

Right care, first time: a highly personalised and measurement-based care model to manage youth mental health

Ian B Hickie¹, Elizabeth M Scott^{1,2}, Shane P Cross¹, Frank Iorfino¹, Tracey A Davenport¹, Adam J Guastella¹, Sharon L Naismith¹, Joanne S Carpenter¹, Cathrin Rohleder¹, Jacob J Crouse¹, Daniel F Hermens^{1,3}

Summary

- Mood and psychotic syndromes most often emerge during adolescence and young adulthood, a period characterised by major physical and social change. Consequently, the effects of adolescent-onset mood and psychotic syndromes can have long term consequences.
- A key clinical challenge for youth mental health is to develop and test new systems that align with current evidence for comorbid presentations and underlying neurobiology, and are useful for predicting outcomes and guiding decisions regarding the provision of appropriate and effective care.
- Our highly personalised and measurement-based care model includes three core concepts:
 - ▶ A multidimensional assessment and outcomes framework that includes: social and occupational function; self-harm, suicidal thoughts and behaviour; alcohol or other substance misuse; physical health; and illness trajectory.
 - ▶ Clinical stage.
 - ▶ Three common illness subtypes (psychosis, anxious depression, bipolar spectrum) based on proposed pathophysiological mechanisms (neurodevelopmental, hyperarousal, circadian).
- The model explicitly aims to prevent progression to more complex and severe forms of illness and is better aligned to contemporary models of the patterns of emergence of psychopathology. Inherent within this highly personalised approach is the incorporation of other evidence-based processes, including real-time measurement-based care as well as utilisation of multidisciplinary teams of health professionals.
- Data-driven local system modelling and personalised health information technologies provide crucial infrastructure support to these processes for better access to, and higher quality, mental health care for young people.

Collaborating authors: Joanne S Carpenter, Shane P Cross, Jacob J Crouse, Tracey A Davenport, Adam J Guastella, Ian B Hickie, Frank Iorfino, Dagmar Koethe, F Markus Leweke, Sharon L Naismith, Cathrin Rohleder, Ashleigh M Tickell (Brain and Mind Centre, University of Sydney, Sydney, NSW); Daniel F Hermens (Brain and Mind Centre, University of Sydney, Sydney, NSW, and Sunshine Coast Mind and Neuroscience – Thompson Institute, University of the Sunshine Coast, Birtinya, QLD); Vilas Sawrikar (Brain and Mind Centre, University of Sydney, Sydney, NSW, and University of Edinburgh, Edinburgh, UK); Elizabeth M Scott (Brain and Mind Centre, University of Sydney, Sydney, NSW, and University of Notre Dame Australia, Sydney, NSW); and Jan Scott (Brain and Mind Centre, University of Sydney, Sydney, NSW, and Institute of Neuroscience, Newcastle University, Newcastle Upon Tyne, UK).

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Chapter 1

Multidimensional outcomes in youth mental health care: what matters and why?

Frank Iorfino¹, Joanne S Carpenter¹, Shane P Cross¹, Tracey A Davenport¹, Daniel F Hermens^{1,2}, Adam J Guastella¹, Cathrin Rohleder¹, Jacob J Crouse¹, F Markus Leweke¹, Dagmar Koethe¹, Sharon L Naismith¹, Elizabeth M Scott^{1,3}, Ian B Hickie¹

Mood and psychotic syndromes (including anxiety, depression, bipolar disorder and psychosis) present one of the most serious public health challenges in the 21st century. They affect fundamental aspects of human life — our ability to work, function and develop quality social relationships — and too often lead to the early loss of life. About one in every three individuals is affected by such mental disorders over their lifetime, and studies continuously show they are a leading cause of years lost to disability.^{1–3} Young people in particular are at risk, with over 75% of adult mental disorders emerging before the age of 25 years^{4,5} and over 45% of the total burden of disease for those aged 10–24 years being attributed to mental disorders.⁶ Consequently, a key population health priority is to reduce the burden of these disorders so that their impact does not endure a lifetime.^{7–9}

Much of the burden can be attributed to prevalence and early age of onset, which influence the chronicity and secondary risks (eg, suicidal thoughts and behaviours, alcohol or other substance misuse) associated with these disorders. Lifetime prevalence estimates indicate that up to one-third of young people meet diagnostic criteria for a mental disorder,¹⁰ while the 12-month prevalence among Australian young people aged 16–24 years was the largest across all age groups at about 26%.¹¹ Studies consistently report such high prevalence rates for mental disorders before the age of 25 years, irrespective of whether or not they adhere to strict diagnostic rules about symptom thresholds and impairment.^{12–14} The prevalence of mental disorders during youth poses a risk for future health and wellbeing outcomes precisely due to the time at which they tend to emerge.

Adolescence and young adulthood is a critical period of biological and social development. Usually beginning with the onset of puberty, major physical and neurobiological changes occur, characterised by the development of key brain circuits responsible for higher order cognitive and emotional functions that, if suboptimal or disrupted, can have a significant impact on behaviours and the development of disorder.^{15–22} This period is also characterised by significant social development as young people embark on the early phases of their careers via education and employment, and engage in more complex relationships with friends, family, and intimate and sexual partners. During this time young people face increasing diversity in potential life trajectories as they move from relatively restricted and homogenous environments, such as school and home life, to environments characterised by greater independence and variability in new educational, employment and social environments.²³ For some, this transition may occur without major disruption; however for others, this change in context and roles can lead to maladaptive functioning or can manifest and amplify underlying problems.²⁴ Thus, the biological and social complexity of adolescence and young adulthood means that young people are

Summary

- Mood and psychotic syndromes present one of the most serious public health challenges that we face in the 21st century. Factors including prevalence, age of onset, and chronicity contribute to substantial burden and secondary risks such as alcohol or other substance misuse.
- Mood and psychotic syndromes most often emerge during adolescence and young adulthood, a period characterised by major physical and social change; thus, effects can have long term consequences.
- We propose five key domains which make up a multidimensional outcomes framework that aims to address the specific needs of young people presenting to health services with emerging mental illness. These include social and occupational function; self-harm, suicidal thoughts and behaviours; alcohol or other substance misuse; physical health; and illness type, stage and trajectory.
- Impairment and concurrent morbidity are well established in young people by the time they present for mental health care. Despite this, services and health professionals tend to focus on only one aspect of the presentation — illness type, stage and trajectory — and are often at odds with the preferences of young people and their families.
- There is a need to address the disconnect between mental health, physical health and social services and interventions, to ensure that youth mental health care focuses on the outcomes that matter to young people.

susceptible to the onset of mental health problems that may have a long term impact on outcomes in adulthood.^{15,25,26}

Evidence for a multidimensional outcomes framework

The impact of mood and psychotic syndromes extends beyond the symptoms that define them. They affect many aspects of human life which typically establish during adolescence and young adulthood (ie, social relationships, education, employment skills and experience). Thus, it is not surprising that 22 years of age is identified as the age at which the maximum negative impact of a disabling illness occurs.²⁷ Since young people are more likely to present with multidimensional needs,²⁸ health service strategies should be in place to identify and respond to a range of health and social issues with the appropriate type and intensity of intervention.²⁹ We propose five key domains that make up a multidimensional outcomes framework to address the specific needs of young people presenting to health services with emerging mental illness (Box 1):

- social and occupational function;
- self-harm, suicidal thoughts and behaviours;
- alcohol or other substance misuse;

1 Multidimensional outcomes framework for young people with emerging mood and psychotic syndromes



NEET = Not in Education, Employment or Training. Icons from www.flaticon.com: alarm bell, bicycle and magnifying glass/brain made by Freepik; wine bottle/glass made by srip; team education made by Eucalyp. The key findings for each domain within the multidimensional outcomes framework from the Brain and Mind Centre's Optimyse Youth Cohort are shown. The outer circle includes the domain headings, while the inner circle includes key clinical findings. Superscript numbers indicate in-text reference to the relevant study. ♦

- physical health; and
- illness type, stage and trajectory.

Some of the studies discussed below come from the University of Sydney's Brain and Mind Centre's Optimyse Youth Cohort.^{33,41} This cohort includes 6743 individuals aged 12–30 years, 57% of whom are female. They presented to the Brain and Mind Centre's youth mental health clinics in the Sydney suburbs of Camperdown and Campbelltown and, after consenting, were recruited to a research register between June 2008 and July 2018. Individuals were either self-referred, referred via a family member or friend, or the community (eg, general practitioner) to these clinics which include primary care services (ie, headspace) as well as more specialised mental health services. Demographic data, clinical data such as presentation by *Diagnostic and statistical manual of mental disorders* diagnosis, substance use, personal history of mental illness, current treatment and functional data such as scores on a social and occupational functional assessment scale and engagement in education and employment were collected from research and clinical files to assess longitudinal outcomes. Subsets of this cohort have completed neuropsychological and neurobiological assessments as part of additional associated research protocols (Chapter 3). All participants received clinician-based case management and psychological, social,

and/or medical interventions as part of standard care. Data for longitudinal follow-up were collected for the duration of each participant's engagement with the clinical services and/or participation in research sub-studies.

Social and occupational function

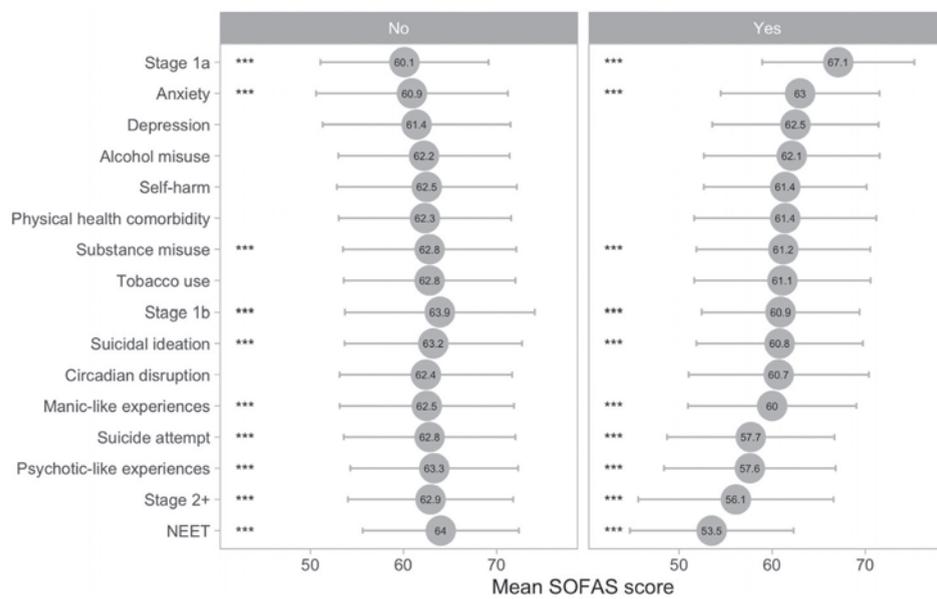
Prospective longitudinal studies have demonstrated that the presence of a mental disorder before the age of 16 years affects economic potential (ie, reduced income by 28%) and social relationships (ie, marriage instability) of adults aged 50 years.⁴⁴ Moreover, individuals who had a mental disorder between the ages of 18 and 25 years were more likely to have lower occupational participation, income and living standards by 30 years of age.⁴⁵ The effect of mood and psychotic syndromes on these outcomes is greater than the impact of physical health problems among young people,⁴⁴ and is present even when the mental disorder is subthreshold or has remitted.⁴⁶ This illustrates that even though adolescent-onset mood and psychotic syndromes may dissipate by adulthood, due to the nature of the adolescent and young adulthood period, they may have already affected an individual's ability to function economically and socially over the course of their life.

Among young people presenting to health services, well established social and occupational functional impairment is common. Rates of disengagement from education, employ-

ment and training are about 25%, which is nearly twice the national average for young people,^{30,31,47,48} although for those engaged in employment or education, functional impairment due to mental ill health tends to manifest as higher rates of days out of role.³² While such findings have been common in the literature on individuals at risk of psychosis and those who have experienced first-episode psychosis,⁴⁹ they have not been as extensively delineated in these early mood disorder populations. Further, greater functional impairment at entry tends to be associated with neurocognitive problems or difficulties, more severe mood or psychotic symptoms and concurrent substance (notably cannabis) misuse.³¹ Over time, while impairment may vary considerably for individuals, the overall pattern is largely one of stable trajectories, whereby the degree of impairment at entry to care is the main predictor of long term course.^{33,50}

Social and occupational function typically varies at entry into care and has a discrete relationship with each of the other key outcomes (Box 2). Most importantly, there is a significant subpopulation (characterised as stage 1b, see Chapter 2) of people who have not yet developed a persistent or full-threshold disorder but are already impaired and often remain largely impaired or deteriorate further despite the provision of standard clinical care.⁵¹ As would be expected, prior research suggests that young

2 Associations between social and occupational function and other multidimensional domains at entry to care



NEET = Not in Education, Employment or Training. Unpublished data from the Brain and Mind Centre's Optimyse Youth Cohort (n = 2767). Mean Social and Occupational Functional Assessment Scale (SOFAS) scores for each of the other domains of the multidimensional outcome's framework are depicted. The grey circles and lines display the mean and standard deviation of SOFAS score for young people who have (or do not have) the corresponding outcome at entry into care (ie, "no" indicates individuals without the corresponding outcome). Differences in mean SOFAS score between these groups ("no" v "yes" for each outcome) were compared using Welch's t-test and significant differences are depicted using an asterisk (***) adjusted $P < 0.001$. ♦

and they are not restricted to those with more severe illness types.^{35,36} This contrasts with data from an Australian survey which showed that 8% of teenagers had expressed suicidal ideation and 2% had attempted suicide in the previous 12 months.⁶⁰ While engagement with care is associated with a reduction in repeated suicidal behaviours, new experiences of suicidal thoughts and behaviours emerge during care, particularly among those whose illness course and trajectory is worsening and in association with alcohol or other substance misuse.³⁴ These findings have important implications for an enhanced focus on reducing self-harm, suicidal thoughts and behaviours throughout the course of clinical care for all of those who present to such services, not just those who are perceived as higher risk.

Alcohol or other substance misuse

Concurrent alcohol or other substance misuse is often recognised as an important comorbid condition for anxiety and depressive disorders but is rarely subject to systematic evaluation, or intervention within mental health care services.^{61,62} Up to 15% of young people with a prior mental disorder engage in alcohol or other substance misuse,⁶³ while about one-third of young people have established alcohol or other substance misuse at entry to health services.³⁷ More frequent alcohol or other substance misuse is associated with older age, being male and having psychotic or bipolar disorders.³⁷

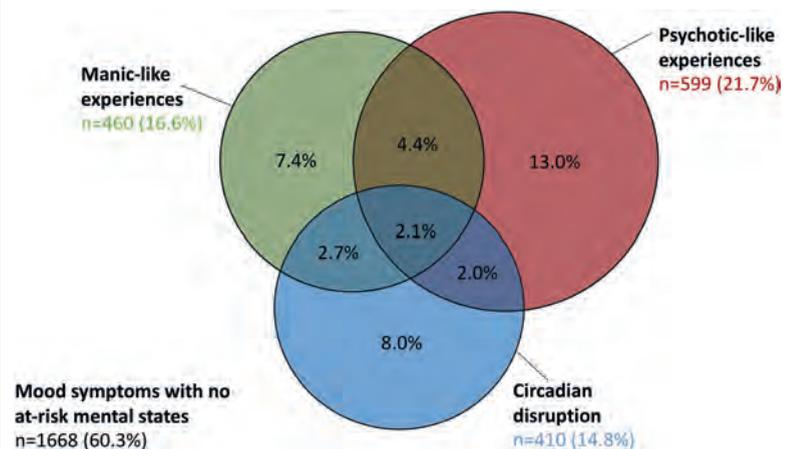
people who present with greater impairment and further developed mental health syndromes require more intensive treatments and resources, yet are less likely to recover. In contrast, those with milder symptoms and impairment are more likely to recover after a briefer period of care.⁵¹

Self-harm, suicidal thoughts and behaviours

Mood and psychotic syndromes are consistently associated with self-harm, suicidal thoughts and behaviours, which increase the risk of death by suicide and the overall burden of these disorders.⁵² Lifetime prevalence estimates indicate that almost 10% of the population across the world experience suicidal ideation and about 5% engage in suicidal behaviours (ie, plans or attempts), with the peak age of onset occurring during adolescence and young adulthood.^{53,54} The overall rate of these behaviours is up to three times higher among young people than older adults, yet young people are also less likely to die from a suicide attempt, indicating the potential for these behaviours to be ongoing.^{55,56} Specifically, population-based studies have shown that suicidal thoughts and behaviours among young people are associated with the onset and persistence of mental health problems, physical health comorbidity, and poorer social and occupational outcomes in adulthood.^{46,57-59}

Alcohol or other substance misuse contributes to the overall impact of mood and psychotic syndromes, since it tends to be associated with greater disability⁶⁴ and impaired productivity and interpersonal functioning.⁶⁵ The outcomes are particularly poor among those who start to use alcohol or other substances

3 Prevalence and patterns of comorbidity between at-risk mental states in the Brain and Mind Centre's Optimyse Youth Cohort (n = 2767) at entry to care



Note: Manic-like experiences, psychotic-like experiences and circadian disruption are common (~40% of the sample) in young people and are often comorbid phenomena. ♦

Similarly, among young people with early-stage disorders, these behaviours are not only a determinant of immediate distress and additional impairment but also a predictor of later onset of more severe illness (bipolar-type or mood instability) and greater functional impairment.³⁴ Importantly, at entry to services, up to one-third of young people already experience suicidal thoughts,

at an early age, with lower socio-occupational functioning, manic-like experiences, suicidal ideation and risky drinking being more common than among those who start later.³⁸

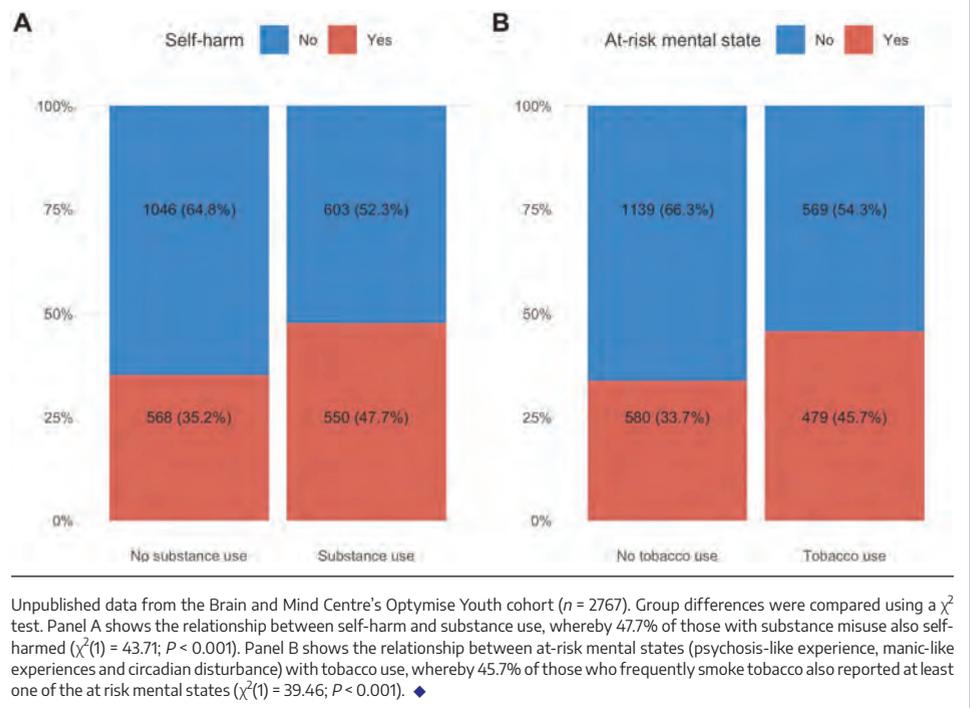
These results emphasise the importance of early assessment regarding the potential contribution of alcohol or other substance misuse to the individual's current impairment and any self-harming behaviours which may be present, as well as the potential impact on physical health, illness type (particularly bipolar disorders) and illness course. Additionally, these data emphasise the potential for secondary prevention of alcohol or other substance misuse by active management of common mood and psychotic syndromes before the age of likely exposure to such substances. Again, broad-based secondary prevention strategies should be a core feature of service delivery — particularly for younger people (ie, under the age of 18 years) presenting for care. Active management of comorbid disorders early in the course of illness has the potential to not only reduce longer term substance misuse-determined morbidity and mortality but significantly improve functional outcomes more broadly and reduce the morbidity due to self-harm and suicidal thoughts and behaviours.

Physical health

The pervasive impact of mood and psychotic syndromes extends to other chronic physical illnesses, such as diabetes and cardiovascular disease,^{66,67} and is particularly evident in the relationship between depression and early death due to cardiovascular disease.⁶⁸ All mood and psychotic syndromes are associated with an increased risk for the onset of a range of chronic physical health conditions, with population estimates suggesting that the onset of up to 13% of physical health conditions could be attributed to such syndromes.⁶⁹ The comorbidity between physical and mental health conditions is associated with an increased burden of disease, with evidence suggesting that comorbidity is more burdensome than physical health conditions alone or in combination.⁷⁰

While the adverse physical health consequences of persistent mental illness in middle-aged people is now well recognised, the opportunity to prevent this morbidity and premature mortality in those who present with adolescent-onset mood and psychotic syndromes has not yet been realised. Current data suggest that physical health problems and risk factors for later poor physical health are common in young people presenting to care, with up to one-third smoking daily, which is three times higher than the age-matched Australian population.³⁹ While, the patterns of overweight (20%) and obesity (10%) are comparable to the age-matched Australian population, the rate of women who are underweight is higher than that of the general population at 10%.³⁹ Youth cohorts engaged in mental health care tend to have increased weight and often develop insulin resistance,⁷¹ and recent evidence suggests that increasing body mass index is associated with emerging insulin resistance.⁴⁰

4 Illustrative relationships between some of the domains in the multidimensional outcomes framework



These data highlight key opportunities, notably related to cessation of smoking tobacco, preventing weight gain and providing early active interventions for metabolic disturbance, hormone dysfunction or concurrent autoimmune and other inflammatory conditions. Given the notable emergence of comorbid physical health problems in those who continue to engage with care, particularly among those who are treatment-resistant or develop significant neurological or metabolic side effects from medications,³⁹ there is a gap in knowledge and thus a need for more interventional studies that attempt to reduce risks of later onset cardiovascular disease,⁷² or more proactive approaches (eg, metformin therapy) for those at risk of developing insulin resistance.⁷³ It is likely that we will need to develop and evaluate new screening and active intervention protocols to achieve better outcomes in this at-risk population. While a current focus on dealing with these risks in early psychosis cohorts is laudable, we need to adopt a much more proactive and evidence-informed approach to the clinical care of those with adolescent-onset mood and psychotic syndromes.

Illness type, stage and trajectory

Many mood and psychotic syndromes that emerge early in life persist into adulthood, particularly those with longer duration of illness or recurrent episodes in adolescence.^{25,74–76} While diagnostic manuals are used to guide the diagnosis and treatment of these disorders, they have been heavily criticised for their lack of validity and inability to account for the huge heterogeneity of disorders among young people.^{77–81} Consequently, there has been a major shift towards transdiagnostic approaches among younger populations, to better match diagnosis and treatment with the common developmental psychopathology of mood and psychotic syndromes and specific service settings.^{9,81,82} Part of this shift has been to apply clinical staging as an adjunct to formal diagnosis. Clinical staging recognises that the boundaries between common mood and psychotic syndromes are often

unclear and that an approach which accounts for their comorbidity is needed (Chapter 2).^{43,79,83-87}

The comorbidity between different mood and psychotic syndromes has been well established in both clinical and community samples.⁸⁸⁻⁹¹ About 40% of adolescents with one mental disorder meet the criteria for two or more lifetime disorders²⁵ and studies consistently show that major depression and anxiety disorders are particularly comorbid conditions.⁹² The presence of comorbidity is associated with greater illness severity,^{75,93} poorer response to treatment,⁹⁴ greater role impairment,^{92,95} and higher rates of suicidality.⁹⁶⁻⁹⁸ Thus, young people with mood and psychotic syndromes are not only at risk of persistent disorders in adulthood, but at risk for multiple disorders that often lead to poorer outcomes.

In addition to clinical staging, knowledge of the underlying pathophysiology (Chapter 2) which may be driving the development of a mental disorder is important for guiding treatment decisions. The validity of three common illness subtypes (psychosis, anxious depression and bipolar spectrum) based on proposed pathophysiological mechanisms (neurodevelopmental, hyperarousal and circadian) is supported by demographic, family history and neuropsychological data (Chapter 2).^{39,42} In the Brain and Mind Centre's Optymise Youth Cohort, psychotic or bipolar phenomena (including psychosis-like experiences, mania-like experiences and circadian disruption) are common, occurring in 40% of the sample, and are often comorbid, with considerable overlap between these phenomena⁴¹ (Box 3). Our previous work has demonstrated the extent to which

5 Various stakeholder perspectives of what should be the focus for mental health care across multidimensional domains

	Young people	Families and carers	Mental health professionals and service providers	Policy makers and funders
Social and occupational function	<ul style="list-style-type: none"> Rate importance of social relations higher for quality of life than health professionals¹⁰¹ Forced to coordinate their own social needs¹⁰² Social function rated higher than vocational function¹⁰³ Recovery must focus on economic and social inclusion¹⁰⁴ 	<ul style="list-style-type: none"> Family members value more social and community involvement¹⁰⁴ 	<ul style="list-style-type: none"> Recent move from service activity, to clinical outcomes, quality of life and recovery-oriented measures¹⁰⁵ Often a disconnect between mental health care and social services¹⁰⁶ 	<ul style="list-style-type: none"> Major focus on improving educational and economic participation^{102,106} Targeted interventions for economically inactive young people to prevent chronic disability and poorer illness trajectories¹⁰⁷ Recognise the costs of mental illness for society as a whole and of the health benefits of employment¹⁰⁸
Self-harm, suicidal thoughts and behaviours	<ul style="list-style-type: none"> Want to be involved in improving policy and services to address suicidal thoughts and behaviours¹⁰⁹ Forced to navigate the health care system to manage suicidality¹⁰² 	<ul style="list-style-type: none"> Families often first point of call, but can be unhelpful in response¹⁰⁹ High burden placed on families to navigate the health care system to access support for suicidality¹⁰⁶ 	<ul style="list-style-type: none"> Many health professionals or service providers are unwilling to engage with suicidal individuals¹¹⁰ 	<ul style="list-style-type: none"> Participation in whole-of-community responses to reducing suicide¹¹¹
Alcohol or other substance misuse	<ul style="list-style-type: none"> Low rates of access to mental health services by young people linked with high rates of alcohol or other substance misuse¹¹² Relatively small numbers of consumers seek help for substance misuse, and will often instead present with other physical or mental health-related complaints¹¹³ 	<ul style="list-style-type: none"> Major challenges for families to deal with both mental health and substance misuse 	<ul style="list-style-type: none"> There is often a disconnect between mental health care and addiction services^{106,114} Active exclusion of individuals with substance misuse from mental health services Negative attitudes towards patients with substance use disorders¹¹³ 	<ul style="list-style-type: none"> Integrating mental health and alcohol or other substance use treatment is often recommended but poorly resourced or organised¹⁰⁶
Physical health	<ul style="list-style-type: none"> Rate physical health higher for quality of life than health professionals¹⁰¹ Often forced to manage these needs themselves¹⁰² Value overall health higher than the general public¹⁰³ Recovery must include medical care¹⁰⁴ 	<ul style="list-style-type: none"> High burden placed on families to navigate the health care system to access support for physical health needs¹⁰² Carers often want to help their young people reduce smoking habits, yet feel isolated and that there is limited support from services to assist them¹¹⁵ 	<ul style="list-style-type: none"> Despite increased physical and sexual health risks, a young person's mental illness often becomes the single focus There is often a disconnect between mental health care and medical services¹⁰⁶ Avoidance of responsibility for reducing smoking among people with mood and psychotic syndromes¹¹⁶ 	<ul style="list-style-type: none"> Social, existential, mental, substance misuse and somatic care should be integrated at the local level¹⁰⁶ A focus on reducing risk factors that contribute to morbidity and premature mortality¹¹¹
Illness type, stage and trajectory	<ul style="list-style-type: none"> Do not rate symptom reduction as highly as health professionals for quality of life¹⁰¹ Those with severe symptoms value symptom reduction higher¹⁰³ Believe recovery should go beyond symptom control¹⁰⁴ 	<ul style="list-style-type: none"> Formal diagnostic processes are largely relevant to gaining access to care 	<ul style="list-style-type: none"> Rate symptom reduction for quality of life higher than young people¹⁰¹ Most outcome measures focus on symptoms¹⁰⁵ Services are focused exclusively on group level symptom reduction¹⁰⁶ 	<ul style="list-style-type: none"> Social, existential, mental, substance misuse and somatic care should be integrated at the local level¹⁰⁶

Note: The findings presented here are based on a literature review. The shading of each box indicates the priority level for each of the domains across the different stakeholder groups, based on group consensus of the available literature. Dark shading = high priority; medium shading = moderate priority; light shading = low priority. ◆

psychosis-like experiences and circadian disruption predict progression to more severe mood and psychotic syndromes, as determined by clinical staging.⁴¹ In this cohort, these phenomena were measured at a low threshold and were not necessarily sufficient to warrant inclusion in a psychotic or bipolar illness category; however, the data demonstrate the overlap in key characteristics, softening the boundaries between different illness types and trajectories.⁴¹

Expanding the focus in youth mental health care

Collectively, these studies underscore the broader impact of mood and psychotic syndromes on the capacity of young people to make the transition into adulthood and reach their actual health, social and economic potential. It is also clear that impairment and concurrent morbidity are well established among young people by the time they present for mental health care (Box 4). These results emphasise the extent to which the treatment of mood and psychotic syndromes should not be limited to a discrete set of symptoms, but rather, focus more broadly on outcomes across multiple domains to address the core needs of young people with emerging disorders. Psychological symptoms, such as depression or anxiety, are often reported as the main reason for presentation to services;^{99,100} however, as discussed above, educational, vocational, social and physical health problems are also prevalent issues.

The extent to which the focus of mental health care extends beyond mental illness type or psychological symptoms is variable. The priority for focus differs depending on whether you are a young

person, family member or carer, health professional or service provider, policy maker or funder (Box 5). Young people do not tend to rate symptom reduction as high as health professionals in relation to quality of life, whereas they do tend to rate social relationships and physical health as more important for quality of life.^{101,103} This type of mismatch in focus, or expectations about positive outcomes, is often reflected in the outcomes on which services and health professionals traditionally focus. Most outcome measures focus on symptoms, and services tend to focus exclusively on group-level symptom reduction as indicators of improvement or positive outcomes.^{103,105,106} The consequences of this are that young people are left to coordinate their own social and physical health needs, which places increased burden on family and carers who try to help them navigate the health system to get the support they require for these areas.^{102–104} Together, this emphasises the need to address the disconnect between mental health, physical health and social services and interventions, to enable mental health care to focus on the outcomes that matter most to young people.

Conclusion

Young people with mood and psychotic syndromes are susceptible to poorer social, physical and mental health outcomes — many of which are already present and well established at their entry into care. This emphasises the need for models of care which prioritise a multidimensional outcomes framework and more closely align to their preferences and needs, as well as those of their families. We believe this will give them the best chance of leading fulfilled and engaged lives in adulthood.

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