Development of an online interactive depression risk assessment and tailored preventive intervention for healthy young people at high genetic risk of depression or bipolar disorder

Chief Investigator: Dr Alex Wilde
The University of New South Wales

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FINAL REPORT

MAIN MESSAGES

MindExpress – the skills to build resilience

MindExpress™ is a web-based preventive intervention that helps healthy young people at increased risk for major depressive disorder (depression) due to their family history, to improve their chances of resilience.

- MindExpress is the first online depression preventive intervention to tailor protective strategies to personal circumstances of healthy 18 to 25 year olds at elevated risk of depression.

- The use of e-technology tailored to the individual needs of the young person is a key innovation of this program - several custom interactive features have been developed in consultation with young people, which offers a greater level of sophistication in online depression intervention.

- Preliminary findings suggest that MindExpress helps young adults to improve mood and make positive changes to risk factors for depression, especially thinking and coping styles. This provides a sound basis for further development of MindExpress as a national depression prevention tool.
• MindExpress showed actual positive change in coping behaviour as identified by mean increase in Stages of Change¹ scores and showed anecdotal change in several other risk factors. This means that a risk factor-based online intervention has promise as a model for reducing depression risk.

• The MindExpress pilot study has proven potential for translation for use as a mobile phone App, and in other populations e.g. school students and general practice attendees, to facilitate dialogue about mental health and prevention of mood disorders.

• If proven effective in a randomised control trial, MindExpress will fill an unmet need for primary prevention of depression and promotion of mental health tailored to individual circumstances of young people with familial vulnerability.
Depression is one of the leading cause of disability worldwide. Peak age of first onset of affective disorders is typically 15–19 years, with an estimated 25% of young people having had at least one depressive episode by 18 years of age. As 60% of adults with major depressive disorder have their first episode prior to age 21, adolescence to young adulthood is an optimum life stage to introduce preventive interventions.

Prevention trials show that it is possible to prevent depression in nearly one quarter of people each year who would otherwise develop depression for the first time. Trials show that half of new cases of depression can be prevented every year by following a step-by-step preventive program.

Having a family history of depression is the strongest documented risk factor for affective disorders. A meta-analysis found that risk for major depressive disorder was almost three times higher in individuals with a first degree relative with major depressive disorder. Having multiple relatives with major depressive disorder, as well as early age of onset, recurrence and severity of the depression in affected relatives, is associated with an even higher familial risk.

Separating the impact of heritable factors for depression on offspring from the influence of childhood family environment with one or more depressed relatives is complex. The evidence suggests that parental depression (especially when a depressed mother is the primary caregiver) can disrupt early attachment and bonding experiences. There is also evidence that children and adolescents of depressed parents may learn negative thinking and coping styles as well as being exposed to disharmonious family functioning, which increases risk of depression.

In addition to genetic factors, a recent large systematic literature review reported strong evidence that familial (e.g. family functioning) and social (e.g. social isolation) factors, negative or unhelpful thinking styles, poor coping styles, exposure to traumatic life events (e.g. abuse, trauma, bullying or bereavement), substance abuse disorders, and the interaction of multiple factors during adolescence and young adulthood increases the risk of major depressive disorder.
**Insights from previous multiple risk factor interventions**

A randomised pilot study that targeted multiple individual risk factors for depression found a statistically significant 50% reduction in depression scores at four months and six months and positive changes in target behaviours. The study reported that multiple risk factor intervention was feasible to offer within a healthcare system. Such strategies have been identified as a priority for future research because of the cost and complexity associated with treatment of depression in young people.

The Internet, which is a major source of mental health information for young people provides an ideal platform for preventive mental health interventions. Recent studies indicate that the use of e-applications for prevention of affective disorders in young people is effective. Several e-initiatives are already shown to be effective as a secondary intervention for people experiencing mental health problems. These include MoodGym (http://moodgym.anu.edu.au) and its subsidiary program e-couch (with a general CBT component aimed at the broader population); Reach Out! (www.reachout.com.au), run by the Inspire Foundation (www.inspire.org.au) for people aged 14-25 years; and e-headspace (www.eheadspace.org.au), which offers online counselling and referrals to 12-25 year olds who have mild to moderate mental health issues. Existing online youth mental health websites generally provide services to young people already experiencing symptoms of depression and are not tailored to individual risk profiles. The current study aims to fill an unmet need by developing and evaluating an innovative web program for young adults at elevated risk for depression due to family history tailored to individual risk profiles.

**Implications**

The pilot study provides data that will inform a randomised controlled trial (RCT). If the RCT is proven effective, Mind Express will fill an unmet need for primary prevention and risk reduction of major depressive disorder in young people at increased familial risk. It will facilitate the engagement of
healthy young people in their mental health care, which could help reduce stigma that surrounds mental health and illness.

**Implications for health economists**

Affective disorders in young people are associated with academic failure, substance abuse, disrupted interpersonal relationships, multiple hospitalisations and high rates of suicide attempts and completions. In addition, early-onset affective disorders tend to run a chronic course resulting in a heavy financial burden to the health care system. Economic constraints make it is necessary to selectively target initiatives to prevent the onset of depressive disorder in individuals at increased risk. Identification of such individuals and changing modifiable risk factors are important steps in reducing depression morbidity and preventive strategies that target adolescents and young adults are likely to be the most cost-effective.

Reducing depression risk of young people at a critical stage of brain and emotional development will make an important contribution to reversing current high rates of poor mental health in adolescents and young adults.

**Implications for health care providers – primary practice**

If proven effective in an RCT, MindExpress has potential to become a nationally available program with important applications in community and clinical settings including:

- Translation to primary health care to assist GPs to identify and engage young people at increased risk for depression in dialogue about their mental health at a preventive stage.
- Facilitation of engagement of young people with low or no attendance with primary health care by forging links to general practice through youth-friendly web portals.
- Adaptation for use as a primary prevention tool for other psychiatric disorders.

**Implications for educators**

- Translation to high schools for use as an education tool to promote awareness of effective strategies that help maintain good mental health and diffuse stigma about mental illness for children and adolescents.
Implications for mental health NGOs

- MindExpress complements existing youth web-based mental health online programs by offering an intervention at a presymptomatic stage for people with a familial risk who are within typical age of first onset (less than 25 years). The provision of targeted education and personalised CBT activities tailored to individual circumstances offer a model for tailored online depression intervention that augments current online programs.

Approach

MindExpress consists of a depression-risk assessment based on eight risk domains with feedback, and up to eight education and cognitive behavioural modules that are personalised to the individual’s depression risk profile.

Web platform

The web program was built within the framework of a University of New South Wales Drupal content management system (CMS). A reference panel met regularly using an iterative process to determine how this would proceed. MindExpress is developed with custom functions and design relevant to youth culture including a unique web theme. A visually dynamic interactive personal progress indicator was developed as a centrepiece for the user dashboard, designed to engage and motivate participants. After consultation with the target demographic this feature was developed as an interactive dynamic Personal Progress Tree graphic, as shown in Appendix 1.

Development of web functions and design

 Consultation group – recruitment and participation

One semi-structured consultation group was held in December 2011 in which 10 students from University of New South Wales aged 18-25 years were selected for web user knowledge to discuss preferences for program functions. Iteration and feedback from this consultation led to modifications to the prototype and customization of a range of functions to suit the 18-25 year old age group with a family history of depression. A web developer was contracted to develop custom coding for MindExpress, including the personalised feedback function and the Personal Progress Tree. A graphic
designer was engaged to design a unique web theme, the MindExpress logo, banners and a design elements for the Personal Progress Tree.

Development of content

Content for MindExpress was derived from a comprehensive literature review. A search of studies was conducted using MEDLINE (OvidSP), PUBMED and EMBASE (OvidSP) databases using medical subject headings (MeSH) and keyword searches including (CBT or cognitive behavioural therapy or cognitive behavioral therapy or psycho education or education) and (online or Internet or Internet-based or web or web-based or computer*) and (major depressive disorder or major depression or MDD or depress* or unipolar depress* or bipolar depression or affective disorder* or mood disorder*) and (youth or young adults or adolescents). The reference lists of captured literature were hand searched to identify any additional papers that were not retrieved in the electronic searches.

Focus groups on content – recruitment and participation

Three semi-structured focus groups involving 29 people were held in September 2012. Inclusion criteria matched future users of the web program: Aged 18-25 years with a family history of major depressive disorder. Participants included the MindExpress projects’ youth community representative, an Inspire Foundation’s Reach Out Youth Ambassador and a youth mental health advocate, who attended multiple focus groups. The other 17 participants were predominantly undergraduate university students (not selected for this status) from two universities in Sydney. Twelve participants attended one session, six attended two sessions and the Reach Out Youth Ambassador attended all three sessions. This strategy provided continuity across sessions as well as fresh input, and resulted in 9-10 participants per group. Participants discussed the content of three of the web program’s eight modules, ‘Thinking Styles’; ‘Family Dynamics’ and ‘Alcohol and Cannabis Use’ (the latter was subsequently divided into two modules) at each focus group. Participants explored preferences for acceptability and relevance of the content, amount, level of detail, satisfaction with length, format, presentation of information, images and graphics, perceived relevance, emotional impact, and reading level and understanding.
Development of design

Risk assessment measure - One session of 30 minutes

A 100 question risk assessment instrument, known as the Personal Profile, was specifically developed for the program using validated measures based on eight risk factor domains. This includes a socio-demographic measure (8 items), a modified version of the Family History Screen (FHS) (7 questions) to confirm eligibility, Patient Health Questionnaire-9 (PHQ-9) to measure current depression symptoms with two additional questions to determine past depressive episode and perceived risk of a future depressive episode (12 questions), the Neuroticism-Extroversion-Openness (NEO) personality inventory (neuroticism questions only (12 items) to measure thinking styles; the brief COPE inventory (14 items) to measure coping styles; items from Household, Income and Labour Dynamics in Australia (HILDA), social connections questions only (10 items); Adolescent Alcohol and Drug Involvement Scale (AADIS) (10 items) to measure alcohol and cannabis use; List of Threatening Life Experiences measure (LTE-Q) (12 items) to measure recent exposure to traumatic life events; and Measure of Parenting Styles (MOPS) (15 items) to measure exposure to abusive, controlling or neglectful parenting styles during childhood and adolescence. After completing each measure, participants received feedback in the form of a bar graph or personalised text about their risk or protective status for each risk factor domain. A feedback graphic using the thinking styles assessment as an example is shown in Appendix 2.

The Personal Profile measures were matched to eight interactive evidence-based education and CBT modules, one for each risk domain. In addition, participants completed the Stages of Change measure (5 items) before and after each module to measure intention to and actual behavioural change, related to module-specific risk or protective factors. See Appendix 3 for a sample page of the Thinking Styles module.

Strength of family history

Family history of depression is a measure of both genetic risk and liability to depression due to childhood environment. Assessment of strength of family history was based on Scheuner et al.21
(1997) guidelines for the assessment of risk for developing physical chronic diseases. As well as the number of relatives affected and degree of closeness to the individual, the guidelines take into account the age of onset and severity of the illness in the affected relative. As it was beyond the scope of the study to collect data about age of onset or severity of parental depression, family history categories were based on number of affected relatives and degree of closeness in the pedigree. Thus, for the purposes of analysis, participants were divided into the following three groups according to strength of family history: i) ‘Average’ (no affected relatives or only one affected SDR; ii) ‘moderate’ family history (one affected FDR or two affected SDRs) or iii) ‘strong’ family history (two affected FDRs or three or more affected SDRs).21, 22

Crisis management
Participants who scored ≥10 in the PHQ-916 or indicated risk of self-harm in response to the suicide risk question were managed on a case-by-case basis. The lead researcher followed up such participants by email and triaged them for follow-up by one of the two clinicians in the research team. The PHQ-916 was repeated halfway through the program (after completion of the core modules) and with the evaluation survey at the end of the program. Information about helplines and other support were provided in the program and on the dashboard.

Modules – 20 minutes per module over six weeks
The MindExpress program is based on eight modules including three compulsory core modules i) Genes, Family and Environment (family history of depression, family environment and genetic factors); ii) Thinking Styles; iii) Coping Styles; and up to five custom modules iv) Social Connections; v) Alcohol Use; vi) Cannabis Use; vii) Tough Times (traumatic life events) and viii) Family Dynamics (parenting styles). Direction to complete modules iv) to viii) depended on participant responses in the corresponding sections of the Personal Profile.

Evaluation – one online session of 10 minutes (closed questions) and one telephone interview (open questions) of 20 minutes
Depression symptoms were assessed at baseline (T0), at the end of the core program (T1) and at the end of the tailored program/evaluation survey (T2) prior to telephone interview. At the end of the program participants repeated the PHQ-9\textsuperscript{16} measure as well as an evaluation incorporating the Internet Evaluation and Utility Questionnaire\textsuperscript{23} (13 of 15 items) and the Internet Impact and Effectiveness Questionnaire\textsuperscript{23} (6 of 19 items). Evaluation telephone interviews were scheduled with participants within one week of completion of the program to qualitatively explore acceptability, perceived relevance, emotional impact, improvement in understanding, as well as usability and functionality of MindExpress. Qualitative data from interviews are given descriptors thus: male/female (M or F), age (number), family history average (Av), moderate (Mod) or strong (Str). Thus a quotation by 21 year old female with a strong family history of depression would be identified as [F, 21, Str].

Observational study

Four volunteers who met eligibility criteria for the pilot study were recruited via the study’s youth community representative from the Inspire Foundation and via City of Sydney Rotaract youth to test the web program functions observed in real time by the study researcher and to provide feedback on content.

Pilot of the interactive web program – participants and recruitment

Participants were recruited via an advertisement on the Black Dog Institute website and the Black Dog Institute Volunteer Research Register and social media channels. A total of 43 people registered for the MindExpress pilot program between 3 July 2013 and 13 October 2013. Thirteen registrants did not proceed beyond registration. The remaining 30 registrants were recruited to the study resulting in a participation rate of 70%. Mean age (SD) was 22.5 (4.7) years (range 18-25 years) and 25/30 were female. Participants had at least one first or second degree relative with major depressive disorder. The data were analysed using qualitative methodology, which was appropriate to explore the range of participant experience rather than extent to which particular experiences occurred.\textsuperscript{24} Twenty-five participants met the FHS\textsuperscript{15} criteria for a moderate or strong family history of.
depression. They were grouped as: ‘moderate’ (one affected FDR or two affected SDRs) (18 participants) and ‘strong’ family history of depression (two affected FDRs or three or more SDRs) (6 participants), respectively. Five participants had no family history and one had weak family history (one affected SDR). These were grouped as ‘average’ family history of depression (6 participants).

Participant characteristics are shown in Appendix 4.

**Plans for dissemination**

The findings will be disseminated via publication in peer reviewed journals, oral presentations at relevant medical conferences and via mainstream media and medical press. A lay summary of results will be disseminated to participants. Written and oral presentations will be made to mental health community groups, including Inspire Foundation and Sydney City Rotaract members.

**Results**

**I. Development of the program**

**Web function and design preferences**

Function and design preferences from the consultation group included ability to have achievements to be added to profile/personal progress indicator; unique web theme and home page style; anonymous private log in function; log in prompts; reminders; offline tasks (homework between modules); ability to receive feedback; bandwidth enabling quick downloads; ability to only download some of the text with ‘see more’ function; “modules to work through like Mood Gym”; and a save and continue function. The personal Progress Tree has been developed as an outcome of the consultation process with young people. “Something that grows, like a tree with leaves, maybe a bird comes to nest in it.”

Participants stated that such a feature should accommodate: “Continuity points that builds on impact/progress;” “A sense of achievement;” “A change in the home/profile page.”
The Progress Tree sits on the dashboard and represents powerful visual changes to participants' risk and protective factors as they respond to the interactive activities within the modules (see Appendix 1).

Each leaf represents a risk factor or protective factor. Leaves grow as participants respond to each section of the Personal Profile. Acquisition of knowledge and skills that help to build resilience to depression triggers changes to leaf colour based on a traffic light system (red = risk, amber = intermediate, green = protective). Each branch/distinct leaf cluster represents one module (e.g. Coping Styles). Individual leaves within a distinct cluster represent a risk or protective factor (e.g. a particular coping style). The color distribution of leaves across the canopy provides an overview of the participant’s risk and protective status across eight facets of life (the modules).

Preferred functions that have not been included in MindExpress are functions that would require a 24/7 site moderator which include: ability to personalise dashboard; ability to add text/photos; ability to submit own authored short articles; ability to add comments to stories.

**Content preferences**

*Reading level and scientific evidence*

Focus groups yielded a majority preference for greater scientific tone and depth of content, in the ‘Flexible Thinking’ (now called Thinking Styles module) and ‘Childhood Environment’ module (now called Family Dynamics module) which probably reflects the education level of the participants. The Cannabis and Alcohol Module (now separated into two modules) had more scientific content (epidemiology data) which participants found satisfactory. To accommodate all reading levels in the active program participants agreed that tone and language should be unchanged, but additional scientific information be placed on an optional Science Tab for each module. In addition, participants elected that more specialised terms, definitions and meanings could be placed on a Glossary Tab. An optional Science Tab has been included in the program consisting of 3-4 pages of bulleted scientific evidence for risk factors associated with depression. We have also provided a scientific quality assessment of evidence based on the Grading of Recommendations Assessment, Development and
Evaluation (GRADE) framework. GRADE offers four levels of evidence quality, represented to users as text and ‘smilie’ faces and presented in Appendix 5.

Language and terminology

Participants expressed a strong preference that straightforward language and terminology names be used. In response to the three sample modules, general comments included “Conversational”, “Straightforward”, “Non-judgmental”, “Much better than expected”, “More depth needed”. (The latter comment was resolved by the Science Tab).

Participants preferred that pronouns like ‘you’, ‘my’ ‘I’ and phrases like ‘My Mood’ not be used. Participants deemed terms such as ‘mood’ and ‘mental’ to be negative, while terms like and ‘manage’ and ‘head start’ were associated with “charity work for intellectually disabled or mentally ill.” Participants were clear that any terms, acronyms or ‘text-speak’ from popular youth culture should not be used by program researchers.

Participants expressed preferences for names of the modules, functions and the program and its tagline through an iterative process across each focus group. Individual participants named the following elements of the program: ‘Personal Profile’ (risk assessment); ‘Social Connections’ (module 4); ‘Family Dynamics’ (module 8); ‘Skills Workshop’ (CBT section in each module); ‘Sharpen your Skills’ (CBT skills practice sections). Other names and terms used in the program were derived by participant consensus.

Relevance and appeal

The focus group participants endorsed that the modules were relevant to target demographic, and were interesting and insightful.

Emotional impact

Two modules contain potentially sensitive content; the Tough Times (life events) modules and the Family Dynamics (childhood environment) module. Discussion revealed that low overall risk of adverse reaction to sensitive topics covered in these modules. Participants identified two sensitive areas: “Writing about someone you don’t trust – I don’t even know who I trust” in the Tough Times
(life events) module and “Rewriting the ending of a traumatic experience could be upsetting” in the Family Dynamics module. Another participant observed that this content was: “Very direct – asserts the reality but may be difficult for those who haven’t come to terms with things.” One participant stated that there was a “possibility of prompting unhappy memories”. Another participant said “It can’t be helped, it’s got to be done.” Participants remarked that the “use of [advance] warnings was good and should be sufficient.” As a result, the following alert statement has been inserted at the beginning of the above modules: ‘The following content may trigger an emotional reaction in some users of the program.’

Help and support

Participants did not endorse a help and support page to be inserted in every module but preferred an ‘ever-present’ help and support tab that could be accessed as required. In addition we inserted a help and support page to follow the depression screen (PHQ-9[16]) that would be visible within the page sequence to participants whose scores suggested current symptoms of depression or crisis. Such participants would be immediately directed to appropriate help and support resources.

Incentive to complete and return

Participants believed they would be motivated to continue the program to completion if there was sufficient interaction and personal meaning. Comments included: “If it was stimulating, engaging and prompted me to think deeply.” Another participant wanted interpretation: “How does it translate for me.” Another remarked that the program should be fresh and original: “Make website insightful, helpful, unlike anything else available online, not vague or generic as there are many generic sites already. Participants endorsed ‘feedback’ and ‘homework’ activities to motivate and engage them. They commented that facilitation of return to the program was “essential” to minimise attrition.

Graphics

Participants strongly endorsed the inclusion of film stills as a framework to describe behavioural examples in the modules. They endorsed realistic colour illustrations of film stills in lieu of using actual movie stills [thus meeting copyright legislation]. As a result of this consultation a professional
illustrator was commissioned to provide 22 realistic illustrations of selected movie scenes to describe CBT scenarios. Four sample illustrations are presented in Appendix 6.

Refinement of the program

The final content was guided by the systematic literature review, input from the mental health consumer representatives and the outcome of the focus groups. Web development and syntax coding was completed during 2013.

Observational testing results

The observational tests resulted in minor revisions to the web program including one survey question, a page sequence and minor syntax changes.

II. Web program evaluation

Thirty participants completed the compulsory Personal Profile, 15 participants completed the compulsory core modules (Family, Genes and Environment, Thinking Styles and Coping Styles) in chronological order and 10 participants completed the full (core plus tailored) program. The five optional modules tailored to personal risk factors (Social Connections, Alcohol Use, Cannabis Use, Tough Times and Family Dynamics) were available depending on participant responses in the corresponding sections of the Personal Profile. Number of participants completing the Personal Profile and modules compared to number of participants prescribed the items is shown in Appendix 7.

Depression screen

Thirty participants completed the PHQ-9 at baseline (T0). Of these, 15/30 completed the PHQ-9 at the end of the core program (T1), and 9/30 completed the PHQ-9 at the end of the full program (T2).

Total mean depression scores decreased from 9.0 (mild-moderate depression) at T0 (N=30) to 5.1 (minimal-mild depression) at T2 (N=9). The ‘average’ family history group had highest mean depression score of 14.8 (moderately-severe depression) at T0 (N=6) which decreased to zero at T2 (N=2) compared to the ‘strong’ and ‘moderate family history groups. The ‘strong’ family history
group had highest mean depression score of 10 (moderate depression) by T2 (N=2) compared to the ‘average’ and ‘moderate family history groups. While, numbers of participants remaining in each family history group at T2 were too small to make generalisations about depression symptom changes by strength of family history, overall the program indicated positive change in depression scores. Mean depression scores over time are presented in Table 3.

Table 3. Mean(SD) PHQ-9 scores by family history group over time

<table>
<thead>
<tr>
<th>Family history group</th>
<th>T0 N</th>
<th>Mean(SD) depression scores</th>
<th>T1 N</th>
<th>Mean(SD) depression scores</th>
<th>T2 N</th>
<th>Mean(SD) depression scores</th>
</tr>
</thead>
<tbody>
<tr>
<td>Averagea</td>
<td>6</td>
<td>14.8 (10.7)</td>
<td>3</td>
<td>4.7 (5.7)</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Moderateb</td>
<td>18</td>
<td>7.3 (5.6)</td>
<td>9</td>
<td>3.7 (2.9)</td>
<td>6</td>
<td>4.4 (2.9)</td>
</tr>
<tr>
<td>Strongc</td>
<td>6</td>
<td>8.3 (5.1)</td>
<td>3</td>
<td>9.3 (8.3)</td>
<td>2</td>
<td>10 (8.2)</td>
</tr>
<tr>
<td><strong>Total mean (SD) depression scores</strong></td>
<td><strong>30</strong></td>
<td><strong>9.0 (6.7)</strong></td>
<td><strong>15</strong></td>
<td><strong>5.5 (4.7)</strong></td>
<td><strong>10</strong></td>
<td><strong>5.1 (4.7)</strong></td>
</tr>
</tbody>
</table>

aAverage family history: No affected relatives/ one affected SDR/ no known family history/adopted person with unknown family history
b Moderate family history: One affected FDR and/or two affected SDRC
Strong family history: Two affected FDRs and/or three or more SDRC

Stages of change

Participant intentions to change or make actual changes to risk factors before and after modules (education plus CBT related to the module topic) are presented in Table 4. There was an overall positive mean increase in Stages of Change scores by 0.2 steps (all modules pooled). The Coping Styles module yielded the highest mean change by one step from 2.2 to 3.3 This is likely due to prevalence of unhelpful coping styles at baseline and high overall endorsement of helpfulness of the Coping Styles module. The Thinking Styles module yielded no increase in Stages of Change scores. The majority of participants scores were stage 3-5 before starting the Thinking Styles module, which could explain nil detection of mean change. Mean negative change was seen in the Alcohol Use and Tough Times modules. It could be that the numbers of participants completing the latter tailored modules were too low to attribute meaning. The Genes, Family and Environment module was
introductory and did not evaluate change. Anecdotally, the Alcohol Use model showed positive change: “Because of the program I stopped having alcohol on Mondays and Tuesdays” [F, 22, Str].

Table 4. Stages of change¹*

<table>
<thead>
<tr>
<th>Module</th>
<th>Pre intervention Mean (SD) scores</th>
<th>Post intervention Mean (SD) scores</th>
<th>Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Core program</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Thinking Styles (N=18)</td>
<td>2.5 (1.0)</td>
<td>2.5 (1.4)</td>
<td>0</td>
</tr>
<tr>
<td>Coping Styles (N=15)</td>
<td>2.2 (1.3)</td>
<td>3.3 (1.5)</td>
<td>1.1</td>
</tr>
<tr>
<td>Tailored program</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social Connections (N=4)</td>
<td>3.8 (1.3)</td>
<td>3.8 (0.4)</td>
<td>0</td>
</tr>
<tr>
<td>Alcohol Use (N=3)</td>
<td>2.3 (1.6)</td>
<td>1.3 (1.9)</td>
<td>-1</td>
</tr>
<tr>
<td>Cannabis Use (N=0)</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Tough Times (N=5)</td>
<td>3.8 (2.2)</td>
<td>2.6 (1.5)</td>
<td>-1.2</td>
</tr>
<tr>
<td>Family Dynamics (N=8)</td>
<td>2.4 (1.8)</td>
<td>2.5 (1.3)</td>
<td>0.1</td>
</tr>
<tr>
<td>Total mean change</td>
<td>2.9</td>
<td>3.1</td>
<td>0.2</td>
</tr>
</tbody>
</table>

¹Stages of change scale
1= I am not thinking of making this change
2= I am thinking about making this change, but not in the next fortnight
3= I am thinking about making this change in the next fortnight or so
4= I am trying to make this change at the moment
5= I have already made changes to this, and have done so for longer than 2 weeks

Time to completion

The mean (SD) time taken to complete the MindExpress program was 8.6 (3.3) weeks (range 4.4 weeks to 15 weeks). This is longer than the prescribed six weeks. Participant feedback cited as reasons forgetting to return and log in due to busy lives rather than unwillingness to return.

User evaluation of program and user experience

A total of 10/30 participants completed the evaluation survey and 9/30 completed the telephone interview. Reasons for enrolling in the program focused on both family history and personal
circumstances. Once participant spontaneously stated: “I have a strong family history, this played a big part in motivation to do the program” [F, 18, Str].

Others cited the relevance of the program to their current situation:

“The range of factors I had to consider….with reference to my own situation was extensive, and therefore [MindExpress] was really helpful for recommitting to iron out things tactically” [M, 25, Mod].

“When I was doing MindExpress I was going through a difficult time, I was able to relate to the thinking style and coping style modules, they were useful to how I could deal with my challenges” [F, 25, Mod].

Usefulness

The majority of participants rated the program as ‘mostly’ or ‘very’ useful. One participant commented: “The ease of use, as well as the foundation upon current/appropriate research was particularly helpful” [M, 25, MFH]. “I could to be 'accountable' by writing the changes down after seeing that these changes could be helpful” [M, 25, Mod]. “MindExpress was a very useful program, it is easily accessible and easy to navigate” [F, 18, Str].

Compliance

Returning to the program each week proved challenging for many participants due to timing of the activities and of the reminders: “I found the program interesting and useful but sometimes it was difficult to remember to come back and complete the next section as I would receive the email reminders at times when I couldn’t continue. I was still thinking about the content though” [F, 21, Mod].

Another said: “I enjoyed the program when I was engaged with it, but I found myself repeatedly forgetting to return. I think an option to receive more automated email reminders could have been useful for maintaining engagement with the program.” [F, 20, Mod]. One participant found the timing of the ‘Two alcohol-free days’ in the Alcohol Use module inconvenient: “At that time I did have a party it wasn’t the best time to do the activities of the module” [F, 18, Str].
Another participant who completed the core program but not her prescribed modules said: “I was busy and not enough time to log in each week. It was the email prompts that got me logging in again, they were good. More prompts would be good” [F, 25, Mod].

Alternatively, one participant said: “The need for prompts depend on user. If the user is interested in program they won’t depend on prompts”[M, 23, Av]. Endorsement of usefulness of MindExpress is shown in Fig 1.

**Fig 1. Proportion of participants endorsing usefulness of MindExpress.**
**Impact and effectiveness**

The majority of participants found MindExpress helpful. Some participants commented that their knowledge of risk factors for depression did not increase because they were already well-informed. One participant stated: “I had knowledge of quite a few of my risk factors. The information was good but because I knew the information already it wasn’t new to me” [F, 18, Str]. One participant cited that MindExpress had an empowering impact: “Some of these programs that talk about genetic risk, you can fall into a fatalistic attitude. [MindExpress] is for people who are vulnerable, but the program helps you feel you have control over it” [F, 21, Mod].

Several participants noticed that they experienced positive change after completing the program: “I had more negative thinking styles at the beginning than at the end. I think more carefully of my coping patterns and thinking styles – I’m more likely to change them because I got into the habit of changing that during the program – this is the benefit of a longer program” [F, 21, Mod]. “The effort from me was repaid multiple times by the benefits of completing the program” [M, 25, Mod]. “The most helpful part was when I was given time to reflect on my own experiences and apply strategies to past or future events” [F, 22, Mod]. Endorsement of impact and effectiveness of the program is shown in Fig 2.

**Fig 2. Proportion of participants endorsing impact and effectiveness of MindExpress.**
The innovative features of MindExpress were well-endorsed but participants expressed challenges to doing the practice activities. Busy lives and short-term attention was the most cited reason: “I think that people might forget about the program if they are given one week to try and do activities” [F, 22, Mod].

Another participant said: “I did the activities in-between the modules and gave them a good go” [F, 25, Mod].

**Illustrated scenarios**

Response to the illustrated scenarios varied but they were generally well received. One participant commented that: “Scenarios paint a picture for the user, makes it easier to understand context.” [M, 23, Av].

One participant expressed a preference for “real person examples” [F, 24, Str], while another suggested that “Illustrating scenarios from movies was the best possible way to present the information without having video” [F, 21, Mod].

Most participants found the movie choices accessible, for example: “I haven’t seen Harry Potter or Bridget Jones but I could follow the scenarios easily” [M, 25, Mod], while others were less impressed: “The references to literature/movies were well-meant but I didn't find that it made me more interested” [F, 24, Str].

**Personal Progress Tree**

The dynamic Personal Progress Tree appeared to stimulate participants: “It didn’t necessarily motivate me to continue through, just interesting. I liked seeing the leaves growing as I went through” [F, 25, Mod].

Endorsement of the innovative features of MindExpress and Skills Workshop practice activities is shown in Fig 3.
**Helpfulness of the module content**

Several participants mentioned relevance and application of the program to their current situation: “I was struggling at work at the time of starting MindExpress. I recognised that my thinking and coping styles weren’t ideal” [F, 21, Mod].

Another participant said: “My thoughts play a big part in triggering things and the way I do things, the thinking styles module helped me identify different events, what my thinking style was and how it played a part in my mood” [F, 18, Str].

“[I already knew a fair bit of the content of the Genes, Family and Environment module because it is close to home, but this was a good introduction to the program and useful to have at the beginning” [F, 25, Mod].

“The thinking styles module was the most helpful and the information contained in all the modules” [F, 18, Str].

A summary of the endorsement of the core module content is shown in Fig 4.
Fig 4. Proportion of participants endorsing content of core modules as helpful and recommendation of program to peers

<table>
<thead>
<tr>
<th>Optional components</th>
</tr>
</thead>
<tbody>
<tr>
<td>Six or fewer participants completed each of the tailored modules, or viewed the optional supporting science information or topic-related help and support information. Half or less of these participants endorsed these items as helpful. Based on responses in the Personal Profile the Cannabis Use module was only prescribed to one participant and was completed by 0 participants. Response to the supporting scientific information was mixed: “I didn't really pay much attention to additional information provided” [M, 23, Av]. “I found the supporting information/research really helpful, in that it helped me to justify why I would commit to taking on some changes” [M, 25, Mod].</td>
</tr>
<tr>
<td>Recommendations to peers</td>
</tr>
<tr>
<td>Overall, participants reported a positive experience using MindExpress and would recommend it to peers. One participant said: “I really appreciate the love and effort that the MindExpress team has put into this resource. I already have recommended people check it out, and in my opinion has been as helpful as other successful online tools (e.g. MoodGym for CBT” [M, 25, Mod].</td>
</tr>
</tbody>
</table>
Another participant said: “The staff are also great at checking up on you if they are concerned about your mood/wellbeing at any point. I would definitely recommend it to people :”) [F, 18, Str].

“I’d be happy to recommend program to students school age. In fact I recommended it to one guy. There’s not much needed to be done to adapt to school age, this is where it would be very useful” [M, 25, Mod].

Several participants expressed hesitation to recommend the program on the grounds of not knowing a peer’s family history status: “I would recommend [MindExpress] but I would be more likely to mention it if a person had already told me about their family history [of depression] in case I seemed to be making an assumption. I would have to already be having a conversation about depression” [F, 21, Mod].

“It’s about very personal issues, I wouldn’t necessarily feel comfortable talking about it to other people I know” [F, 22, Mod].

“I don’t know whose parents who have depression. I recommended it to one friend but I would be scared to recommend it to someone if I didn’t know” [M, 18, Mod].

Improvements

Suggested improvements centred on functions, increasing interactivity and multimedia. Participants suggested that MindExpress could offer: accessibility in a group setting “so I could try the strategies with others”[F, 22, Mod] and [F, 24, Str]; audio and video story telling with interactive follow up [F, 24, Str] “with actors playing out the scenario [F, 21, M]; and option to skip pages when reviewing responses [F, 18, Str]. One participant had a preference for a summary of previous responses when logging in [F, 21, Mod]. One participant suggested that an App format would improve incentive to complete and return: “I have my phone with me all the time. I reckon if it was an app and I got push notifications on my phone at times when I was bored, like when I was in bed, I that would have got me through the program” [F, 21, Mod].

Conclusion
The preliminary findings show that depression symptomatology reduced while completing MindExpress. The program had an overall positive effect on intent to change and actual change of preventive behaviours. The program had less effect on improving user’s understanding of personal risk factors for depression as users already had good mental health literacy. It is likely that a proportion of future users will have some depression symptomology and it may not be realistic to only target those who are depression-free for intervention. The findings show that MindExpress program is well suited to a healthy population or those with only mild depression, to optimise the use of preventive strategies in everyday life. The MindExpress pilot study provides a sound basis for further development of MindExpress as a national program for users to address personal risk factors for depression in a fun, interactive way whilst exploring core issues of familial vulnerability.

Additional resources

MoodGym http://moodgym.anu.edu.au/
e-couch (with a general CBT component aimed at the broader population),
Inspire Foundation www.inspire.org.au
Reach Out! www.reachout.com.au for people aged 14-25 years
e-headspace www.eheadspace.org.au offers online counselling and referrals.

Further research

The preliminary findings show that MindExpress will fill a gap in the needs of people with a family history of depression and that targeting personal risk factors will be useful and effective. It will be necessary to build on these findings to further evaluate, using quantitative methodology in a large randomised control trial, which risk factors will be most amenable to change and to determine whether such changes are sustained over time e.g. 3 or 6 month post intervention. It is likely that an App with a systematic reminder system tailored to individual needs will be the most effective format for delivery to encourage compliance. Future development of MindExpress should incorporate App building technology. Delivery via an App option will improve translation to and usability of
MindExpress to other settings such as general practice, schools and youth community organisations. There is a tendency for online mental health interventions to try to ‘teach’ individuals didactically about depression and overlook that users have knowledge and experience to teach to health providers. E-health programs for people with a lived experience and/or family history of depression should not assume a one-way delivery of information. MindExpress should be branded to users as a ‘personal partner’ in mental health care for people with experience of family history of depression. Future development of MindExpress should include strategies to help diffuse stigma surrounding family history of depression so that users may readily discuss or recommend the program to peers.

Bibliography
Appendix 1. Personal Progress Tree presented on the dashboard. Participants’ modules are listed on the left.
Appendix 2. Feedback graphic from Personal Profile assessment of thinking styles
Appendix 3. First page of Thinking Styles module

Welcome to the Thinking Styles Module

Ever thought that when things go wrong it’s your fault? Do you ever see a situation your are in as brilliant one day and hopeless the next? These are just two common ‘thinking styles’ that influence our interactions with other people and shape our lives.

By observing our thinking styles, it is possible to confront unhelpful thinking and tap into thinking styles that are more helpful and ‘flexible’. Thinking flexibility can change the way we respond to life’s stresses and help make us more resilient to depression.

Flexible thinking styles protect against depression – the evidence...

Exciting scientific evidence shows that among people with an optimistic or more flexible thinking style the risk of depression is almost halved compared to people who are the least optimistic thinkers.

It is especially helpful for people who have relatives with depression to have a look at their thinking styles. Practising flexible thinking as a regular part of a healthy lifestyle provides a good opportunity to send the risk of a low mood packing.

In this module you have an opportunity to have a look at your individual thinking styles and help you expand your ability to be a flexible thinker.

How do you feel about changing your thinking styles?
### Appendix 4. Demographic characteristics of participants of the pilot interactive program

<table>
<thead>
<tr>
<th>Participant characteristics</th>
<th>Familial depression history</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Average&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td>N=6</td>
</tr>
<tr>
<td>Mean age (SD) 22.5 (4.7) years (range 18-25 years)</td>
<td>6</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>4</td>
</tr>
<tr>
<td>Male</td>
<td>2</td>
</tr>
<tr>
<td><strong>Work status</strong></td>
<td></td>
</tr>
<tr>
<td>Work full time or part time</td>
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</tr>
<tr>
<td>Full-time student</td>
<td>1</td>
</tr>
<tr>
<td>Student and work part-time</td>
<td>1</td>
</tr>
<tr>
<td>Homemaker</td>
<td>1</td>
</tr>
<tr>
<td>Unemployed</td>
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</tr>
<tr>
<td><strong>Highest level of completed education</strong></td>
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</tr>
<tr>
<td>Year 10 or below</td>
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</tr>
<tr>
<td>Year 12</td>
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</tr>
<tr>
<td>TAFE or College certificate or diploma</td>
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</tr>
<tr>
<td>Bachelor’s degree</td>
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</tr>
<tr>
<td>Postgraduate qualification</td>
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</tr>
<tr>
<td><strong>Marital status</strong></td>
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</tr>
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<td>Single or never married</td>
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</tr>
<tr>
<td>Married, de facto, or serious relationship</td>
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</tr>
<tr>
<td>Widowed, separated or divorced</td>
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</tr>
<tr>
<td><strong>Main language spoken at home</strong></td>
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<tr>
<td>Other</td>
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</tr>
<tr>
<td><strong>Country of birth</strong></td>
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<td>Australia</td>
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</tr>
<tr>
<td>Other</td>
<td>2</td>
</tr>
<tr>
<td><strong>Geographic location</strong></td>
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</tr>
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<td>Town/city</td>
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</tr>
<tr>
<td>Rural/remote</td>
<td>0</td>
</tr>
</tbody>
</table>

<sup>a</sup>Average family history: No affected relatives/ one affected SDR/ no known family history/adopted person with unknown family history

<sup>b</sup>Moderate family history: One affected FDR and/or two affected SDRs

<sup>c</sup>Strong family history: Two affected FDRs and/or three or more SDRs
Appendix 5. GRADE framework for assessment of quality of scientific evidence

<table>
<thead>
<tr>
<th>Quality Level</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>High quality</td>
<td>Further research is very unlikely to change our confidence in the evidence (estimate of effect)</td>
</tr>
<tr>
<td>Moderate quality</td>
<td>Further research is likely to have an important impact on our confidence in the evidence and may change the evidence</td>
</tr>
<tr>
<td>Low quality</td>
<td>Further research is very likely to have an important impact on our confidence in the evidence and is likely to change the evidence</td>
</tr>
<tr>
<td>Very low quality</td>
<td>Any estimate of effect is very uncertain</td>
</tr>
</tbody>
</table>
Appendix 6. Four sample illustrations based on movie stills to depict thinking and behavioural scenarios.

Amelie from the movie of the same name demonstrates how she reaches out in the Social Connections module.

Bridget Jones demonstrates her unhelpful thinking style – interpreting feelings as facts – in the Thinking Styles module.

Ron Weasley from Harry Potter demonstrates his avoidant coping style in the Coping Styles module.

Rose and Jack from Titanic demonstrate their response to a stressful life event in the Tough Times module.
### Appendix 7. Proportion of participants completing each module (completers/total prescribed module)

<table>
<thead>
<tr>
<th>Module</th>
<th>Module completed</th>
<th>Module prescribed according to Personal Profile scores</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Core program</strong></td>
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<td></td>
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<tr>
<td>Personal Profile*</td>
<td>30</td>
<td>30*</td>
</tr>
<tr>
<td>Genes, Family and Environment*</td>
<td>30</td>
<td>30*</td>
</tr>
<tr>
<td>Thinking Styles*</td>
<td>18</td>
<td>30*</td>
</tr>
<tr>
<td>Coping Styles*</td>
<td>15</td>
<td>30*</td>
</tr>
<tr>
<td><strong>Tailored program</strong></td>
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<td></td>
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<tr>
<td>Alcohol Use</td>
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<td>13</td>
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<tr>
<td>Cannabis Use</td>
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<td>1</td>
</tr>
<tr>
<td>Tough Times</td>
<td>5</td>
<td>24</td>
</tr>
<tr>
<td>Family Dynamics</td>
<td>8</td>
<td>30</td>
</tr>
</tbody>
</table>

*Compulsory components
Appendix 8 – Annotated references


   Paper to determine the feasibility of using a single, comprehensive family history as a method for stratifying risk for many preventable, common genetic disorders.

   Paper evaluating family history as a tool to stratify risk for common chronic diseases and thereby identify individuals with increased disease susceptibility.

   A detailed description of SHUTi an online intervention for insomnia and examination of users’ perceptions of the intervention’s usefulness and effectiveness

   Textbook on focus group methodology

   Paper on development of guidelines to grade quality of evidence-based research