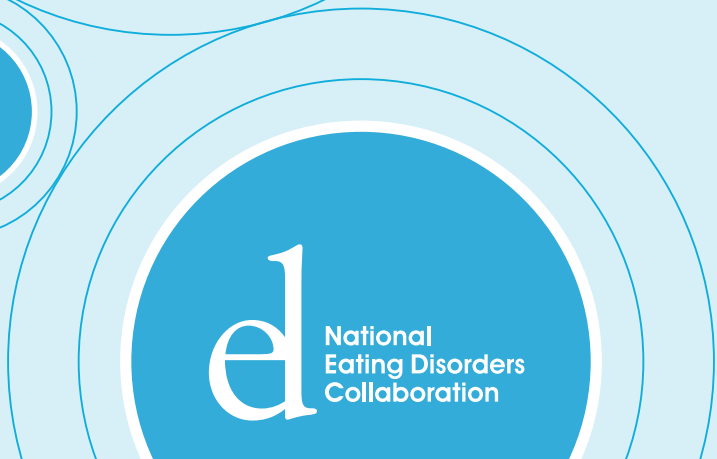
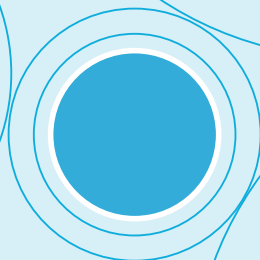
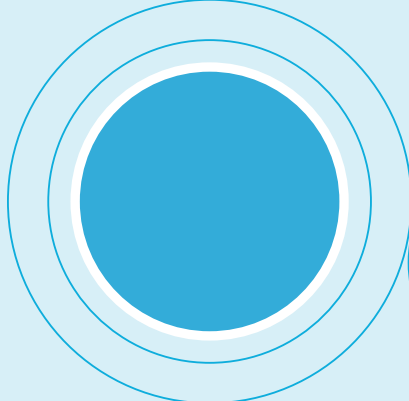
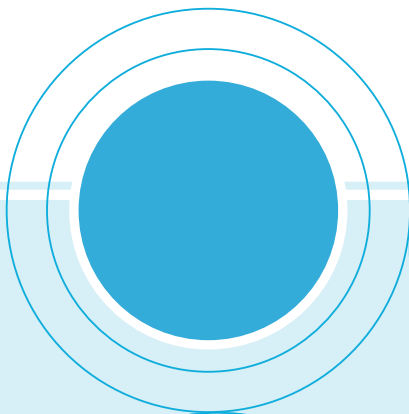


Eating Disorders & Online Resources for Young People

User Experience Guidelines for Prevention & Early Intervention of Eating Disorders



In partnership with



e
d National
Eating Disorders
Collaboration

Eating Disorders & Online Resources for Young People

User Experience Guidelines for Prevention & Early Intervention of Eating Disorders



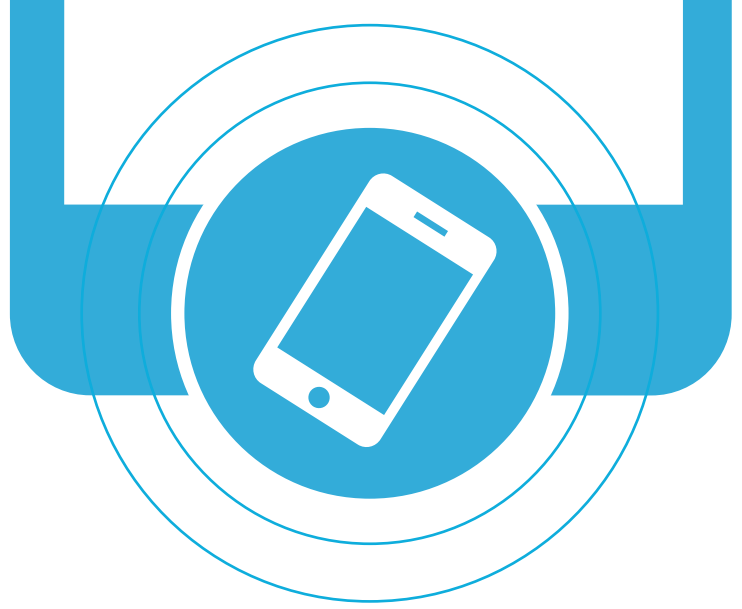
© Copyright, The Butterfly Foundation 2014

The National Eating Disorders Collaboration (NEDC) is an initiative of the Australian Government Department of Health.

December 2014

For more information about the National Eating Disorders Collaboration and this report, please contact the CEO of the Butterfly Foundation:

Christine Morgan, CEO
103 Alexander Street
Crows Nest NSW 2065
Ph: 02 9412 4499
E: christine@thebutterflyfoundation.org.au



Foreword

Eating disorders have a significant and underestimated impact on Australian society.

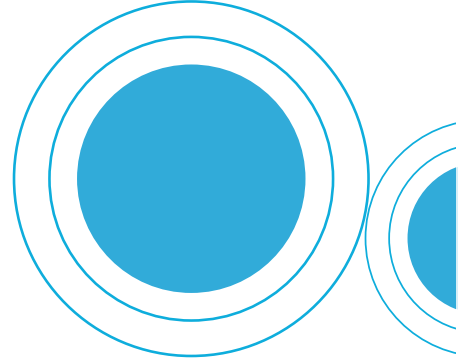
They occur in individuals of any gender, age, cultural or socioeconomic background. While estimates of the incidence of eating disorders vary between countries and studies, there is consensus that eating disorders, disordered eating and body image issues affect approximately 9% of the population and have increased worldwide over the last 30 years.

Developing strong prevention and early intervention programs and tools online is critical in addressing the increasing prevalence of eating disorders in Australia, and this is especially the case for children and adolescents, who regularly interact, learn and connect in online spaces.

In 2014, a need was identified in relation to online access to information for young people about eating disorders. The National Eating Disorders Collaboration partnered with ReachOut.com to run workshops with young people, to better understand their online information needs and to explore how to increase engagement with online resources.

Research has shown that having the correct information and gaining the right education about eating disorders can help prevent an eating disorder from developing and can encourage early help-seeking for those requiring support. Being informed can also ease the suffering of a person in the early stages of the illness and can reduce the stigma and misconceptions that often surround those who have an eating disorder.

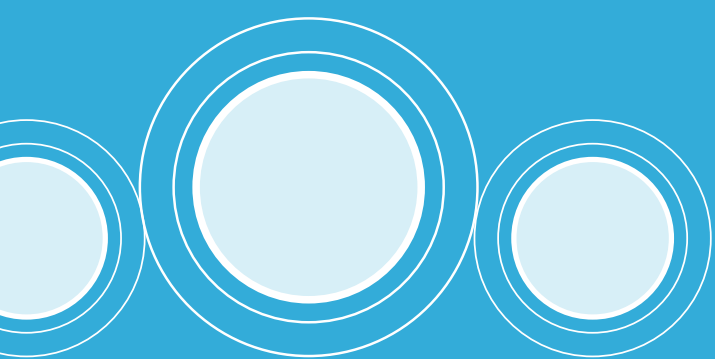
The collaborative process between the NEDC and ReachOut.com to carry out this project has been invaluable, bringing expertise in evidence-based eating disorders information together with expertise in engaging with young people and interpreting their needs. The findings and outcomes of the project provide a guide for developing an online resource that seeks to educate, assure and help young people facing an experience with eating disorders.



Thank you to all of the young participants who took part in this research. The NEDC and ReachOut.com appreciate your enthusiasm, dedication and generosity.

For further information about eating disorders in Australia, visit: www.nedc.com.au.

Regards
Christine Morgan
National Director, The National Eating Disorders Collaboration



Contents

Foreword	3
Executive Summary	6
Methodology	8
Digital Technologies & Youth Help Seeking	9
Key Findings	10
Key Outcomes	14
User Experience Goals	14
User Experience Guidelines	16
Communicating About Eating Disorders	18
References	20
Further Information	21

Executive Summary

Eating disorders are becoming increasingly prevalent in Australia: approximately 9% of the population will experience an eating disorder.

In June 2014, the National Eating Disorders Collaboration consulted ReachOut.com to carry out a research project in order to better understand the needs of young people using online services.

Studies have shown that digital technologies are a significant part of a young person's everyday life, with Internet usage ever increasing. Research has also indicated that young people search the Internet and use online resources to assist them in finding information on various mental health issues.

This project sought to explore young people's help seeking and information needs online, particularly in relation to eating disorders. This was used to inform the development of an online resource that would be relevant and engaging to young people who are either at risk of or experiencing an eating disorder or who want to access online resources to help a friend or family member.

Findings from the workshops indicated that young people possess low literacy around disordered eating and eating disorders. Participants were not able to recognise the need for relevant support for those in the early stages of an eating disorder and believed that personas could overcome an eating disorder via self-help and information seeking.

Friends and family were seen as the first points of contact for support and participants stated that friends or family would be instrumental in motivating change or help seeking for an eating disorder.

Identified barriers or deterrents to help seeking included the portrayal of unattainable body images in the media, lack of community awareness and education, general stigma around eating disorders and a lack of information or advice around a 'healthy alternative' to help prevent or overcome an eating disorder.

Young people's low literacy about eating disorders means that they would be unlikely to seek out a dedicated online resource in this area. They were more likely to seek help or information for comorbid issues rather than an eating disorder specifically.

Participants generated a set of User Experience Guidelines and goals to help stakeholders understand what young people want in an online resource. It became apparent that products for young people need to: help them understand what is happening, provide easy access to relevant information, provide actionable help, show them they are not alone, be accessible on their smartphones and allow them to remain anonymous when accessing information.

Young people also stated that language, messaging and design and experience in an online resource also need to be tailored in order to reach and appeal to young audiences. Language used should be informal, to the point and easy to understand, with minimal use of statistics and complex terminology. Messages should be clear and relevant, with an emphasis on letting young people know they are not alone in their experience. Messaging should also avoid any use of confronting terms (e.g. “mental illness”).

In addition to being accessible on a smartphone, resources must also be designed in a way that is simple to navigate, highly visual (infographics, videos), relevant in terms of imagery (i.e. no generic stock images) and gender neutral.

Methodology

The project was informed by a desk-top literature and information review and two interactive workshops with young people aged 16 – 22.

The workshops used methods from participatory design research that placed emphasis on play, co-operative learning and design-by-doing, with the aim of involving end-users in the design of services. The workshops were based around fictional ‘personas’ that represented typical young people who may use or need an online resource. The first workshop explored how young people broadly conceptualise eating disorders and help seeking. The second workshop focused on the way young people use technology and the creation of user experience guidelines for an online product.

The research questions addressed were:

- What is the typical help-seeking journey for young people in the early stages of an eating disorder?
- How do young people currently access information and support for themselves or friends and family?
- What does the ideal journey look like (from a clinical and user perspective)?
- What are the key barriers to seeking help for an eating disorder?
- What media are young people using and in what context?



Digital Technologies & Youth Help Seeking

Studies have shown that digital technology is a prominent part of the everyday lives of young people.

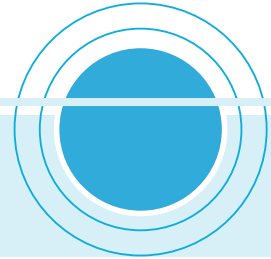
Schooling, entertainment and work are progressively becoming more reliant on technology with 97% of 15-17 year olds and 96% of 18-24 years olds online in Australia in 2012-13 (Ewing, & Thomas, 2012). Portable devices like smartphones, iPods and tablets have also made Internet access much more widespread.

The 2014 *Young and Well* National Survey found that:

- 46% of young people aged 16-25 talked about their problems on the internet with other young people
- 75% had used the internet to find information on a physical health problem.
- 50.5% used the Internet to find information for a mental health, alcohol or substance abuse problem.
- Overall, 97.5% found the information they needed.
- 74% felt the internet helped them deal more effectively with the problem.

Evidence also shows that technology, when used to support or deliver accurate strategies and approaches, can improve mental health states in young people and can help them overcome help-seeking barriers and stigma (Blanchard et al. 2014).

Key Findings



Mental Health Literacy

Participants demonstrated a low level of literacy around eating disorders. In general, most of the participants had heard of ‘bulimia’ and ‘anorexia’ but had not heard of ‘binge eating disorder’ and were not easily able to identify issues relating to disordered eating or other specified eating disorders. Although all the personas provided were in the early stages of an eating disorder, participants had trouble recognising that their personas needed support and help for their disordered eating problems.

When mapping out help-seeking journeys, participants instead looked for ways to solve other life issues that their personas might be going through, such as overcoming isolation, stress and family conflict. With reference to eating, they frequently focused on behavioural change, often encouraging potential risk in their personas, for example; suggested that their personas needed to improve their meal planning abilities, eat more healthily or less volume and ask their parents to “cook less carbs.”

One particular persona was created to include the symptoms of binge eating disorder. This persona often felt a loss of control over the food he was eating, consumed large amounts in one sitting and felt guilt and shame afterwards. When designing his help-seeking journey, participants felt that this persona simply needed to “learn recipes for healthier food” in order to overcome his binge eating problem.

Only one of the six storyboards created by participants linked personas to professional support. Despite discussion by facilitators about the fact that personas might not be able to deal with issues on their own, participants still failed to recognise the need for support. Instead, they focused on self-help and information seeking.

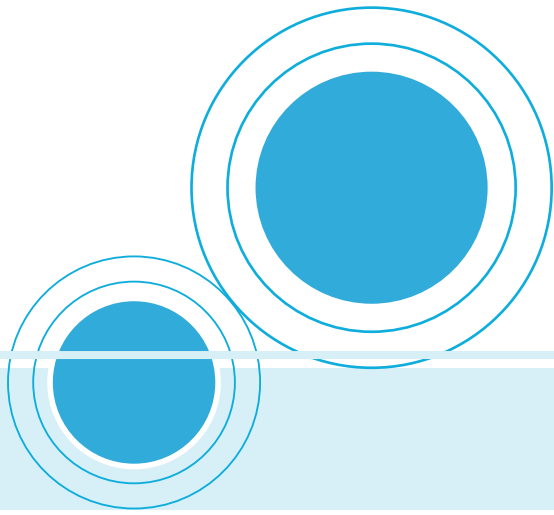
Overall, eating disorders were not seen as issues that required help seeking or support. Participants believed that an eating disorder was a problem that the persona could fix on their own and did not need the help of peers or family members. Generally, they did not feel that their personas needed any tools to help them through their problem.

Help Seeking

Turning to Someone for Help

When prompted to consider help seeking most of the participants said that they would turn to friends to talk about their issues and would rely on them for advice and support. Participants also said they would talk to family. They perceived that the motivation to change or to seek help would need to come from their family and friends. They saw it as imperative to educate friends and family on what to look out for in regards to the signs and symptoms of an eating disorder.

Similarly, participants also spoke of the importance of having an older, experienced mentor. Many of the participants’ journeys included a role model or mentor who was an ‘informal’ expert because they had a lived experience of an eating disorder and was therefore relatable.



Once personas had spoken to a peer or family member, they might then search for information on the Internet. Participants included Google Answers and Yahoo Answers on their journey maps as places they would go to for help online.

Young people indicated that their personas harboured feelings of guilt about their disordered eating behaviour. Some of the questions and thoughts personas had along the way included “what help is the best help?”, “who [do I] talk to first?”, “will anything change?”, “what if they don’t understand?” and “what am I doing with my life?”

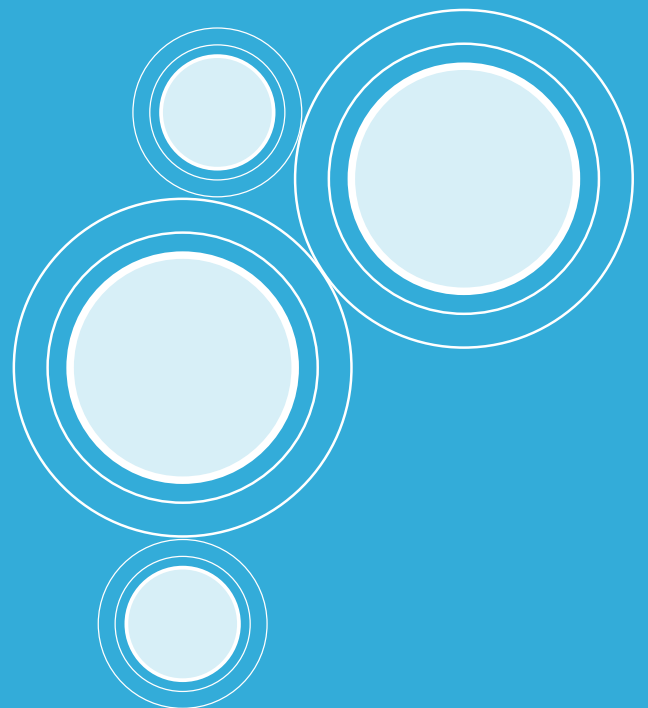
Identifying Help-Seeking Barriers

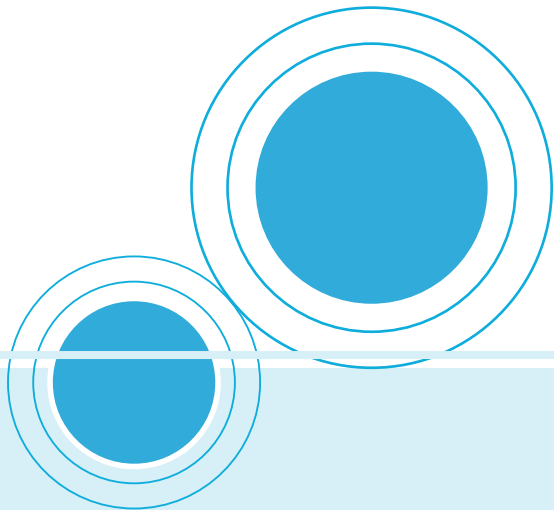
Participants identified a number of barriers that they felt exacerbated disordered eating and negative body image and that made it difficult for young people to seek help.

The participants could see that these were challenges for both males and females. In particular:

- The media was viewed as presenting unattainable body images that could aggravate negative body image in individuals and thus become a help-seeking barrier
- There was much focus amongst participants on the importance of raising general community awareness and educating others about disordered eating in order to reduce the stigma that prevented young people from accessing help.
- One of the participants specifically mentioned that support for over-eating or bingeing was most significantly lacking”
- Another issue which created a barrier to help seeking was the lack of provision of a healthy alternative. For example, websites highlighted what disordered eating was, but did not provide a ‘healthy alternative’ that advised young people on how to eat properly.

“Overall, eating disorders were not seen as issues that required help seeking or support.”





Use of Technology

Accessing Information & Support Online

When participants were asked where they would go to access general information (e.g. if they wanted to go on an overseas trip or find out about a computer problem or purchase a book) their most common answers included Google, YouTube, and talking to friends or family.

When using Google, there was consensus that they would not usually look past the first page of search results as felt that the first page would be more relevant and trustworthy.

When asked specifically about mental health services online, the only mental health websites that the participants had heard of were 'beyondblue' and 'Kids Helpline.' They attributed this to hearing or seeing these sites advertised on television and in places they often interact (e.g. at a music concert).

Favourite Websites and Apps

The participants were asked to write down two apps/websites that they loved and then two apps/websites that were targeted at their age group that they disliked.

The most popular websites and apps mentioned were those that enabled young people to socialise and connect with friends and family, such as Instagram, Facebook and Snapchat. These were most popular as participants could keep up to date, stay in touch with their networks and be reminded of upcoming events. Participants also commented that these apps were easy to use and visually appealing.

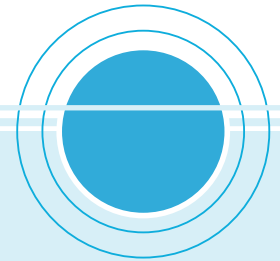
Tumblr was also popular (included by 3 participants). Young people saw Tumblr as a tool that allowed them to follow their interests and gain inspiration.

Participants also mentioned YouTube for entertainment and utility apps that made life easier (e.g. TripView).

Participants used these websites and apps predominantly on their phones and commented that any online resources created should be easy to use on a smartphone.

Unfavourable apps included those that were seen to be inaccurate, slow, and difficult to navigate. The most commonly mentioned app in this respect was Twitter, which they found confusing to use and unappealing. They also reported that the majority of their friends didn't use Twitter and there was "no sense of community" on Twitter.

Key Outcomes



User Experience Goals

From the consultation, a set of user experience goals or “rules” were established by participants to guide the future creation of online resources. The aim of these goals is to make the user experience easy, straightforward and helpful for young people.

Goal 1. “Help me recognise what’s going on for me”

The participants stated that any product designed to address an eating disorder issue would first need to help the user work out “what was going on for them.” Half of the groups mentioned that quizzes, questionnaires or the ability to build their own story would be useful.

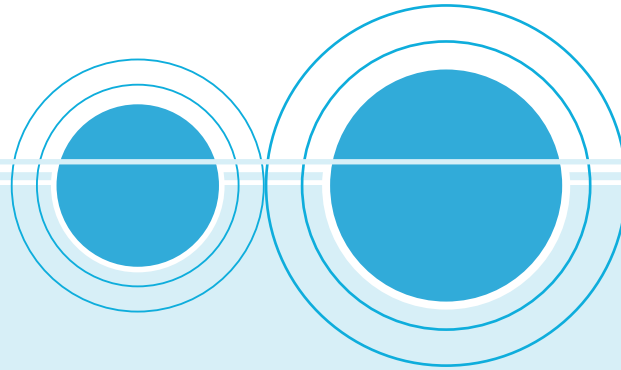
Goal 2. “Help me easily access information that’s relevant to me”

When accessing the online resource, young people wanted to access information that was highly relevant to them. To achieve this, they mentioned that the resource should include: easy to navigate tabs, relatable language within the navigation menu, search bars, and stories of other young people they could identify with.

Participants noted that if they felt a website, upon first viewing, was either difficult to use or “not for them”, they would be unlikely to persist or browse further.

Goal 3. “Provide me with actionable help”

Young people saw actionable help as the highest priority for an online resource. There was an emphasis on content that is solution-focused. They stated that fact sheets should always contain practical information, and this information should stand out. Participants also said that they would come back to a product/resource if they felt it was useful or contributed to their recovery progress.



Goal 4. “Show me that I’m not alone”

A number of participants wanted to hear or read about real stories of others who had been through the same eating disorder issues. However, they did not want these stories to be sugar-coated.

Goal 5. “Be where I am”

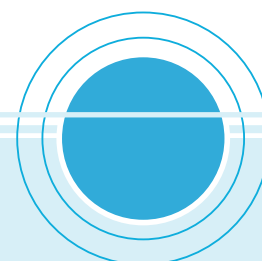
In order to make any given resource accessible, it also needs to be presented in a context relevant to young people. All participants suggested that an online resource should be available and easy to use on their smartphones, as this is where they would be most likely to access such information.

Goal 6. “Give me the choice to remain anonymous”

Participants claimed that they would prefer not to have to sign up to a site to access information and would prefer to remain anonymous. They also stressed that it was important for information to be free to access, so that they could afford to participate and could do so independently without having to disclose their activities to an adult.

Goal 7. “Show me that I can trust the site”

For young people to use and engage with a site/app, it was very important that it appeared trustworthy. Including hyperlinks to other sites or being endorsed or supported by other organisations added credibility. Some of the participants also stated that if a site was endorsed by a celebrity, it would also increase credibility.



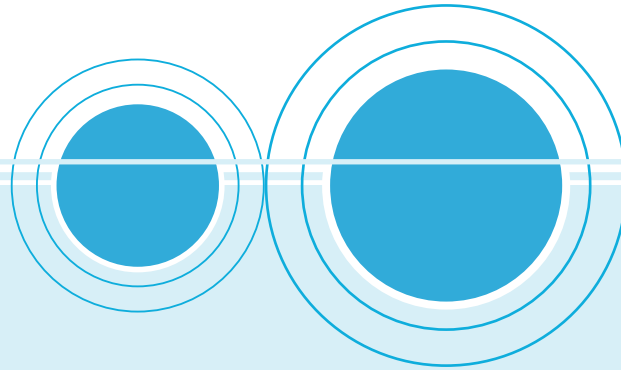
User Experience Guidelines

The workshop outcomes additionally prompted the creation of various guidelines to inform the language, messages and design and experience of online products aimed at prevention/early intervention of eating disorders in young people.

Language & Content

When creating any online website or application for young people, the language and content should:

- **Be easy to understand.** Avoid the use of long, flowing sentences or overly technical terminology. Language should be simple and easy to read for any young person.
- **Be conversational and informal.** Young people are not interested in reading professional or academically-styled content. Language should be appealing for young people to read and should use data minimally.
- **Elaborate on complex or technical terms.** Where technical terminology is used, terms should be explained in simple, everyday language (e.g. 'What is a protective factor?')
- **Be succinct and straightforward.** Young people are not inclined to spend time reading large amounts of text or reading content that does not add value or provide relevant information. Participants suggested using language that is straight to the point, with minimal preamble.
- **Present actionable terms and language.** The majority of young people in the workshops stated that they would prefer less descriptive text and more actionable language. Online products should prioritise practical content and ensure it stands out or is easy to find.
- **Be gender neutral.** Language should speak or refer to both females and males, not one or the other. It should also be inclusive of gender diversity.
- **Utilise typography.** Content for young people should be easily and quickly readable. Use bullet points, sub/headings, short paragraphs and bold text to break up information.



Messages

When composing content for young people, messages need to:

- **Be relevant for their age group.** Information and messages should focus on the specific problems young people may be facing. The right messages should be emphasised to help young people discern what is important and which information they should be reading.
- **Avoid terms like ‘mental illness.’** Young people may find terms like ‘mental illness’ too confronting and such messaging can have adverse effects on individuals. Workshop participants suggested using terms like ‘mental health issue’ instead. Product creators should be aware that young people with eating disorders need time to understand they have a ‘mental illness.’
- **Use normalising statements.** Where applicable, use normalising statements to let young people know that they are not alone (e.g. “eating disorders can affect anyone”). The use of videos to “tell stories” can also help young people feel like they are not alone. (Personal stories should follow communication guidelines to ensure their presentation is safe).
- **Include “myth busting” information.** Participants felt that this type of information could help young people understand what is true/false about eating disorders.

Design & Experience

Young people would like online products to be designed in a way that is:

- **Easy to navigate**, with understandable headings, simple menus and easily locatable information.
- **Highly visual**, with information presented visually or in “bite-sized chunks” e.g. infographics, rather than through chunks of text.
- **Inclusive of videos** to present content or tell personal stories about people with eating disorders.
- **Exclusive of stock images** that are not appealing to young people or relevant to eating disorder issues. Many young participants felt that stock images were over-used and were not authentic.
- **Simple and concise**, with the option to find out more.
- **Gender neutral** in look, feel and design.
- **Technologically reliable**, with quick page load times and the ability to save/download content to their phones or devices so that it could still be accessible offline.

Communicating About Eating Disorders

There are several guidelines that inform how any online product, resource or program should portray eating disorders.

The Mindframe National Media Initiative (2012) elaborates on best practices and a 'do no harm' approach when communicating about eating disorders in any type of medium, to any audience group.

Conveying the Right Messages

- Always present eating disorders as serious mental illnesses (not a lifestyle choice or a trivial matter)
- Do not glamorise eating disorders or present them as entertainment; similarly, do not include eating disorder reports in entertainment segments/columns (this is a frequent error when reporting on celebrities)
- Avoid presenting eating disorders as irreparable; instead, emphasise that treatment and full recovery is possible
- Emphasise the importance of seeking help

Using Appropriate Language

- Avoid labelling a person with an eating disorder by their illness (e.g. "she is an anorexic"); instead language should utilise phrases like "is living with an eating disorder" or "has a diagnosis of" or "is being treated for"
- Try not to use language that portrays those with an eating disorder as victims (e.g. "suffering from" or "a victim of")
- Do not use language that glamorises an eating disorder or presents the illness as trivial, entertaining or an acceptable way of dealing with life problems

Communicating Information

- Focus on risk factors that can help audiences identify the signs
- Focus on the physical and psychological impact of eating disorders on the person, and their friends and family
- Talk about behaviours in general and avoid including information on disordered eating activities that could prompt dangerous ‘copycat’ behaviour
- Avoid including quantifiable details (measurements, weight, BMI) in the content to reduce the risk of comparison behaviour by viewers
- Always consult with a qualified expert or organisation for clarity and accuracy of information
- Always include practical help seeking and support service information, such as a help line number or website

Including the Right Images

- Utilise images that portray a diversity of people, including people with a variety of shapes and sizes
- Do not utilise images of people with extreme body weights or shapes (e.g. images of someone with anorexia or someone who is obese)
- Avoid including quantifiable details (measurements, weight, BMI) in images
- Avoid portraying images of celebrities or other figures as the ‘norm’ in terms of weight and body shape
- Do not show ‘before’ and ‘after’ images of a person with an eating disorder

For further information on communicating about eating disorders, view the Mindframe Guide at: www.mindframe.com.au

References

Ewing, S. & Thomas, J. (2012) CCI Digital Futures 2012: The Internet in Australia. ARC Centre of Excellence for Creative Industries and Innovation, Swinburne University of Technology, 2012.

Burns, J. M., Davenport, T. A., Christensen, H., Luscombe, G. M., Mendoza, J. A., Bresnan, A., Blanchard, M.E. & Hickie, I. B. (2013) Game On: Exploring the Impact of Technologies on Young Men's Mental Health and Wellbeing. Young and Well Cooperative Research Centre, Victoria.

Blanchard, M., Herrman, H., Frere, M. & Burns, J. (2011) Attitudes informing the use of technologies by the youth health workforce to improve young people's wellbeing: Understanding the nature of the "digital disconnect". National Youth Sector Conference 2011, Sydney.

Blanchard, M., Bresnan, A., Christensen, H., Davenport, T., Hickie, I., Burns, J., Collin, P., Luscombe, G. & Mendoza, J. (2014) 2014 Young and Well National Survey. Young and Well Cooperative Research Centre, Victoria.

Mindframe National Media Initiative. Reporting and Portrayal of Eating Disorders (2012). Retrieved from: <http://www.mindframe-media.info/for-media/reporting-suicide/Downloads/?a=5140>

Further Information



About the NEDC

The National Eating Disorders Collaboration (NEDC) is a collaboration of people and organisations with an expertise in eating disorders. The purpose of the NEDC is to develop nationally consistent and evidence-based approaches to the prevention and management of eating disorders in Australia. The vision of the NEDC is to see eating disorders as a priority health issue in Australia and to ensure every Australian at risk has access to ongoing support, care and treatment.

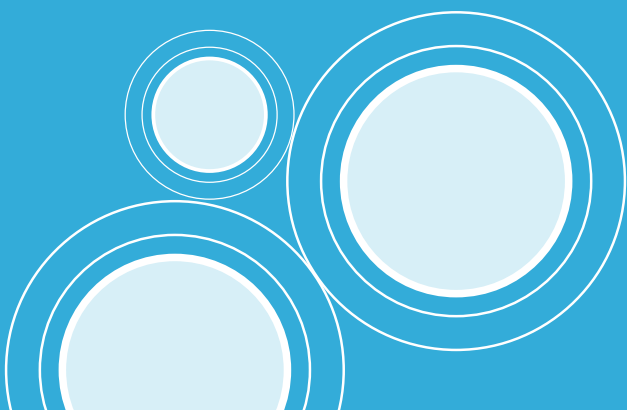
Learn more about eating disorders at www.nedc.com.au



About ReachOut.com

ReachOut.com is Australia's leading online youth mental health service that helps young people under 25 get through tough times. ReachOut.com features a range of practical tools for making everyday life a little easier, with resources such as fact sheets, stories, videos, apps, forums and general information.

Learn more about young people's mental health at: www.au.reachout.com



The National Eating Disorders
Collaboration

103 Alexander Street
Crowds Nest, NSW 2065
Phone: +61 2 9412 4499
Email: info@nedc.com.au
www.nedc.com.au

The National Eating Disorders
Collaboration (NEDC) is an initiative
of the Australian Government
Department of Health

