

13 December 2023

Dear Ms Kruk,

Thank you for the opportunity to provide a submission to the Covid-19 Response Inquiry, which we would like to do in relation to the impacts of the pandemic on people who experience eating disorders and their loved ones and the **broader health supports** required by them during this type of extraordinary event.

About InsideOut Institute

InsideOut Institute (IOI) is Australia's national institute for research, translation and clinical excellence in eating disorders. IOI comprises a team of expert researchers, clinicians and public policy-makers committed to ensuring every person with an eating disorder has access to the best possible care. IOI also leads the Australian Eating Disorder Research and Translation Centre.

About Eating Disorders

Eating disorders are common serious mental illnesses that are potentially life threatening. Compared with the general population and people with other mental illnesses, people with eating disorders are at higher risk of suicide, death and poor quality of life^{1,2}. Eating disorders have a negative impact on the individual's life physically, emotionally, occupationally and socially, and 'carer burden can lead to adverse personal, family and patient outcomes'^{3,4}. They affect people of all genders, cultural backgrounds and socioeconomic status and from across the age spectrum – with onset in children as young as 5 years old⁵ and most people developing the illness during childhood/adolescence and young adulthood. The majority of people with eating disorders experience co-occurring mental illness such as anxiety and depression.

Despite significant advocacy over recent years and the implementation of the Australian Government MBS Review initiative to provide Eating Disorder specific item numbers supporting access to an evidence-based dose of treatment, eating disorders are under-diagnosed and under-treated – with low levels of clinician knowledge and confidence reported by GPs^{6,7,8} and limited screening and assessment occurring in primary care⁹. Only a small proportion of people who do access care receive evidence-based treatment¹⁰. Delayed diagnosis and intervention has significant impacts on outcomes and health care costs for the person, their loved ones and the health care system¹¹.

Eating Disorders and the Covid-19 Pandemic

- Incidence of eating disorders increased globally during the Covid-19 pandemic^{12,13,14,15}. International studies reported increased ED referrals/presentations to a range of settings (primary care, acute care, specialist care, inpatient care) when compared with pre-pandemic rates¹⁶ particularly, among children and adolescents^{17,18,19} and females²⁰.

In Australia:

- Eating disorder behaviours increased in people with existing illness; eating disorders re-emerged in those who had been in recovery prior to the pandemic; and new experiences of eating disorders were triggered²¹.
- Emergency department presentations of children with eating disorders increased where presentations for other reasons decreased e.g. a 104% increase in Perth²²
- There were 'striking increases' in admissions of children and adolescents with anorexia nervosa and atypical anorexia nervosa to paediatric hospitals and eating disorder units – e.g. the Adolescent Medicine Eating Disorder Unit at Monash Children's Hospital found an increase of 125.70%²³ and the Royal Children's Hospital demonstrated a 63% increase²⁴.
- Data in preparation for publication by our team demonstrates that in QLD, Victoria and NSW these trends in presentation rates preceded the pandemic: from 2012-2019 significantly increased rates across the whole health system in hospital, community and emergency departments were observed for eating disorder diagnoses year on year, and most markedly in younger people.

A range of reasons have been posited or reported as contributing to these significant shifts in eating disorder presentations during the pandemic, particularly in relation to lockdown restrictions, for example:

- Stress, anxiety, increased uncertainty and feelings of loss of control often relate to eating disorder pathology onset and deterioration²⁵ creating the *'perfect storm'* for people with eating disorders²⁶ when these also occur as the result of a pandemic.
- *'worries about COVID-19 infection, lockdown, concerns about lack of structure and social support, and concerns about accessing food consistent with one's recovery meal plan predicted increases in ED symptoms'*²⁷ - people experiencing food insecurity are known to be at higher risk for eating disorders and increased eating disorder behaviours, particularly binge eating type disorders²⁸
- for children and young people – school closures, online learning, limited peer, sport and recreational activities, disrupted school and social routines²⁹; greater engagement with social media triggered weight and body checking behaviours, there was greater preoccupation with cooking recipes and more eating-related conflict with parents³⁰
- social isolation and loneliness³¹ was significantly associated with increased severity in all eating disorder symptoms except for over-exercise³²
- reduced treatment access and quality, in the context of increased anxiety and depression³³
- videoconferencing for work/study-related purposes is associated with performance anxiety, impaired engagement, and avoidance among individuals at-risk for EDs³⁴

Recommendations for future pandemic response planning in relation to broader health supports for people with eating disorders include:

1. That **eating disorders be identified as a priority at-risk group** in regard to policy, planning, service delivery and supports during a pandemic response, and as such, be deemed eligible for any temporary arrangement made, such as:
 - a. bulk billing of telehealth with GPs, paediatricians, psychiatrist, psychologists and dietitians, as well as other mental health professionals who are eligible providers of treatment under the eating disorder care plan
 - b. inclusion as a priority group listed for any Priority Assistance Programs such as in relation to food delivery and other programs delivering services or supports related to the condition
 - c. provision of working from home arrangements for parents and carers of people with eating disorders who may be home through school or workplace closures
2. That GPs and other health professionals be provided with advice regarding predicted increases in eating disorder experiences alongside other health and mental health advice generated during a pandemic, so that attention to screening and assessment are heightened, and additional supports are put in place for people with eating disorders and their families. This capacity would be greatly enhanced if GPs and other health professionals received training in eating disorders as part of their health professional undergraduate education, and where they have access to professional development, tools and practice-based resources required to undertake screening, assessment and provide evidence-based treatment at point of care – such as can be provided through InsideOut Institute. For example, our GP Hub and Tools is a point of care resource for General Practitioners being rolled out in 2024 with funding by the Australian Government Leadership in Mental Health Program.
3. That information campaigns are explicit in informing people with eating disorders that they are at particular risk for experiencing an increase in their eating disorder symptoms and/or a decline in their mental health and outlining additional supports and services that are available³⁵.
4. That national mental health telephone crisis providers (e.g. Lifeline, Kids Helpline) and PHN Intake Assessment and Referral (IAR) telephone support services are upskilled around eating disorders, to ensure the advice provided is aligned with best practice and most likely to produce a positive outcome for the person – directing them towards people and supports that might help. For example, InsideOut Institute delivers training and support through our eLearning portal, via webinar and face to face to headspace and head to health services nationally, and to PHN Intake Assessment and Referral (IAR) providers, around screening, assessment and evidence-based care for people with eating disorders.
5. That adaptive, flexible, support services are established and available to people with eating disorders and their families – accessible regardless of geographical area³⁶. This might include initiatives such as Hospital in the Home, and online components of care, such as provision of eating disorder groups and individual treatment, peer supports, single session interventions and digital eTherapy. For example, InsideOut's

eClinic provides evidence-based digital therapies accessible for pure self-help and supported self-help for people with the most common eating disorders. Our eClinic will be rolled out nationally in 2024 with funding from the Australian Government Leadership in Mental Health Program.

6. That mental health clinicians and educators are made aware of the need to provide increased monitoring of patients with eating disorders and provide additional support to people with eating disorders using videoconferencing who may experiencing additional concerns in relation to use of the medium for school/work/treatment³⁷.
7. That additional supports be put in place for families of people with eating disorders in regard to online meal supports, family supports and treatment, and peer mentoring, such as is provided by Eating Disorders Families Australia, Eating Disorders Victoria and Eating Disorders Queensland.

In summary, while the overall public health response in Australia was timely, consistent, and comprehensive, people with eating disorders were disproportionately affected, including those with existing illness, those who had previously achieved recovery, and those developing the illness for the first time. Research findings highlight the importance of prioritising the mental health of those at risk of eating disorder, and of ensuring enhanced care options and supports implemented for those with eating disorders during critical points in time during a pandemic. Increased awareness, screening, assessment, and an increase in the available options for treatment may well be needed to better manage the effects of the pandemic on people with eating disorders.

Relevant evidence:

Source	Study site reported	Relevant findings/comments
Zipfel, S., Schmidt, U., Giel, K.E., (2022) The hidden burden of eating disorders during the COVID-19 pandemic. The Lancet Psychiatry. 9(1):9-11. DOI: https://doi.org/10.1016/S2215-0366(21)00435-1	Expert Comment	<i>'Multiple reports from different countries, in Europe, Australia, and North America, have shown an increase in the incidence of eating disorder behaviours or diagnoses in the community, or deterioration of eating disorders in patient populations, often with more severe symptoms and comorbidities since the start of the COVID-19 pandemic.'</i>
Hyam L, Richards KL, Allen KL, Schmidt U. The impact of the COVID-19 pandemic on referral numbers, diagnostic mix, and symptom severity in Eating Disorder Early Intervention Services in England. Int J Eat Disord. 2023 Jan;56(1):269-275. doi: 10.1002/eat.23836. Epub 2022 Oct 21. PMID: 36271511; PMCID: PMC9874422.	First Episode Rapid Early Intervention for Eating Disorders (FREED) is a service model and care pathway which aims to provide timely, well-coordinated, developmentally informed and evidence-based care for young people with eating disorders (EDs). This article investigates the impact of the COVID-19 pandemic on FREED patient presentations and service provision in England.	<i>'Significant increases in referral numbers were found from September 2020 onward, coinciding with the end of the first UK national lockdown. The percentage of AN presentations significantly increased after the onset of the first national lockdown (April 2020-December 2020).'</i> <i>'Our research suggests that early intervention eating disorder services across England faced significant increases in patient referrals and presentations of anorexia nervosa over the COVID-19 pandemic. This increase in referrals is not due to a rise in milder eating disorder cases, as baseline symptom severity remained stable across the pandemic.'</i>
Miskovic-Wheatley, J., Koreshe, E., Kim, M. et al. The impact of the COVID-19 pandemic and associated public health response on people with eating disorder symptomatology: an Australian study. J Eat Disord 10, 9 (2022). https://doi.org/10.1186/s40337-021-00527-0	One of the largest national observational studies to capture the impact of the pandemic with over 1700 respondents; capturing the course of Australia's second wave, including Victoria's major lockdown.	<i>Widespread increases in all eating disorder symptoms noted, particularly body image concerns (88% of participants), food restriction (74%) and binge eating (66%). Of participants with clinically significant eating disorders, 40% had never received formal diagnosis or treatment.</i>
Carison A, Babl FE, O'Donnell SM. Increased paediatric emergency mental health and suicidality presentations during COVID-19 stay at home restrictions. Emerg Med Australas. 2022 Feb;34(1):85-91. DOI: 10.1111/1742-6723.13901	Retrospective electronic medical record review of all emergency department patients with mental health discharge codes at a large tertiary children's hospital in Australia during the period of stay at home restrictions from 1 April to 30	<i>Despite an overall decrease in Emergency Department presentations, the absolute increase in mental health presentations for children and adolescents during the stay at home restriction period was pronounced. Diagnoses with greatest percentage increases were eating disorders, social issues and suicidality.</i>

	September 2020 compared with the same dates in 2019.	
National Health Service (NHS) (2023) <i>Mental Health of Children and Young People in England Survey</i> https://digital.nhs.uk/data-and-information/publications/statistical/mental-health-of-children-and-young-people-in-england/2023-wave-4-follow-up	<i>Mental Health of Children and Young People in England, 2023 - wave 4 follow up to the 2017 survey</i> Official statistics, Survey: 21 Nov 2023 Date Range: 01 Jan 2017 to 30 Apr 2023	After a rise in prevalence between 2017 and 2020, rates of probable mental disorder remained stable in all age groups between 2022 and 2023. For children aged 11 to 16 years, the rate of possible eating problems rose from 6.7% in 2017 to 13.0% in 2021. Rates then remained stable over subsequent waves. In young people aged 17 to 19 years, the prevalence of possible eating problems rose from 44.6% in 2017 to 58.2% in 2021. Rates remained stable over subsequent waves (2022 and 2023). For 20 to 23 year olds, rates of possible eating problems were similar in 2021, 2022 and 2023. There was no 2017 data for this age group.
Haripersad YV, Kannegiesser-Bailey M, Morton K, <i>et al</i> Outbreak of anorexia nervosa admissions during the COVID-19 pandemic <i>Archives of Disease in Childhood</i> 2021; 106 :e15. https://adc.bmj.com/content/106/3/e15.long	Perth Children's Hospital – the only tertiary paediatric hospital in Western Australia. Admits all pts <16 years with AN requiring medical stabilisation.	"Similar to paediatric hospitals internationally, ¹ our emergency department presentations and overall hospital admissions have fallen significantly in 2020 (figure 1). However, since the commencement of the COVID-19 pandemic in Australia, we have observed a 104% increase (95% CI +56% to +166%, p<0.001) in children with anorexia nervosa (AN) requiring admission to the hospital for nutritional rehabilitation compared with the three previous years (online supplementary table 1).
Springall, G., Cheung, M., Sawyer, S.M. and Yeo, M. (2022), Impact of the coronavirus pandemic on anorexia nervosa and atypical anorexia nervosa presentations to an Australian tertiary paediatric hospital. <i>J Paediatr Child Health</i> , 58: 491-496. https://doi.org/10.1111/jpc.15755	Royal Children's Hospital Eating Disorder Service, Melbourne	'A striking increase in the presentation of adolescents with new cases of AN to a specialist ED service during the pandemic, with the timing closely mirroring the extent of social restrictions. ' Annual presentations increased from a mean of 98.7 per annum from 2017 to 2019 to 161 in 2020 (63% increase).' 'COVID-19 restrictions were reported to be a trigger for ED behaviours in 40.4% of adolescents diagnosed with anorexia nervosa in 2020. There was no significant difference in severity across years despite increased cases.'
Heeney, C., Lee, S., Gillman, K. and Kyprianou, K. (2022), Impact of the Coronavirus Pandemic on Anorexia Nervosa and Atypical Anorexia Nervosa	Adolescent Medicine Eating Disorder Unit (AMEDU) at Monash Children's Hospital	"5-year retrospective chart review data (2016–2020) showed a statistically significant increase of 125.79% in total admissions in 2020 (n = 359) compared to the mean yearly admissions from

Presentations. J Paediatr Child Health, 58: 210-211. https://doi.org/10.1111/jpc.15827		2016 to 2019 ($n = 159$, $P = 0.027$). There was also a 73% ($P = 0.035$) increase in patients who were admitted multiple times within 1 year , with this group contributing to hospital burden considerably. The largest peak was seen in September 2020 with a 233.33% increase in admissions, which coincided with the final months of lockdown prior to reopening of schools in October. ²
Caldirola A, La Tegola D, Manzo F, Scalia A, Affaticati LM, Capuzzi E, Colmegna F, Argyrides M, Giaginis C, Mendolicchio L, Buoli M, Clerici M, Dakanalis A. The Impact of the COVID-19 Pandemic on Binge Eating Disorder: A Systematic Review. Nutrients. 2023 Aug 29;15(17):3777. doi: 10.3390/nu15173777. PMID: 37686811; PMCID: PMC10490470.	systematic review was to synthesise the impact of the COVID-19 pandemic on binge eating disorder (BED) the new onset and course	With the exception of one study, the available literature indicates both an increase in BED diagnoses and a clinical worsening during COVID-19. Binge Eating Disorder [BED] patients are particularly vulnerable to events characterised by social distancing and over-worry, and should be, therefore, carefully monitored
McLean CP, Utpala R, Sharp G. The impacts of COVID-19 on eating disorders and disordered eating: A mixed studies systematic review and implications. Front Psychol. 2022 Sep 6;13:926709. doi: 10.3389/fpsyg.2022.926709. PMID: 36148134; PMCID: PMC9487416.	This mixed systematic review provides a timely insight into COVID-19 eating disorder literature and will assist in understanding possible future long-term impacts of the pandemic on eating disorder behaviors.	It appears that the role of stress in the development and maintenance of eating disorders may have been intensified to cope with the uncertainty of the COVID-19 pandemic. Future research is needed among understudied and minority groups and to examine the long-term implications of the COVID-19 pandemic on eating disorders and disordered eating behaviors.
Khraisat BR, Al-Jeady AM, Alqatawneh DA, Toubasi AA, AlRyalat SA. The prevalence of mental health outcomes among eating disorder patients during the COVID-19 pandemic: A meta-analysis. Clin Nutr ESPEN. 2022 Apr;48:141-147. doi: 10.1016/j.clnesp.2022.01.033. Epub 2022 Feb 3. PMID: 35331484; PMCID: PMC8810264.	Meta analysis aimed at evaluating the impacts of the Covid-19 pandemic in relation to the pooled prevalence of psychological comorbidities in patients with eating disorders.	'This meta-analysis provides evidence that there is an increased prevalence of anxiety, depression, and worsening of eating disorder symptomatology in eating disorder patients during the COVID-19 pandemic. It is vital that we provide unconditional support to ED patients during this period of uncertainty. This could be done through the close monitoring of these patients as well as providing complete support through developing preventive strategies and personalized treatment approaches. We also recommend developing telemedicine interventions and online nutritional support in order to decrease the impact of such psychological distress.'

<p>Hart LM, Mitchison D, Fuller-Tyszkiewicz M, Giles S, Fardouly J, Jarman HK, Damiano SR, McLean SA, Prichard I, Yager Z, Krug I. "Can you see me?" Videoconferencing and eating disorder risk during COVID-19: Anxiety, impairment, and mediators. <i>Int J Eat Disord</i>. 2023 Jan;56(1):235-246. doi: 10.1002/eat.23844. Epub 2022 Nov 4. PMID: 36331070; PMCID: PMC10100378.</p>	<p>This research aimed to investigate whether eating disorder (ED) risk was associated with videoconferencing performance for work or study and to explore whether the use of safety behaviors and self-focused attention mediated the relationship between ED risk and perceived control over performance anxiety, impaired engagement, or avoidance of videoconferencing for work or study.</p>	<p><i>Our cross-sectional findings suggest videoconferencing for work/study-related purposes is associated with performance anxiety, impaired engagement, and avoidance among individuals at-risk for EDs. Poorer videoconferencing outcomes appear more strongly related to social anxiety variables than ED status. Clinicians and educators may need to provide extra support for those using videoconferencing.</i></p>
<p>Richardson C, Phillips S, Paslakis G. One year in: The impact of the COVID-19 pandemic on help-seeking behaviors among youth experiencing eating disorders and their caregivers. <i>Psychiatry Res</i>. 2021 Dec;306:114263. doi: 10.1016/j.psychres.2021.114263. Epub 2021 Nov 3. PMID: 34758404; PMCID: PMC8572344.</p>	<p>We analyzed service utilization data from the National Eating Disorder Information Centre's (NEDIC) toll-free helpline/chat to assess the impact of the COVID-19 pandemic on help-seeking behaviors among youth with disordered eating and their caregivers. Toronto, CANADA</p>	<p><i>The number of contacts from affected youth (n = 650) and caregivers (n = 823) was significantly higher in the pandemic year than 2018 and 2019. The proportion of affected youth reporting dieting/restriction, perfectionism, and weight pre-occupation was significantly higher during the pandemic than in 2018 and 2019. Our findings lend support to accounts from expert clinicians reporting an increase in youth presenting with eating disordered symptoms during the pandemic.</i></p>
<p>Maunder, K., McNicholas, F. Exploring carer burden amongst those caring for a child or adolescent with an eating disorder during COVID-19. <i>J Eat Disord</i> 9, 124 (2021). https://doi.org/10.1186/s40337-021-00485-7</p>	<p>Carer Burden</p>	<p><i>The Coronavirus Disease 2019 (COVID-19) pandemic has made caring for youth with an ED even more onerous and preliminary research is beginning to emerge demonstrating the profound negative impact the pandemic is having upon individuals with EDs and their carers. Themes are beginning to emerge as to why COVID-19 may further exacerbate carer burden: (1) reduced access to ED services; (2) increased physical vulnerability and exacerbation of psychiatric co-morbidity amongst youth with EDs; (3) increased practical demands placed on carers; and (4) social isolation and decreased social support.</i></p>
<p>Baudinet J, Konstantellou A, Hambleton A, Bialluch K, Hurford G, Stewart CS. Do People Want the 'New</p>	<p>mixed method study explored young person, parent/caregiver, and clinician</p>	<p><i>online treatment is considered helpful and acceptable by all groups. Nevertheless, face-to-face assessment sessions (young</i></p>

Normal'? A Mixed Method Investigation of Young Person, Parent, and Clinician Experience and Preferences for Eating Disorder Treatment Delivery in the Post-COVID-19 World. <i>Nutrients</i> . 2023 Aug 25;15(17):3732. doi: 10.3390/nu15173732. PMID: 37686764; PMCID: PMC10490168.	experiences of child and adolescent eating disorder treatment	<i>people: 52.2%; and parents/caregivers: 68.9%) and final sessions (young people: 82.6%; and parents/caregivers: 82.2%) were preferred compared to online. There was also a preference for early treatment sessions to either be always or mostly face-to-face (young people: 65.2%; and parents/caregivers: 73.3%). The middle and latter parts of treatment were a time when preferences shifted slightly to a more hybrid mode of delivery. Participants reported finding engagement with the therapist (young people: 70.6%; and parents/caregivers: 52.5%) easier during face-to-face treatment. Stepping away from the binary of online or face-to-face, the current data suggest that a hybrid and flexible model is a way forward with current findings providing insights into how to structure this.</i>
Hallward L, Nagata JM, Testa A, Jackson DB, Ganson KT. Associations between gender identity, eating disorder psychopathology, and food insecurity among Canadian adolescents and young adults during the COVID-19 pandemic. <i>Eat Behav</i> . 2023 Apr;49:101723. doi: 10.1016/j.eatbeh.2023.101723. Epub 2023 Apr 7. PMID: 37030063.	the purpose of this study was to explore associations between food insecurity and ED psychopathology by gender identity among a national sample Canadian adolescents and young adults	<i>There is a clear association between food insecurity and eating disorder (ED) psychopathology. Generally, those with no food insecurity reported the lowest ED psychopathology compared to higher ED psychopathology among those with food insecurity.</i>

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