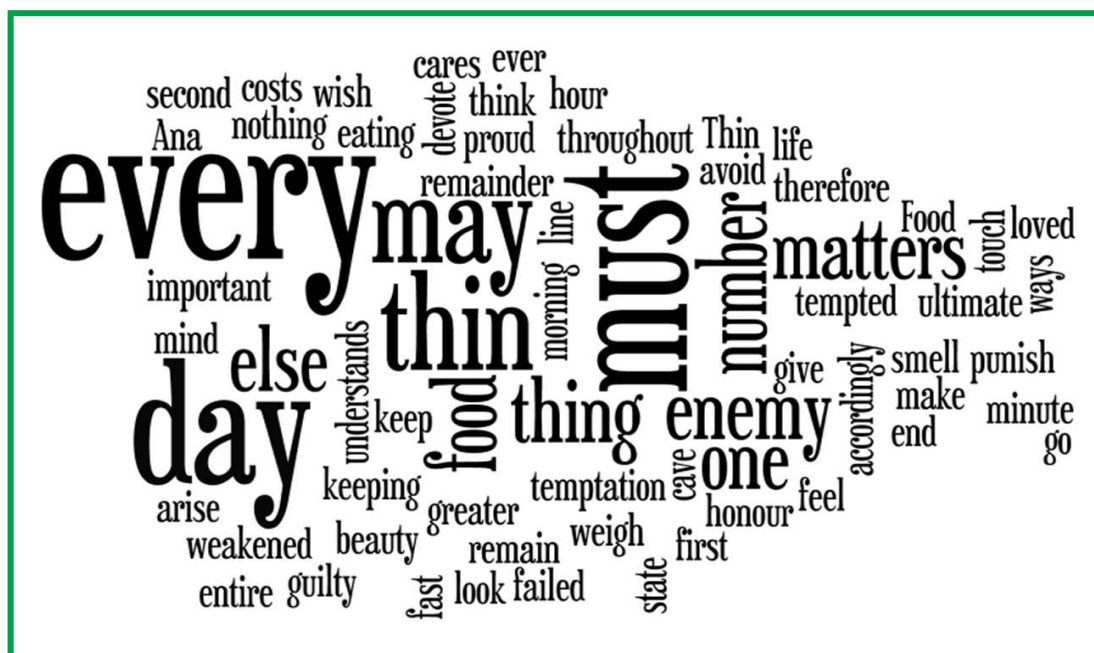
5.2.6. "Eating disorders revolve around privacy and secrets"[87] and "the efforts of stigmatized persons not only 'normify' their own conduct but also encourage others to embody the stigmatised behaviour."[88] One diary based Blog described weight gain following some weeks 'at home' over the Christmas period. On returning to college the Blogger wrote that she was going to undertake a three day fast to 'gain control' again. Within two hours of the posting the Blogger had 36 followers also declaring that they would also fast for three days in support. Sharing is important to relationships and is based on trust and intimacy and understanding the reciprocal dependence and familiarity[89] in the pro-ana community is essential.

5.2.7. It is both the secretive nature of the pro-anorexia movement and the intimacy that participants feel towards the disease itself and one another and that make online environments ripe for self-disclosure.[90] Thus "concealing anorexic practice is then a symbolic site as these young women struggle not only to reassert their self-determination but also to attempt to regain an identity, albeit an anorexic identity."[91] Through the establishment of an 'audience for ana', pro-ana bloggers engage in co-constructing personal identities that are in keeping with the group ana membership to fit in with the expectations of a perceived audience.[92]

5.2.8. Therefore, whilst these sites and forums have pictures of users themselves uploaded for other people to comment on and thus offer encouragement for weight loss, these activities actually nurture each other's harmful behaviour[93] which leads to an alternative type of

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86 Norris et al.op. cit.

87 Kirkwood, R. (2005: 119). Support Choice, Support People: An Argument for the Study of ProAnorexia Websites. In *Atenea: a bilingual journal of the humanities and social sciences, 25(1), 117-129.*

88 Goffman op. cit.

89 ibid.

90 Haas et al. op.cit.

91 Rich op.cit. (298)

92 Haas op.cit. (48).

93 Collins, J M. (2004) Nurturing Destruction: Eating Disorders Online. In *Off Our Backs November-December pp. 20-22.*

support group - an Online Negative Enabling Support Group (ONESG) as they further encourage and support negative and often harmful behaviours.[94]

5.2.9. Synchronous chat rooms are different in nature to an asynchronous Blog environment in that they are not image but text dominated. The synchronous chat rooms display a high volume of interaction and are a popular form of communication. Drawing on a symbolic interactionist perspective, the loss of self felt by many people with chronic illness suggests that individuals commonly not only lose self-esteem, but even self-identity.[95] Through the sharing painful experiences and disclosing intimate feelings, a pro-ana identity is strengthened, and the support group gains momentum through message exchange with an anonymous audience. However, "whilst feeling 'supported', individuals visiting pro-anorexia websites are likely become further entrenched in their disordered eating behaviours and thoughts."[96]

5.2.10. The chat rooms visited in the study displayed a wide range of topics under discussion predominantly focused on EDs, and on disordered eating. The participants in the chat rooms shared intimate details about their feelings and their failures and the responses from other members of the groups observed in the study were mainly supportive and positive. There was much discussion in relation to their relationships with others – family, friends and romantic partners often detailing the isolation they felt and the lack of understanding displayed by non-ana's. Talk of visits to doctors or psychologists were frequent and discussions about doses and prescribed medication for the treatment of the ED and/or depression were common.

5.2.11. New members were sometimes treated with suspicion initially. Although it varies according to the site, sub-group and the nature of the individuals in correspondence, support is a key characteristic of the chat rooms, possibly as a result as receiving little offline support.[97]

5.2.12. The pro-ana community places emphasis on medical diagnosis and the type of ED users are experiencing. There can often be conflict between different groups of users as well as between the community and outsiders as members not only construct their self-identities as members of a cultural group but also as a member of sub-groups (pro-ana; pro-mia or EDNOS) and that of others as 'normals'; 'wannabes' or 'haters' who are the outsiders[98]. Thus the selective passing on of practices or techniques of anorexia is a way of reaffirming not identity, but also ensuring that it is the 'right' and 'accepted' identity.

94 Haas op.cit.

95 Charmaz, K. (1983) Loss of self: a fundamental form of suffering in the chronically ill. In *Sociology of Health and Illness Vol. 5 No. 2 pp. 168- 195.*

96 (Bardone-Cone and Cass op.cit. (257).

97 Botsky and Giles op. cit.

98 Giles op. cit.

5.2.13. This label or self-identity is often displayed through the wearing a red bracelet and many online many sites advocate the wearing of a red beaded bracelet as illustrated below:

5.2.14. The research confirms that trust, mobilised by mutual shared disclosure, is one of the key sustaining dynamics of a relationship.[99] However, the "idealized perceptions of others based on reduced cues, optimal self-presentation and information management through mindful message construction in asynchronous exchanges and the potential for an 'intensification loop' where extreme views are validated and escalated among members of an a online group."[100]

5.2.15. Therefore, engaging with pro-anorexia sites, reinforces an existing 'eating disordered' identity and "visiting such resources could cement the positive association individuals derive from the label 'anorexic.'"[101]

5.2.16. What is also characteristic of these environments is the competitive nature of the talk between the participants. Young women with anorexia seek sanctuary and support from other sufferers but the paradoxical nature of the relationship becomes a source of comfort and competition simultaneously.[102]

Risks identified:

- Competitive nature of sites
- Belonging to and reinforcement of an out group
- Eating disordered self-identity
- Encouragement of harmful behaviours

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99 see Giddens, A. (1991) *Modernity and Self-Identity Self and Society in the Late Modern Age* Cambridge: Polity Press.

100 Haas et al. op. cit. (46-47)

101 (Tierney op. cit. (183).

102 Rich op. cit.

5.3. Protection

5.3.1. Often misrepresented in the media and misunderstood by family, friends and even the medical profession, is the notion that "anorexia is not a fad for these girls. It is part of who they are."[103] The social identity of someone with an eating disorder is complicated. Anorexia functions as a "site in which subjectivity is constantly negotiated."[104] Through the performance of perfection (as discussed above 5.1 and 5.2) the users of the pro-ED sites achieve self-identity as an eating disordered person and group identity as belonging to the online cultural group. The protection of both self-identity and the group identity and, indeed, the eating disorder itself becomes of paramount consideration as they strive to protect themselves, their group and their online environments from outsiders and from being closed down.

5.3.2. The users of the sites went to considerable lengths to protect themselves and their ED. They exchanged detailed information about how to hide the condition form others – family, friends and the medical profession. This is "perhaps also suggestive of the ways in which those people with anorexia may come to 'resist' the pathologising stereotypes that often ensue from their interactions with others."[105]

5.3.3. The 'tips and tricks' sections of the sites offered advice on hiding the symptoms of weight loss or how to prevent people from noticing that a person was not eating. The individual Blogs also detailed how difficult it was to hide the condition:

"I'm stressing about how am I going to hide not eating in front of my family or how am I going to work out three times today".

103 Kirkwood op. cit. (117)
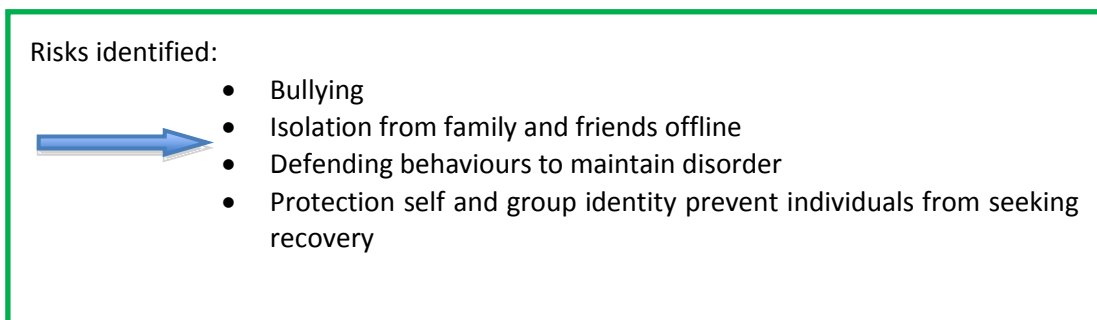
104 Giles op. cit. (474)

105 Rich op.cit. (285)

5.3.4.   It was clear from the data that the users of the sites felt isolated and that other people (those without an ED) did not understand them. They justified their behaviours in order to both protect themselves but also protect their ED. Frequently this need for protection was intensified in the online environments because of 'cyberbullying'. In both chat rooms and on asynchronous Blogs people commented on posts and on the images uploaded. Mostly the comments were encouraging and supportive of weight loss and towards the pro-ana identity but sometimes the comments were bullying and aggressive. The following example illustrates [Wordled™ to protect the identity of the source] the tone and language used in a bullying comment in response to a post on the blog:
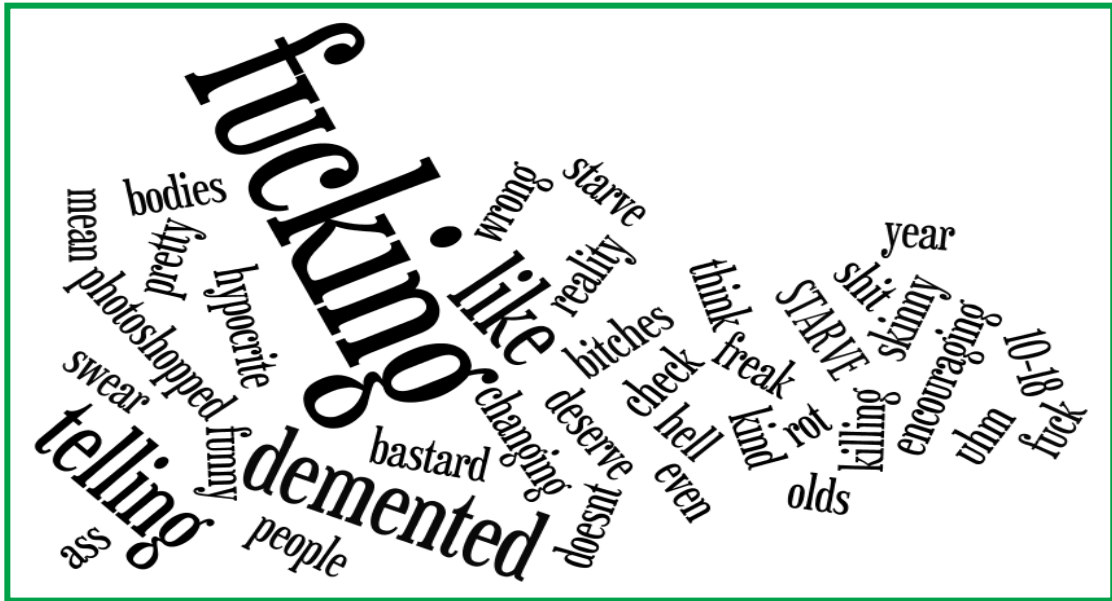
5.3.5.   Users also had to protect themselves from being targeted from people interested in 'skinny pornography', sometimes pornography agencies or other types of grooming. Bearing in mind that this is a vulnerable group often lacking in self-esteem this poses a clear risk for the members of the pro-ED community. The users try to protect themselves and others from this form of exploitation as the following posts on a Blog illustrates [Wordled™ to protect the identity of the source]:

5.3.6. Protecting the group from outsiders is an important aspect of the online shared spaces. The data from the study suggests that the pro-ED communities developed a protective cocoon of basic trust[106] in order to manage the climate of risk[107] which was predominantly posed by outsiders. Many websites and Blogs were password protected in order to protect the community or individual from being reported to ISPs or from being targeted by unsympathetic outsiders.

5.3.7. This threat from outsiders included academic researchers and one website detailed the name, email address and department of a UK university researcher who was identified for contacting members of the pro-ana community after which the site was subsequently shut down.

5.3.8. Being password protected or having a disclaimer are clear examples of control mechanisms to minimise the risk of being closed down by ISPs. However, different characteristics were observed in relation to different websites and communities in that asynchronous discussion boards and notice boards tend not to be password protected but that synchronous chat rooms and online environments do tend to be password protected.[108]

5.3.9. Many ISPs have blocked sites and others insist that sites incorporate disclaimers and warnings regarding the minimum age of the user and the fact that some content may be upsetting.[109] Information on purging, for example, is not permitted.[110] Fearful of negative publicity and in response to increasing public concerns, ISPs have in recent years, starting with Yahoo, made significant attempts to close down pro-ana sites.[111] In response pro-ED sites may use elaborate (or not so elaborate) disclaimers (see 4.5.9) to try to avoid being shut down and protect the online community.

5.3.10. It is through the pro-ED online communities that users obtain a sense of belonging which reinforces their identity as an anorexic or as a bulimic or other eating disordered person and which can make leaving the group to seek recovery difficult[112] as no longer being anorexic would "entail the loss of a particular subject position."[113]

Risks identified:
- Bullying
- Isolation from family and friends offline
- Defending behaviours to maintain disorder
- Protection self and group identity prevent individuals from seeking recovery

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106 See Goffman op cit.

107 See Beck, U. (1992) *Risk Society Towards a New Modernity* London: Sage and Giddens op. cit.

108 Brotsky and Giles op. cit.

109 Giles op. cit.

110 Norris op. cit.

111 Hill , A. (2001) Girls in danger as anorexics give weight-loss tips on web *The Observer, Sunday 12 August 2001*

112 Csipke and Horne op. cit. (203)

113 Rich op. cit. (299)

5.4. Paradoxes

5.4.1. It is the paradoxical relationship between pro-ED and self/group-identity that is fundamental to understanding the risk in relation to pro-ana communities online as anorexics/eating disordered people experience ambivalence towards their condition. As they experience and have both positive and negative feelings about their ED,[114] evidence suggests that the users of pro-ana online communities also view anorexia as a serious disease that requires treatment.[115]

5.4.2. People with eating disorders often have both positive and negative emotions about both the anorexia itself and the idea of recovery. The subjective perceptions of the pro-ED websites users are that whilst they understand them as harmful, (as they encourage disordered eating and competition between users has a negative impact in self-esteem) they also view the sites as enabling them to receive support to maintain restricted eating and disordered eating behaviours and to obtain valuable emotional support.[116]

5.4.3. It is this relationship that is key to understanding the ambivalence to treatment and change.[117] Families of the person with an eating disorder also find it hard to accept the lack of incentive and motivation to recover and to change behaviour.[118] Users visit these sites to either sustain or increase disordered eating behaviours, they obtain food and exercise information, for thinspiration and 'tips and tricks'. However, users also reported receiving valued social support which had a positive effect on mental health and, whilst passive participation (viewing sites) is associated with maintaining an ED, active participation (communicating in chat rooms) is associated with emotional support.[119]

5.4.4. People with an ED are often not well understood by their families, friends or the medical profession and this motivates them to find alternative contexts where they can find sanctuary, support and comfort with other suffers.[120] The anonymous nature of online environments may be more comfortable for people who do not want or have access to face-to-face support.[121] Pro-anorexic sites are, therefore, appealing; the participants have issues in common and develop positive supportive relationships with each other demonstrating their love for each other in the online environments.[122]

5.4.5. There are many different perspectives in relation to the pro-ED debate and in spite of the diversity, it is the increasing availability and popularity of pro-ED sites that is concerning for health professionals.[123] Anorexia, seen negatively by healthcare professionals as a disorder to be treated and cured, is viewed differently by those actually experiencing anorexia, who do not see it as problematic.[124]

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114 see also Freedman, G.; Leichner, P.; Manley, R.; Sanduhu, P. and Wang, T. (2006) Understanding Anorexia Nervosa Through Analysis of Thematic Content of Letters in an Adolescent sample. In *European Eating Disorders Review Vol 14. Pp 301-307.*

115 Williams and Reid op.cit.

116 Csipke and Horne op. cit.

117 Higbed and Fox op .cit.

118 Dimitropoulos et al., op. cit.

119 Csipke and Horne op. it.

120 Rich op. cit.

121 Tierney op. cit.

122 Williams and Reid op. cit.

123 Custers and Van den Bulck op. cit.

124 Williams and Reid op. cit. (552)

5.4.6. This "narrow medicalized view of suffering, solely defined as physical discomfort ignores or minimizes the broader significance of the suffering experienced by chronically ill"[125] but research, drawing on a feminist, post-structural analysis of interviews with young women with an ED, highlights firstly how they felt disconnected from friends, family, teachers and health professionals and secondly what she terms the "public privileging of the 'visual' dimensions of illness."[126]

5.4.7. In explaining these seemingly opposing viewpoints, the pro-ana phenomenon challenges the medical, social and feminist perspectives that view anorexia as an illness to be 'cured'. There are different explanatory models (EM)[127], of anorexia which illustrate how anorexia is perceived by health professionals as a highly dangerous condition, by social scientists and feminists as a consequence of Western cultural preoccupations or to patriarchy but by those with an ED as a source of security and predictability.[128] These differing viewpoints are fundamental to understanding the use of pro-ana sites.[129]

Risks identified:

- Paradoxical relationship between negative aspects of online content and positive aspects of online support.
- The paradox of being isolated and stigmatised offline but identifying with and feeling belonging online.
- The ambiguous nature of users' feelings towards the eating disorder prevents them from seeking recovery.
- Opposing viewpoints of different approaches to understanding the pro-anorexia community.

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6.   Understanding risk – Conclusions

6.1. Perceptions of risk connect individuals, communities and the social structure.[130] This report presents the findings from a six month online study funded by Nominet trust to explore the risk in relation to pro-ana and pro-EDs websites. In summary the risks reflect the relationship between the increasing accessibly and availably of pro-ED websites, online forums and Blogs and the nature and content of the online spaces. The risk varies according to the amount of time spent online in the pro-ED communities, the frequency of site visits and the individual vulnerability of the user.

6.2. In order to understand the risk, it is essential to understand how people with eating disorders seek and strive for perfection. Their idea of perfection is based on a desire for thinness and this disordered viewpoint becomes normalised through the viewing of images and engaging

125 Charmaz op. cit. (168)

126 Rich op. cit.(290)

127 narrative frameworks used by lay and professional people

128 Fox, N. ; Ward, K and O'Rourke (2005) pro-anorexia, weigh-loss drugs and the internet: an 'anti-recovery' explanatory model of anorexia. In *Sociology of Health and Illness doi: 10.1111/j.1467-9566.2005.00465.x* pp.944-971

129 ibid.

130 Hart, G. (1997) 'Introduction' in Green, J. *Risk and Misfortune The Social Construction of Accidents* London: UCL Press.

with other eating disordered people in online environments. Through the repeated and continued exposure to extreme dieting advice and discussions their already poor self-esteem and self-confidence are lowered further. The online spaces can be competitive and further encourage harmful behaviours. Cyberbullying is frequent and users are sometimes targeted for pornography but it is the feeling of belonging to and identifying with the group that reinforces an eating disordered self-identity especially as people with an eating disorder are often isolated and stigmatised in the offline world.

6.3.   It is the sense of belonging that can prevent individuals from seeking help towards recovery and they may further defend their behaviours in order to maintain their disorder. Furthermore, the different and sometimes opposing viewpoints in understanding the pro-ED community make understanding the risk in relation to pro-ana and pro-ED websites even more complex. It is the paradoxical relationship between the negative aspects of the online content and the positive aspects of online support combined with the ambiguous nature of the individual's feelings towards the disease that makes it so difficult to manage the risk in relation to these online environments. Risk refers to the probability not the inevitability of harm[131] and some recommendations are made in section 7 which aim to minimise the potential harm posed by pro-ana and pro-ED websites.

6.4.   **Risk in relation to pro-anorexia websites can be understood as due to the increasing accessibility of pro-ED websites, online forums and blogs. The nature and content of sites varies according to the type of online space. Risk varies according to the type of content and frequency of visits and risk varies according to the vulnerability of the user.**

6.5.   The risk is categorised along four aspects:

- **Perfection** in seeking a disordered view of perfection and the normalising of an ultra-thin body image, the exposure to extreme of dangerous dieting advice or behaviours and having a low self-esteem and lacking in self-confidence.
- **Performing** due to the competitive nature of the sites and belonging to and the reinforcement of the out group, having an eating disordered self-identity and the encouragement of harmful behaviours.
- **Protection** as a result of bullying, the self and group identity preventing individuals from seeking recovery, the isolation from family and friends off line and defending behaviours to maintain the disorder.
- **Paradoxes** derived from the paradoxical relationship between negative aspects of online content and positive aspects of online support, of being isolated and stigmatised offline but identifying with and feeling belonging online. The ambiguous nature of users' feelings towards the eating disorder prevents them from seeking recovery and the opposing viewpoints of different approaches to understanding the pro-anorexia community.

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131 Livingstone et al. op cit. (30)

7. Recommendations

7.1. Education and awareness raising

7.1.1. "Visual imagery is never innocent; it is always constructed through various practices, technologies and knowledges. A critical approach to visual images is therefore needed: one that thinks about the agency of the image, considers the social practices and effects of its viewing, and reflects on the specificity of that viewing by various audiences, including the academic critic."[132]

7.1.2. Awareness raising in relation to the risks from Pro-Anorexia sites is problematic. Health professionals, educators, parents, carers need to be aware of Pro-Anorexia sites and the risks they may pose but it is important not to unnecessarily advertise their existence to children and young people. Educational strategies aimed at children and young people should emphasise the importance of critical thinking around visual images in relation to the wider context of harmful content online.

7.1.3. The EU Kids Online (2011) study, the most comprehensive study on risks, young people and the Internet to date, emphasises the importance of developing critical media literacy and self-protective skills as well as the role of self-regulatory and/or co-regulatory management of online environments.[133] It is essential that education responses to risky online spaces are based on developing critical media literacy skills.

7.1.4. A comprehensive approach to improve children's and young people's Internet safety is required through the UK Council for Child Internet Safety[134], and industry self-regulation. An integrated e-safety strategy and a clear action plan is essential which includes pro-eating disorder sites in their discussions of harmful web-content.

7.1.5. Furthermore, the measures proposed in the Byron action plan to raise awareness of e-safety amongst parents and teachers should specifically address pro-eating disorder sites and their harmful effects. Such educational efforts need to be coordinated with wider efforts to educate parents and teachers in the early detection and management of eating disorder symptoms.[135]

7.1.6. To this end carefully designed and appropriate awareness raising resources are required. Organizations like Childnet International are fundamental in helping children and young people to use the Internet constructively. Childnet International's role is giving advice to children, industry, organizations, parents, teachers and carers about Internet safety to protect children from being exploited in the online environments provided by new technologies as well as seeking to initiate and respond to policy changes.

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132 Rose op cit. (17)

133 Livingstone et al. op. cit.

134 See http://www.education.gov.uk/ukccis

135 Beat *Position Paper on Pro-Anorexia and Pro-Bulimia websites* Written by the Royal College of Psychiatrists in collaboration with Beat. [online available from http://www.b-eat.co.uk/about-beat/media-centre/press-releases/position-paper-on-pro-anorexia-and-pro-bulimia-websites/

7.2 Understanding risk and harm in relation to young people

7.2.1. 21% of European children have encountered websites containing potentially harmful user generated content such as sites containing hate messages, pro-anorexic and pro-bulimic sites, sites promoting self-harm or which discuss drug taking. Approximately 10% of children have experienced some form of personal data misuse but to date little is known about the effects of such experiences.[136]

7.2.2. The experience of mental health practitioners and allied professionals in this field may be valuable in addressing how such potentially negative features of children's online experience should be addressed through policy.[137] Mental health professionals need to be equipped with up-to-date information about Pro-Anorexia websites and harmful content online. A significant number of young people are visiting pro-ED websites and online forums and further research into understanding why young people use them and their view and experiences of these sites is desperately needed.

7.1. Media responsibility

7.3.1. According to Beat[138] the media coverage of eating disorders that either glamorises or else trivialises the illness makes it harder to build the kind of compassionate understanding that is so vital to beat an eating disorder as people with eating disorders are mostly so ashamed and disgusted with themselves, their lives are ruled by intense fear and dread and their self-esteem is so low that they often do not feel they deserve to live, much less get treatment to recover.

7.3.2. Beat has called upon the media not to make pro-ana websites into headline news, not to report their content in a sensationalised way and not to report how to access them, as this may lead to increased use of such sites. Guidance for the media on reporting of pro-ana sites should be part of the development of wider guidance to them on de-sensationalising reporting on eating disorders in general.

7.3.3. It is their need to be understood, taken seriously and not judged harshly by others that can sometimes drive people with eating disorders to seek refuge and support in the desperately dangerous pro-anorexia and pro-bulimia websites that prey on their insecurities and further trap them in the illness. Concerns in relation to the pro-eating disorder phenomena are reflected in the current media discourses and media coverage frequently highlight the potential dangers of these sites.

7.3.4. However, the publicity exemplifies the double-edged sword of modernity[139] in that whilst, "the ever-foolish media attempts to educate young girls of the danger, they accidently glamorise the disease".[140] Reporting eating disorders honestly, truthfully and with compassion for those affected makes a tremendous difference. It helps overcome the stigma and shame many people feel – making it easier for them to accept the treatment and support they need

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136 Livingstone et al. op. cit.

137 Ibid.

138 Beat op. cit.

139 As discussed by Giddens, A. (1990) *The Consequences of Modernity* Cambridge: Polity Press.

140 Collins op. cit. (20)

to beat an eating disorder.[141] The media, therefore, needs to take a responsible role in identifying, representing and discussing this topic.[142]

7.4. Developing a culture of respect

7.4.1. Eating disorders often leave sufferers feeling isolated, ashamed and cut off from support. On-line support is an easily accessible and powerful way of providing support to those people. Young people with eating disorders and their families need to be able to access reputable sources of information and support such as that provided by Beat.

7.4.2. Previously positive attitudes to anorexia have been dismissed as an irrational consequence of the disorder. However, it is recommended that the pro-anorexia phenomena should be taken seriously in order to develop a more sophisticated approach to theoretical models that consider the positive motives to maintaining the condition.[143]

7.4.3. Arguing the 'voice for the pro-ana community' (whilst not advocating the practice of pro-ana), Kirkwood considers that "we are not as troubled by the conditions which help to create anorexia or with anorexia itself or else we would be working as actively to prevent it as some do to remove the websites" and suggests that the pro-ana community to be viewed through the lens of disability.[144]

7.5. Warnings

7.5.1. Pro-eating disorder websites are likely to be set up and maintained by young people who themselves have an eating disorder. In view of this, making them illegal would lead to criminalising a vulnerable group of young people. The Byron[145] action plan mentions The 'joint working between industry and the third sector to improve the support offered to vulnerable groups, including providing links to support services and improving moderation practices where users discuss harmful behaviours'. These measures should be extended to explicitly include pro-eating disorders websites.[146]

7.5.2. "Effective censorship on the Internet is near impossible, and that such attempts will prevent only technically naïve users from accessing such content and communicating with others."[147] Pro-ED websites are unlikely to disappear and research demonstrating the negative consequences of pro-ED websites argues for actions that might minimise damage.[148]

7.5.3. The essential role of industry is consistently emphasised in European Internet safety policy and expressed through self-regulatory codes developed to promote good practice in safer Internet safety use.[149] Warnings on websites are such an example of good practice and can be an effective strategy.

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141 Beat op. cit.

142 Kirkwood op. cit. (128)

143 Williams and Reid op. cit.

144 Kirkwood op. cit. (123)

145 Byron, T. (2008) Safer Children in a Digital World: Full Report [online] available from http://webarchive.nationalarchives.gov.uk/20100407120701/dcsf.gov.uk/byronreview/

146 Beat op. cit.

147 Bell op. cit. (451)

148 Bardone-Cone and Cass op. cit. (546)

149 Livingstone et al. op. cit.

7.5.4. Research suggests that the warning website can be effective with about one third of intended visits not translated into an actual visit to a pro ED site subsequent to the warning provided and a warning message on the outside of a website may be helpful in preventing young visitors from entering the website.[150]

7.4. Fostering critical debate

7.6.1. To date "critical discourses have not only shaped public awareness but also have challenged traditional biomedical theories."[151] It is essential that this debate does not end here but that we continue to gain further insight into the way that cultural settings influence the perceptions and people's experience of a stigmatized mental illness including the way people who suffer from such a disease communicate and express themselves online and offline.[152]

7.6.2. Further research is required as "an improved understanding of the function of these sites in the lives of those who use them would provide grounds for a well-informed, moderate debate on the subject of pro-anorexia/pro-bulimia websites."[153]

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150 Martijn et al. op. cit.

151 Fedyszyn, I. E. and Sullivan, G. S. (2007: 198) Ethical re-evaluation of contemporary treatments for anorexia nervosa: Is an aspirational stance possible in practice? In *Australia Psychologist Vol. 42 N. 3 pp 198-211.*

152 Hwang et al. op. cit. (1106).

153 Csipke and Horne, op. cit. (198).