

# **Developing and evaluating an online psychoeducation package for adolescent depression**

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## Summary

### Background

Depression is common in adolescence, and leads to distress and impairment for individuals and families. Adolescent depression is difficult to recognise and treat. Treatment and prevention guidelines stress the need for good information and evidence-based psychosocial interventions for individuals/families. There has been growing interest in psychoeducation, which is broadly about delivering accurate information about health issues and self-management. However, there is a lack of engaging online psychoeducation for adolescents with, or at high risk of, depression.

**Aims:** To design, develop and undertake an early evaluation of a user-friendly online psychoeducation multimedia package for young people with (or at high risk of) depression and their families/carers, friends and professionals.

### Methods

The initial prototype of the package was informed by: i) a systematic review of family/group, individual, school-based and online psychoeducation programmes, ii) findings from semi-structured interviews and focus groups with adolescents (with depressive symptoms or at high-risk), parents/carers and professionals, iii) workshops/discussions with a multimedia company and experts. For the evaluation phase, adolescents and parents/carers completed pre/post questionnaires and were interviewed, online usage was monitored, and there was a focus group for professionals.

### Results

The systematic review showed that existing psychoeducation studies were limited in number and heterogeneous. Key themes in the interviews/groups were: aims of the package, design and content issues and integration/context. The prototype was designed to be multi-platform, person-centred, engaging and interactive. Mood-monitoring and goal-setting components, and an 'app', were recommended by user groups. The results of the evaluation showed that the package was acceptable, feasible, clear and easy to use, and informed its further development.

**Conclusions**

The online package was developed with user-input and rigorous methods. Further development and a feasibility trial are needed prior to its implementation in health, education, youth and social services and charities, to help young people, families/carers, friends and professionals.

**The online package can be accessed at: <https://www.moodhwb.org>**

## Table of contents

	Page no.
<b>Chapter 1: Introduction</b>	
<b>1.1 Introduction</b>	1
<b>1.2 Depression in adolescence</b>	3
1.2.1 Introduction to adolescent depression	
1.2.2 Assessment and diagnosis	
1.2.3 Risk factors and possible causes	
1.2.4 Resilience	
<b>1.3 Importance of prevention and early intervention</b>	7
1.3.1 Principles of management and prevention of depression	
1.3.2 Co-morbidities & differential diagnosis	
1.3.3 Prevention strategies	
1.3.4 Challenges in the assessment & management of adolescent depression	
<b>1.4 Increasing interest in psychoeducation</b>	12
1.4.1 Introduction to psychoeducation	
1.4.2 Psychoeducation in adolescence	
1.4.3 Challenges of defining psychoeducation	
<b>1.5 Emergence of e-mental health</b>	14
1.5.1 Introduction to e-health	
1.5.2 Adolescents and electronic media	
1.5.3 Electronic CBT	
1.5.4 Electronic psychoeducation	
<b>1.6 Aims of research project/doctorate, research question</b>	18
<b>Chapter 2:</b>	
<b>Psychoeducational interventions (PI) in adolescent depression: a systematic review</b>	
<b>2.1 Introduction</b>	21
<b>2.2 Methods</b>	22
2.2.1 Selection criteria	
2.2.2 Search strategy	
2.2.3 Study selection, data extraction	
<b>2.3 Results</b>	26
2.3.1 Description of PI	
2.3.2 Adolescents with depression: PI for adolescents and families/carers	
2.3.3 Adolescents at risk of depression: PI for adolescents and families/carers	
<b>2.4 Discussion</b>	40
2.4.1 Main findings	
2.4.2 Effectiveness of PI	
2.4.3 Active components	
2.4.4 Strengths, limitations	
2.4.5 Challenges in implementing PI, possible adverse effects	
2.4.6 Developments in electronic PI	

## 2.4.7 Conclusions

### Chapter 3: Methods

<b>3.1 Introduction</b>	49
<b>3.2 Overview of research plan</b>	50
3.2.1 MRC framework for complex interventions	
3.2.2 Mixed methods approach	
3.2.3 Consultations and reviews when developing the research plan	
<b>3.3 Stage 1: Review &amp; approvals</b>	57
3.3.1 Systematic Review: Psychoeducational interventions in adolescent depression	
3.3.2 Risks & ethical considerations	
<b>3.4 Stage 2: Interviews &amp; focus groups</b>	59
3.4.1 Recruitment for interviews & focus groups	
3.4.2 Information sheets and consent forms	
3.4.3 Semi-structured interviews	
3.4.4 Focus groups	
3.4.5 Other discussion groups, workshops & consultations	
<b>3.5 Stage 3: Development of initial prototype</b>	73
3.5.1 Development of content & design	
3.5.2 Multimedia company & intellectual property	
<b>3.6 Stage 4: Evaluation of initial prototype</b>	76
3.6.1 Mixed methods approach	
3.6.2 Participants for evaluation phase (stage 4)	
3.6.3 General use of the package	
3.6.4 Quantitative data collection	
3.6.5 Qualitative data collection (stage 4)	
<b>3.7 Data analysis</b>	81
3.7.1 Quantitative analysis (stage 4)	
3.7.2 Qualitative analysis (interviews and focus groups, stage 2 & 4)	
<b>3.8 Stage 5: Further development</b>	83
<b>3.9 Summary and conclusions</b>	84

### Chapter 4: Discovery phase

#### Results of semi-structured interviews with users to generate ideas on content/design for the focus groups

<b>4.1 Introduction</b>	85
<b>4.2 Interview participants</b>	86
<b>4.3 Key themes identified in the interviews</b>	87
<b>4.4 Key theme 1: The need for and aims of the package</b>	89
4.4.1 Accessibility and target group (universal v targeted)	
4.4.2 Increase awareness and tackle stigma	
4.4.3 Lack of resources for young people	
4.4.4 Need to engage young people	
4.4.5 Embrace a medium that's relevant for young people	
4.4.6 Promote self-management/autonomy	
4.4.7 Accessible for a diverse range of users	

4.4.8 Young people find it difficult to talk to adults	
4.4.9 Help for parents, carers and professionals working with young people	
<b>4.5 Key theme 2: Design issues</b>	94
4.5.1 Harnessing multimedia to <i>engage</i> the user	
4.5.2 Harnessing multimedia to <i>communicate</i> information	
4.5.3 Multiplatform approach and ‘app’	
4.5.4 Clear structure and navigation	
4.5.5 Language issues	
4.5.6 Characters, avatars	
4.5.7 Using metaphors to develop a ‘relationship’ with the problem	
4.5.8 Colour	
4.5.9 Images of heads and brains	
4.5.10 Gamification	
4.5.11 Personalising the space	
4.5.12 Monitoring tool	
4.5.13 Forums, security and confidentiality	
<b>4.6 Key theme 3: Content issues</b>	105
4.6.1 General approach	
4.6.2 What are mood, wellbeing and depression?	
4.6.3 Possible reasons for depression	
4.6.4 Prevention and self-management	
4.6.5 Where to get help	
4.6.6 Section for parents, carers, friends, professionals	
<b>4.7 Key theme 4: Integration and context</b>	115
4.7.1 Use of the package with others, e.g. parent, friend, professional	
4.7.2 School/education services	
4.7.3 Health and other services	
4.7.4 Name, branding and promotion	
<b>4.8 Discussion</b>	118
4.8.1 Summary & key issues taken forward to the focus groups	
4.8.2 Comparison of the views of young people, parents, professionals	
4.8.3 Conclusions	
 <b>Chapter 5: Co-design phase</b>	
<b>Results of focus groups with users to inform the development of the package with the multimedia company</b>	
 <b>5.1 Introduction</b>	122
<b>5.2 Focus group participants</b>	123
5.2.1 Adolescents	
5.2.2 Parents	
5.2.3 Professionals	
<b>5.3 Key themes identified in the focus groups, and how they informed the designs</b>	125
<b>5.4 Key theme 1: Why do we need this package? What are the aims?</b>	127
5.4.1 Increasing awareness and tackling stigma	
5.4.2 A lack of resources for young people	
5.4.3 Embrace digital technology as a medium that’s relevant for young people	
5.4.4 Diversity	
5.4.5 Need to target parents/families	

<b>5.5 Key theme 2: Design issues</b>	130
5.5.1 Harnessing multimedia to engage the user	
5.5.2 Multiplatform use and 'app'	
5.5.3 Clear structure, navigation, and distribution of information	
5.5.4 Language	
5.5.5 Characters & avatars	
5.5.6 Imagery and metaphors	
5.5.7 Moodboards	
5.5.8 Gaming element	
5.5.9 Personalising the space	
5.5.10 Monitoring tool	
5.5.11 Technical aspects - security and confidentiality and the use forums/social media	
<b>5.6 Key theme 3: Content issues</b>	146
5.6.1 What are mood, well-being and depression?	
5.6.2 Other difficulties related to low mood/depression	
5.6.3 Causes/reasons/risk factors	
5.6.4 Prevention & self-management strategies	
5.6.5 Where to get help	
5.6.6 Information for parents, carers, professionals	
<b>5.7 Key theme 4: Integration and context</b>	157
5.7.1 Use with parent, carer, friend, professional	
5.7.2 Use within education and health services	
5.7.3 Name, branding, promotion	
<b>5.8 Discussion</b>	159
5.8.1 Summary of findings and development from interviews	
5.8.2 Comparison of focus groups (and other approaches in stage 2)	
5.8.3 Conclusions	
 <b>Chapter 6</b>	
<b>Development of the initial prototype of the online package</b>	
 <b>6.1 Introduction</b>	165
<b>6.2 Project management</b>	166
6.2.1 Consultations and collaboration	
6.2.2 Process of development: From initial sketches to wireframes to prototype	
6.2.3 Translation of findings from interviews and focus groups	
<b>6.3 Theories and approaches</b>	174
6.3.1 Design and educational theories/approaches	
6.3.2 Psychological and behaviour change theories/approaches	
6.3.3 Logic model	
<b>6.4 General design and technical specifications</b>	181
6.4.1 Multiplatform use	
6.4.2 Security and confidentiality	
6.4.3 Language issues	
6.4.4 Name of package	
<b>6.5 Design elements: structure and functionality</b>	184
6.5.1 General structure and components (primary level)	
6.5.2 Welcome screen	
6.5.3 User pathways	

6.5.4 Initial questions	
6.5.5 Dashboard	
6.5.6 'My Profile' section	
6.5.7 General structure and components (secondary level)	
6.5.8 Levels of information	
6.5.9 Interactive sections & 'App'	
<b>6.6 Design characteristics: graphics, colour, moving image</b>	<b>196</b>
6.6.1 General stylistic approach	
6.6.2 Representations and metaphors	
6.6.3 Character design	
6.6.4 Moving imagery – animations	
<b>6.7 Content</b>	<b>202</b>
6.7.1 Section 1: What are mood and depression?	
6.7.2 Section 2: Possible reasons (Why do I feel this way?)	
6.7.3 Section 3: Self help approaches (prevention, management, monitoring)	
6.7.4 Section 4: Where to get help	
6.7.5 Section 5: Other health issues (associated with depression)	
6.7.6 Section 6: Information for family/carers/guardians, friends, professionals	
<b>6.8 Summary and discussion</b>	<b>217</b>
6.8.1 Initial prototype	
6.8.2 Conclusions and next phase	
 <b>Chapter 7:</b>	
<b>Results of early evaluation and consultation phase</b>	
 <b>7.1 Introduction</b>	<b>219</b>
<b>7.2 Questionnaires &amp; online usage (quantitative results)</b>	<b>220</b>
7.2.1 Participants	
<b>7.3 Use of the package</b>	<b>223</b>
7.3.1 Online usage data	
7.3.2 Questionnaire data	
<b>7.4 Acceptability of questionnaires</b>	<b>226</b>
<b>7.5 Comparison of pre- and post-intervention questionnaires</b>	<b>227</b>
<b>7.6 Questionnaire feedback on the package</b>	<b>230</b>
7.6.1 How helpful was the package?	
7.6.2 Design and language	
<b>7.7 Interviews with young people and parents (qualitative results)</b>	<b>234</b>
7.7.1 Participants	
7.7.2 Key themes	
<b>7.8 Key theme 1 (interviews): Design features</b>	<b>236</b>
7.8.1 Overall design and use of colour	
7.8.2 Navigation and ease of use	
7.8.3 Illustrations and animations	
7.8.4 Interactive elements	
7.8.5 Technical issues	
7.8.6 Scroll-down v separate pages	
<b>7.9 Key theme 2 (interviews): Sections and content</b>	<b>241</b>
7.9.1 Structure of sections	
7.9.2 Language, tone and amount of information	
7.9.3 Personal stories	

7.9.4 Sections of the package	
<b>7.10 Key theme 3 (interviews): Integration and context</b>	<b>245</b>
7.10.1 Targeted v Universal	
7.10.2 Use with families and friends	
7.10.3 Integration with schools and health services	
<b>7.11 Focus group with professionals</b>	<b>247</b>
7.11.1 Participants	
7.11.2 Key themes	
<b>7.12 Key theme 1 (focus group): Design features</b>	<b>249</b>
7.12.1 Overall design	
7.12.2 Illustrations and animations	
7.12.3 Interactive elements	
7.12.4 Technical issues	
7.12.5 Scroll-down v separate pages	
<b>7.13 Key theme 2 (focus group): Sections and content</b>	<b>252</b>
7.13.1 Package content	
7.13.2 Language and text	
7.13.3 Personal stories	
<b>7.14 Key theme 3 (focus group): Integration and context</b>	<b>254</b>
7.14.1 Integration with schools and health services	
7.14.2 Challenges in implementation	
<b>7.15 Discussion</b>	<b>256</b>
7.15.1 Summary of quantitative results	
7.15.2 Summary of strengths of package (qualitative results)	
7.15.3 Conclusions	

## **Chapter 8:**

### **Discussion: Development and evaluation of an online psychoeducation package for adolescent depression**

<b>8.1 Introduction</b>	<b>261</b>
<b>8.2 Summary of project and findings</b>	<b>262</b>
<b>8.3 Implications for redevelopment phase (stage 5)</b>	<b>263</b>
<b>8.4 Comparisons with other online packages</b>	<b>268</b>
<b>8.5 Strengths and limitations</b>	<b>269</b>
8.5.1 Strengths	
8.5.2 Limitations	
<b>8.5 Integration and context</b>	<b>275</b>
<b>8.6 Future research</b>	<b>278</b>
8.6.1 Research in the field in general	
8.6.2 Research for the online package	
<b>8.7 Summary and conclusions</b>	<b>282</b>

<b>References</b>	<b>284</b>
-------------------	------------

<b>Appendix</b>	<b>299</b>
-----------------	------------

Appendix 1 Recruitment and consent documents	
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Appendix 2 Focus group discussion slides  
 Appendix 3 Further themes from the interviews (stage 2)  
 Appendix 4 Further themes from the focus groups (stage 2)  
 Appendix 5 Figures related to the development of the package

## List of figures

Fig 1.1: ICD-10 and DSM-5 diagnostic criteria  
 Fig 1.2: NICE guidelines - stepped-care model for the treatment of depression in children and young people  
 Fig 1.3: Overall research plan for the project  
 Fig 2.1: Broad stages of the research plan  
 Fig 2.2: Flow diagram: Methodology for article selection  
 Fig 3.1: MRC Framework for complex interventions  
 Fig 3.2: Key elements of the development and evaluation process  
 Fig 3.3: Broad stages of the research plan  
 Fig 3.4: Information sheets for young people  
 Fig 3.5: Topic Guide – for the semi-structured interviews  
 Fig 3.6: Flow chart – sequence of interviews and focus groups  
 Fig 3.7: Photograph of focus group set-up at the Hadyn Ellis Building, Cardiff University  
 Fig 3.8: Questions and selection of slides shown during a focus group  
 Fig 3.9: Other workshops and consultations  
 Fig 3.10: Overseas placements/visits during fellowship  
 Fig 3.11: Influences on the design and content of the online package  
 Fig 3.12: Photographs from some of the workshops held with the multimedia company  
 Fig 3.13: Recruitment centres for stage 4, in south and west Wales  
 Fig 3.14: Steps in data analysis  
 Fig 4.1: Broad stages of the research plan  
 Fig 5.1: Broad stages of the research plan  
 Fig 5.2: Slide shown in young person focus group 2 to show the overall structure of the package  
 Fig 5.3: Welcome screen in the initial prototype for the young person and parent focus groups, showing the different options for the user  
 Fig 5.4: ‘Metaphors of the mind’ illustration  
 Fig 5.5: ‘Drawing depression’ image  
 Fig 5.6: Moodboards presented in the focus groups  
 Fig 5.7: Screenshot of young person section, with quiz on right side  
 Fig 5.8: Screenshots of part of parent section of the package, with quiz questions  
 Fig 5.9: Examples of initial questions in the prototype presented in the latter groups  
 Fig 5.10: Screenshot of ‘Stuff I like’  
 Fig 5.11: Screenshots of goal-setting option  
 Fig 5.12: Screenshots of an initial prototype of the ‘app’ for monitoring experiences (e.g. mood), shown in the latter focus groups  
 Fig 5.13: Welcome screen shown in young person focus group, with ‘stealth mode’ button (top right)  
 Fig 5.14: Screenshots from ‘What is depression’ module  
 Fig 5.15: Initial designs for parents, carers, and professionals’ package  
 Fig 5.16: Dealing with difficulties and online resources subsections in the initial prototype  
 Fig 5.17: Slide presented in the latter focus groups on possible names for the package  
 Fig 5.18: Structure of the package changed from the first young person group, to the second group, to the initial prototype in the third focus group  
 Fig 6.1: Broad stages of the research plan  
 Fig 6.2: Development of welcome screen/user flow: ‘Post-its’/sketches, wireframes, black /white and colour designs  
 Fig 6.3: Kolb’s theory  
 Fig 6.4 Logic model

Fig 6.5: Welcome screen for 'HwbHwyliau', Welsh language version of the package

Fig 6.6: Initial designs and typography for the name, including final choice

Fig 6.7: 'Primary level' user flow diagram from the 'information architecture' document

Fig 6.8: Welcome screen and menu

Fig 6.9: Questions when entering the package and when monitoring mood/other issues

Fig 6.10: Dashboard: Early design and latest design showing sections and subsections

Fig 6.11: Designs for the 'my profile' section

Fig 6.12: Sketches, wireframes and early colour designs showing the structure of the 'what are mood and depression?' section

Fig 6.13: Collapsible block, and feature block

Fig 6.14: Colour design for the mood monitor

Fig 6.15: Designs for 'Stuff I Like' introductory screen on a desktop, and app

Fig 6.16: Designs for 'My goals' on a desktop, and app

Fig 6.17: The colour-coded sections of the package

Fig 6.18: Examples of the typography considered, including the final choice

Fig 6.19: Initial ideas for metaphors and metaphors' subsection in the 'What are mood and depression?' section

Fig 6.20: Experimental character designs including the final versions

Fig 6.21: Designs for facial expressions, particularly for the mood monitor

Fig 6.22: Initial sketches and storyboard for the 'How can this help me?' animation

Fig 6.23: Key points for parents & patients in PE for depression

Fig 6.24: 'Information architecture' for the 'What are mood and depression?' section

Fig 6.25: Subsections on the possible symptoms and effects of low mood and depression.

Fig 6.26: Subsection on prevalence and other statistics on depression and mental health difficulties in young people

Fig 6.27: Subsection on 'strengths, difficulties', with elements of resilience theory

Fig 6.28: Information architecture for the 'possible reasons' section

Fig 6.29: Subsection and illustration on the complex relationship of risk factors

Fig 6.30: Subsections on developmental issues and psychosocial risk factors

Fig 6.31: Subsections on depression in the family, and scientific explanations

Fig 6.32: Information architecture – self help section

Fig 6.33: Identifying symptoms/ triggers subsection

Fig 6.34: Subsection on living healthily

Fig 6.35: Subsection on self-belief

Fig 6.36: Information architecture for the 'where to get help' section

Fig 6.37: Subsections on getting help from family and friends, and from services

Fig 6.38: Subsections on psychological therapies and medication

Fig 6.39: Information architecture – 'Other health issues'

Fig 6.40: Subsections in 'Other health issues'

Fig 6.41: Information architecture – Family, friends, professionals

Fig 6.42: Subsections in the 'Family, friends, professionals' section

Fig 7.1: Broad stages of the research plan

Fig 7.2: Flow chart of participants in the quantitative evaluation phase

Fig 7.3: Use of the package

Fig 7.4: Frequency of use by young person (left) and parent (right)

Fig 7.5 Acceptability of questionnaires (young people)

Fig 7.6 Acceptability of questionnaires (parents)

Fig 7.7: Feedback on how helpful the package was for the young person

Fig 7.8: Feedback on how helpful the package was for parents

Fig 7.9: Feedback on the amount of information in the package

Fig 7.10: Feedback on design and language

Fig 8.1: Broad stages of the research plan

Fig 8.2: Possible research plan - further development and feasibility trial of online programme

## List of tables

Table 2.1:	Studies of psychoeducational interventions (PIs) for adolescents with depression, and families/carers
Table 2.2:	Studies of psychoeducational interventions (PIs) in adolescents at high-risk of depression, and families/carers
Table 3.1:	Data captured on general use of package
Table 3.2:	Content of questionnaires (pre and post intervention):
Table 4.1:	Participants - semi-structured interviews
Table 4.2:	Themes arising from the interviews
Table 5.1a:	Participants in the three focus groups for young people
Table 5.1b:	Participants in the focus group for parents
Table 5.1c:	Participants in the focus group for professionals who work with young people
Table 5.1d:	Participants in the focus group for researchers (with a special interest in child & adolescent mental health)
Table 5.2:	Themes arising from the focus groups
Table 6.1:	How findings from the interviews and focus groups influenced the development of the online package
Table 7.1:	Characteristics of young people participating in study at baseline
Table 7.2:	Use of package – by young people & parents/carers
Table 7.3:	Comparison of pre-and post-intervention questionnaires (young person)
Table 7.4:	Comparison of pre-and post-intervention questionnaires (parent)
Table 7.5:	Characteristics of young people who were interviewed
Table 7.6:	Participants in the focus group for professionals
Table 8.1:	Further development of package (stage 5)

## Glossary of abbreviations

AACAP	American Academy of Child and Adolescent Psychiatry
ADKQ	Adolescent Depression Knowledge Questionnaire
ALPHA	Advice Leading to Public Health Advancement
APA	American Psychiatric Association
ASD	Autism spectrum disorder
BADS	Behavioural Activation for Depression Scale
CAAP	Child and adolescent psychiatry
CAMHS	Child and adolescent mental health services
CBT	Cognitive behavioural therapy
CPN	Community psychiatric nurse
DECIPHer	Centre for the Development and Evaluation of Complex Interventions for Public Health Improvement
DPMCN	Division of Psychological Medicine and Clinical Neurosciences
DSM	Diagnostic and Statistical Manual of Mental Disorders
DSS	Depression Stigma Scale
EPAD	Early Prediction of Adolescent Depression (Study)
FG	Focus group
GHSQ	General Health-Seeking Questionnaire
GP	General practitioner
HCRW	Health and Care Research Wales
ICD	International Classification of Diseases
ICT	Information and Communication Technology
IPT	Interpersonal therapy
MDD	Major depressive disorder

MFQ	Moods and Feelings Questionnaire
MRC	Medical Research Council
NCMH	National Centre for Mental Health
NIHR	National Institute for Health Research
NISCHR	National Institute for Social Care and Health Research
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
ONS	Office of National Statistics
PE	Psychoeducation
PHQ	Patient Health Questionnaire
PI	Psychoeducational intervention
PMH	Primary mental health
PRA	Privacy Risk Assessment
R&D	Research and development
RCPsych	Royal College of Psychiatrists
RCT	Randomised controlled trial
REC	Research Ethics Committee
SCARED	Screen for Child Anxiety Related Disorders
SDQ	Strengths and Difficulties Questionnaire
SEWTU	South East Wales Trials Unit
SEQ-DA	Self-efficacy Questionnaire for Depression in Adolescents
TAU	Treatment as usual
TIME	Institute of Translation, Innovation, Methodologies and Engagement
UHB	University health board
WHO	World Health Organisation
YP	Young person

# Chapter 1: Introduction

## 1.1 Introduction

Depression is common in adolescence, and leads to distress for the young person and their family. It is associated with social and educational impairments and poor physical health. It also predicts suicide, deliberate self-harm, and can mark the beginning of long-term mental health difficulties (Thapar et al. 2012). Early treatment and prevention of adolescent depression is therefore a major public health concern (Department of Health 2009). However, depression is difficult to recognise and treat in this age group, and engaging young people in prevention and early intervention programmes is a challenge for health and other services (Thapar et al. 2010).

Guidelines for depression in young people (e.g. UK National Institute for Health and Care Excellence (NICE 2005); American Academy of Child and Adolescent Psychiatry (AACAP) (Birmaher et al. 2007)) stress the need for good information and evidence-based psychosocial interventions for the young person, family and carer. Psychosocial interventions are likely to be important in young people for promoting resilience and preventing relapse (Collishaw et al. 2016; Thapar et al. 2012).

Over recent years there has been growing interest in psychoeducational interventions (PI); which can be described as the delivery of accurate information to individuals, families and carers about mental health or a specific diagnosis, management and prognosis and how affected individuals can stay well (Birmaher et al. 2007; Smith, Jones, & Simpson 2010; Colom 2011; Brent & Maalouf 2015). The AACAP (2007) Practice Parameters in children and young people describe psychoeducation as *'education of family members and the patient about the causes, symptoms, course, and different treatments of depression and the risks associated with these treatments as well as no treatment at all. Education should make the treatment and decision-making process transparent and should enlist parent and patient as collaborators in their own care.'* (Birmaher et al. 2007, p1510).

E-health and electronic multimedia have also been explored to help engage and inform young people and families/carers (Hollis et al. 2015). Whilst the risk factors and possible causes of adolescent depression are complex, individuals with a family history of depression and psychosocial stress are known to be at a higher risk, and could be targeted for such strategies, along with those with a history of depression (Thapar et al. 2012).

This thesis uses mixed methods to develop and evaluate a user-friendly online psychoeducation multimedia package for adolescents with (or at high risk of) depression, and their families and carers, as part of a National Institute for Health Research (NIHR)/Health and Care Research Wales (HCRW) fellowship. This work builds on previous studies by research groups at Cardiff University on the prediction and prevention of adolescent depression (Mars et al. 2012) and the development of online psychoeducation for bipolar disorder (Smith et al. 2011; Poole et al. 2015).

The package was informed by a review of the literature and practice in this area as well as findings from interviews and focus groups with adolescents, families/carers and professionals who work with this age group. An initial prototype of the package was evaluated before being reassessed and improved. The package will be assessed in a future feasibility trial and if successful a further large scale randomised controlled trial (RCT). If proved to be effective it could be rolled out into health, education, youth and social services settings where the individual could work on it independently or with a carer, family member or health care worker, to engage, inform and help prevent and manage depressive symptoms.

This chapter introduces adolescent depression - the definition, epidemiology, associated impairment and difficulties, possible causes, risk and protective factors, and an overview of the importance and approaches to prevention and treatment. This is followed by an account of the emergence of psychoeducation and electronic or 'e-mental health' approaches to engage and deliver information to young people and their families, and to help with the prevention and management of depression. The chapter ends with a description of the aims of the doctoral research project and thesis.

## **1.2 Depression in adolescence**

### **1.2.1 Introduction to adolescent depression**

Depression is a common, debilitating condition, predicted to become the second highest medical cause of disability in the world by 2020 (Murray & Lopez 1997; Lopez et al. 2006). Depression frequently begins in adolescence and is around twice as common in females than in males (Hyde et al. 2008). The prevalence rises substantially throughout adolescence (Green et al. 2005), and there is an estimated 12-month prevalence of 4 to 5 % in mid to late adolescence (Costello et al. 2005 & 2006). The prevalence of depressive symptoms has increased in the last 50 years (Angold & Costello 2001; Collishaw et al. 2004), and there is evidence to suggest the age of onset has become earlier (Kessler & Walters 1998). The risk of recurrence is very high for such early cases (Harrington 2001). As adolescent onset depression is a major clinical problem, with adverse consequences, early identification and treatment are important both in the short term and to improve long term prognosis.

In addition, depressive symptoms that fall below the diagnostic threshold are often accompanied by impairment, and can predict risk of future depressive disorder. This is consistent with the approach of depression lying along a continuum (Pickles et al. 2001).

### **1.2.2 Assessment and diagnosis**

Depression as a diagnosis is defined as a mood or affective disorder in the tenth version of the International Classification of Diseases (ICD-10) (WHO 1992) and fifth version of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) (APA 2013). The criteria are set as a cluster of symptoms with associated impairment, which can range in severity (mild, moderate, severe, with or without psychotic symptoms). The diagnostic criteria for depression in adolescence is the same as that for adults according to the ICD-10 (WHO 1992), whilst in the DSM-V, irritable mood can feature as one of the core symptoms instead of depressed mood (APA 2013) (see fig 1.1). Possible warning signs for adolescent depression include a decline in academic performance, disengagement with leisure activities, changes in peer and family relationships, and social withdrawal (Thapar et al. 2012).

A clinical mental health assessment is required by a trained professional to diagnose depression in young people. Assessment should involve sensitive, empathic questioning about symptoms and impairment, and include reports from various sources, including the individual, family, school and other agencies involved. An assessment of functioning and impairment in all settings, including at home and school, and of associated risks, for example of suicide, is paramount. Physical assessments and investigations might also be required to exclude an organic cause such as hypothyroidism or anaemia. There should be an opportunity to assess the young person alone, and to allow them to talk or ask any questions in private (NICE 2005).



**Figure 1.1: ICD-10 and DSM-5 diagnostic criteria**

**ICD-10: Depressive episode**

At least four of the following symptoms in total for mild episodes, six for moderate episodes and eight for severe episodes. Two core symptoms must be present for mild or moderate episodes and all three for a severe episode.

***Core symptoms:***

- depressed mood most of the day that is abnormal for the individual, most of the day & almost every day for at least 2 weeks
- loss of interest or pleasure in activities that are normally pleasurable
- decreased energy or increased fatiguability

***Other symptoms:***

- Loss of confidence or self-esteem
- Unreasonable feelings of self-reproach or excessive inappropriate guilt
- Recurrent thoughts of death or suicide, or any suicidal behaviour
- Diminished ability to think or concentrate e.g. indecisiveness or vacillation
- Change in psychomotor activity, with agitation or retardation
- Sleep disturbance
- Change in appetite with corresponding weight change

**DSM-5: Major depressive episode**

At least five of the following symptoms present nearly every day during the same 2-week period, representing a change from previous functioning, including at least one core symptom.

***Core symptoms:***

- Depressed **or irritable\*** mood most of the day
- Diminished interest or pleasure in all, or almost all, activities

***Other symptoms:***

- Significant weight loss or weight gain, or decrease or increase in appetite
- Insomnia or hypersomnia
- Psychomotor agitation or retardation
- Fatigue or loss of energy
- Feelings of worthlessness or excessive or inappropriate guilt
- Diminished ability to think or concentrate, or indecisiveness
- Recurrent thoughts of death, recurrent suicidal ideation without a specific plan for committing suicide

\* in children and adolescents only

Clinical aids to screen for depression include the Patient Health Questionnaire (PHQ), (Richardson et al. 2010), the Strength and Difficulties Questionnaire (SDQ) (Goodman 1997), the Mood and Feelings Questionnaire (MFQ), or short MFQ (sMFQ) (Daviss et al. 2006) and the Children's Depression Inventory (CDI) (Kovacs 1985). NICE (2005) recommend the use of the self-report MFQ as an adjunct to clinical judgement in the screening and monitoring of depression in secondary care.

Structured diagnostic interview tools are more commonly used in a research setting, although NICE (2005) state that interviewer-based instruments such as the Kiddie-Sads (K-SADS) (Kaufman et al. 1997) and Child and Adolescent Psychiatric Assessment (CAPA) (Angold & Costello 2000) could be used to help with the diagnosis of depression in a clinical setting. However, they note that these would need to be modified for regular use in busy, routine Child and Adolescent Mental Health Service (CAMHS) settings.

### **1.2.3 Risk factors and possible causes**

The risk factors and possible causes of adolescent depression are heterogeneous and diverse, with many individual biological, psychological and social (bio-psycho-social) risks. One of the strongest risk factors for adolescent depression is a family history of depression. The offspring of parents who have depression are 3-4 times more likely to experience depression compared with the offspring of healthy parents (Rice et al. 2002). This is an important group to consider therefore for early intervention and prevention strategies.

Another strong risk factor for adolescent depression is exposure to psychosocial stress, including acute stressful events and chronic adversity for example, negative family relationships, bullying and maltreatment (Thapar et al. 2012). Social isolation and poverty are also risk factors. Adolescents with poor coping mechanisms, a negative cognitive style and low self-esteem are also thought to be more vulnerable (Gladstone 2011). Although both genetic and environmental factors contribute (Rice et al. 2002), there are no replicated significant findings regarding specific genes for depression in adolescence (Shyn et al. 2011; Shi et al. 2011).

### **1.2.4 Resilience**

As well as risk factors, it is important to consider protective factors and resilience. Resilience is defined as better than expected functioning across psychosocial outcomes over time in the context of known risk factors. Though at high risk for depression, children of depressed parents, for example, show considerable variability in outcomes, and clarifying reasons for resilience will inform the development of prevention and early intervention programmes (Rutter 2006, National Research Council and Institute of Medicine 2009). In the context of adolescents with a depressed parent, protective or resilience factors for young people can include supportive relationships with peers and parents. Both parents play an important role – protective factors can include the expression of positive emotions by the depressed parent about the child, and also support from the other parent. Self-efficacy and frequent exercise by the young person also play a part (Collishaw et al. 2016).

It is important to note that resilience is not merely the opposite of risk. Furthermore, the evidence for a range of protective and risk factors, and their possible cumulative effects, suggest the importance of the development of complex, tailored and possibly multi-modal approaches to the prevention of depression in adolescents, addressing psychological, social and biological issues (Collishaw et al. 2016).

## **1.3 Importance of prevention and early intervention**

### **1.3.1 Principles of management and prevention of depression**

The principles of management of adolescent depression are focused on the reduction of early and later adversities (including environmental stressors); modification of ways of thinking and feeling, such as cognitive behavioural therapy (CBT) approaches; and reduction of core symptoms by alteration of biological pathways with medication, particularly Selective Serotonin Reuptake Inhibitor (SSRI) antidepressant medication, such as Fluoxetine (NICE 2005, Thapar et al. 2012). Engagement of the whole family is also important, and educational and psychological (including inter-personal therapy (IPT) and family therapies) approaches should be considered (NICE 2005, AACAP 2007). As with the assessment, the

approaches to the management and prevention of depression in adolescents are different to those in adults. NICE guidelines (2005) for depression and children and young people recommend following a step-wise approach (figure 1.2).

**Figure 1.2: NICE guidelines - stepped-care model for the treatment of depression in children and young people (NICE 2005):**

- Step 1 and 2 refer to detection and recognition.
- Step 3 describes how the management of mild depression (and dysthymia) should include watchful waiting, non-directive supportive therapy, group CBT and guided self help.
- Step 4 describes approaches to moderate and severe depression, including brief psychological therapy (individual CBT, IPT or shorter-term family therapy) for at least 3 months' duration, with or without antidepressant medication (Fluoxetine).
- Step 5 describes how more intensive psychological therapy and antidepressants (possibly augmented by an antipsychotic medication) should be considered if depression is unresponsive to treatment, or in the case of recurrent or psychotic depression.

Focus	Action	Responsibility
Detection	Risk profiling	Tier 1
Recognition	Identification in presenting children or young people	Tiers 2–4
Mild depression (including dysthymia)	Watchful waiting Non-directive supportive therapy/group cognitive behavioural therapy/guided self-help	Tier 1 Tier 1 or 2
Moderate to severe depression	Brief psychological therapy +/- fluoxetine	Tier 2 or 3
Depression unresponsive to treatment/recurrent depression/psychotic depression	Intensive psychological therapy +/- fluoxetine, sertraline, citalopram, augmentation with an antipsychotic	Tier 3 or 4

*Tier 1: universal services e.g. primary care, schools; tier 2: combination of specialist CAMHS and community services e.g. primary mental health; tier 3: specialist outpatient CAMHS; tier 4: inpatient CAMHS units and intensive community treatment services.*

### **1.3.2 Co-morbidities & differential diagnosis**

Co-morbidities are common amongst adolescents with depression. Two-thirds of adolescents with depression have at least one other psychiatric disorder (Ford et al. 2003). The most common co-morbidities of depression in adolescents include anxiety disorders, disruptive behaviour disorder, substance misuse, psychotic disorders (including schizophrenia), eating disorders (anorexia nervosa, bulimia nervosa), neurodevelopmental disorders (autistic spectrum disorders and ADHD), and physical/medical illnesses such as diabetes and obesity (Brent & Maalouf 2015; Thapar et al. 2012; WHO 1992).

It is important to diagnose co-morbidities, as if they go unrecognised or untreated, this may affect the improvement following depressive episodes. Through consultations with health, education, social and other services, comorbid diagnoses and developmental, social and educational problems should be assessed and managed, along with the treatment for depression (NICE 2005). For example, the management of self-harm in young people could include physical/medical treatment and monitoring, a thorough mental health assessment, follow-up appointments and individual or family work as indicated and the consideration of involvement of social services (NICE 2011).

It is also important to consider whether depression is the correct diagnosis, and that the diagnosis may change over time. This is true in all medical specialties, but is especially pertinent in adolescence given that there are so many biological, psychological and social changes during this time, and diagnosis are often complex. A developmental approach is essential in the assessment and management of adolescent depression. Differential diagnoses include adjustment disorder, dysthymic disorder and bipolar affective disorder, which consists of depressive and manic episodes. Most of the diagnoses listed previously as co-morbidities should also be considered as differentials. The presentation of the individual might change over time, which could suggest that another disorder is more appropriate; for example bipolar disorder or schizophrenia can be preceded by a depressive episode prior to the initial psychotic symptoms. Physical illness, such as endocrine disorders, should also be considered and physical, including blood investigations, might be required (Brent et al. 2015; Thapar et al. 2012; WHO 1992).

### **1.3.3 Prevention strategies**

Depression prevention programmes usually have an educational or psychological approach (particularly cognitive behavioural or interpersonal) or a combination of both. Prevention strategies for adolescent depression can be classified as ‘targeted’ or ‘universal’ approaches. Targeted interventions are for individuals at high risk of depression, whereas universal interventions are typically broader programmes, often within schools or communities (Bennett et al. 2014). Targeted interventions can be further subdivided into two types of programmes. Indicated targeted programmes are for adolescents with depressive symptoms below the threshold required for a formal diagnosis of major depression – as noted earlier those with depressive symptoms are at greater risk of developing depressive disorder (Lewinsohn 1998). Selective targeted programmes are for high-risk groups such as adolescent offspring of parents with depression (Clarke 2001; Garber 2009).

Targeted prevention strategies have been found to be the most effective for adolescent depression, although there is emerging research to suggest that universal prevention approaches are also effective (Merry et al. 2011). Targeted interventions are usually more cost-effective through better use of limited resources. Disadvantages include the resources needed to identify individuals and deliver the intervention, the possible stigmatisation and increased anxiety associated with being identified, and the possibility of unnecessarily treating those who may not develop depression. Universal interventions may be less stigmatising, and benefit more young people, including those missed through screening. However, they are variable in quality and can be costly and difficult to implement, particularly given the possible scale of the programmes required (Bennett et al. 2014).

As noted above, research into resilience has gained increasing prominence, and could inform prevention strategies, since the promotion of protective factors can be as important as the reduction of modifiable risk factors.

### **1.3.4 Challenges in the assessment & management of adolescent depression**

Early identification, recognition of risk, prevention and early intervention are especially important in adolescent depression (Department of Health 2009). However, depression is difficult to recognise and treat in this age group. Diagnosis is more often missed in adolescents than in adults (Leaf et al. 1996), possibly because of the presence of irritability (one of the core symptoms according to DSM-V criteria), mood reactivity and fluctuating symptoms in adolescent depression. Also, the primary presenting problems may be non-specific or symptoms of a disorder other than depression, for example unexplained physical symptoms, anxiety, school refusal, decline in academic performance, or behavioural problems (Thapar et al. 2012).

As noted previously, there are numerous co-morbidities and differential diagnoses to consider, and the risk and protective factors to address are complex. The assessment and management of comorbid diagnoses and developmental, social and educational problems is a key priority of the NICE guidelines for depression in young people. Another priority is the treatment of parents' own psychiatric problems (especially depression), in parallel to the management of the child's mental health issues, 'bearing in mind the availability of adult mental health provision and other services' (NICE 2005).

Furthermore, NICE (2005) stress that psychological therapies for young people should be provided by trained child and adolescent mental healthcare professionals. A key challenge however is the lack of provision of primary and secondary mental health services for child and adolescents (National Assembly for Wales 2014). Best practice and guidelines vary, and there is a lack of antidepressant medication available for use with children and adolescents.

A large proportion of adolescents with depression may not approach health services, and so it is important that all agencies dealing with this age group, including education, social and youth organisations, are trained in the primary identification of mental health symptoms (Potter et al. 2012). There is a need to engage young people because it may be their first contact with the medical services, especially considering the stigma young people might have regarding mental health issues (Wisdom et al. 2006). Furthermore, concentration and motivation may be impaired in those with depression (WHO 1992). Developing engaging and

effective intervention and prevention programmes for young people with depression is therefore a major challenge for services. One approach that may be useful is psychoeducation.

## **1.4 Increasing interest in psychoeducation**

### **1.4.1 Introduction to psychoeducation**

Psychoeducation or psychoeducational interventions can be described as the delivery of accurate information to individuals, families and carers about mental health or a specific diagnosis, management and prognosis and how affected individuals can stay well (Birmaher et al. 2007; Smith, Jones, & Simpson 2010; Colom 2011; Brent & Maalouf 2015). With appropriate psychoeducation, the adolescent, family and carer may feel more informed and empowered when making decisions about their welfare and care, and this can help with their general well-being and in the long-term management of any difficulties (Donker et al. 2009). There is some evidence that psychoeducational interventions for adults, particularly group interventions (alongside standard medical care), help individuals to develop self-management skills and greater confidence to make decisions about their own care (Smith et al. 2010 & 2011).

Much of the literature on psychoeducation has been in relation to individuals with schizophrenia and bipolar disorder and their families, although there has been increased interest in depression of late. A recent systematic review of the effectiveness of psychoeducation for depression in adults (Tursi et al. 2011), concluded that psychoeducation is effective in improving the clinical course, treatment adherence, and psychosocial functioning of individuals with depression. However, there is currently no published review focused on psychoeducation in adolescent depression. A review was conducted as part of this thesis to fill this knowledge gap (chapter 2).

### **1.4.2 Psychoeducation in adolescence**

AACAP recommend that psychoeducation is part of the early phase of treatment for children



and adolescents with depressive disorders, along with supportive management, and family and school involvement (Birmaher et al. 2007). Whilst the UK NICE guidelines (2005) do not explicitly use the term 'psychoeducation', it promotes the communication of good information to the patients and parent(s)/carer(s), especially with regards to the nature, course and treatment of depression. Psychoeducation could play a particularly useful part in the initial stages of management of adolescent depression (fig 1.2).

NICE also state that healthcare professionals should always ask patients about, and be prepared to give advice on, self help materials or other useful sources of info/help, including educational leaflets, helplines, self-diagnosis tools and peer, social and family support groups. Several organisations have explored how best to deliver information on mental health issues to young people and families, from illustrated literature to multimedia packages. For example, more consideration has been given over the last few years to the design and content of the information sheets and other publications of the Royal College of Psychiatrists in the UK (RCPsych 2011).

Educational tools for children and young people can be particularly creative and engaging, using formats such as fully-illustrated leaflets and narrative books, such as the 'Medikidz' series (medikidz.com), for depression and other disorders. There are also board games, for example 'Positive Thinking', which helps children become more aware of cognitive responses to situations, and interactive CDs to inform and educate.

### **1.4.3 Challenges of defining psychoeducation**

There is a lack of clarity about the definition of psychoeducation, and its distinction from other psychological approaches. Many might argue that psychoeducation is an essential component of various forms of psychotherapy, such as CBT, particularly in the early sessions, and might see psychoeducation as 'diluted CBT'. Colom, a pioneer of psychoeducation in mood disorders, stated in an editorial in the British Journal of Psychiatry in 2011, that psychoeducation has a 'branding problem', and 'blurry boundaries' with psychological and other approaches. There are also various approaches to the content of psychoeducation programmes, the mode of delivery - including family, group, individual, school-based and electronic formats - and their evaluation.

The definition, relationship with psychological therapies (such as CBT), content, design and evaluation of psychoeducational programmes are explored further in the review chapter (chapter 2) of the thesis. An investigation into how psychoeducational programmes should be designed and evaluated could provide guidance on how and what practitioners communicate with young people and families regarding depression. In addition, this would help to inform the development of future resources and interventions, and could help raise awareness of adolescent depression.

## **1.5 Emergence of e-mental health**

### **1.5.1 Introduction to e-health**

The use of digital technology is growing rapidly in personal and professional contexts, and has changed the way in which individuals and groups communicate and seek information. E-health is the application of digital technologies in health care, from the use of online educational websites for patients to the communication of healthcare data between clinicians (Hollis et al. 2015). 'E-mental health' or 'e-mh' are the terms used to describe the use of digital technologies in mental health care. This is a recognised UK government and NHS priority, demonstrated for example by the Chief Medical Officer's report which outlines 'information and communication technology' (ICT) to improve public access to health care information (CMO 2014; HM Government 2011; NIB 2016).

Online interventions address several issues, including autonomy and self-management, empowering patients to have greater choice and control; NHS costs in a difficult economic climate; waiting lists/time; and treatment flexibility, all of which are priorities for the NHS (Department of Health 2009; NICE 2006; Hollis et al. 2015). Accessibility is also a key priority. The internet and multimedia feature prominently in the lives of young people. In 2016, 89% of households had internet access, according to the Office of National Statistics (ONS), compared with 57% in 2006. Seventy-five percent of adults had used the internet 'on the go' using a portable device, and the most common type was a mobile phone or smartphone (ONS 2016). This rise has led to an increase in the number of e-health packages designed to be delivered via mobile phone, referred to as 'm-health' (Harrison et al. 2011; Donker et al.

2013).

There are also challenges in this area, including issues related to data protection, privacy and security, and the 'digital divide' between those who have access to the internet and those who do not, including those from poorer backgrounds and those with learning disabilities (Hollis et al. 2015). However, Ennis et al. (2012) found that the use of technological devices (such as computers, mobile/smart phones) was similar in patients with mental health disorders compared to the general population.

Many e-health programmes are developed without significant user involvement (including patients, families and professionals), and their evaluation is limited. Centres such as the NIHR MindTech Healthcare Technology Co-operative are building an evidence base and framework for evaluating digital products, and argue that the safety and efficacy of such interventions should be evaluated with the same rigour as that required for new drug and psychological treatments (Hollis et al. 2015).

### **1.5.2 Adolescents and electronic media**

In the authoritative textbook, 'Rutter's Child and Adolescent Psychiatry', the use of social media, technology (e.g. smartphones), and on-line material is identified as a key area of future clinical practice and research in the identification, prevention and treatment of depression in children and adolescents (Brent and Maalouf 2015).

The use of mobile devices has been explored as part of e-mental health packages for this age group. In 2016, almost all individuals aged 16 to 24 (97%) had accessed the internet 'on the go' using a mobile device, and the most commonly used was a mobile phone or smartphone, and 49% within this age group had searched for health-related information online (ONS 2016).

Young people use the internet more than other age groups for recreational activities such as social networking and playing or downloading games (ONS 2016). Gamification is an important component of recent packages for mental health to engage young people. For example, SPARX is a computer game developed in New Zealand, featuring an avatar

travelling around fantasy lands. It is CBT-based, but has elements of psychoeducation. Findings from a multicentre randomised controlled non-inferiority trial showed that the intervention was not inferior to treatment as usual, and could be a potential alternative for adolescents presenting with depressive symptoms in primary care settings (Merry et al. 2012).

As stated earlier, there is a need to develop and test engaging and interactive programmes for young people. E-health and ICT have been identified as particularly helpful for young people in addressing issues of social inclusion and access to mental health services (Hollis et al. 2015). Young people can have anxiety and stigma regarding mental health issues and accessing services (Wisdom et al. 2006). They may experience social withdrawal and problems with concentration or motivation during depressive episodes (WHO 1992). Online interventions can also address the issue of waiting time from primary care to secondary care (van Voorhes et al. 2009). Additionally, online psychoeducation packages can mobilise family and social support for the adolescent, by encouraging family/carers and friends to use the packages with the individual, and provide a focus for discussion on how to manage any difficulties.

### **1.5.3 Electronic CBT**

Online interventions for depression in adults, particularly using CBT, have been shown to be effective (Spek et al. 2007) and are recommended by NICE (2006) (e.g. Beating the Blues). Fewer are aimed at young people, although in recent years a number of computerised, online and mobile application interventions have been developed, including Stressbusters (Abeles et al. 2009) and Think Feel Do (Stallard et al. 2011) in the UK.

A systematic review of web-based interventions for youth emotional problems by Reyes-Portillo et al (2014) included seven programs for depression, five of which were based on CBT. They concluded that most studies reported reductions in symptoms of depression and/or anxiety, or improvements in diagnostic ratings post-intervention, and at follow-up. However, many studies were limited, for example because of their small sample sizes. Of the depression programs, 'MoodGYM' (O'Kearney et al. 2009) and 'Master your Mood Online' (Gerrits et al. 2007) were considered most promising, with both described as 'possibly

efficacious' (level 3 out of 5 levels of efficacy). Given the limited evidence, the authors recommended further research in this area and suggested that more web-based programs are developed in the future. Most of the programs have an element of psychoeducation, particularly at the introductory stages, although it is difficult to evaluate how much this contributed to the overall patient outcomes.

#### **1.5.4 Electronic psychoeducation**

The literature on online psychoeducation packages is sparse. Christensen et al. (2004), evaluated the efficacy of a psychoeducation website called 'Blue Pages' offering 'depression literacy' in a community-based three arm RCT of adult participants. This website was compared with 'MoodGYM', a CBT website, and attention placebo controls (telephone calls). They found that both online psychoeducation and CBT reduced symptoms of depression, and 'BluePages' significantly improved understanding of evidence-based treatments for depression.

There are many websites with general information on mental health issues for young people (YoungMinds, r-u-ok (UK), Headspace (Australia), Headstrong (Ireland)). Some take a more creative approach, for example by designing the website in the form of a park or other setting through which the user can navigate (depressioninteenagers.co.uk (UK)). There are also more complex packages, such as 'Biteback' (Australia) and 'The Lowdown' (New Zealand), where musicians and television personalities guide the user through the package, with music, short videos and personal accounts of depression by young people and celebrities. However, little has been published on their development and evaluation.

Current psychoeducational programmes for adolescent depression are explored further as part of the review chapter on psychoeducation for adolescent depression (chapter 2). There is a lack of well-researched online psychoeducation packages developed with user input and specifically targeted at adolescent depression. Most are aimed only at those with depression or depressive symptoms, and not at those at high risk. The packages available tend to focus on CBT, rather than psychoeducation. Few are based on extensive mixed research methods that include the involvement of potential users (including adolescents, families and carers),

professionals from various agencies and experts in aspects such as multimedia, education and psychotherapy.

The more advanced packages have been developed in the USA, with some in Scandinavia and Australasia. There are potentially important cultural differences, for example in service structure and language, which might make it difficult to implement these packages in different countries. Those in the adolescent age group might be particularly sensitive to such differences. Finally, few interventions have rigorous development and testing in line with recognised frameworks for the development and evaluation of complex interventions, such as those of the MRC (Craig et al. 2010).

With increasing use of digital technologies in the everyday lives of young people, and the benefits of e-mental health described earlier, the emergence of e-health may be inevitable, especially in the context of child and adolescent mental health. It is possible that 'electronic psychoeducation' or 'psychoeducational interventions' will emerge as important components of child and adolescent services.

## **1.6 Aims of research project/doctorate, research question**

The overall aim of the doctoral research project is to design, develop and evaluate a user-friendly online psychoeducation multimedia package with and for young people with (or at high risk of) depression and their families/carers, which could be used regularly within everyday health, social, education and youth services. This is done using a mixed methods approach in line with the MRC framework for development and evaluation of complex interventions (Craig et al. 2010). A detailed account of the methodology is given in chapter 3 of the thesis.

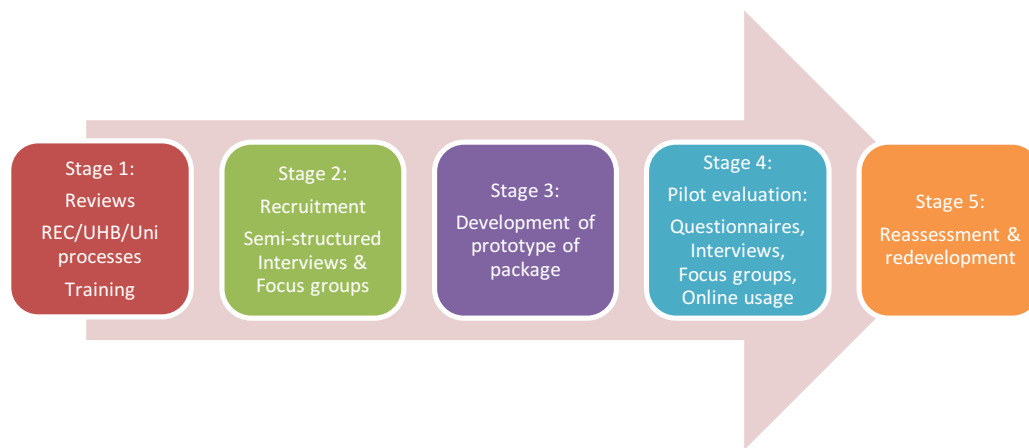


Fig 1.3: Overall research plan for the project

The specific aims of the doctoral research project are as follows.

1. To systematically review the literature and practice of psychoeducation in adolescent depression, which will give clarity on the definition of psychoeducation as an approach, and inform the content and design of the psychoeducation programme (see chapter 2);
2. To gather and understand the views of potential users on how the online package should be developed, by collating and analysing qualitative data from semi-structured interviews and focus groups with adolescents, families/carers and professionals (see chapters 4 and 5);
3. To develop a prototype of the package in conjunction with a multimedia company (see chapters 5 and 6);
4. To explore the feasibility and acceptability *of the evaluation process* (e.g. with regards to questionnaires included) of the initial prototype (quantitative and qualitative analysis - see chapter 7);
5. To assess the feasibility, acceptability, ease of use, clarity, relevance and persuasiveness *of the initial prototype* (quantitative and qualitative analysis - see chapter 7);
6. To explore the impact of the prototype on depression and anxiety symptoms, depression literacy and stigma, help-seeking behaviour and self-efficacy (quantitative analysis - see chapter 7);
7. To reassess and redevelop the package in response to this evaluation (see chapter 8 - discussion);
8. To disseminate the findings of the study in newsletters for individuals and families/carers, reports for policy makers, academic journals and online

communication for the general public (see chapter 8 - discussion).

Whilst there are specific research questions aligned with each of these aims, the overall research question is:

**Is a psychoeducation package for adolescent depression developed through a process of engagement with users and professionals - feasible, acceptable and potentially effective?**



## **Chapter 2:**

# **Psychoeducational interventions in adolescent depression: a systematic review**

## **2.1 Introduction**

Much of the literature on psychoeducational interventions (PIs) has been in relation to individuals with schizophrenia and bipolar disorder and their families (Birmaher et al. 2007; Smith et al. 2010; Miklowitz et al. 2013), although there has been increasing interest in depression. Findings from a recent systematic review concluded that PIs are effective in improving the clinical course, treatment adherence, and psychosocial functioning of adults with depression (Tursi et al. 2013). However, there is no published review on PIs in adolescent depression. This is an important knowledge gap; depression is more common than bipolar disorder and schizophrenia, and the presentation and management of depression is different in young people compared to adults, as might be their response to PIs.

PI has been described as the delivery of accurate information to individuals, families and carers about mental health or a specific diagnosis (including possible causes and symptoms), management (including associated risks/side-effects) and prognosis, and how affected individuals can stay well (Birmaher et al. 2007; Smith, Jones, & Simpson 2010; Brent & Maalouf 2015). However, there is a need for more clarity about the definition of PIs and how these programmes should be designed and evaluated. Further investigation could not only help inform the development of the current online package, but have implications on clinical practice, by informing the way in which practitioners communicate with young people and families regarding depression (and future resources, interventions and guidelines), and raising public awareness of adolescent depression.

A systematic review was conducted of the published literature on PIs for adolescents with (or at high risk of) depression, as part of the first stage of the research plan (see fig 2.1). The aim of the review was to i) define/describe PIs; ii) systematically search and review the

literature investigating PIs in the context of adolescent depression; iii) summarise the evidence for the effectiveness of different PI programmes.

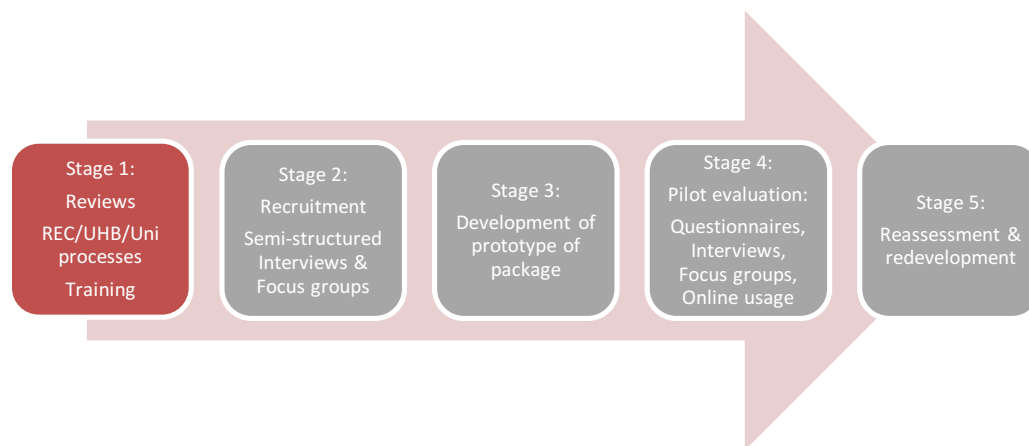


Fig 2.1: Broad stages of the research plan

## 2.2 Methods

### 2.2.1 Selection criteria

Inclusion criteria were: studies of PIs (as defined earlier) targeting depression as part of prevention or management approaches in the adolescent age group (studies were included if participants were within the age range of 12 to 18 years); targeted programmes for individuals with depression/depressive symptoms (which could include relapse prevention) OR those at high-risk, and/or their families/carers. Studies were included only if there was some evaluation of the response of adolescents or families/carers (and no other groups, such as teachers), with quantitative or qualitative methodology.

Articles were restricted to those published or translated into English. Articles were also considered if only elements of the published study were of relevance, for example if the control group in a trial was given a PI.

Exclusion criteria were as follows: only adults or young children, other mental disorders only (including bipolar disorder), non-psychiatric disorders, established therapeutic approaches alone (including cognitive behavioural therapy (CBT)) or no evaluation of the programme. Universal programmes or general health information/education (e.g. in printed leaflets)

were not considered. Single case reports/studies were excluded, but otherwise there were no restrictions on the format of the PI, study design, presence of a comparison/control group, or length of follow-up. This inclusive approach to the search was taken, as the initial search for PI randomised controlled trials (RCTs) returned a small number of papers.

### **2.2.2 Search strategy**

Searches were conducted in PubMed, PsycINFO and EMBASE by two independent investigators (the student and Zoe Stone (Medical Student, Cardiff University)). Search terms included 'adolesc\*' or 'young' or 'youth' or 'teen\*' or 'famil\*' or 'school' or 'college' AND 'psychoed\*' AND 'depress\*' in the title or abstract, with no restriction regarding publication dates (see fig 2.2, flow diagram). These searches were performed up to March 2016.

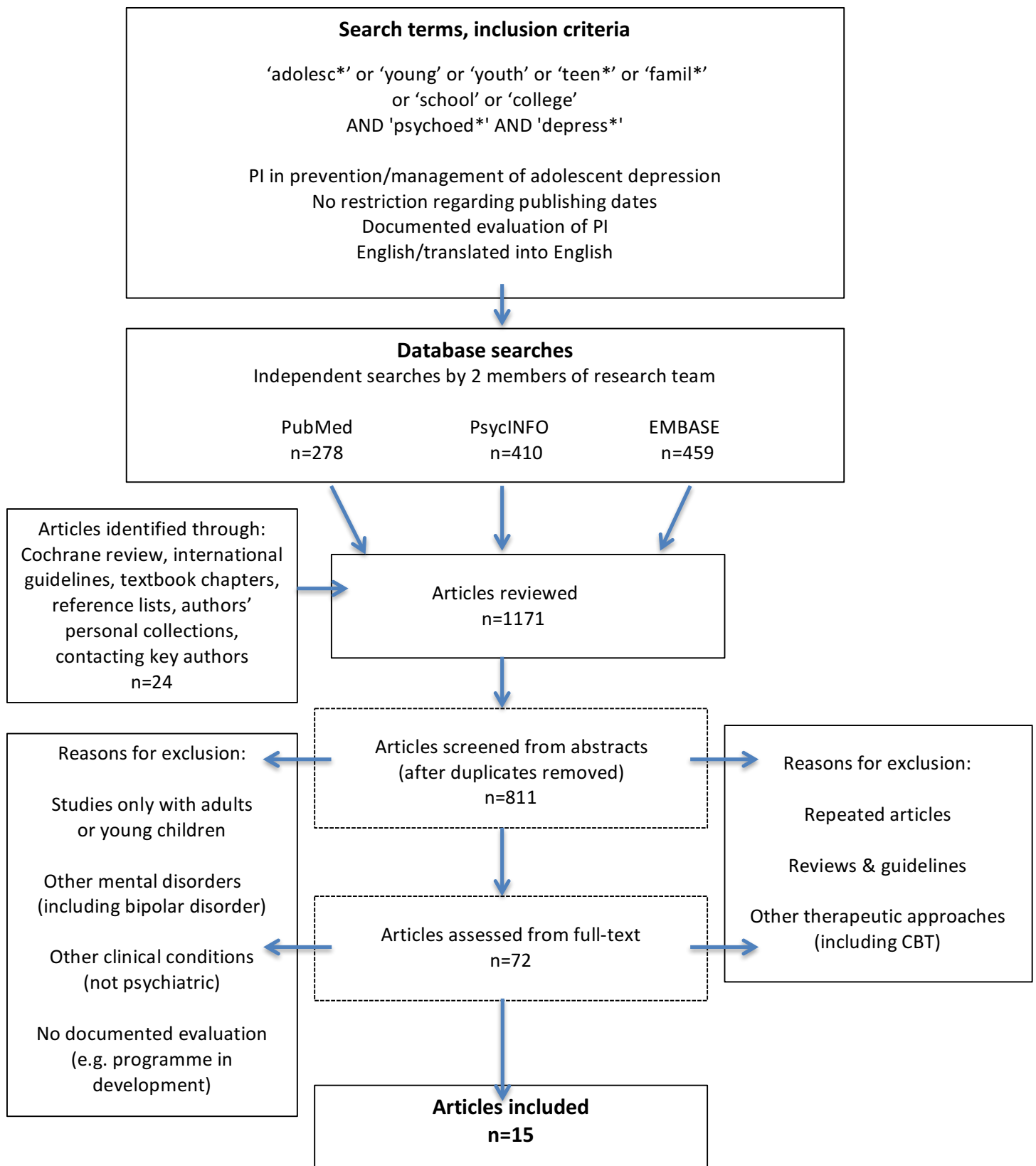
Articles were also identified through reference lists and the authors' personal collections, including studies in the Cochrane review on 'Psychological and educational interventions for preventing depression in children and adolescents' (Merry et al. 2011). International guidelines were also reviewed on the assessment and management of adolescent depression (including those of NICE (2005) and AACAP (Birmaher et al. 2007), chapters in relevant textbooks (e.g. 'Rutter's Child and Adolescent Psychiatry' (Thapar et al. 2015)), and printed/online educational material by various organisations (e.g. Royal College of Psychiatrists (RCPsych), NICE (UK), AACAP (USA), Black Dog Institute, Orygen Youth Health (Australia)). Key authors with expertise in adolescent depression interventions were contacted, and authors were contacted for further details on studies, for example with regards to included participants and follow-up.

### **2.2.3 Study selection, data extraction**

Data extracted from the studies were recorded independently by the investigators in a table, with columns including mode of delivery of PIs, study design, participant characteristics, assessment/follow-up, and findings. Zoe Stone and the student independently reviewed all the abstracts and extracted data, and discussed the final studies to be included in meetings held following the independent searches. Where there was disagreement, both researchers

reviewed the studies together before deciding on whether the studies were included. Other research team members (Sharon Simpson, Daniel Smith (both University of Glasgow), Anita Thapar, Ajay Thapar, Ian Jones (all Cardiff University)) were also consulted where there was uncertainty or disagreement.

**Fig 2.2: Flow diagram: Methodology for article selection**



## 2.3 Results

### 2.3.1 Description of PI

The findings from the review suggested there are many ways in which PI for adolescent depression can be delivered and categorised, broadly ranging from ‘one-to-one’ approaches to multi-group and family approaches. Programmes can also vary according to the number of participants (individual, family, group), setting (community, school, service), and mode of communication (printed, online, game, lecture). Several formats and approaches can also be adopted by a single programme.

PIs have been described as passive or active (Donker et al. 2009). However, a search of the literature suggested that programmes may be a mixture of both, for example online interventions could communicate information ‘passively’, but with interactive components and access to therapists or forums. A similar approach was used to categorise studies according to whether programmes were ‘proximal’/‘in person’ or ‘long distance’ (e.g. online, mail-outs). They could also be described according to the participants or whose response was evaluated – young person, family, other (e.g. teacher), or a combination.

Fifteen studies were identified that met the inclusion criteria (see flow diagram). In the following sections, the studies are presented according to whether they targeted adolescents with a current diagnosis of depression or depressive symptoms, and/or their families (some included relapse prevention) (7 studies), or whether they focused on adolescents ‘at risk’ (8 studies), for example if there was a family history of depression. PIs were also subcategorised according to whether they took a predominantly family/group (10 studies), individual (2 studies), or online approach (3 studies). All ‘in person’ studies in the review (12 studies) involved a professional as a facilitator, whilst the ‘long distance’ studies (3 studies) did not.

Within each subcategory, the studies are presented according to a hierarchy of evidence, whereby RCTs are presented first, whilst small-uncontrolled studies are discussed last. Eight of the studies were RCTs. The outcomes of interest included understanding, attitude, behaviour change, (family) communication and support, and mental health outcomes (depression, anxiety, aggression).

## **2.3.2 Adolescents with depression:**

### **PI for adolescents and families/carers (seven studies, table 2.1)**

#### **2.3.2.1 Family PI**

Sanford et al. (2006) carried out a pilot RCT of a programme in Canada, comparing the effectiveness of twelve structured sessions conducted at home, with usual treatment for adolescents meeting DSM-IV criteria for major depressive disorder (MDD). Sessions aimed to increase family knowledge about depression, understand effects and improve communication and coping strategies. Sixteen adolescents (aged 13-18 years) and their families participated in the intervention group, and 15 in the control (individual or group counselling). Assessments were done at baseline and three-monthly intervals up to nine months. The programme improved adolescent social functioning, family relationships, depressive symptoms and duration of remission, and participants reported greater satisfaction compared to counselling.

The 'Children's Medication Algorithm Project' in the USA targeted young people with depressive disorder, ADHD or both (diagnosed by the treating psychiatrist) - to improve compliance with medication and coping strategies (Lopez et al. 2005). The information encompassed medication, self-monitoring, lifestyle and coping advice. It was general at first, but then tailored to families' needs and developmental age, and available in different formats. There was no fixed number of sessions (median=6). Ninety participants (aged 6-17 years) were recruited from community clinics, and asked to complete surveys at baseline and after four months. Most caregivers and children were happy with the amount of information and found it helpful. The authors reported (in personal communication) that the programme was completed, but follow-up results were not analysed.

Brent et al. (1993) described a feasibility study of a programme for parents of adolescents with depression, cited in AACAP parameters. This consisted of a session on diagnosis (depression as a chronic, recurrent illness), course and treatment, and methods of coping with a family member with depression. Sixty-two parents and 34 adolescents participated.

There was an improvement in their knowledge, and modification of dysfunctional beliefs about depression and treatment. Almost all participants described this as useful and interesting.

### **2.3.2.2 Individual PI**

PI was provided to a control group in a factorial RCT to evaluate low-intensity interventions in young people, with mild-moderate depression and/or anxiety, in Australia (Parker et al. 2016). The mean age of participants was 17.6 years (range 15-25 years). The group was delivered 'lifestyle' PI, particularly on physical activity, sleep and substance use, by psychologists in six manualised weekly sessions. Eighty-six young people participated in this group, whilst 88 received the 'intervention', behavioural activation physical activity (BAPA). Depressive symptoms reduced in both groups, but BAPA was more effective, although there was no reported follow-up.

### **2.3.2.3 Computerised/Online PI**

A school-based RCT in New Zealand included a 'psychoeducation computer programme' (CPE) in the control arm, versus the main intervention, a computer 'fantasy game' with CBT content, 'The Journey' (Stasiak et al. 2012). The latter comprised seven modules, including ones on problem solving, conflict resolution, challenging unhelpful thoughts and relaxation techniques. CPE had a similar structure, but was more 'instructional' than therapeutic, and covered depression, 'mental health hygiene' and stress reduction. Seventeen adolescents (aged 13-18 years) with low mood participated in each group, referred from school counsellors. These were assessed at baseline, post-intervention and one month. Reductions in depression scores were seen in both groups, but greater in the CBT group. Participants reported the CPE had been helpful. There was favourable feedback on the computer-based format, although some felt it was more suited to younger ages.

The 'Depression Experience Journal' website served as a platform for children and adolescents, families and professionals to share their personal experiences of living/working with mental illness (Demaso et al. 2006). This aimed to 'facilitate healthy coping', and could



be used individually or with others. A feasibility trial in the USA included 38 primary caregivers, each with a child aged 8-19 who had been admitted to hospital because of mental health difficulties. Assessments were done at baseline and 2-4 weeks after use. Parents were satisfied overall with the way information was presented, and personal stories were most helpful. They suggested increasing the number and range of narratives, and making the site more interactive.

Stjernswärd and Hansson (2014) conducted an exploratory trial of a web-based supportive intervention for relatives of those with depression, in Sweden. This included a psychoeducation module, diary and forum. One of the discussion themes was the youth to adult transitions. The 25 participants (aged 18-80 years), included parents and other relatives of young people with depression, or those who had suffered from a young age, although the authors noted (in personal communication) it was unclear how many were adolescents. The tool was generally well-received, and highlighted how web-based support could help with feelings of social isolation.

### **2.3.3 Adolescents at risk of depression:**

#### **PI for adolescents and families/carers (eight studies, table 2.2)**

A family history of depression is one of the best-known risk factors for adolescent depression (Rice, Harold, & Thapar 2002). Children of depressed parents are therefore a potential target group for depression prevention programmes. Another major risk factor for depression in young people is psychosocial stress, which is another consideration when developing prevention programmes (Institute of Medicine 2009).

##### **2.3.3.1 Family PI where there is parental depression**

Five studies focused on adolescents at risk because they had a parent with depression. Beardslee et al. (1997a) described an intervention targeting parents with depression and their asymptomatic child, in the USA. It consisted of 6-10 sessions facilitated by clinicians,

and the main concepts were increased familial understanding of the disorder, and appreciation of children's experience of parental illness. The pilot study included 19 families in the intervention group, 18 in the control (lectures on depression, its effects and warning signs), each with an 8-15-year-old child. Assessments were done at baseline and after eight weeks. Adults in the intervention group were happier with the information received, and reported greater understanding of their feelings about mood disorders and increased marital support. There was also improved communication with their children about their illness because of increased understanding in both parent and child.

The authors established sustained positive effects on these outcomes 1.5 years after enrolment (Beardslee et al. 1997b), and identified specific 'healing principles' that contributed to the positive changes in family behaviour and attitudes, which enhanced resilience in children (Beardslee et al. 1998). These principles were based on findings from the first 12 families to complete the intervention, and included demystification of the illness, modulation of shame and guilt, increase in the capacity for perspective taking, development of a hopeful perspective and a belief in one's own competence.

AACAP parameters referred to a RCT by Beardslee et al. (2003) with the same recruitment criteria. The study design was updated with telephone contacts/refresher meetings carried out at 6-9 month intervals. There was focus on linking the educational material to a family's individual experience, reducing feelings of guilt and blame, and helping children learn to build relationships within and outside of the home. Fifty-three families participated in the intervention arm, and 40 in the 'lecture' control group. Assessments were made at baseline, post-intervention, after 1 and 2 years. There were long-term effects on how families address problems regarding parental mental illness. Parents reported that the intervention was more beneficial than the lecture in changing child-related behaviour and attitudes. Children reported increased understanding of parental illness and reduced depressive symptomatology after the intervention over two years.

PI was a substantial component of the 'Family Talk Intervention' (FTI) in Finland (Solantaus et al. 2010). This consisted of a minimum of six sessions, and guidebooks were provided to participants. Two parent sessions were followed by one with each child. Parents were taught about depression, and how to talk about it with family members, cope with family problems and answer children's questions. In an RCT, 53 parents treated for a mood disorder (and

partners) participated in FTI, and 56 (controls) underwent 'Let's Talk about the Children (LT)', a brief PI parent discussion to assess and support the child (aged 8-16). They completed questionnaires at baseline and 4, 10 and 18 months post-intervention. An improvement was seen in children's prosocial behaviour and reduction in their emotional symptoms and anxiety in both groups, although they were noted earlier in the group who received FTI.

### **2.3.3.2 Other family PI**

Two family PI studies targeted adolescents at elevated risk of depression due to psychosocial stress exposure. Jordans et al. (2013) conducted a controlled (pilot) trial of a parenting group PI, in Burundi. This was part of a larger mental health package for low and middle-income countries, and targeted families reporting high levels of psychosocial stress due to political violence. Sessions focused on communication, problems affecting children and how to manage them. Fifty-eight children aged 10-14 years (and their parents) were recruited from the 'treatment school', and 62 from the 'control school' (waiting list for intervention). Assessments were made at baseline and three weeks post-intervention. No improvement was seen in child depressive symptoms or perceived family support, although parents in the intervention arm saw an improvement in their child's aggression, especially in boys. Most parents reported they were satisfied and had learned to be 'better parents'.

A controlled (exploratory) trial of 'Egokitzen', a post-divorce intervention for parents and their children, comprised 11 weekly sessions on divorce, interparental conflict, and parenting styles and discipline (Martinez-Pampliega et al. 2015). Thirty-four parents and 51 children (aged 2-23 years) participated, and six parents and nine children were in a comparison group (waiting list). They did not state how many adolescents participated, although eight were over 13 years old. The outcomes included child depression, anxiety and aggression symptoms, as well as interparental conflict, family communication, perception of family relationships, and parental symptomatology. There was some effect of the intervention on the children's mental health symptoms, including depression, particularly in the 6-month follow-up.

### **2.3.3.3 Individual PI**

Barnet et al. (2007) described a RCT in the USA of a community-based home-visiting programme for adolescent mothers. The authors noted how this group was at risk of becoming pregnant again, depression, school dropout, and poor parenting. Home visitors were paired with each adolescent through the child's second birthday, and delivered a parenting curriculum, encouraged contraceptive use, connected the adolescent with primary care, and promoted school continuation. Forty-four adolescents (aged 12-18 years) were in the home-visited group, and 40 in a control group (usual care), predominantly with low incomes and of African-American origin. Structured interviews were done at baseline and 1 and 2 years' follow-up. This programme improved adolescent mothers' parenting attitudes and school continuation, but it did not reduce their odds of depression or repeat pregnancy, or achieve coordination with primary care.

**Table 2.1: Studies of psychoeducational interventions (PIs) for adolescents with depression, and families/carers**

Study, country	Details of Intervention (and control)	Study Design	Participant characteristics (n)	Assessment, follow-up	Findings
<b>Family PI</b>					
Sanford <i>et al</i> (2006), Canada	<p><b>Intervention:</b> Adjunctive PI: group sessions with all family members at home, PLUS usual treatment.</p> <p>Twelve structured interactive 90-minute sessions, with manual. Aims: increase family knowledge about depression, appreciate effects on family, improve communication between adolescent and family and coping strategies.</p> <p><b>Control:</b> Usual treatment: individual/group counselling.</p>	Randomised controlled trial  (feasibility, effectiveness)	31 adolescents aged 13-18 years (20 females: 11 males), meeting DSM-IV criteria for MDD, and their families.  (16:15)	<p><b>Primary outcomes:</b> Reynolds Adolescent Depression Scale (RADS); Structured Social Adjustment Interview (SSAI) (adolescent social functioning); Family Assessment Device (FAD) (family functioning); Adjective Checklist (ACL) (adolescent-parent relationship)</p> <p><b>Secondary outcomes:</b> Children's Global Assessment Scale (CGAS) (adolescent); Client Satisfaction Questionnaire (CSQ) (parent satisfaction with services)</p> <p>Baseline (plus retest at 2 weeks), 3 months (mid-treatment), 6 months (post-treatment), 9 months (follow-up)</p>	<p>Intervention improved RADS, SSAI, ACL post-treatment and follow-up, compared to usual treatment: effect size &gt;0.5 for all. Effect size for RADS on follow-up: 0.64.</p> <p>Greater satisfaction reported with intervention.</p>
Lopez <i>et al</i> (2005), USA	<p><b>'Children's Medication Algorithm Project (CMAP)':</b> Group intervention facilitated by clinicians/assistants, with manual, on medication, self-monitoring, lifestyle, coping strategies. Programme structured but could be tailored to families' needs. Several available formats. No fixed number of sessions (median:6).</p>	Feasibility trial with 2 arms	90 children aged 6-17 years (26 females: 64 males) with diagnosis of depressive disorder, ADHD or both, being treated with medication in 4 community clinics.	<p>Parent Satisfaction Questionnaire; Child/Adolescent Satisfaction Questionnaire; CMAP Education Log</p> <p>Baseline, then 4-month intervals</p>	<p>Majority of caregivers (63%) and children (60%) happy with amount of information and found this helpful. 20% of parents and 14% of children/adolescents received much more information than they wanted. 90-100% of children and parents found written materials helpful.</p> <p>Programme successfully implemented, but follow-up data not analysed</p>

	Aims: improve compliance with medication and coping strategies.				(confirmed from personal communication with student).
Brent <i>et al</i> (1993), USA	2-hour session with manual, for parents on diagnosis, course, treatment, methods of coping with family member. Depression described as a chronic, recurrent illness.	Trial of acceptability, feasibility, efficacy	62 parents of 34 adolescents (22 females: 12 males) with mood disorder (primarily depressive disorder).	Questionnaire on attitude and knowledge about depression, and views of the programme  Baseline, post-intervention	Improvement in knowledge, modification of dysfunctional beliefs about depression and treatment. 'Significant improvement' on 8/21 questionnaire items, decline in one item.  Useful, interesting for almost all (97%) participants.

#### INDIVIDUAL PI

Parker <i>et al</i> (2016), Australia	<p><b>Simple low-intensity interventions.</b></p> <p>Up to 6 manualised weekly sessions.</p> <p>Exercise: Behavioural activation physical activity (BAPA) v <b>Lifestyle psychoeducation</b> (e.g. physical activity, sleep, substance use)</p> <p>Psychological: Problem solving therapy v Supportive counselling.</p>	<p>Factorial (2x2) randomised controlled trial</p> <p>(acceptability, effectiveness)</p>	<p>176 help-seeking 15-25 year olds (mean age 17.6 years) with sub-threshold or mild-moderate depression/anxiety.</p> <p>Lifestyle PI:86 (53 females:33 males), BAPA:88 (53 females:35 males)</p>	<p><b>Primary outcomes:</b></p> <p>Beck Depression Inventory-II (BDI-II); Montgomery-Asberg Depression Rating Scales (MADRS); Beck Anxiety Inventory (BAI)</p> <p><b>Secondary outcomes:</b></p> <p>Clinical caseness; Substance (use) and Choices Scale; Social and Occupational Functional Scale; Active Australia (physical activity) Survey; Questionnaire on other interventions received</p> <p>Baseline, post-intervention</p>	<p>Reduction in depression symptoms in BAPA and PI groups, greater reduction with BAPA, but not anxiety symptoms. Effect size post-intervention: BDI-II: d=0.41 (95% CI 0.07-.0.76); MADRS: d=0.48 (95% CI 0.13-0.82).</p> <p>Lifestyle PI: BDI-II (mean): Baseline: 22.23, Post-intervention 14.09; MADRS (mean): Baseline: 20.44, Post-intervention 12.87; BAI (mean): Baseline: 15.56, Post-intervention 7.88.</p> <p>Problem solving therapy not superior to supportive counselling. No interactions between interventions.</p>
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## COMPUTERISED/ONLINE PI

Stasiak <i>et al</i> (2012), New Zealand	<p><b>Intervention:</b> <b>‘The Journey’</b>, computerised CBT programme (cCBT) at school, with guidebook. No school counsellor support unless requested.</p> <p>7x 25-30 minute multimedia modules (‘fantasy game-like environment’), on problem solving, conflict resolution, identifying and challenging unhelpful thoughts, relaxation techniques.</p> <p><b>Control:</b> <b>Psychoeducation computer programme (CPE).</b> Same structure as above but different content – on depression, ‘mental health hygiene’, stress reduction. CPE more ‘instructional’ than ‘therapeutic’.</p>	Randomised controlled trial  (feasibility, acceptability, effectiveness).	34 adolescents (13-18 years) with low mood (14 females: 20 males), self-referred to school counsellors across 8 urban schools.  (17:17)	<p>Primary outcome: Child Depression Rating Scale Revised (CDRS-R);</p> <p>Secondary outcomes: RADS-2; Pediatric Quality of Life Inventory (PedsQL); Adolescent Coping Scale (ACS)</p> <p>Acceptability: Brief satisfaction questionnaire</p> <p>Baseline, post-intervention, 1-month follow-up</p>	<p>Reductions in depression scores in both groups, greater reduction with cCBT.</p> <p>CDRS-R mean change: cCBT=17.6 (CI=14.13-21.00); CPE=6.1 (CI=2.01-10.02); <math>p&lt;.001</math>. Effect size between groups: 1.7.</p> <p>CPE had been helpful, positive feedback on computer-based format. Some felt it was more suited to younger ages.</p>
Demaso <i>et al</i> (2006), USA	<b>‘Depression Experience Journal (EJ)’</b> : website for children/adolescents, families and healthcare professionals to share personal experiences of living/working with mental illness (to ‘facilitate healthy coping’). Used individually or with others.	Development trial – feasibility, safety	38 primary caregivers, each with a child aged 8-19 years (26 females: 12 males) with depression, during a psychiatric hospital admission.	<p>2 semi-structured interviews: First assessed families’ experiences of child’s depression and management; Second on views of intervention: using satisfaction &amp; safety, concerns/areas for improvement, specific impacts, coping response &amp; attitude change scales.</p> <p>Baseline, 2-4 weeks after use</p>	<p>Parents satisfied overall with EJ and presentation of stories and facts. Personal stories most helpful.</p> <p>They suggested greater number and wider variety of narratives, and more interactivity.</p>
Stjernswärd & Hansson (2014), Sweden	Web-based support for relatives of individuals with depression – psychoeducation module, diary, forum.	Explorative open trial	25 relatives of individuals (including adolescents) with depression.	<p>System usability scale (questionnaire); Content analysis of forum</p>	<p>Generally well-received.</p> <p>Intervention could help e.g. with feelings of isolation.</p>

**Table 2.2: Studies of psychoeducational interventions (PIs) in adolescents at high-risk of depression, and families/carers**

Study, country	Details of Intervention (and control)	Study Design	Participant characteristics (n)	Assessment, follow-up	Findings
<b>Family PI (parental depression)</b>					
Beardslee <i>et al</i> (1997a), USA	<p><b>Intervention:</b> Preventive group intervention facilitated by clinicians, with manual. 6-10 sessions (mean 7.7) attended mainly by parents; adolescents attended at least one clinician meeting and one family meeting.</p> <p>Main concepts: increased familial understanding of the disorder, appreciation of children's experience of parental illness and potential effects.</p> <p><b>Control:</b> 2x1-hour lectures to small groups, attended by parents only - on depression, its effects and warning signs.</p>	<p>Randomised controlled trial</p> <p>(‘First-phase pilot study’)</p>	<p>37 families, each with an asymptomatic (non-depressed) 8-15-year-old child (53 children in total, 21 females: 32 males), and at least one parent who had experienced a mood disorder (primarily depression) within 18 months</p> <p>(19:18)</p>	<p>Semi-structured Interview about Disorder Impact and Intervention (parent) (SII) (family functioning; illness-related behaviour; benefits from intervention)</p> <p>Semi-structured Child Interview (SCI) (functioning; knowledge, feelings, experience of parent depression; coping style, perception of change)</p> <p>Baseline, post-intervention (8.6 weeks on average)</p>	<p>Intervention parents:</p> <ul style="list-style-type: none"> <li>-happier with factual information received than controls.</li> <li>-reported greater understanding of their feelings about mental illness and increased marital support.</li> </ul> <p>Improved communication with children about their illness because of increased understanding in parent and child.</p>
Beardslee <i>et al</i> (1997b), USA	See details above	<p>Randomised controlled trial</p> <p>(Efficacy study to establish sustained effects)</p>	See details above	<p>Semi-structure interviews as above</p> <p>Second follow-up, 1.5 years after enrolment</p>	Intervention parents reported more positive changes than controls. Scores similar to those recorded post-intervention, which demonstrated sustained effects.



Beardslee <i>et al</i> (1998), USA	As above  Authors explored 'healing principles' that contributed to positive changes in family behaviour and attitudes, which in turn enhanced resilience in children.		First 12 families to complete intervention above	As above; clinical case discussions  Follow-up (at least 3 years)	Healing elements identified included: - demystification of illness, - modulation of shame and guilt, - increase in capacity for perspective taking, - development of hopeful perspective and belief in own competence.  Families developed shared understanding of illness.
Beardslee <i>et al</i> (2003), USA	As above  Telephone contacts/refreshers meetings at 6-9 month intervals, with psychologists, social workers, nurses.  Educational material linked to family's experience, reducing feelings of guilt/blame and helping children to build relationships within/outside of home.	Randomised controlled trial  (Large-scale efficacy trial)	93 families (121 children, 52 females: 69 males), same criteria as above  (53:40)	Schedule for Affective Disorders and Schizophrenia-Lifetime Version (SADS-L) & Streamlined Longitudinal Interval Continuation Evaluation (SLICE).  Schedule for Affective Disorders and Schizophrenia for School-Age Children, Epidemiologic Version Revised (Kiddie-SADS-E-R) & Kiddie-Streamlined Longitudinal Interval Continuation Evaluation (K-SLICE).  Global Assessment Scale (GAS).  Youth Self-Report (YSR).  SII & SCI (see previous Beardslee et al. studies)  Baseline, post-intervention, 1 and 2 years after enrolment	PI had long-term effects on how families address problems regarding parental mental illness. Parents found intervention more beneficial than lecture in changing child-related behaviour and attitudes.  Children reported increased understanding of parental illness over lecture group ( $\chi^2_1 = 8.2$ , $p = 0.004$ ).  All children reported reduced depressive symptomatology over 2 years since intervention. ( $\chi^2_1 = 7.3$ , $p = 0.007$ ), but no significant effect of group on this change ( $\chi^2_1 = 0.2$ , $p = 0.69$ ).
Solantous <i>et al</i> (2010), Finland	<b>Intervention:</b> <b>'Family Talk Intervention (FTI)'</b> preventive programme, included psychoeducation. Minimum 6 sessions	Randomised controlled trial  (Efficacy study)	109 parents with a mood disorder (primarily depression) and their partners, who had at least	Beck Depression Inventory (BDI); Spielberger State Anxiety Inventory (STAI); Strengths and Difficulties Questionnaire (SDQ); Screen for Child Anxiety Related Emotional Disorders	In both groups: - improvement seen in children's prosocial behaviour - reduction in

	(more for families with >1 child), with manual. 2 parent-focussed sessions followed by session with each child - on depression, how to talk about it with family members, coping with family problems and answering children's questions.		one child aged 8-16 years (not treated for psychiatric disorder)  (53:56)	(SCARED).  Baseline, 4, 10 and 18 months post-intervention.	emotional symptoms and anxiety.  Changes noted sooner with FTI (baseline-4 months) than LT (4-10 months). No group differences after 10-18 months follow-up.  Marginal decrease in hyperactivity in both groups.
	<b>Control:</b> <b>Let's Talk about the Children (LT)'</b> : brief, child-focussed, discussion with parents to assess child's situation and support them. Duration: single 15-minute session to 2x45-minute sessions.				

### Family PI (psychosocial stress)

Jordans <i>et al</i> (2013), Burundi	<p><b>Intervention:</b> Group-based parenting programme, adapted from manual for parents about helping children cope with political violence.</p> <p>Facilitated by 2 community counsellors (attended by parents only). 2 sessions: First (2.5 hours) on problems affecting children and communication, second (3 hours) on how to manage difficulties.</p> <p>Part of larger mental health package for low and middle-income countries.</p> <p><b>Control:</b> Waiting list.</p>	Controlled trial	<p>120 children aged 10-14 years with high levels of psychosocial stress on screening due to political violence (and their parents)</p> <p>(58 (32 females: 27 males): 62 (39 females: 23 males))</p>	<p>Primary outcomes: Depression Self-Rating Scale (DSRS); Aggression Questionnaire.</p> <p>Secondary outcome: Family Social Support scale</p> <p>Baseline, 3-weeks post-intervention</p>	<p>Intervention parents saw improvement in child's aggression, effect size <math>d=0.60</math> (<math>p&lt;.001</math>), especially in boys.</p> <p>No improvement in depressive symptoms or perceived family support.</p> <p>Majority of parents satisfied with intervention, and learned to be 'better parents'.</p>
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Martinez-Pampliega <i>et al</i> (2015), Spain	<p><b>Intervention:</b> ‘Egokitzen’: Post-divorce parent intervention. 11 weekly (1.5 hour) sessions, with role-playing, debates, group activities - on divorce, interparental conflict, parenting styles and discipline.</p> <p><b>Control:</b> Waiting-list</p>	Controlled trial (exploratory, ‘quasi-experimental’)	34 parents, total of 51 children (31 females: 25 males), aged 2-23 years (including 6 family controls).	<p>Child Behavior Checklist (CBCL); Symptoms Checklist (parental) (SCL-90); O’Leary-Porter Scale of Marital Conflict (OPS); Family Communication Scale.</p> <p>Baseline, post intervention, 6-months follow-up</p>	Differences, especially in follow-up, in perceived family conflict (d=0.85, p=0.01) and children’s mental health symptoms: anxiety/depression (d=0.57, p<0.001) and aggression (d=0.65, p<0.001).
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#### INDIVIDUAL PI

Barnet <i>et al</i> (2007), USA	<p><b>Intervention:</b> Community-based program for adolescent mothers. Trained home visitors paired with mothers through child’s second birthday.</p> <p>Parenting curriculum - encouraged contraceptive use, connected adolescent with primary care, promoted school continuation.</p> <p>Rationale: Adolescent mothers at risk for rapidly becoming pregnant again, depression, school dropout, and poor parenting.</p> <p><b>Control:</b> Usual care.</p>	Randomised controlled trial	<p>84 pregnant adolescents aged 12-18 years (predominantly with low incomes and African-American), from urban prenatal care sites.</p> <p>(44: 40)</p>	<p>Adult-Adolescent Parenting Inventory (AAPI); Center for Epidemiologic Studies Depression (CES-D); School status - self-report.</p> <p>Baseline, 1 and 2 years follow-up</p>	<p>Intervention improved parenting attitudes (by 5.5 points higher than controls (95% CI 0.5-10.4, p=0.3)) and school continuation (3.5 times greater than control, 95% CI 1.1-11.8, p&lt;0.05).</p> <p>Did not reduce odds of repeat pregnancy or depression, or achieve coordination with primary care.</p>
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## 2.4 Discussion

### 2.4.1 Main findings

This is the first systematic review of PIs in adolescent depression. The main objective was to identify studies on PIs for adolescents with, or at high risk of, depression, by rigorous methods, to explore the content and design of existing programmes and to evaluate their effectiveness. This could help inform clinical practice and the development of future programmes, in particular the current online package, and guidelines, and increase awareness of adolescent depression.

Fifteen PI studies for adolescent depression were identified in this review. The studies showed a range of approaches to PI, and the clear majority were 'in person' ('proximal') and 'active', and most involved content presented to families/groups facilitated by a professional. NICE (2005) and AACAP parameters (2007) state that the involvement of the family is important in the management of adolescent depression, and that any parental and child mental health difficulties should be treated in parallel. AACAP state that the motivation for treatment often comes from parents, and they may observe aspects (of the child's functioning or symptoms) of which the young person is unaware or does not wish to disclose. They can also monitor the young person's progress, and can act as a 'safety net' (Birmaher et al. 2007).

Whilst only a few studies in the review were categorised as 'individual PI' or 'group PI', many of the studies in other categories, such as 'family PI' or 'computerised PI', embraced one-to-one or group approaches. This demonstrated how programmes could incorporate a range of formats to engage and communicate information, consistent with 'blended learning' educational approaches (Singh 2003).

There is emerging literature on computerised and online interventions, although many were not included in the review because there was no evidence they had been evaluated (e.g. Välimäki et al. 2012; thelowdown.co.nz).

Some of the studies described in the review had links with schools, for example Stasiak et al. (2012) and Jordans et al. (2013) recruited adolescents via school counsellors. Most school-

based programmes found, however, were universal mental health programmes (such as the Adolescent Depression Awareness Program (Swartz et al. 2010), and Gatehouse Project (Bond et al. 2004)), and were not included in the review. There were also programmes developed for teachers only (Vieira et al. 2014), and those focused on the assessment of mental health literacy (Melas et al. 2013), but not in association with PI.

PIs for mental health difficulties other than depression were not included in the final review, but could help inform the development of future programmes. For example, elements of PIs for bipolar disorder (Lucksted et al. 2012; Miklowitz et al. 2013), anxiety and suicide (King et al. 2009), could be examined, particularly where dealing with depressive symptoms. There were also case studies of depression programmes (e.g. Navalta et al. 2006), which could be explored further with more participants.

#### **2.4.2 Effectiveness of PI**

In general terms, PIs aim to inform and empower users to make decisions about their welfare and care, and promote resilience. In the current review, most studies showed PIs to have some beneficial effect on a range of measures, including knowledge and understanding of depression and its effects, behaviour and attitudes, treatment adherence, and depression and other mental health and wellbeing outcomes. Family-based interventions appeared to be the most effective form, and most studies were based on these. Such programmes can mobilise social support for the young person. Increased parental and child understanding can lead to improved communication, conflict resolution and problem-solving, and this appears to be important in managing/preventing depressive symptoms in adolescence (Beardslee et al. 2003).

The emerging evidence for PI in adolescent depression is therefore promising. All this is consistent with a review of PIs for depression in adults, which concluded that whilst few studies have been published in this field, PIs can help improve the clinical course, treatment adherence and psychosocial functioning in adult depression, and family PI is seen as part of its 'optimal treatment' (Tursi et al. 2013). Furthermore, there is some evidence that PIs, particularly group interventions (alongside standard medical care), can help patients in the long-term management of other mental health difficulties (Smith et al. 2010).

An overall endorsement of the effectiveness of PIs for adolescent depression is difficult, however, given the limitations of the review (see 'limitations' subsection), including the small number and variable methodological quality of the included studies. More research is needed; for example on PI as a self-management approach (NICE 2005), and programmes currently in development could help to inform this field.

### **2.4.3 Active components**

There were difficulties in analysing and comparing PIs (see 'limitations'), and deconstructing the components of programmes was challenging, particularly when evaluating the elements associated with beneficial effects. As with the review of PIs in adult depression, the mechanism of action of PIs was difficult to assess based on the current evidence. Also, for those who are currently depressed and even those at risk, PIs might well be used as an adjunct to established depression and depression prevention treatments such as CBT, interpersonal therapy (IPT) and/or antidepressant medication. Factors such as depression literacy, help-seeking behaviour or self-efficacy may be important ingredients but evidence is lacking. When developing and evaluating PIs, it would be helpful if authors developed a programme theory or logic model which described the mechanism of effect of their intervention, and evaluated this using methods like mediation analyses and/or through the study process evaluation (Craig et al. 2008).

Personalising the content and taking a person-centred approach might be important in the success of programmes (Samuelowicz & Bain 2001). Beardslee et al. (2003) stated that combining a PI with a family's individual experiences ensured lasting improvements. Parents in some interventions preferred to have the amount and level of information tailored to their needs, so that it was relevant to them. Incorporating personal stories might be particularly helpful (Demaso et al. 2006).

It might also be helpful if there were opportunities for the participant to build on the knowledge and experiences from the package, for example through reflection and planning (Kolb & Kolb 2005). With regards to the specific content of programmes, learning to identify symptoms and plan activities could be important, and information on lifestyle approaches

such as exercise. In their RCT of low-level interventions in young people, Parker et al. (2016) found that physical activity was most effective in reducing depressive symptoms. In adults, Tursi et al. (2013) hypothesised that 'teaching lifestyle regularity' may help with the prevention of depression, whereas early detection of prodromal symptoms may be important for preventing relapses.

It is also likely that the success of a programme is related to the way it is delivered. The skills of the facilitator and therapeutic relationship could be key factors (Green 2006). Colom (2011), a pioneer of PIs in mood disorders, particularly in adults, noted that interpersonal skills and 'common sense' were especially important facilitator characteristics. A family member or friend, as well as a professional, could act as the facilitator, and provide support in programmes. The mode of communication, such as the use of multimedia, can also accommodate personal learning styles and preferences, and make it more engaging and accessible (Stasiak et al. 2012). Repeating key themes and messages in various ways might also help (Beardslee et al. 2003), which is again consistent with 'blended learning'.

#### **2.4.4 Strengths, limitations**

This review has several important strengths; it is the first of its kind exclusively on PIs in adolescent depression, it was conducted rigorously, and efforts were taken to minimise bias, for example through two people completing independent searches and data extraction. However, the findings should be interpreted bearing in mind several considerations and limitations.

##### ***2.4.4.1 Heterogeneity in approaches***

There was a diversity of approaches in the research design and PI approaches in the papers selected, which made it difficult to compare programmes directly and measure the overall effectiveness, and therefore no meta-analysis was attempted. The lack of consensus and diverse methodological approaches was a difficulty encountered by other reviewers of PIs in depression (Tursi et al. 2013).

The studies targeted a range of participants – young people with depression, those at high-risk, and parents/families. The programmes ranged in format, number and duration of sessions and the use of facilitators. PIs were also not always tested in isolation, and often were incorporated, for example with or versus CBT, and the use of control groups varied. The outcomes related to the individuals or parents/carers, or both, and a range of instruments was applied. Some papers did not describe these elements. All this made comparative analysis difficult.

The studies included were at various stages, from early development/evaluation to efficacy trials. Many had small sample sizes and short-term follow up. It was unclear how many of the programmes were developed using relevant theory, following extensive mixed-methods approaches with user input, and for a wide range of settings or services, in line with recognised frameworks (Craig et al. 2008). The review included only published studies, and some studies/programmes might not have been documented or accepted for publication. This review might have been scientifically more robust had it included only RCTs. However, this approach would have yielded few studies, and excluded several relevant and interesting programmes, which could help inform future work in this field.

Furthermore, most studies were conducted in high-income countries, and few in less economically developed countries. The review confirmed that the more advanced packages were developed in the USA, with some in Scandinavia and Australasia – especially e-health interventions. As stated previously, there are differences in each country, for example in service structure, culture and language, and there might be difficulties in implementing them elsewhere. Those in the adolescent age group might be particularly sensitive to such differences. Only English-language studies were selected, and so this may also have introduced bias.

#### **2.4.4.2 Defining PI**

The approach to the definition of psychoeducation was variable in the programmes and studies in the review. There was a lack of clarity on the difference between ‘psychological’, ‘psychoeducational’, and ‘educational’, and the terms were used inter-changeably in some publications (Merry et al. 2011). Many programmes reviewed had elements of psychological therapies such as CBT or IPT, and it was difficult at times to separate the psychological and



educational components. This was consistent with the description of the 'blurry' boundaries between 'simple' interventions (such as PI) and 'skilled' approaches (such as CBT) (Colom 2011), and how both approaches are needed in the treatment of mood disorders.

The distinction between general health information and psychoeducation was also unclear at times, for example in relation to the many examples of printed or online resources for young people (e.g. RCPsych, Headspace, Black Dog Institute). More consideration has been given over the years to the design and content of such educational resources, from fully-illustrated leaflets and narrative books to interactive websites. Certain trials have used printed literature with a control group. For example, Stice et al. (2010) used the 'educational brochure' 'Let's Talk About Depression', a National Institute of Mental Health publication. However, there was little literature on the development and evaluation of such resources.

It is possible that the term 'psychoeducation' should be reserved for 'active' intervention programmes with individualised/tailored information for young people and families, to help prevent and manage difficulties, as opposed to general 'passive' resources.

Another limitation of this review was that the searches were for articles with 'psychoeducation' (or psychoed\*) in the title or abstract. This meant that relevant studies might have been missed, for example those involving programmes described as 'educational'. Furthermore, given there are many possible psychosocial risk factors for adolescent depression, PIs that targeted such factors may have been missed. However, the searches went beyond the use of search engines, for example by going through reference lists, authors' personal collections, a Cochrane review, international guidelines, chapters in relevant textbooks, educational material, and by contacting key authors in the field (see section 2.2.2 – search strategy).

#### **2.4.5 Challenges in implementing PI, possible adverse effects**

There was little consideration of the cost-effectiveness in the studies in this review. A roll-

out of a PI would need to be evaluated, for example with regards to time and cost-effectiveness, particularly where services/resources are limited. Authors such as Colom (2011) argue that establishing intensive multi-level PI programmes in the clinical setting could be challenging and require proper investment in resources. However, it can be argued that the delivery of PIs is an essential part of practice in health and other services, particularly during initial sessions with individuals and families, and formalising the approach could help with communication and engagement more efficiently and effectively (Donker et al. 2009).

Referring families to 'passive' resources, such as existing printed literature or computerised programmes, could require minimal effort and expense. Furthermore, this review showed that facilitated PI (individual or group) could be delivered by a range of professionals, including nurses, psychiatrists, psychologists and health visitors. Colom (2011) noted that those delivering PIs need to be an expert on the 'disorder', not the 'technique', and this would avoid the 'complex training' and associated funding required, for example for CBT. Furthermore, such skilled approaches are not always available; not only in lower-middle income countries (LMIC), but also in higher income countries, and PIs could help address this need.

Whilst the effects of PIs can be positive, as with all interventions, it is important to consider any possible side-effects. Adolescents with depression can experience difficulties with concentration, energy levels and motivation (WHO 1992). Some studies included in the review noted that research participants had stated there was too much information in the programmes (e.g. Lopez et al. 2005). Detailed health information could make the individual, family and carers anxious and distressed, or lead to excessive 'self-checking' and rumination. It is important therefore not to overwhelm individuals with information. There may also be a risk of dependence on, or over-compliance with, the PI facilitator, or at the other extreme, an over-reliance on self-management strategies that leads to a failure to engage with professionals when needed. However, there could also be adverse consequences if individuals are not fully informed when making decisions about their health, and PIs can facilitate this.

## 2.4.6 Developments in electronic PI

Whilst the evidence for the effectiveness of electronic PI (or e-PI) is limited thus far, many packages are in development (e.g. Välimäki et al. 2012), and there is some evidence to support the use of other online packages, such as CBT-based programmes (Merry et al. 2012). A systematic review of web-based interventions for youth emotional problems included seven programs for depression, and concluded that most reported reductions in symptoms of depression and/or anxiety, or improvements in diagnostic ratings (Reyes-Portillo et al. 2014). Whilst it was difficult to evaluate how much psychoeducation within the programs contributed to the outcomes, online PI for depression in adults ('Blue Pages') has been shown to reduce symptoms of depression, and improve understanding of treatments (Christensen, Griffiths, & Jorm 2004).

As noted previously, the use of social media, technology (e.g. smartphones), and on-line material has been identified as a key area of future clinical practice and research in depression in children and adolescents (Brent & Maalouf 2015). With increasing use of digital technologies by young people, the emergence of e-health, and possibly e-PI (or mobile phone/m-health or m-PI), may be inevitable. According to a ONS (2016) survey, almost all individuals aged 16 to 24 (97%) had accessed the internet 'on the go' using a mobile device, and the most commonly used was a mobile phone or smartphone. Within this age group, 49% searched online for health-related information. Young people used the internet more than other age groups for recreational activities (ONS 2016), and gamification is an important component of recent packages for mental health to engage young people (Merry et al. 2012).

However, as noted previously, there are also challenges in this area, including issues related to data protection, privacy and security, and the 'digital divide' between those who have access to the internet and those who do not although this gap is narrowing (Hollis et al. 2015). Evaluating 'long distance' interventions can also present difficulties, associated with knowing how the individual received the information, or the quality of the learning (Tursi et al. 2013).

### 2.4.7 Conclusions

There were a limited number of PIs developed and evaluated in line with recognised research frameworks and using rigorous methods of evaluation, and the large variation in approaches made it difficult to evaluate the overall effectiveness of PIs for adolescent depression. However, the findings to date for PIs in adolescent depression are promising, especially for family-based programmes. Although evidence is limited a range of potential benefits have been reported, from increased understanding and change in behaviour and attitudes, to improved family communication and effects on mood symptoms and wellbeing.

PIs could benefit clinical and other services, because they have the potential to raise awareness of adolescent depression, and they fit with the drive towards self-management and autonomy (NICE 2005, AACAP 2007). Furthermore, some PIs may be more easily administered, more accessible and more cost-effective, than other interventions (Donker et al. 2009). They might be particularly important as part of the prevention and early stages of treatment of adolescent depression (e.g. in the stepped care model (NICE, 2005)).

Future work should include defining 'psychoeducation' in international guidelines, to help remedy the 'branding problem' referred to by Colom (2011). Programmes should also be developed and evaluated according to recognised research frameworks (Craig et al. 2008). Further research is required testing PIs in adequately powered RCTs, possibly alongside other therapies such as CBT, with process and economic evaluations included as part of the trial. There needs to be more emphasis on the theory, content and design of interventions, and an exploration of the active components of PIs, and potential mechanisms of PIs through process evaluation and investigations such as mediation analyses.

Further research is also needed to understand how to personalise the information and design, and incorporate multi-modal approaches, given the variety of experiences of depression. Programmes need to accommodate and engage males and females with a range of ages, backgrounds and abilities – particularly when motivation and concentration is impaired during depressive episodes. Future studies could explore how PIs could be integrated into the daily lives of young people and their families/carers, and into health, social, education and youth services.

## Chapter 3: Methods

### 3.1 Introduction

This chapter describes the mixed methods approach of the research project to develop and evaluate an online psychoeducation package for adolescent depression. The opening section covers the overall research plan, which is in line with the initial stages of the Medical Research Council's (MRC) 'framework for the development and evaluation of complex interventions'. This is followed by an account of the methodology for each individual stage.

The first stage of the research involved a comprehensive review of the literature and practice in the field of psychoeducation in adolescent depression (see chapter 2). The second stage was a qualitative study consisting of a series of semi-structured interviews and focus groups with adolescents, families/carers and professionals working with young people (see chapters 4 and 5). The findings from the literature review and thematic analysis of the qualitative data informed the development of the design and content of the package, during the third stage (see chapter 6).

The fourth stage consisted of an early evaluation of an initial prototype (see chapter 7), with further interviews and a focus group to assess the ease of use, clarity, feasibility and acceptability of the package. Questionnaires were administered before and after using the package to generate preliminary data on effectiveness, gain feedback on the package, and assess acceptability of the questionnaire pack. Patterns of use were also assessed via questionnaire and online data provided by the multimedia company. The findings from this evaluation period informed the reassessment and improvement of the package (Stage 5; currently underway).

The package was developed with involvement from adolescents and families/carers to enhance engagement, and so that they may feel more informed and empowered when making decisions about their welfare, to help with their general well-being and in the long-term management of any difficulties. It was designed with the input of clinicians and other relevant groups so that it could be integrated with, and used regularly within everyday NHS clinical practice, social, education and youth services.

## **3.2 Overview of research methods**

### **3.2.1 MRC framework for complex interventions**

The MRC guidance for the development and evaluation of complex interventions defines complex interventions as composed of several interacting components and modalities. Components can include behaviours, parameters of behaviours and methods of delivering these behaviours. The MRC advise that many health service activities should be complex, and that developing and evaluating such interventions is challenging and requires substantial investment of time and planning (Campbell et al. 2000).

The current research project involved the development and early stage evaluation of a 'complex intervention'. It brought together audiovisual, interactive and online media, backed by the research and practice from the areas of adolescent depression (particularly prevention and management strategies), psychoeducation (and learning), e-mental health and design.

The overall research plan was in line with the 'preclinical/theory' and 'phase I/modelling' phases of the MRC 'framework for complex interventions', and the 'development' phase of the new guidance on developing and evaluating complex interventions (Craig et al. 2010). The guidance was first published in 2000 as a stepwise process (Campbell et al. 2000) (fig 3.1). The framework was updated in 2008 to address limitations and to reflect developments in methodological techniques. Amendments included greater attention to early phase piloting and development and presentation of a less linear, more recursive model (figure 3.2) (Craig et al. 2010).

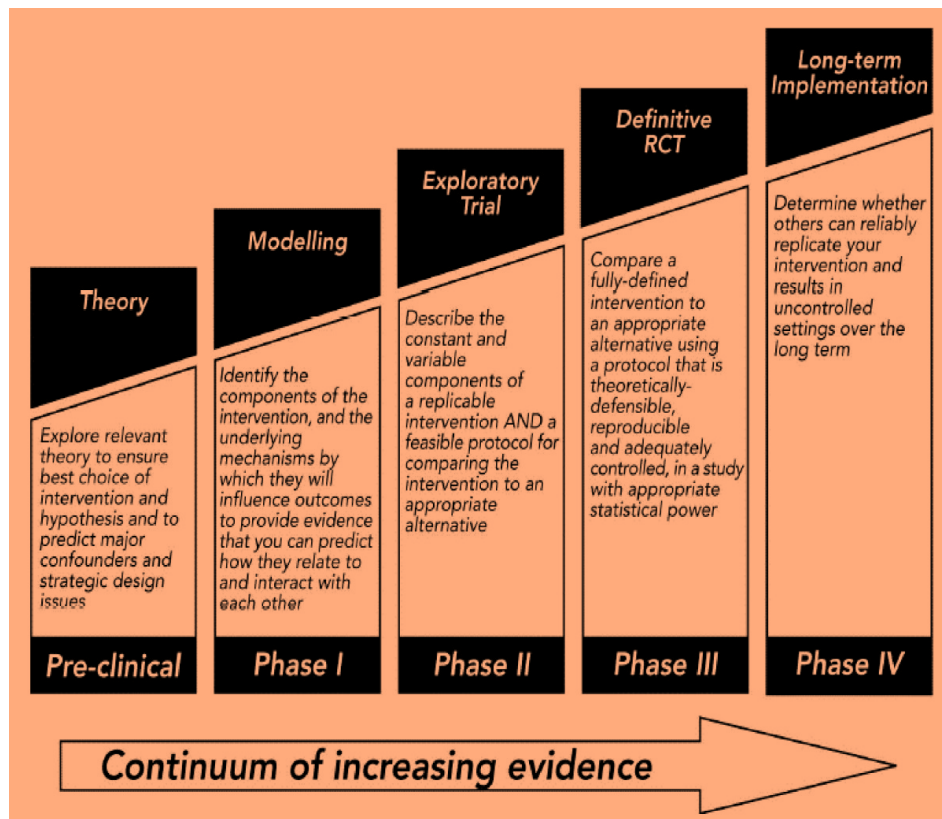


Fig 3.1: MRC Framework for complex interventions (biomedcentral.com)

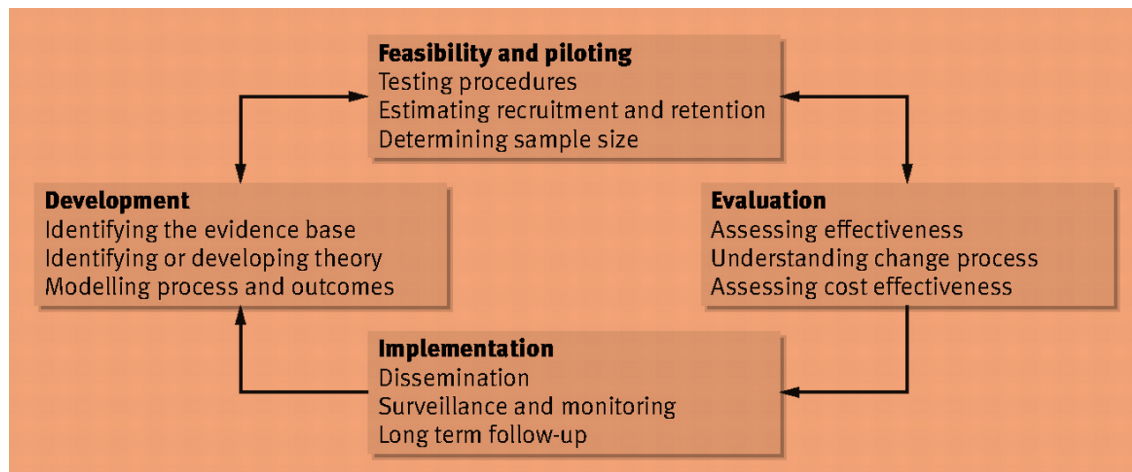


Fig 3.2: Key elements of the development and evaluation process (bmj.com)

### 3.2.2 Mixed methods approach

The current study used a mixed methods approach combining both qualitative and quantitative methods, following the MRC guidance (Craig et al. 2010). By mixing both methods, it was possible to examine the potential effectiveness of the intervention, as well as explore the components that may have influenced effectiveness. The mixed methods approach ensured that the online package was developed with information sourced in different ways and from a range of perspectives, taking advantage of the different characteristics of and insights from each methodology (Bryman 2006). Whilst there was an overlap in the timeline of the activities of each stage, the figure below shows the linear staged process of the research project for the sake of clarity.

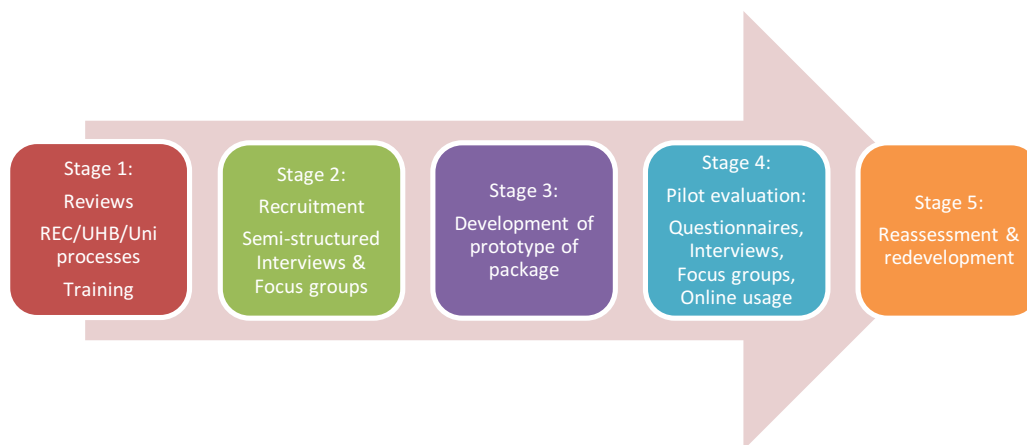


Fig 3.3: Broad stages of the research plan

The developmental approach was ‘person-centred’ or ‘person-based’, as described in guidelines for digital health-related intervention by Yardley et al. (2015). This focuses on understanding and accommodating the perspectives of the users, and complements the MRC framework. Firstly, this approach embraces qualitative research with a wide range of individuals from the target user population(s), at every stage of the intervention development –this was done for the current study with interviews, focus groups and other consultations (described later). This is not only to help to assess acceptability, usability, and satisfaction, but also to appreciate the context, to anticipate usage and outcomes, and modify the intervention to make it persuasive, feasible and relevant. Secondly, the approach helps to identify underlying ‘guiding principles’ to address the aims of the intervention.



Other e-health frameworks were also considered (Mohr et al. 2014; Oinas-Kukkonen & Harjuma 2009), and these are discussed further, along with other underlying theories and approaches, in chapter 6.

Interviews and focus groups are two of the main methods of qualitative data collection, and are often used in combination in research studies (Morgan 1997). Semi-structured interviews were used because they can be structured around the topics to cover, but also allow flexibility to explore other areas, for example that the interviewee or interviewer wanted to raise at the time. They allow individuals to define their own agendas and discuss factors they feel to be important in depth. This was particularly important as many of the participants had experience of mental health difficulties, and might have found it more comfortable to be interviewed on a one-to-one basis (or with a trusted parent/carer) in a private setting in which they felt secure (usually their home). This may have been because of the sensitivity of the subject matter, symptoms of depression or anxiety, and associated embarrassment and stigma. Interviews also produce data with high credibility and face validity, allow the interviewer to probe for more details, and ensure that participants are interpreting questions in the way they were intended (Kvale & Brinkmann 2009). The interviews helped to generate detailed views and ideas from a range of potential users of the package, which were carried forward to the focus groups.

In general, the aim of focus groups is to encourage an assembled group of individuals to interact, share and refine thoughts, feelings, and views on a topic (Morgan 1997). The focus groups for the current project, enabled a greater breadth of discussion on the ideas from the interviews, from the diverse groups of potential users of the package, but also allowed new ideas to be generated. In the later groups, it was possible to show designs for the package and get feedback from the participants, and for them to build on each other's perspectives. This was invaluable in shaping the package. The focus groups explored participants' knowledge and experience of depression, and discovered not only what they think, but also how and why they think that way. With the appropriate guidance and facilitation, they also acted as a 'safe' forum for expression of views and possible 'empowerment'. Further to these advantages, the groups were more economic and efficient than one-to-one interviews (Kitzinger 1995).

Qualitative data were collected and analysed using rigorous methods (discussed in section 3.7.2). The interviews and focus group recordings were transcribed and data analysis proceeded using an inductive (or 'bottom up') thematic analysis approach. This is a process of identifying, analysing, reporting and interpreting patterns or themes, and one of the most commonly used qualitative approaches in health research (Pope & Mays 2006). The more open-ended and exploratory analysis allowed examination of all suggestions, comments and cautions from potential users of the package. Although the interviews and focus groups were guided by questions around how the package should be developed, there were few pre-conceived ideas about this, and the research team was interested in taking all the views of the potential users of the package into account.

For the evaluation phase, a mixture of quantitative and qualitative methods was used. Participants were asked to complete questionnaires before and after using the package, and this data was used to provide descriptive statistics on patterns of use, feedback, and effectiveness. Statistical tests were performed to assess whether there had been any changes in scores (e.g. depression literacy) after using the package.

### **3.2.3 Consultations and reviews when developing the research plan**

#### **3.2.3.1 Involvement of patients/service users, carers and members of the public**

The active involvement of patients/service users, their families/carers, and members of the public was encouraged at each stage of the research process by the i) MRC framework, ii) funders of the project (National Institute for Health Research (NIHR); Health and Care Research Wales (HCRW)), and iii) Research Ethics Committee (REC) guidelines ([hra.nhs.uk](http://hra.nhs.uk)). Potential users of the psychoeducation package were consulted from the initial stages of development. This is a key step in the development of interventions as without buy-in from clinicians and other professionals, it might not be used in practice. Also without considering the context it will be difficult to rollout, and without considering the patients' and families'/carers' views it is unlikely to be engaged with and therefore be effective in helping the target group.

Over the years before starting the project, possible interventions were discussed with young people and their families and carers during clinical appointments on an informal basis,

especially service users with depression or a history of depression. The research team at the Child and Adolescent Psychiatry Section, Cardiff University, also discussed these issues informally with young people and families when visiting them as part of the assessment process for the 'Early Prediction of Adolescent Depression' (EPAD) study (Mars et al. 2012), a longitudinal study of adolescents at familial risk of depression. Whilst collecting data for this study, many families stated that they hoped that an intervention would be developed for depression in young people, and their families/carers. Young people and families were also consulted informally at Cardiff University public engagement events, such as the 'Translation: From Bench to Brain' event. In all the above examples, the idea of using the internet and multimedia as part of the intervention was often raised because they are used so much by young people.

As noted previously, adolescents, families/carers and professionals participated in interviews and focus groups during stage 2 of the project, to inform the development of the content and design of the package. These groups were also consulted in stage 4, to evaluate the initial prototype so that the package could be improved.

### **3.2.3.2 Peer reviews**

The research plan was peer-reviewed, approved and funded by NIHR and HCRW (formerly National Institute for Social Care and Health Research (NISCHR)), for a Doctoral Research Fellowship Programme, awarded to the student. During the application process for this fellowship, the written research plan was reviewed and the student interviewed. Before submitting the application, the plan was also reviewed at Cardiff University by the Institute of Translation, Innovation, Methodologies and Engagement (TIME), and members of the Child and Adolescent Psychiatry Section, Mood Disorders Team (including developers of online psychoeducation for Bipolar Disorder) at the Division of Psychological Medicine and Clinical Neurosciences (DPMCN) and the South East Wales Trial Unit (SEWTU).

### **3.2.3.3 Research sponsor – Cardiff University**

Cardiff University agreed to be the sponsor for the study and meetings were held from an early stage with legal, technology transfer and other relevant officers at the university. University contracts were completed with all participating individuals and groups, covering issues such as confidentiality and intellectual property. The project fits with the institute's mission of translating the fundamental discoveries made by Cardiff researchers in neuroscience and mental health through to clinical interventions.

Spanning the period from childhood to old age, two of the major themes of the DPMCN at the university are developmental disorders and major affective disorders. Adolescent depression is relevant to both these areas of research. The current study translated and developed the work of the EPAD programme grant (Mars et al. 2012). Over recent years, the Child and Adolescent Psychiatry Section tracked and monitored over 300 parents who have had depression and their adolescent children, in one of the largest studies of its kind in the world. The aim of this work was to identify a set of simple predictors that identify which adolescents are at highest risk of depression so that these families could be targeted for appropriate resources and interventions. The proposed online package was planned so that it was integrated into this work, for example so that it could be used by those identified by a risk prediction tool developed by the EPAD team.

The study also built on the work of another team of researchers at the DPMCN and the SEWTU who developed the online psychoeducational package 'Beating Bipolar' ([beatingbipolar.org](http://beatingbipolar.org)). This is the world's first internet-based psychoeducation treatment for patients with bipolar disorder. An exploratory trial found a statistically significant impact on psychological quality of life for patients using it (Smith et al. 2011).

Affiliated with the division is the National Centre for Mental Health (NCMH) ([ncmh.info](http://ncmh.info)). The NCMH's work aims to improve life for patients through research and sharing knowledge and best practice. NCMH is a major focus for translational research that improves clinical care, and the proposed research in adolescent depression fits with this focus. It was proposed that the psychoeducation package would link with the NCMH website, and potentially other electronic resources developed at the centre, such as 'Beating Bipolar'.

There was also an active Public Engagement Group within the Institute, and the student was a member of its committee. This gave a further opportunity to increase awareness of adolescent depression, and consult with potential users and the public.

### **3.3 Stage 1: Review & approvals**

#### **3.3.1 Systematic Review: Psychoeducational interventions in adolescent depression**

The first stage of the project consisted primarily of the literature review. Please refer to the previous chapter (chapter 2) – ‘Psychoeducational interventions in adolescent depression: a systematic review’ - for a detailed description of the methods used for the review.

During this first stage, there were also consultations with the REC, university health boards and various departments of the university. The student also had extensive training in systematic reviews, qualitative methodology, multimedia and complex interventions.

#### **3.3.2 Risks & ethical considerations**

##### **3.3.2.1 NHS and University REC opinion and R&D approval**

The Dyfed-Powys REC gave a favourable opinion for the research project. Research and development (R&D) approval was granted by five university health boards (UHB) in South and West Wales - Cwm Tâf, Cardiff and Vale, Abertawe Bro Morgannwg, Aneurin Bevan and Hywel Dda UHBs, five of the seven UHBs in Wales – for the development phase (stage 2), and in addition Powys UHB for the evaluation phase (stage 4). Honorary contracts and research passports were sought and granted by these UHBs, and contracts were drafted by the legal team at Cardiff University with each board. For the evaluation phase (stage 4), Cardiff University School of Medicine REC gave a favourable opinion for the study, and to involve individuals recruited via school counsellors within the above UHB areas.

### **3.3.2.2 Potential risks and burden for research participants**

Adolescents, especially those with depression, are considered vulnerable, as are parents who have a history of mental health difficulties. Furthermore, discussing sensitive subjects such as mental health problems can be embarrassing and distressing, especially for young people. However, it was vital to obtain the views of young people, including those with a history of mental health difficulties, to inform development of the package, because the package was targeted at this age group.

The distress and intrusion was minimised as far as possible - the research team had considerable experience in working with people with mental health problems of all ages, and included Child and Adolescent Psychiatrists, a General Adult Psychiatrist and a General Practitioner (GP). The student had advanced training in Child and Adolescent Psychiatry and General Adult Psychiatry. Informed consent was required from parents or guardians of the participating adolescents. It was made clear to participants that they could withdraw from the study at any stage, without giving a reason and without this affecting their future medical care.

There was a plan in place for the interviews and groups, which stated that if an individual became distressed or upset, they would be taken to a private room and the student would aim to reassure and assess the severity of the difficulties. If required, the student would advise the individual to see their GP (who may refer the person on if necessary) and signpost to relevant health resources, including mental health information sheets and websites. If the individual needed more urgent attention, the student would contact their GP directly to discuss the options, including whether an urgent medical review was appropriate.

### **3.3.2.3 Potential risks for researchers**

It was possible that some participants would find themes raised by the interviews or focus groups distressing or they might use the sessions as an opportunity to describe grievances about aspects of their mental health difficulties and their care, and this might be uncomfortable for the researchers. However, all involved (the student and facilitators) were

experienced in interviewing service users and research participants. The student also received training and mentoring from more experienced study team members and supervisors on these issues.

## **3.4 Stage 2: Interviews & focus groups**

### **3.4.1 Recruitment for interviews & focus groups**

#### **3.4.1.1 Inclusion and exclusion criteria**

For the semi-structured interviews and focus groups, potential users of the psychoeducation package were recruited – adolescents (aged 13 and older), parents/guardians/carers and professionals who work with young people. The adolescents targeted were 1) those with depression or a history of depression or depressive symptoms, or 2) those at high-risk, particularly children of parents with a history of depression. Parents/guardians/carers were targeted if 1) they had an adolescent in their care with depression or a history of depression/depressive symptoms, or 2) they had a history of depression themselves and had a child in the adolescent age group. Professionals were approached from health, social, education and youth services, if they worked with young people, particularly those who might present with mental health difficulties.

Participants were not eligible if:

- They had severe mental health difficulties which would make it difficult for them to contribute, and which may make it more likely for them to become distressed in interviews/focus groups and for their mental state to deteriorate as a result.
- They were unable to understand the intervention or the questions/discussions in the interviews/focus groups, e.g. because of insufficient understanding of English.

#### **3.4.1.2 Recruitment centres**

Adolescents with depression or a history of depression/depressive symptoms were recruited from CAMHS teams in each of the five UHBs in South and West Wales, as listed above. The

Child and Adolescent Psychiatry Section at Cardiff University has strong links with health boards across Wales, particularly Cwm Tâf UHB. Consultant Child and Adolescent Psychiatrists acted as local study leads in each UHB.

Adolescents at 'high risk' were recruited from those in the Cardiff University EPAD study sample who had consented to be contacted about future studies. The NCMH study sample of young people with depression was also considered, but there were no individuals who met the inclusion criteria. Parents were recruited in the same way as the adolescents – via CAMHS, or the EPAD sample. Finally, professionals were recruited from health, social, education and youth services in South and West Wales, or those who had been involved in the EPAD study.

#### **3.4.1.3 Approaching potential participants**

If approached through the CAMHS, the clinical teams responsible for their care sent letters and information sheets to families which met the study inclusion criteria to ask whether they would be happy to take part in the study (see appendix). The families were asked to send a completed reply card to the study team confirming whether they would like to participate. Those who were interested were then telephoned to discuss the project further and answer any questions.

Individuals from the EPAD study sample who had consented to being contacted about other research were sent a letter and information sheet by mail or email inviting them to participate in the research. They were asked to complete a reply card or respond via email/telephone regarding whether they would like to participate. Participants were then followed up with a telephone call as above

Professionals from the appropriate services were identified and sent a letter and information sheet via mail or e-mail, inviting them to participate, with a reply card as above.



#### **3.4.1.4 Benefits to participants**

It was expected the interviews and focus groups meetings would be a helpful and interesting experience for the participants. In the broader sense, their participation helped to develop a resource which will improve the future care of adolescent depression, and help young people, their families, carers and healthcare workers.

Participants were not offered incentives to take part as such, but were offered gift vouchers for their participation, time and travel where appropriate. Participants who were interviewed were given the choice of being seen at Cardiff University or at a location convenient for them, for example their home. Individuals were offered a £15 gift voucher for their participation and time if seen at home. They were offered a £25 gift voucher if seen at Cardiff University, to cover travel expenses/time in addition to participation and time spent at the interview. Focus group participants were offered a gift voucher for £25 to cover their participation, time and travel. Individuals who completed questionnaires before and after using the package at stage 4 of the research were offered a gift voucher for £15 for their participation and time, or £25 if seen at the university to complete questionnaires before and after the intervention.

#### **3.4.1.5 Sampling Frame: Addressing the diversity of the population**

The aim was for the adolescents and families/cares participating in stages 2 and 4 to be representative of the diversity of the population. This was done by recruiting participants from several areas and communities in South and West Wales, including areas of high deprivation (such as communities in the South Wales Valleys) as well as more affluent areas (e.g. Cardiff). The study also aimed to have a balance with regards to age, gender, location of residence, culture, severity of depressive symptoms, and involvement with various services, when inviting participants to take part. Much of the information on which to base our selections was held by the mental health teams or the research teams consulted to recruit the participants. This allowed the team to make informed decisions on whom to invite. Participants were targeted so that there were a range of interviewees including adolescents with or at-risk of depression, parents with a history of depression or with a child with a history of depression, and individuals from various professional groups.

The invitation letters, information sheets, consent forms and reply cards were provided in Welsh as well as in English, and the package was developed in both languages, making it more inclusive for the population of Wales. There were attempts to recruit at least some individuals and families who were likely to use the Welsh-language version of the package, as well as the English-language version. Adolescents and families whose first language is Welsh might find it more comfortable to deal with sensitive issues such as mental health difficulties if the package was bilingual, and NICE guidelines for depression recommend that children and young people are engaged in their first language (NICE 2005). This also meant the study was compliant with the principles of the Welsh Language Act in the provision of information to participants in Wales (HM Government 1993).

### **3.4.2 Information sheets and consent forms**

Four information sheets were written and designed:

- one for adolescents
- one for parents of adolescents participating in the research
- one for participating parents
- one for participating professionals

All information sheets and consent forms were available in Welsh as well as in English (figure 3.4) – there were therefore eight versions in total. The information sheets and consent forms were designed with the help of a senior graphic designer who worked on bilingual national publications for all age groups. This was done so that the documents would be as engaging as possible for young people. The illustrations, colour and layout were considered appropriate for this purpose, and young people were consulted during the design process. They were also developed with reference to a readability test (FOG index (Gunning 1968)) to ensure that they were understandable, particularly to younger age groups.

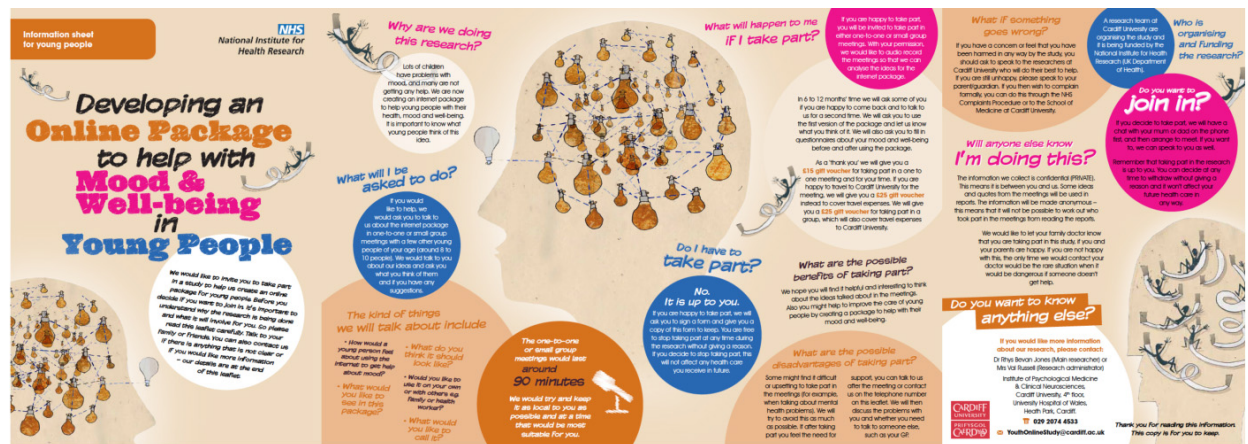


Fig 3.4a: Information sheet for young people – in English

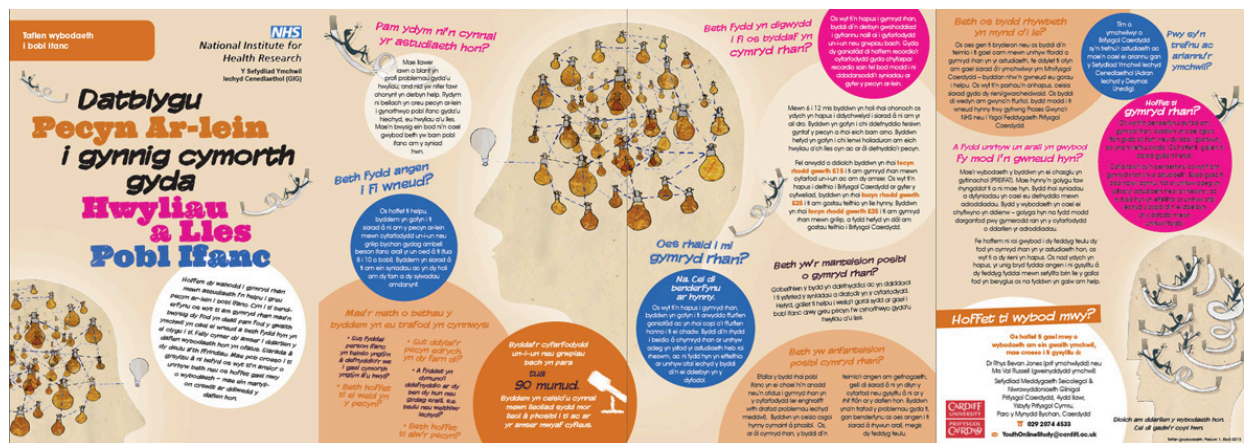


Fig 3.4b: Information sheet for young people – in Welsh

Five variations of the consent forms were produced for the adolescents, parents/guardians and professionals (see appendix). Assent forms were designed for adolescent participants under the age of 16, where consent was required from the parent/guardian. Each of these forms were also available in Welsh. The student discussed the information sheets and consent forms with the adolescents and parents prior to participation in the study, and gave them the opportunity to ask questions.

### 3.4.3 Semi-structured interviews

A series of 12 semi-structured interviews were conducted to generate initial ideas for the focus groups; four each with adolescents, parents/carers and professionals. Further details and participant demographics are provided in the interview chapter (chapter 4).

The interviews were held either at Cardiff University or a location convenient for the participant (e.g. home or school) and lasted up to 90 minutes. All interviews were completed by the student. A topic guide was used to structure the interview (see fig 3.5), although the interviews were informal, so that the interviewee perceived them more as a discussion. Care was taken to be sensitive to the language and concepts used, checking that interviewee's meanings were understood rather than relying on assumptions (Britten 2006). Where possible, the interviews were conducted in front of a computer screen so that initial ideas and imagery, and examples of existing resources could be discussed. All interviews were audio recorded digitally, and recordings were transcribed by a third party company approved by the University.

**Fig 3.5: Topic Guide – for the semi-structured interviews**

(Some topics were more relevant for certain groups e.g. adolescents, parents/guardians, professionals)

*Opening questions:*

How would you use the internet to get help?

What do you look for when looking for information/help?

Any general thoughts about the development of an online psychoeducation package?

How would a young person feel about using the internet to get help about mood?

What would you like to see in this package?

a. Various sections e.g. diagnosis, investigations, management

b. How would you differentiate this from psychotherapies such as CBT?

What do you think it should look like?

a. What would be the various formats? E.g. visual, audio, animation, interactivity?

b. What would be the X-factor or essential ingredient for it to work?

How would you personalise it?

Should it be used alone or with others e.g. family or health worker?

How would you monitor your mood or scores?

How would you ensure it would integrate into services?

a. Health b. Social c. Education d. Youth

What do you think might be the difficulties?:

a. in its development, b. in it being used e.g. side effects

What would you like to call it?

Any thoughts about the examples shown, and any elements which could help develop the package?

e.g. Beating Bipolar, YoungMinds, Headspace, other graphic work

Any other comments/questions? Thank you for participating

### **3.4.4 Focus groups**

Following the completion and analysis of the semi-structured interviews, a series of focus groups were held with adolescents, parents/carers and professionals to inform the content and design of the package, and discuss other issues related to its development. There were six groups in total, three with young people (with current/past depression or at high risk), one with parents/carers (who had a child with current/past depression), one with professionals (from a range of disciplines) working with young people, and one with clinical and other academics in child and adolescent psychiatry. The focus groups were completed sequentially so that ideas from previous sessions could feed into the discussion in the next group (see figure 3.6). Further details on the composition of the groups, and participant demographics are provided in the focus group chapter (chapter 5).

The focus groups were held in Cardiff and Swansea. The aim was for each group to include eight to ten people and to last approximately 90 to 120 minutes, although more participants attended for some of the groups. These could be described as 'full groups', and can be differentiated from the other types of focus groups – 'mini groups', which are similar, but consist of four to six individuals (Greenbaum 1998). There were attempts to ensure that the focus groups for young people were balanced, for example regarding gender, age, location of residence, severity of symptoms and contact with services (see sampling strategy).

The focus groups were all facilitated by the student, accompanied by a colleague (clinical fellow, research psychologist or medical student at Cardiff University). The role of the

facilitator or moderator was to encourage discussion with minimal input, ensuring everyone had the chance to participate, but with some 'ground rules' (see fig 3.8). The approach of the facilitator or moderator has been described as the most important ingredient of the focus group process (Greenbaum 1998). As well as engaging in a verbal discussion, participants were asked to draw or write ideas to help with the design of the package, and to reflect on images and ideas presented on a screen.

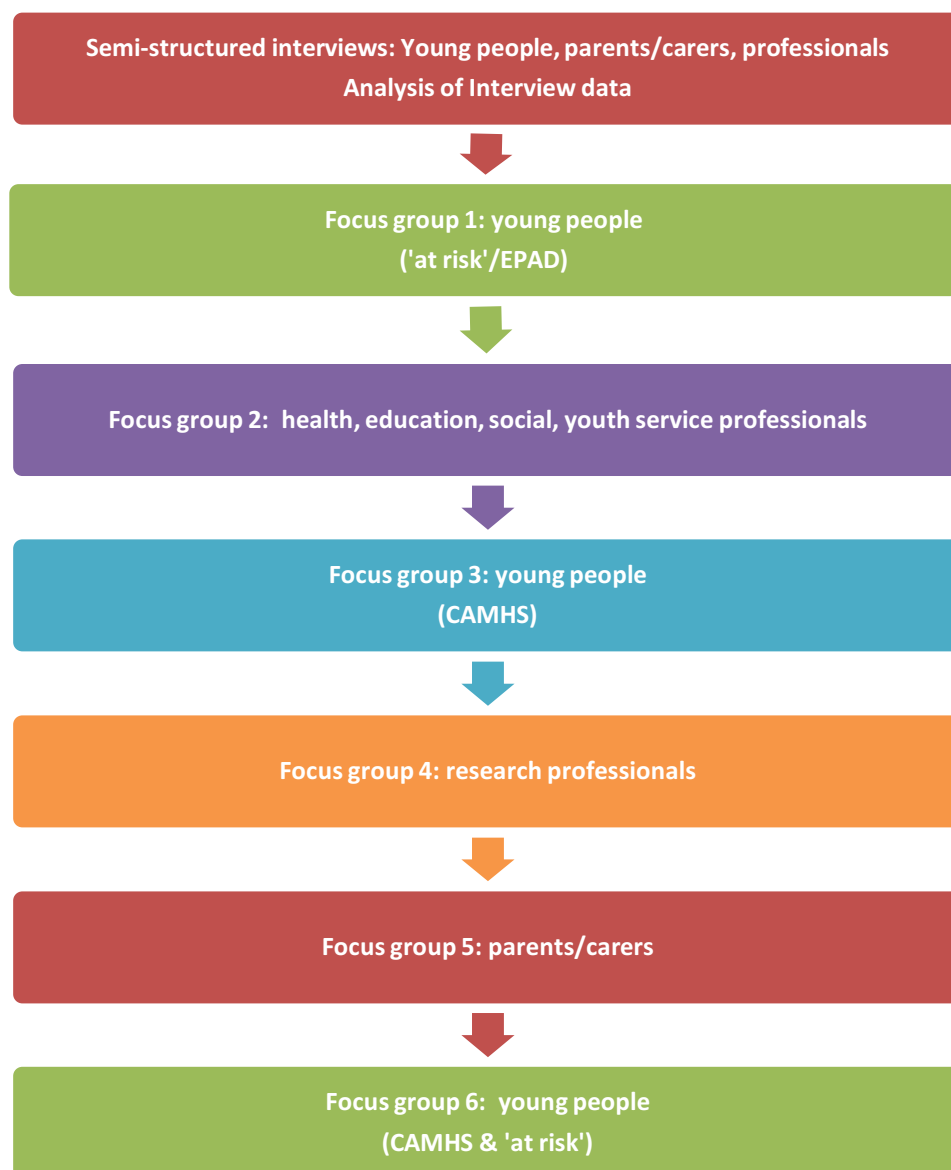


Fig 3.6: Flow chart – sequence of interviews and focus groups



A focus group moderator guide, or 'discussion outline' was followed. This evolved from the topic guide used in the interviews, based on the responses given by participants. Most of the questions and images discussed were projected on a screen with multimedia content - text, images, online resources, videos, animation and audio (see fig 3.7). The slides helped to direct and shape the discussion during the sessions, which was required given the number of issues to discuss, and composition of the groups (i.e. the range and/or number of participants). These slides therefore served as the discussion outline for the groups. Although there was an overall structure to the focus groups, the discussion would sometimes deviate from the slides, as new and relevant information emerged.



Fig 3.7: Photograph of focus group set-up at the Hadyn Ellis Building, Cardiff University

The groups were completed sequentially (see fig 3.6). Between groups, ideas for presentation and content were developed by the research team, and this shaped the multimedia slides for the next group. In this way, the programme was developed in a staged, iterative manner where each focus group built on the findings from the previous one. In the earlier groups, general ideas for the package were discussed. In the latter groups, draft

designs were shown, and the participants could interact with preliminary elements of the package using tablets and laptops. Figure 3.8 includes examples of the slides shown and questions asked to participants. As with the interviews, each of the focus groups was audio recorded and transcribed.

**Figure 3.8: Questions and selection of slides shown during a focus group**

**Aim of project:** To develop an online package for mood & well-being in young people (aged 14-18 years) & their families/carers

**Aim of group meeting:** To discuss ideas for the content & design of the package & related issues

**Why should I help?**

- Package will benefit young people & families
- Opportunity to develop a package rolled out across the UK
- £25 gift voucher for taking part

**Ground rules**

Everyone to contribute (some more familiar with study than others)  
One person to talk at a time  
Respect each other's comments  
No wrong answers  
Not asking about personal experiences  
Discussion not to go outside of the group  
You may leave at any time (please let us know)  
Any questions?





### Initial questions

How many here access the internet regularly?

How many use the internet to look up information on health & mental health?

How many would use an online package for mood and well-being?

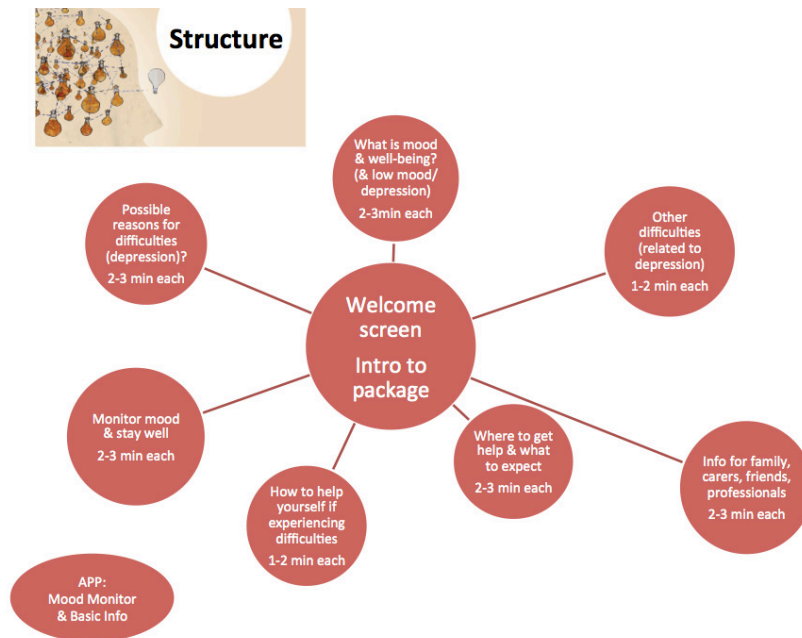
Briefly explain:

why you are interested in this study

&/or whether this package is needed and why (or any general comment about the study)

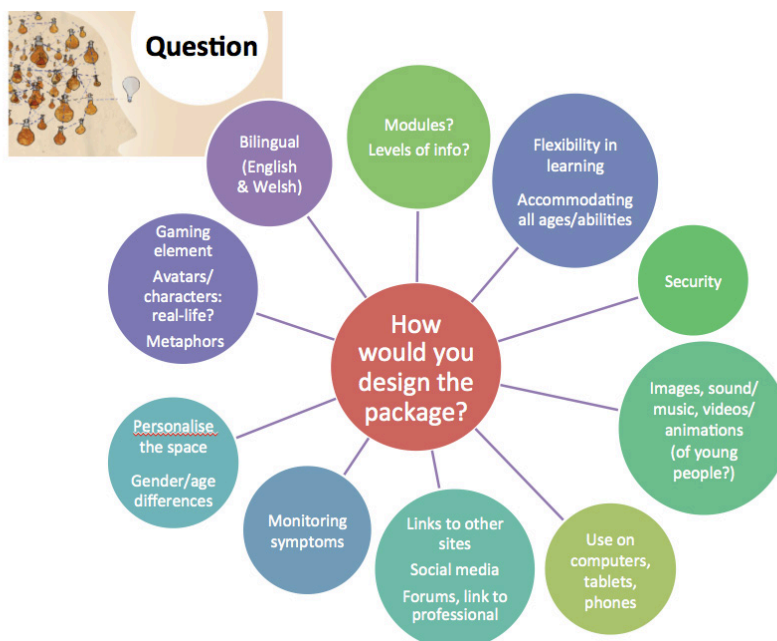
### Structure and content of package

The content and structure was discussed, with a general initial question on 'what information should be included in the package?' – then each of the modules or circles below would appear in sequence.



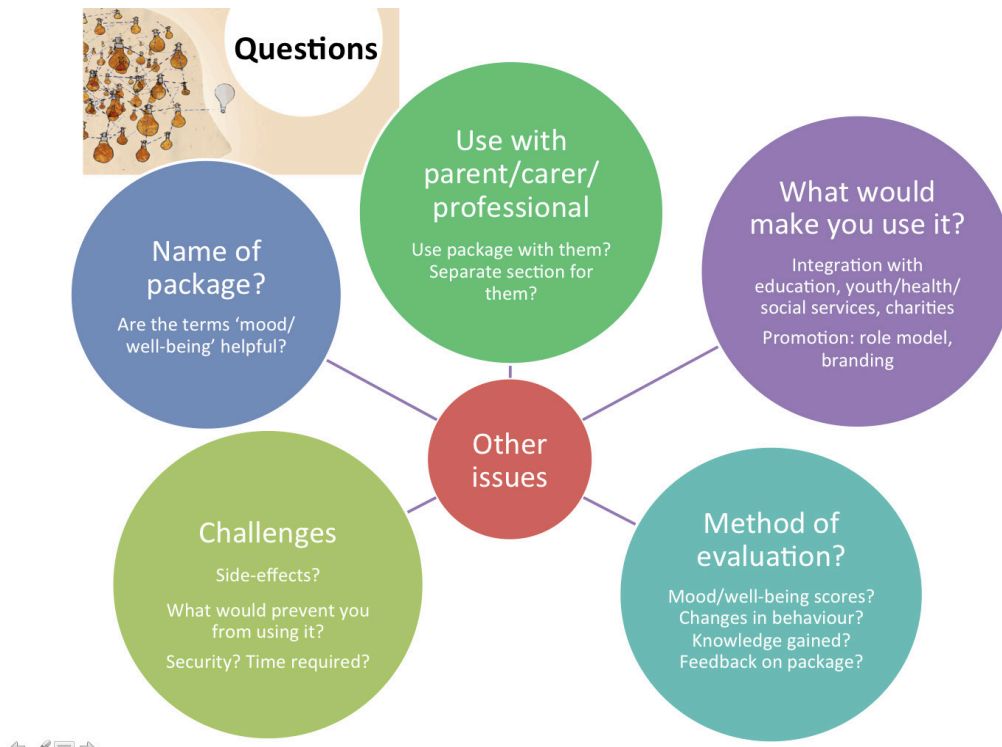
### Design issues

The specific design issues of the package were then discussed in sequence.



### Other topics

Finally, there were additional questions regarding the package's use with others, what would make the person use the package, how would it be evaluated, the challenges and side-effects and the potential name for the package.



### Examples of educational packages

Examples were then shown of educational healthcare packages and websites to help inform the current project, with certain components of the packages shown, and participants asked to respond to aspects of these. These included Beating Bipolar ([beatingbipolar.org](http://beatingbipolar.org)), Spring ([myptsd.co.uk](http://myptsd.co.uk)), YoungMinds ([youngminds.org.uk](http://youngminds.org.uk)), Headspace ([headspace.org.au](http://headspace.org.au)), Mindfull ([mindfull.org](http://mindfull.org)), and Headspace ([headspace.com](http://headspace.com)).

The **final slides** allowed participants to raise any other issues and ask questions. Participants were thanked, and directed to resources on depression and other difficulties. They were informed that they could write any comments (or draw any images) if they did not feel able to do so during the focus group itself, and leave them in a box in the room. They were also informed that the facilitators would be available after the meeting to discuss any issues, particularly if they felt distressed or concerned about any issues arising from the meeting.

### 3.4.5 Other discussion groups, workshops & consultations

In addition to the interviews and focus groups discussed above, there were several other less structured approaches used to consult with young people, families/carers, professionals, and researchers in the field of youth mental health and e-health (see fig 3.9).

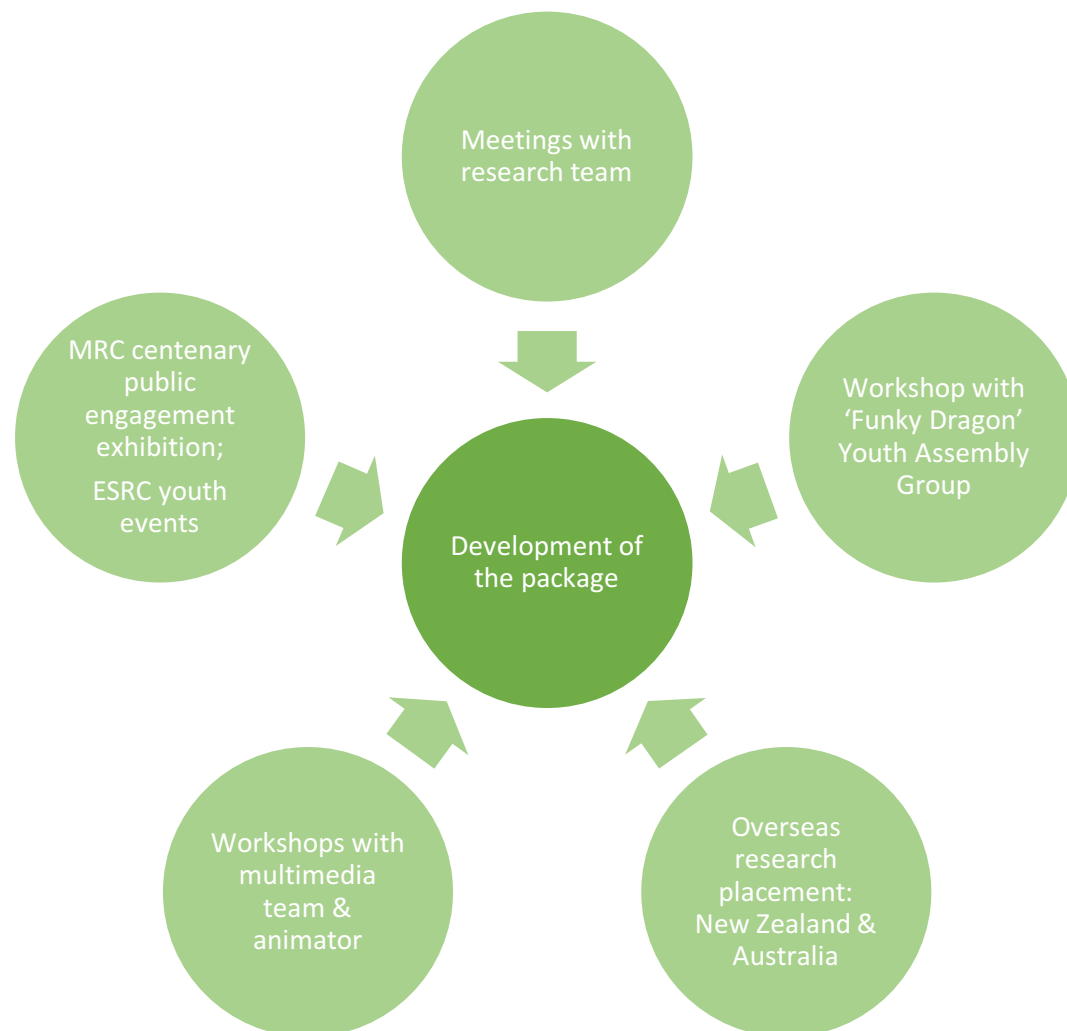


Fig 3.9: Other workshops and consultations

A workshop was also held with the National Youth Assembly of Wales – ‘Funky Dragon’ ([funkydragon.org](http://funkydragon.org)) - between focus groups 4 and 5. ‘Funky Dragon’ was a peer-led organisation of young people (between 11 and 25-years-old) gathered and elected from

around Wales. They met regularly to discuss issues that affected young people in Wales, and fed back to the Welsh Assembly Government. The workshop consisted of 22 participants, and from the discussion, it seemed that many from this group had some experience or knowledge of mental health difficulties and/or contact with mental health services. Questions were posed to the participants with the use of slides (as with the focus groups). The participants were separated into small groups, and each one discussed the question and wrote and drew answers on large pieces of paper. The answers of the small groups were then discussed with the group. The discussion was audio recorded, notes were taken, and the materials from each group were collected at the end of the session.

There were also public engagement events, where various public groups were consulted on their ideas on the content and design of the package. One example was a public engagement exhibition entitled 'How the light gets in', organised as part of the MRC Centenary Events in 2013. There were also consultations in national and international conferences (e.g. Mental Health Today Wales (2014); BASPCAN meetings (2013 & 2014); Royal College of Psychiatrists conferences (2013 & 2014); International Youth Mental Health Conference (2013)), and departmental meetings.

Several meetings were held during this stage with researchers (in psychology, psychiatry, primary care and education), multimedia groups, schools, and charities from around the UK and overseas. The student organized a placement at the University of Auckland (New Zealand), and visited various other centres in New Zealand and Australia, including the Health Promotion Agency (Wellington, New Zealand), the Black Dog Institute (Sydney, Australia), the National Institute for Mental Health (Canberra, Australia) and the Orygen Youth Centre (Melbourne, Australia) (fig 3.10). At each of the locations, the outline of the project was presented and discussed with the resident researchers and clinicians, and suggestions were made on how to proceed. Advisors gave guidance on elements of the project such as resilience theory, learning theory, psychotherapy, visual/multimedia design, computer science and public engagement/communication.



Fig 3.10: Overseas placements/visits during fellowship (Google Maps, [google.co.uk/maps](http://google.co.uk/maps))

### 3.5 Stage 3: Development of initial prototype

#### 3.5.1 Development of content & design

Figure 3.11 demonstrates how the design and content of the package was developed based on the findings from stage 1 and 2, and the consultations described above. The findings from the literature reviews and consultations also guided the qualitative work, and the various consultations helped to guide a further investigation of the literature. The package was developed as bilingual - in English and Welsh - but also suitable to be distributed on an international level. The package was tailored to be appropriate for those who were depressed and those who were at high risk for depression. As noted above, a team of supervisors and advisors pooled together expertise and experience in various fields of research and practice to inform the development of the package.

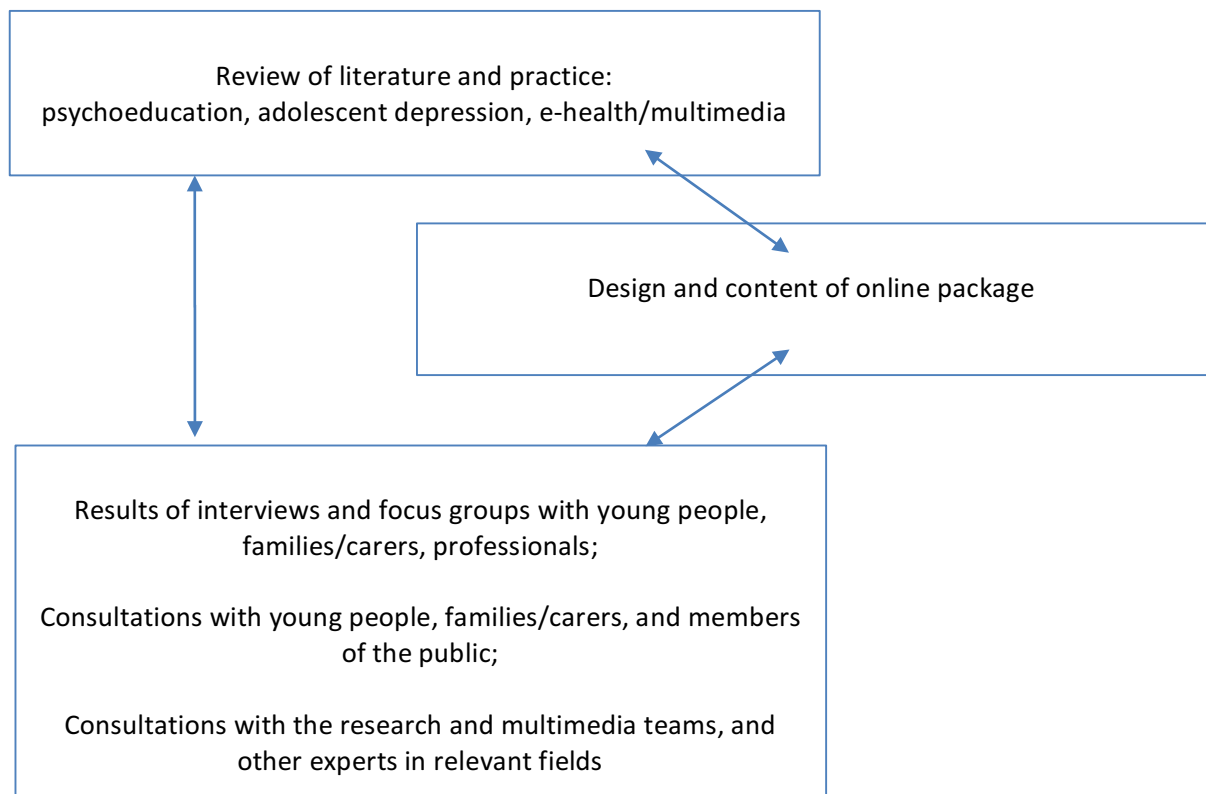


Fig 3.11: Influences on the design and content of the online package

### 3.5.2 Multimedia company & intellectual property

The search for the multimedia company started in the early stages of the project. The specifications were based on the findings from the review and initial interviews, which helped to determine the skillset required. The main requirements were for a company that could create an engaging and sophisticated multimedia package for young people, as well as a secure and confidential database. It was also important that the company chosen represented good value for money.

There were two tender processes for the multimedia company, which were processed by the Cardiff University tender office. There was a requirement to approach several companies so that at least three officially registered an interest. They were then invited to submit a report and present to the research group on how they would meet the specifications.

The first tendering process was unsuccessful because the companies which bid did not meet the specifications required, particularly that they would be able to create a youth-friendly and engaging package – and this led to some delays. During the second tendering process, the company ‘Made by Moon’ (madebymoon.com) was chosen, which consisted of two experienced multimedia professionals, a designer and a programmer. They had evidence they had developed work that was engaging for young people, in commercial, cultural and public sector settings. An animator, who also had such experience, was sub-contracted to this company.



Fig 3.12: Photographs from some of the workshops held with the multimedia company

Several workshops were held with the multimedia company to develop the initial prototype (see fig 3.12, and chapter 6), in which the design and content of the package was discussed and refined, alongside the latter focus groups with the research participants – with the focus groups influencing the workshop discussions and vice versa. The student, multimedia

company and animator were all involved in the development of the designs, based on ideas/feedback from the participants.

Meetings were also held with legal and technology officers and the tendering department at Cardiff University to discuss issues regarding intellectual property and other terms and conditions – which were then finalised with the multimedia company. There were specific intellectual property issues in relation to the name of the package, which was changed several times during the project, and aspects of the animation, such as the soundtrack recordings. Cardiff University own the intellectual property for the package, and its IT department host the site.

### **3.6 Stage 4: Evaluation of initial prototype**

#### **3.6.1 Mixed methods approach**

There was an early evaluation of the prototype of the package to evaluate ease of use, clarity, feasibility and acceptability (stage 4). This also helped to explore the potential effect of the intervention as well as inform the approach to take (e.g. selection of outcome measures) to evaluate the package in a future larger trial. This stage involved both qualitative and quantitative evaluation.

Data were collected from several sources including i) further interviews with young people/parents who used the package, and a focus group with professionals, ii) online usage data and iii) Pre and post-intervention questionnaires (used to assess mental health and wellbeing, use of the package, and opinions on the package e.g. design, content and how helpful it was).

The evaluation phase therefore consisted of an assessment of:

- a) **Use of the package:** Analysis of online usage data and data from the post-intervention questionnaire completed by participants
- b) **Opinions of the package:** Data from post-intervention questionnaires (quantitative), semi-structured interviews with young people and parents/carers, and a focus group with professionals (qualitative)



- c) **Potential effectiveness:** Data from pre and post-intervention questionnaires (depression literacy and stigma, help-seeking behavior, self-efficacy, depression and anxiety symptoms, and behavior)
- d) **The approach to evaluation:** Data from pre and post-intervention questionnaires on the number and acceptability of the measures included in the evaluation

### 3.6.2 Participants for evaluation phase (stage 4)

Participants were recruited from the EPAD study and secondary CAMHS teams as before, with Powys UHB added to the health boards because of interest from professionals working there. Young people were also recruited from school counsellors/nurses and child and adolescent primary mental health teams. The sources of recruitment were expanded in this way because the findings of the interviews and focus groups showed that the package might help young people and families seen by these services. Additional NHS and university ethical approvals were granted for the new centres.

A total of between 30 and 40 young people were targeted to complete the evaluation phase. Participants in the development phase (stage 2) were also invited to participate in the evaluation phase. Further details on the participants, including demographics, baseline characteristics, retention rates, and how many participated in both phases, are provided in the evaluation chapter (chapter 7). The inclusion and exclusion criteria, methods of approaching potential participants, and process for consenting were the same as for stage 2. Participants included adolescents with, or high-risk of, depression/depressive symptoms, recruited from south and west Wales (see fig 3.13). The parents/carers/families of the participating adolescents were also invited to use the package and participate in this phase. The sampling frame was also similar to that of stage 2, and a balance was sought of participants from each of the recruitment centres. For the post-intervention interviews, participants were also selected based on their usage of the package (i.e. frequent use, or only occasional use/not at all).

Professionals working with young people from health, education, social and youth services, and charities in south and west Wales were also asked for their reflections on the package in

a focus group. These professionals were sent a link to the package two weeks prior to the group, so that they could familiarise themselves with it beforehand.

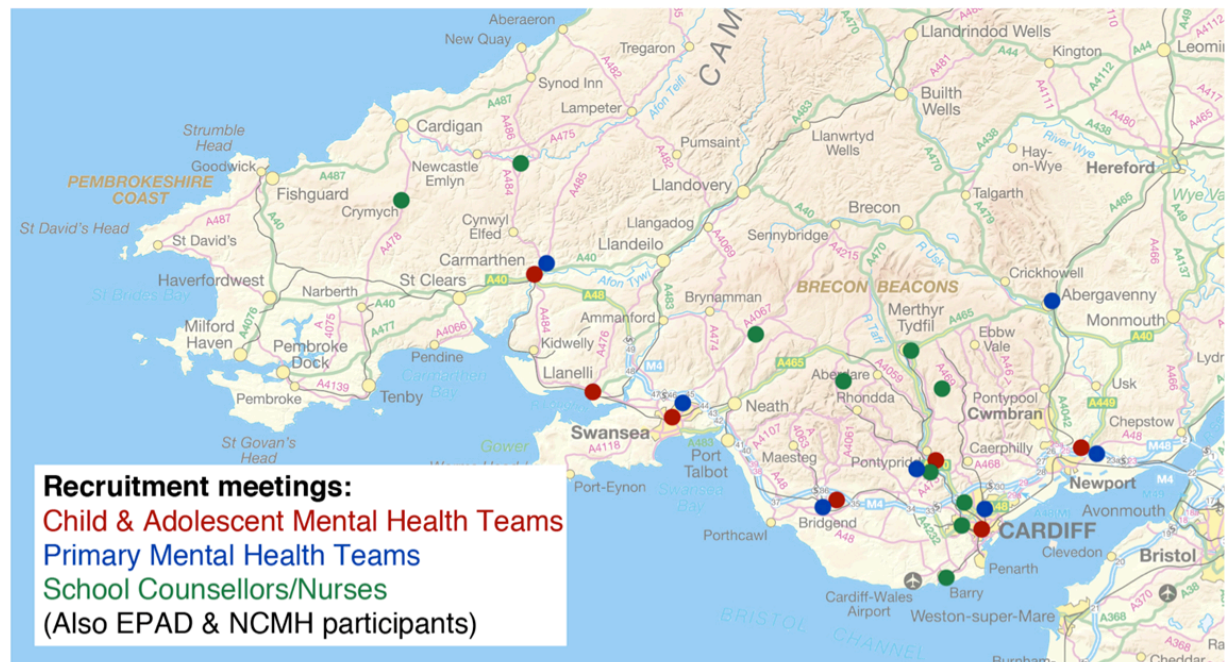


Fig 3.13: Recruitment centres for stage 4, in south and west Wales (mapmoose.com)

### 3.6.3 General use of the package

General online usage data was recorded using Google Analytics ([google.co.uk/analytics](https://google.co.uk/analytics)), however, on closer inspection of the data, it was not of sufficient quality to enable any analysis. However, individual user interactions of those participating in the evaluation were captured by the multimedia company. Data on general use of the package was also derived from the post-intervention questionnaire (table 3.1).

**Table 3.1: Data captured on general use of package**

Individual user interactions (multimedia company)	Questionnaire data
	Frequency of use (e.g. once or twice, once a week)
Number of visits to each section	Sections looked at the most
Language used on each visit (English or Welsh)	Language option chosen (English, Welsh, both)
	Average time spent on site each time (e.g. few minutes, half an hour)
	Use with others (e.g. parent/guardian/carer, friend, professionals)
User pathway (for self or for other person)	

### 3.6.4 Quantitative data collection

To explore the potential effect of the intervention as well as to assess outcome measures for use in a larger trial, adolescent participants and their parents/carers, were asked to complete questionnaires before and after having access to the package for at least two months. All participants were given the choice of being seen in person to discuss the project and complete the consent forms and questionnaires, or to do this by post (and phone/email). A summary of the outcome measures included in the questionnaires is provided in table 3.2. Parents completed questions both about their child and themselves.

The authors of the questionnaires were contacted to approve their use, where required. All questionnaires were developed using Formic software, so that they could be scanned and

the data could be stored digitally for analysis. The questionnaires for the evaluation phase were reviewed by seven young people (and their parents/carers), and some of the layout and wording were refined to make them more understandable and acceptable.

**Table 3.2: Content of questionnaires (pre and post intervention):**

Outcome	Questionnaire	Rater
Depression literacy	Adolescent Depression Knowledge Questionnaire (ADKQ) (Hart et al. 2014)	Child self-report Parent self-report
Depression stigma	Depression Stigma Scale (DSS) (Griffiths et al. 2004)	Child self-report Parent self-report
Help-seeking behaviour	General Health-Seeking Questionnaire (GHSQ) (Wilson et al. 2005)	Child self-report
Self-efficacy	Self-Efficacy Questionnaire for Depression in Adolescents (SEQ-DA) (Tonge et al. 2005)	Child self-report
Behavioural activation	Behavioural Activation for Depression Scale (BADs) (Kanter et al. 2007)	Child self-report
Depression symptoms (child)	Moods and Feelings Questionnaire (MFQ) (Angold et al. 1995)	Child self-report Parent about child
Anxiety symptoms	Screen for Child Anxiety Related Disorders (SCARED) (Birmaher et al. 1999)	Child self-report Parent about child
General behaviour, strengths and difficulties	Strengths and Difficulties Questionnaire (SDQ) (Goodman 1997)	Child self-report Parent about child
Depression/anxiety symptoms (parent)	Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith 1983)	Parent self-report

### 3.6.5 Qualitative data collection (stage 4)

A selection of the adolescents (with depression or at high risk) and parents/carers, who participated in the evaluation were also interviewed. The number selected was dependent on data saturation (further details on participants are provided in chapter 7). Young people were asked whether they would like to be interviewed alone or with a parent/carer; the parent/carer was also asked whether they would like to be interviewed separately. The

interviews were conducted at a location of their choice – e.g. home/school/Cardiff University.

Interviewees were first asked their general views of the package, in particular its strengths, and how it could be developed further. They were then shown the sections of the package on a laptop and mobile phone as they were interviewed (from the log-in page, through to the welcome screen and then the various components of the package) – so that they could discuss specific strengths and areas to develop further related to the design and content of the individual sections. At the end, participants were asked about how the package could be used and promoted in ‘real-life’ – in health, education, social and youth services, and charities.

A focus group was also held at Cardiff University with professionals from health, education, social, youth services and charities (further details are provided in chapter 7). The participants were asked the same questions as the interviewees, and were taken through the package, which was projected on a large screen. The interviews and focus groups were all recorded digitally and transcribed.

## **3.7 Data analysis**

### **3.7.1 Quantitative analysis (stage 4)**

Quantitative data was obtained from the questionnaires and from the multimedia company (on use). The available information was analysed and presented descriptively, using summary statistics (means and percentages). A series of paired sample T tests were used to assess changes in outcome scores between the pre and post intervention questionnaires (e.g. for depressive symptoms). This statistical test requires that the distribution of the differences in the dependent variable between the two groups (pre and post intervention) should be approximately normally distributed. Findings from the Shapiro-Wilk test did not show statistical evidence to suggest a deviation from normality for any of the reported outcomes. Mean differences and confidence intervals were presented for these analyses. When generating sum scores for the individual questionnaires, missing values were replaced

with the mean value for that individual, provided there was less than 10% of missing data. Individuals with more than 10% of missing data on a particular questionnaire were classified as missing. Analysis were conducted using STATA software (version 14, Stata Corp LP, College Station, TX, USA).

### 3.7.2 Qualitative analysis (interviews and focus groups, stage 2 & 4)

Qualitative data were collected and analysed using rigorous methods. As noted previously, the interviews and focus group recordings were transcribed and data analysis proceeded using thematic analysis techniques. There has been controversy over whether or not inductive thematic analysis should be seen as a method in its own right, and whether it should be considered as 'a technique that can be used across approaches' (Boyatzis 1998). Others state that it should be seen as a distinct approach, arguing that it is widely used but 'poorly branded' (Braun & Clarke 2006). The overall process of conducting a thematic analysis consists of three broad stages which was followed in this study: breakdown of text, exploration of text, and integration of an interpretation. Braun and Clarke's framework for carrying out a thematic analysis refines this into six steps of data analysis (fig 3.14).

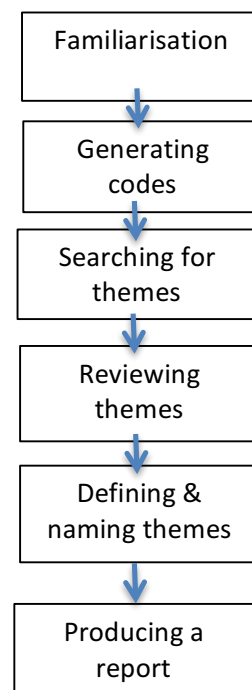


Fig 3.14: Steps in data analysis

All transcripts were coded independently by the student as well as by another researcher at Cardiff University (half the interview and focus group transcripts were coded by Harriet Beeching, and the other half by Rachel Cichosz - both medical students on long-term placements). Agreement on concepts and coding was then sought to ensure reliability. Where there was disagreement, the researchers reviewed the coding together before deciding on how to proceed. Supervisors were also consulted where there was uncertainty or disagreement.

Codes were applied to broad themes which were then broken down further into sub-codes. Transcripts were closely examined to identify themes and sub-themes. The interviewing was iterative, where new themes or areas of interest emerged they were incorporated into the subsequent interviews and focus groups. As noted previously, focus groups were staged sequentially with ideas feeding from one group to the next, and ideas developed by the research team between steps – so that the content and design of the programme progressed in a staged manner. Thematic analysis was supported using computer assisted qualitative analysis software (NVivo for Mac, version 10).

### **3.8 Stage 5: Further development**

The findings from the evaluation period (stage 4) informed a period of reassessment and further development of the package, with the research team and multimedia company (stage 5 – currently in progress). The findings were discussed with the research team and multimedia company, and suggestions to change the programme were prioritised according to whether they might improve the acceptability and feasibility of the package for young people (and parents/carers and professionals). Other factors to consider were the technical ease or difficulty, and financial resources available to make the changes. This is discussed further in chapter 8.

The findings from stage 4 will also be used to inform a future study, which will include further development and evaluation of the package. Upon successful completion of the online package, the aim is to proceed to phase 2 (exploratory trial), and then phase 3 (randomised controlled trial) in line with the MRC guidance for developing and evaluating complex interventions.

### **3.9 Summary and conclusions**

The MRC guidance for the development and evaluation of complex interventions was used to guide the current research. This chapter summarised the methods and approaches to (and importance of) (a) identifying the existing evidence base; (b) collecting and analysing qualitative data to inform the development of the package; (c) the development of an initial prototype; (d) the evaluation of the prototype; and (e) the final development phase. The next two chapters (chapter 4 and 5) describe the results from the initial semi-structured interviews and focus groups which were used to inform the development of the package. These are followed by an account of the development process (chapter 6), evaluation of the initial prototype (chapter 7) and overall discussion of the project (chapter 8).



## **Chapter 4: Discovery phase**

### **Results of semi-structured interviews with users to generate ideas on content/design for the focus groups**

#### **4.1 Introduction**

This chapter gives an account of the qualitative study involving semi-structured interviews during the second stage of the overall research plan to develop an online psychoeducation package for adolescent depression (see figure 4.1). This included a series of interviews with potential users of the package – adolescents, families, carers and professionals who work with this age group, from health, social, education and youth services. The aim of the semi-structured interviews was to gather and analyse views of potential users of the package (young people, parents, professionals), to generate initial ideas regarding the content and design for the focus groups of stage 2 (see chapter 5). Some initial images were created for the design of the package to show and discuss during the interviews as they progressed.

The findings from a thematic analysis of this data, along with findings from the review on psychoeducation in adolescent depression (chapter 2), informed the development of the design and content of the package (third stage, figure 4.1). There were also discussions to complement these findings, with the research team and a range of advisors, from the fields of adolescent depression, resilience, psychoeducation/education, psychological approaches, electronic media and public engagement.

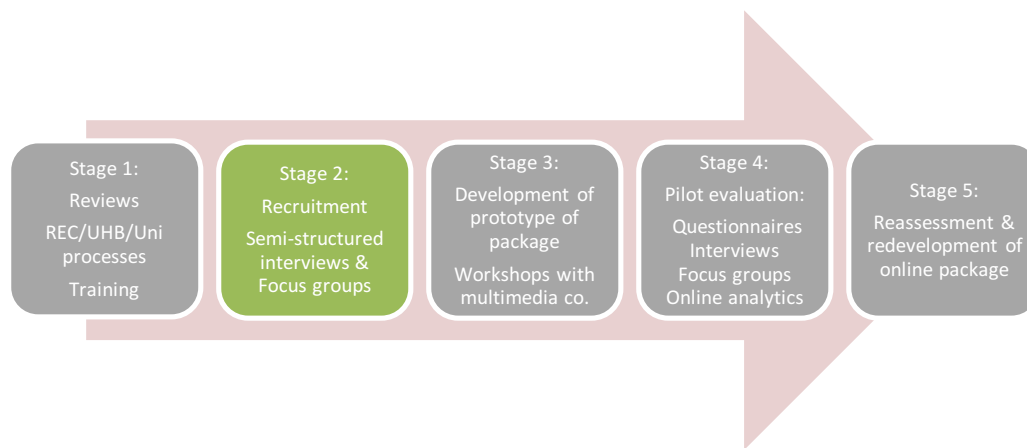


Fig 4.1: Broad stages of the research plan

The chapter describes the key themes and findings from the interviews. The final section summarises the findings, and how the findings will inform the focus groups and development of the package. More detail on the methodology is given in the previous chapter (chapter 3). This chapter is also linked to the next chapter (chapter 5), which gives an account of the findings of the focus groups, and chapter 6, which discusses the further development of the package with the multimedia company, in light of the findings from stages 1 and 2.

## 4.2 Interview participants

Twelve people were interviewed in total (table 4.1) – four young people aged 13 to 18 years old, four parents and four professionals. Of the young people, two were recruited via Child and Adolescent Mental Health Services (CAMHS), one was recruited from the Early Prediction of Adolescent Depression (EPAD) study, and the other was a volunteer who had previously been under the care of CAMHS and was therefore also ‘at risk’ given the history of depression. Two of the parents were recruited from the EPAD study, and had a history of recurrent depression, making their children ‘at risk’. The other two were the mother and father of a young person recruited via CAMHS, and were interviewed together. Two of the professionals were child and adolescent psychiatrists, one was a general practitioner and the other an educational psychologist.

**Table 4.1: Participants - semi-structured interviews**

<b>Participant group</b>	<b>Background</b>	<b>Other demographics</b>
Young person 1	18-year-old female with a history of depression (previously under Child and Adolescent Mental Health Services (CAMHS))	Welsh/British, Caucasian; Language: English, Welsh
Young person 2	13-year-old female with depression (under CAMHS at time of interview)	Welsh/British, Caucasian; Language: English, Welsh
Young person 3	17-year-old male with depression (under CAMHS at time of interview)	Welsh/British, Caucasian; Language: English, Welsh
Young person 4	16-year-old female at high risk of depression (mother has a history of recurrent depression)	Welsh/Lebanese, Asian-British; Language: English, Arabic, Welsh, Spanish
Parent 1	Mother with a history of depression (her 14-year-old daughter is therefore 'at-risk')	Welsh/British, Caucasian; Language: English
Parents 2	Father of a 13-year-old daughter who has a history of depression (under CAMHS)	Welsh/British, Caucasian; Language: English, Welsh
Parent 3	Mother of a 13-year-old daughter who has a history of depression (under CAMHS)	Welsh/British, Caucasian; Language: English, Welsh
Parent 4	Mother with a history of recurrent depression (her 16-year-old daughter is therefore 'at-risk')	Welsh/Lebanese, Asian-British; Language: Arabic, English
Professional 1	Consultant Child and Adolescent Psychiatrist (male) (Advisor to National Assembly for Wales)	Welsh/British, Caucasian; Language: English, Welsh
Professional 2	Consultant Child and Adolescent Psychiatrist (male) (with a special interest in Adolescent Mental Health)	English/British, Caucasian; Language: English
Professional 3	General practitioner (female)	Welsh/British, Caucasian; Language: English
Professional 4	Educational psychologist (female)	Welsh/British, Caucasian, Language: English, Welsh

### 4.3 Key themes identified in the interviews

The content of the discussions in the interviews was guided by issues the student and research team wanted to explore to help develop the online package. The main areas of

exploration, which became the key themes explored in the interviews were: i) the need for and aims of the online psychoeducation package, ii) design issues, iii) content issues, and iv) its integration into the young person's life. A summary of the themes can be found in table 4.2.

**Table 4.2: Themes arising from the interviews**

<b>Key theme 1: The need for and aims of the package</b>	
4.4.1	Accessibility and target group
4.4.2	Increase awareness and tackle stigma
4.4.3	Lack of resources for young people
4.4.4	Need to engage young people
4.4.5	Embrace a medium that's relevant for young people
4.4.6	Promote self-management/autonomy
4.4.7	Accessible for a diverse range of users
4.4.8	Young people find it difficult to talk to adults
4.4.9	Help for parents, carers and professionals working with young people
<b>Key theme 2: Design issues</b>	
4.5.1	Harnessing multimedia to <i>engage</i> the user
4.5.2	Harnessing multimedia to <i>communicate</i> information
4.5.3	Multiplatform approach and 'app'
4.5.4	Clear structure and navigation
4.5.5	Language issues
4.5.6	Characters, avatars
4.5.7	Using metaphors to develop a 'relationship' with the problem
4.5.8	Colour
4.5.9	Images of heads and brains
4.5.10	Gamification
4.5.11	Personalising the space
4.5.12	Monitoring tool
4.5.13	Forums, security and confidentiality
<b>Key theme 3: Content issues</b>	
4.6.1	General approach
4.6.2	What are mood, wellbeing and depression?
4.6.3	Possible reasons for low mood and depression
4.6.4	Prevention and self-management
4.6.5	Where to get help
4.6.6	Section for parents, carers, friends, professionals

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**Key theme 4: Integration and context**

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- 4.7.1 Use of the package with others, e.g. parent, friend, professional
  - 4.7.2 School/education services
  - 4.7.3 Health and other services
  - 4.7.4 Name, branding and promotion
- 

## **4.4 Key theme 1:**

### **The need for and aims of the package**

There was much discussion focused on why participants felt there was a need for an online intervention for adolescent depression. This helped to clarify the aims of the package and how the design and content would help meet these aims.

#### **4.4.1 Accessibility and target group (universal v targeted)**

There was a range of opinions on whom to target for this intervention. Some young people thought that it should be 'universal', and that anyone should be able to access the proposed package.

*'The more people with access the better' (Young person 1: female: under CAMHS).*

However, the overall view from all interviewed was that those with depressive difficulties were particularly in need, and that they should be targeted. One professional specified that it could be a 'fantastic' tool for those in the 'mild and moderate group'.

*'By making it too widely available...there's a risk of losing the chance of catching those who really need it' (Professional 3: female: general practitioner).*

It was also suggested the package could be used to screen as well as help with treatment, and reach those not yet diagnosed.

#### **4.4.2 Increase awareness and tackle stigma**

One parent felt there was a need to increase awareness in young people, particularly because young people do not necessarily think they need help, and another stated there were increasing mental health difficulties in young people, largely because of the stress of schoolwork and exams, as well as social pressures.

Professionals also stated that in general there was a need to increase awareness, as well as promote help-seeking, tackle stigma/prejudice, and enhance motivation.

*‘Give enough information to tip the balance so that the young person takes sensible steps’ (Professional 2: male: psychiatrist).*

#### **4.4.3 Lack of resources for young people**

Young people, parents and professionals stated there was there was a lack of resources at present for youth mental health. Professionals felt that an online package could be ‘filling a gap’, as those which are available have been developed mainly for adults.

*‘There’s a huge gap as to what else that we can offer, beyond the four life hygiens...You’ve certainly hit an area where we’ve got a big, black hole, definitely...huge, huge’ (Professional 3: female: general practitioner).*

Parents also noted that waiting lists, particularly for CAMHS, were too long, and thought this was an area where the package could help.

*‘My daughter didn’t know where to turn’ (Parent 2: male: daughter under CAMHS).*

Parents and professionals also felt there was not enough time for professionals to communicate with young people:

*'There is a limit to what you can get across in an appointment, especially in primary care'*  
*(Parent 1: female: daughter 'at-risk').*

#### **4.4.4 Need to engage young people**

There was a consensus amongst the professionals that the package could help address the 'problem' that exists in engaging young people with mental health issues and services. In fact, professional 4 stated that the two main aims of the package should be that it is '*a useful tool*' and be '*engaging*'.

*'Engaging is crucial – people don't engage with textbooks plans, they want to do things at their own pace, don't want to see a psychiatrist or whatever. There is a need to be theoretically sound and get young people to use it' (Professional 1: male: psychiatrist).*

Professional 2 stated that further research could focus on the barriers to engagement, and how to overcome these.

#### **4.4.5 Embrace a medium that's relevant for young people**

Young people and parents stated that developing an online package would be useful, because electronic media was particularly relevant for this age group.

*'My generation uses technologies' (Young person 4: female: 'at risk').*

*'Everyone does things online' (Parent 4: female: daughter 'at risk').*

The issue of digital technologies in relation to help-seeking behaviour was also discussed. Parents thought that young people talked to friends and went online for help. One professional queried whether young people might use online sites for healthcare information. On the whole, however, professionals felt that using technologies for healthcare information was an area that should be explored further.

*‘There’s genuine interest in young people in computerised tools and the Internet for help seeking – it’s tapping into something they’re comfortable and familiar with’ (Professional 4: female: educational psychologist).*

#### **4.4.6 Promote self-management/autonomy (see also key theme 3: content issues)**

Professionals described how the package could help to promote self-management and autonomy in young people. This could be done by helping them to understand their difficulties, self help approaches and where to get help. One of the main aims could be: *‘to engage young people in really trying to take some responsibility for their own health’ (Professional 3: female: general practitioner).*

Professional 1 noted that health care professionals struggled to give young people that responsibility:

*‘Health workers are fantastically bad in doing this... we disempower people fantastically. As soon as they walk through the door we make decisions on their behalf...Parent say kids need to be talked TO, ‘it’s the model that would help them’...but mostly it’s the last thing they want, parents don’t always know best’ (Professional 1: male: psychiatrist).*

#### **4.4.7 Accessible for a diverse range of users**

Interviewees, particularly professionals, stated that the package would need to accommodate as wide a range of users as possible. One of the parents and one of the professionals stated that the age of the young person was a consideration; although 14 to 18 years is a limited range, there could be a great deal of variation.

*‘Could you actually produce something that attracted all ages? Because also you’ve got quite a wide age range and maturity and even literacy really between thirteen, fourteen year olds and eighteen year olds’ (Parent 1: female: daughter ‘at risk’).*



Professional 1 stated that it was important to address the different 'preferred learning styles', such as verbal, auditory and kinaesthetic – so that all senses are 'engaged'. This could be done through using various media, for example by converting everything into a written script.

*'It's important that they have a say in the way they learn...You need options on how they learn that day e.g. read, do, listen etc' (Professional 1: male: psychiatrist).*

Professionals also noted the package should be user-friendly and accommodate a range of intellectual, learning and reading abilities and difficulties. Professional 4 suggested using various ways of demonstrating information through multimedia, such as introducing small steps, allowing for reviews and 'over-learning' (mastering new skills, so they can become automatic). Professionals also stated it was important not only to target those who are 'well-educated'. Gender was also suggested as a possible consideration by parents.

*'The sort of programme...the sorts of visuals, that are going to attract a teenage girl compared to a teenage boy are opposite ends of the spectrum' (Parent 1: female: daughter 'at risk').*

#### **4.4.8 Young people find it difficult to talk to adults**

Professionals stated that young people find it difficult to talk to adults who were not familiar to them, especially about sensitive issues such as mental health difficulties.

*'Young people struggle to benefit from sitting in a room with an adult called a psychiatrist or psychologist' (Professional 1: male: psychiatrist).*

Professional 2 stated the current options are '*not acceptable, and hard*' for the young person. For example, cognitive behavioural therapy (CBT) requires them '*to do the talking*'. One professional suggested that males find it particularly difficult. Professional 3, a GP, was not confident that even their peer group would advise them to see their doctor or GP, because they might be perceived as 'scary' and 'unreachable'.

Young person 2 also stated that not enough was done by some professionals, for example at school: *'Teachers let it pass'*. It was suggested that the package could help young people to approach professionals.

#### **4.4.9 Help for parents, carers and professionals working with young people**

Parents felt that this package could be a 'big help' for parents as well as young people.

*'I think I would've liked...as we were going through it...in the beginning, I did feel that there was nobody there' (Parent 2: male: daughter under CAMHS).*

One professional stated that adolescents are dependent on parents or others (such as school nurses) to bring them to the surgery or other services, and they should be considered when developing the package.

Professional 2 suggested there was a need to increase training on depression and other mental health issues amongst professionals, including GPs, schools, and educational psychologists.

*'Mental health tends to get shoved to one side, because it is not something that teachers for example have had any great training on, and it is an unknown quantity...and they tend to sort of shy away from that on the whole...They are dealing with mental health half the time without realising it' (Professional 2: male: psychiatrist).*

### **4.5 Key theme 2: Design issues**

The overall 'design issues' of the package was the theme that was most extensively discussed by participants, especially the young people. Parents stated that design was paramount in engaging the young person.

*'Delivery is the probably the place to start with it...what it looks like...Design is very important to teenagers...as soon as you've found the right graphic designer, everything*

*will fall into place...One company for the design, one for the mechanics and therapy’  
(Parent 1: female: daughter ‘at risk’).*

#### **4.5.1 Harnessing multimedia to *engage* the user**

All participants described how multimedia and its various components should be harnessed to engage the user. Whilst engaging and communicating are related, they are dealt with separately here for the sake of clarity.

Young people and parents felt that the use of mixed media – including visual, audio, and kinaesthetic/interactivity – would be especially good to engage the user.

*‘Take advantage of the flexibility and complexity of multimedia’ (Parent 1: female: daughter ‘at risk’).*

In general, professionals suggested the package design should be:

*‘slick, bright, visual’ (Professional 2: male: psychiatrist),*

*‘positive, interesting, attractive to young people...friendly, engaging, approachable, straight-forward and clear...colourful’ (Professional 4: female: educational psychologist).*

Participants, especially parents, stated it should not be *‘cold, sterile, computerised and anonymous’* – as this makes the user feel *‘worse or alone, odd, strange or weird’*.

However, some urged caution regarding the choice of media. Parent 1 stated it was difficult to predict what was engaging for young people. Some advised about the risk of over-complicating the design, as sections could be missed if too *‘busy’*.

A professional stated there was also a need to acknowledge the limitations of digital media:

*‘You need creativity...although it is still not as good as pen and paper...Disney and Pixar can do it, but after a lot of effort’ (Professional 1: male: psychiatrist).*

Another concern was how the package could 'date' quickly, because the advancements in digital technologies, and the 'fashions' and 'trends' in design. There was a recurrent message to 'future-proof' the package:

*'Remember that young people now and in 3 years' time are not the same'*  
(Professional 1: male: psychiatrist).

One young person suggested having a statement in large letters such as 'happy to meet you' on the welcome screen, to help promote engagement. Professional 3 added it could include their name, a greeting, with choices about what they read, and a question *'How do you feel at this point?'*, to get them to communicate their feelings.

#### **4.5.2 Harnessing multimedia to *communicate* information**

Participants suggested a range of approaches to present the information, including text, graphics, graphs, interactive icons, audio, films, short videos (e.g. talking heads), music, or animation. Most thought it should be particularly visual, with several images, rather than all text.

*'I think the visuals are everything where teenagers are concerned'* (Parent 1: female: daughter 'at risk').

Professional 3 stated that 'images are better than words' in her experience of working with young people. Professional 1 stated that young people, especially males, like to learn through visual and auditory as well as verbal (written) mechanisms. However, young person 3 preferred words to pictures. Professional 1 noted that having an element of choice was important:

*'Young people communicate in different ways'* (Professional 1: male: psychiatrist).

Most thought that interactivity was important. With regards to the text, it was recommended that the font should be easy to read, and that the information was presented

in bullet points. Numbers and statistics should be included, with enough 'explanation', although one participant stated there should not be too many statistics.

#### **4.5.3 Multiplatform approach and 'app'**

Most young people thought there should be a multiplatform approach, including phones, tablets, laptops and desktops. Professionals agreed that there should be many '*access points*', and professional 4 noted that '*all young people use phones*'. Most young people also agreed there should be an 'application' or 'app' to accompany the package.

One young person noted that a possible limitation to this approach could be if the young person or family had no access to such devices, although he stated that libraries could help with this.

#### **4.5.4 Clear structure and navigation**

Young people noted that the package should be 'easy to navigate', with a clear distribution of the information, for example through a 'tab' system. Parents also stated there was a need for a clear structure.

*'You need to split things up – be very intentional about each area' (Parent 1: female: daughter 'at risk').*

Professionals suggested it should be full of 'short, bite-sized chunks', but without jargon:

*'something which could be dipped in and out of...reminders of where they've come from, whichever access point they take' (Professional 1: male: psychiatrist).*

There was emphasis on the home page, and whether the user could see clearly all the possible sections. Young people also suggested there could be a short film or animation to introduce the package and various sections.

#### 4.5.5 Language issues

Participants noted that the information should be at the level of the young person, not a health professional, and should avoid jargon and medical terms. Professional 2 (male: psychiatrist) suggested that terms such as 'depressive disorder' can *'freak people out'*, and urged caution when using these terms. Professional 3 (female: general practitioner) suggested people had to *'buy into'* such terms. Professional 4 (female: educational psychologist) suggested focusing on terms such as 'mood' and 'wellbeing', not only 'depression'. 'Wellbeing' was considered important especially in education, although there were reservations about what it meant to young people.

The tone of the language was also considered important. Professional 1 (male: psychiatrist) stated that professionals outside mental health services are sometimes alarmist, and there was a need to be calm and analytical. Professional 3 (female: general practitioner) suggested it should *'avoid sounding like a berating mother'*.

Parent 1 suggested using phrases a young person might use, for example,

*'I'm worried', 'dad shouts at me', 'not sleeping', 'I don't feel attractive', 'I've got a problem and I need it sorted' (Parent 1: female: daughter 'at risk').*

Most participants agreed that the package should be bilingual, in English and Welsh. Professional 3 preferred that either English or Welsh was presented separately, otherwise it would be 'distracting'.

#### 4.5.6 Characters, avatars

Many of the interviewees, particularly young people, discussed having an individual, character or 'talking head' to present information and 'give tips' in the package. It was suggested that a great deal of consideration should go into whether this was an actor or 'real person', and into their qualities, for example reassuring, sensitive, trendy, trustworthy, 'someone to listen to' or 'someone who knows'.

If a character were created or animated, young people noted they should be representations of young people and ‘non-confrontational’, rather than a ‘childish’ character such as ‘SpongeBob Square Pants’. Young person 1 (female: under CAMHS) suggested that characters could reflect the user’s identity, and how they felt at the time, possibly as part of the personal profile. They also discussed how characters could present personal experiences of mental health difficulties (see content issues, section 4.6).

One parent liked the idea of avatars, characters to represent the users, or a companion guide character. However, she was concerned this might reduce the impact, because they would be *‘hiding behind something’*. Parents on the whole felt that characters or photographs of real people were preferable, as in ‘teenage magazines’.

Professionals were particularly positive on the use of characters (guides and avatars) to engage the user. Professional 2 (male: psychiatrist) suggested using superheroes or a traditional-looking doctor, and referenced the ‘Think Good Feel Good’ CBT books and programmes as an example of this approach (Stallard 2002).

#### **4.5.7 Using metaphors to develop a ‘relationship’ with the problem**

The use of visual representations and metaphors to engage young people was discussed extensively throughout the interviews. Professional 3 stated that metaphors, particularly visual ones, could help people better relate to what is happening to them:

*‘They’re standard, aren’t they; those recognisable icons and pictures, and I think they’re very good. I think people would recognise them more than words’*  
(Professional 3: female: general practitioner).

Professional 2 (male: psychiatrist) stated that using metaphors could help to develop a ‘relationship’ with the problem. He discussed developing an ‘externalising’ metaphor, so that the young person can *‘fight against the depression’*. Furthermore, another professional stated that metaphors could help to:

*‘convert the problem into something that’s a) manageable, b) normal with power to change...not an overwhelming monster that’s in control of them’ (Professional 1: male: psychiatrist).*

A range of metaphors was described, particularly for depression.

*‘I describe it like not being able to get to the top of the ocean and you are just sinking downwards as if there’s an anchor pulling you down’ (Young Person 2: female: under CAMHS).*

*‘The metaphor is that raining is bad, the sun is good, people who are depressed and feeling low feel like they have a cloud’ (Parent 4: female: daughter ‘at risk’).*

Organic and inorganic objects were proposed, including flowers, trees, jigsaw puzzle, bows, arrows, stars, and elements of a science lesson.

Professionals were asked about the metaphors/images they used with young people, when discussing mental health issues. These included a thermometer as a mood regulator, carbon atoms (and how the levels reduce in depression), mind-maps, faces, trees and visibility/invisibility. Professional 1 suggested referring to understandable and relevant metaphors and analogies.

*‘Convert things into an understandable experience, e.g. anger metaphor – international rugby player pale with adrenaline before a game’ (Professional 1: male: psychiatrist).*

Professional 3 used metaphors to explain the treatment, such as putting a broken bone in plaster temporarily.

*‘I tend to focus on what the treatment’s about, not the illness or depression...recognisable icons and pictures that relate to this’ (Professional 3: female: general practitioner).*

Professional 2 suggested using ‘active’ metaphors such as ‘beating, overcoming, battling’ depression, and ‘not being a victim’.



Despite much enthusiasm for this approach, there was also caution about using metaphors, as they might be individual to the young person or family.

*‘There are several metaphors for one thing...which is best for you?’ (Professional 1: male: psychiatrist).*

To help address this, several suggested there could be a range of imagery and metaphors within the package.

#### **4.5.8 Colour**

Colour and more abstract imagery could also be used to represent moods and mental states. ‘Bright colours’ were recommended by one of the parents, to represent ‘happy feelings’. Darker images related to depression suggested by professionals included black clouds and dogs, and crossbones (to represent CBT). Parents suggested there should also be ‘upbeat images’, such as ‘light sky’ and ‘birds’, or the package could show how the negative images become positive over time.

One parent suggested there could be one image for the day (with blue skies), another for the night (with a sunset), with the whole package (e.g. as a town, park or space) constantly changing. Professional 3 suggested there could be a change in colour as the user progresses and gets a sense of control, such as from dark purple to yellow.

#### **4.5.9 Images of heads and brains**

The use of the head as a framing device for sections of the package was also discussed, particularly by the adolescents. Different heads were proposed to represent various emotions and other elements.

*‘I think it is good to have a head because that’s where it is going on’ (Young Person 2: female: under CAMHS).*

Professionals overall were positive about the use of heads – and suggested they could be questioning, explaining and show features of depression – making distinctions with ‘normal’ experiences. One professional proposed:

*‘What’s going on in my head?...Visualise this!...Graphics on how you build your understanding of your mind...what’s happening in your life’ (Professional 3: female: general practitioner).*

#### **4.5.10 Gamification**

Some participants suggested having a gaming element to engage the user. The main suggestion by young people was to have a quiz to assess knowledge of depression, and how the individual copes with this. A parent suggested that the package could start with such a quiz.

Professionals referred to existing gamified packages, such the CBT-based SPARX (Merry et al. 2012). Professional 2 suggested a game might help, so that the user is *‘intrigued to go further’*. However, he was also concerned that a game or character could be distracting or off-putting.

#### **4.5.11 Personalising the space**

Personalising the space was a recurrent theme in the interviews, particularly with young people:

*‘Your place...your account...your head’ (Young person 1: female: under CAMHS).*

*‘It’s a very individual thing, mental health, isn’t it?’ (Parent 1: female: daughter ‘at risk’).*

Professionals 1 and 2 stated that a sense of ‘ownership’ to the package was important.

Several ways of personalising were suggested, including having the ability to upload images/ photos and text in a profile section (such as on Facebook), put faces on characters, and change the colour on the screens.

It was also suggested that the content should be personalised, and this could be achieved by asking the user to answer questions at the start.

*'The advice should be personalised...try to make the package feel like it's for them [the user]' (Young Person 3: male: under CAMHS).*

*'Each module should be reactive to input, i.e. if feeding something in, different sets of information and modules are presented' (Parent 1: female: daughter 'at risk').*

A parent also suggested it would be possible to show progress through the package, for example by 'ticking off' sections, to give a sense of achievement. Professional 2 suggested the use of a bar to show progress.

However, another parent acknowledged it was challenge to cater for everyone, and that it was difficult to get the balance right between 'doing everything and doing nothing', and the other option would be to make it 'plain'.

*'Users would personalise it anyway...they would gravitate to what's relevant to them - gender, reasons, age etc.' (Parent 1: daughter: 'at risk').*

#### **4.5.12 Monitoring tool**

Related to the idea of personalising the package, it was suggested that there could be a tool to monitor mood and other health and wellbeing scores. Two of the parents discussed a monitoring tool. They noted the young person might use the package more if there was such a component, it could be a way for parents to see the progress of the young person, and there could be a link to help if needed. Professionals also suggested that self-monitoring, for example with mood and depression scores, was important as it encouraged self-reflection.

However, the young people had mixed feeling on whether they would use this. There was a suggestion it could be more helpful for those scoring highly on depression scores. Parents were concerned that mathematical graphs might be 'off-putting'. They also wondered whether young people would take the monitoring tool seriously enough, and might 'fool' observers so that the readings would not be a true reflection.

One young person suggested a diary to 'release' how they feel. Professionals also discussed a log, journal, mood record, and little entries. However, professional 1 noted he had never observed anyone continue to use these.

#### **4.5.13 Forums, security and confidentiality**

One suggestion discussed frequently was to build a blog, forum or a space where young people could help each other, and this was attractive to many. Professional 2 suggested it could be a good way of helping the young person understand they were not alone.

However, the ideas were largely discredited by young people, as it would require a great deal of monitoring, increased security and could potentially lead to users excluding themselves from the package. There was a risk of 'trolls', making unhelpful comments such as 'do drugs, get drunk'. Some also did not feel they wanted to talk to others, and would find it difficult to trust that it was safe and secure, and might cause distress.

*'You don't want to be talking to someone you don't know about the experiences you've had, and it may bring back all those feelings, that's something you don't want' (Young Person 2: female: under CAMHS).*

Parents generally were not in favour of using forums, stating that it would be difficult to know who's using them, although one thought it might be useful for parents. Professionals had mixed feelings about a forum, with most cautious, for example given the risk of sharing ideas on self-harm and suicide, and of paedophiles posing as young people. Monitoring would be needed, and there might be difficulties if a user would require urgent attention, especially out-of-hours. There were also reservations regarding linking the package to social media, such as Facebook and Twitter, for similar reasons.

The issues of confidentiality, security and anonymity were important for all young people, and they called for a secure portal for signing into the package. Parent 1 also suggested that the package should be password protected, although an element of it could be 'open access'.

## **4.6 Key theme 3: Content issues**

### **4.6.1 General approach**

Most participants noted that the package should have several levels or layers of information, and this could be a design as well as a content issue. This would help address the diversity in the user group. For example, one parent suggested this could cater for those with only some difficulties, as well as those with severe depressive episodes. For those who wanted detailed information, it was suggested there could be links to more specialist sites.

Having various levels would also help those returning to the package for information:

*'When revising you don't go back to the core material – you access reminders, such as helpful coping strategies' (Professional 1: male: psychiatrist).*

Parent 1 suggested that more information could be added to the package as required:

*'Back end can grow as the front end needs it' (Parent 1: female: daughter 'at risk').*

A parent and professional suggested there should be information at the start on how the package works, and the user would know that it's helping.

*'It needs to be clear what it does and doesn't do, for example it's not cognitive behavioural therapy' (Professional 1: male: psychiatrist).*

Related to the earlier section on ‘personalising the space’, it was also thought important to relate the content to the user, for example opportunities to note user experiences.

#### **4.6.2 What are mood, wellbeing and depression?**

##### **4.6.2.1 Mood and depression**

Participants felt that the package could open up conversations on mental health in general, and in particular mood and depression. Young person 1 noted:

*‘When I was diagnosed and they were like you’ve got depression, I was really confused and I didn’t know what it was or what that meant for me or how that would affect my life.’ (Young Person 1: female: under CAMHS).*

Parents supported the idea that adolescents did not fully understand the term depression.

Many participants, particularly young people, suggested including information on the distinction between ‘normal’ life and experiences of sadness, and mental health difficulties such as depression – and noted that statistics could help. Parent 3 suggested there could be information on general mental health in the ‘front end’ of the package, and mental health difficulties beyond that. She also noted the distinction between depression and day-to-day stress or low mood. All suggested including symptoms and signs of depression, and ‘what to look for’, including mental and physical symptoms.

##### **4.6.2.2 You’re not alone, it’s not your fault**

Many young people and parents wished to highlight to adolescents that they’re ‘not alone’ in their experiences of depression. A lack of understanding of adolescent depression can lead to misconceptions, and feelings of isolation and shame.

*'From our experiences, the feelings that were made to us was she was feeling invisible. It's a big wide world and she was alone, considering there were so many around she always felt alone' (Parent 2: female: under CAMHS).*

One way to help with this 'feeling alone' was to note how there were people there for them, and to state how common it was in young people. Another suggested it was a '*shared...common experience...it's ok to feel like this*' (Professional 3). Professional 4 suggested the package should stress the user was not 'odd' or 'abnormal'. At the same time, there could be information on how '*everyone's experiences are different*' (Young person 2). Several young people also explained how the package should stress it's not their fault.

#### **4.6.2.3 Personal experiences**

Several suggested including accounts of other people's experiences of depression. This could be in the form of case studies, quotes, and possibly videos or animations. 'Talking heads' and voices would need to be of young people rather than adults or professionals. Some young people offered their own perspective and experiences, and to highlight that it can be difficult, but young people do recover.

*'Depression, it is evil and a bitch...it chews you up and spits you out...[but] it's green grass and roses at the end...it's going to get better...it's a torrent of hell at the moment...it will be hard' (Young person 3: male: under CAMHS).*

#### **4.6.2.4 Other issues**

Young people proposed including the other difficulties that can happen before, during or after depressive episodes. Young person 2 stated that self-harm and suicide and bullying were especially important, although the latter might be included in a section on possible reasons for depression. A parent suggested information on alcohol and drugs and self-harm/suicide. Professionals described possible co-morbidities and associated factors, including anxiety, and one highlighted how the presentation can change.

*'You need to be open to the development of other disorders' (Professional 1: male: psychiatrist).*

### **4.6.3 Possible reasons for depression**

Most participants suggested having a section on possible reasons for depression in young people would be useful and it should include both environmental and biological factors that might contribute to the development or severity of depression.

#### **4.6.3.1 Life experiences**

Young people suggested these could include school issues, for example exam stress, or even *'starting the day badly'* (Young person 4). Parents suggested covering relationships, low self-esteem, appearance, work/school/exams, family break-up, bullying, falling out with siblings, hormones/puberty, peer pressure, and expectations. Professional 1 felt that recent problems were most important to young people. Another health professional stated that it was important to state what was *'not normal or acceptable'* such as abuse – and that the young person should get help in such cases. They also noted that sometimes the cause is not obvious:

*'Things can be perfect...you still feel low' (Professional 3: female: general practitioner).*

#### **4.6.3.2 Biological explanations**

Parents and professionals noted that a family history of depression should be discussed in this section. One professional stated that when seeing patients, particularly when starting medication, she would refer to 'carbon atoms'.

*'It's just a few carbon atoms that have got a bit low, we're trying to put them back up again' (Professional 3: female: general practitioner).*



## 4.6.4 Prevention and self-management

### 4.6.4.1 General approach

Prevention and self-management of depressive symptoms were considered key issues for many participants. Coping strategies were mentioned in particular. Professional 3 suggested giving responsibility to the young person:

*‘Ask them, so what are we going to do about this? Put them in charge...do you want to do something about this?’ (Professional 3: female: general practitioner).*

A few participants noted how young people should be encouraged to monitor their symptoms, to know when to do something.

*‘I do think some of the psychoeducation and the self-monitoring... it’s already started a therapy that is not the forerunner, that is as soon as you start thinking about it differently you are on your way’ (Professional 2: male: psychiatrist).*

Professionals also stated it was important to distinguish between enhancing wellbeing and helping against depression. They stressed the importance of ‘accepting’ when something was a problem, and to have a ‘relationship’ with this. They noted it was also important to explain that a diagnosis of depression can be unhelpful if it becomes a ‘core part of their identity’, for example if they think they are a ‘terrible person’.

*‘Caution is needed with the depression label – this can reinforce what happens, that the world will happen to them...But one of the reasons for the label is to find what works best...they’ve got a one third chance of improving’ (Professional 1: male: psychiatrist).*

Participants suggested there should be a focus on the positive not only the negatives and difficulties. This could be done for example by looking at the person’s strengths.

*'You need to build on the positive, not magnify the downside...the depressed are quick to do this' (Professional 1: male: psychiatrist).*

Repeating the same advice and themes was an approach taken and suggested by a couple of professionals:

*'I tend to go on and on, and be repetitive' (Professional 3: female: general practitioner).*

Professionals also suggested asking young people what worked for them, and adding this to the package. Professional 3 stated that information on relapse-prevention was relevant for those who had experienced difficulties previously. Professional 1 suggested that the young person be guided to think about issues from an outsider's perspective.

*'What would your friends say?...What would you say to a friend who says this?...Lots of depressed kids are sensitive – friends recognise them as such, so friends might turn to them' (Professional 1: male: psychiatrist).*

#### **4.6.4.2 Personal tool-kit**

Participants suggested the concept of personalisation could be expanded to provide the young person with a 'self help kit bag' (professional 1), or a private 'tool-kit' of self-management strategies.

*'Tools and techniques that maybe they could use themselves in the first instance to better understand how they are feeling, and then look at various different coping strategies' (Professional 4: female: educational psychologist).*

This could give the adolescent a sense of control and autonomy, which could encourage them to manage their mood and well-being in general. Professionals' suggestions also included coping strategies, solution focussed techniques, dealing with critical incidents (bereavement etc.), how to approach others, and promoting physical activity.

#### **4.6.4.3 Short-term measures – quick, easy things**

Young people and professionals emphasised quick, easy, short-term measures to improve the mood, such as rest ('take a break') or 'distraction techniques'.

*'Lots of simple solutions are usually good, these are better than complicated ones...It's rare there are any nice, easy solutions' (Professional 1: male: psychiatrist).*

Some suggestions from young people included listening to music, poetry or speeches, watching a video/film, reading books, games, yoga, going for a long walk, and breathing techniques. 'Relaxing' or 'inspirational' songs and videos were suggested, and online links to these, for example on 'YouTube'. A few young people suggested writing things down, and breathing techniques were also advocated.

*'If you write down your feelings that is a way of describing how it affects people. I mean some people write quotes, some people write poems, however, some people can talk about it...I mean some people bury themselves in their music, others in their books' (Young person 2: female: under CAMHS).*

Parents also suggested 'distraction techniques' – games, drawing, exercise, seeing friends and family, walking, working, books and encouraging them to study something that interests them. Professionals suggested that videos could show a range of relaxation approaches such as yoga.

#### **4.6.4.4 Dealing with stress**

Dealing with stressors was a recurrent issue. Having time to yourself alone, away from stressors, was one approach suggested, although there was a recognition that sometimes it was important to talk to someone you can trust, or enjoy the company of others.

Young people suggested there could be advice on daily living and dealing with specific stresses, for example school stress. It was also important to maintain a balance in life, and

not to put pressure on yourself. Young person 1 proposed that the package could list *‘five useful things for that day’*.

#### **4.6.4.5 Healthy living/hygienes of life**

Lifestyle issues were raised by interviewees, including eating, drinking and exercise. These were referred to as *‘the basics’* by Young Person 3, and *‘hygienes of life’* by Professional 3.

*‘By the time they come to see the GP, the key support processes fall off, there’s poor sleep, less exercising, poor diet, cut off, less socialising’ (Professional 3: female: general practitioner).*

Professionals discussed sleep hygiene (avoid using phones/tablets at night), exercise (going to the gym or for long walks), diet (avoid skipping meals and eating ‘semi-deprived/bad sugar’), and socialising or being ‘pro-social’ (avoid social withdrawal).

#### **4.6.5 Where to get help**

##### **4.6.5.1 Talking to someone you trust**

Most participants noted it was important to know ‘where to get help’, especially when things were particularly severe. This did not necessarily mean health services:

*‘They need to know enough to take the next step... Might not be technical – might be schools, trusted friends/family, bit more informal...Helping someone make the distinctions’ (Professional 2: male: psychiatrist).*

However, some young people were cautious on this issue, stating: *‘it can be complicated, to know whom you can talk to’ (Young person 2: female: under CAMHS).*

One parent suggested including information on how the young person could bring up the subject of depression with a parent, peer or others.

#### **4.6.5.2 Signposting to services and other help**

All parents thought it was important to show the 'right channels', especially GP and schools, and 'do some signposting', especially if things were getting worse or young people were severely ill or self-harming/suicidal. Professionals stated that there was a need to guide the young person in the right direction. Parents and professionals referred to sources of help at school, including friends, teachers, well-being officers, counsellors and nurses. One parent recommended links to local professional help and services, although she recognised that these would vary according to geographical area. A parent and professional suggested links to groups, such as anxiety groups in community centres, and to online mental health resources, and helplines such as ChildLine.

However, professionals acknowledged there was '*no easy pathway*' for young people with mental health difficulties. Parent 1 was concerned about describing the referral processes at length:

*'This is tricky, because you don't want users to think this is never-ending' (Parent 1: female: daughter 'at risk').*

#### **4.6.5.3 Therapies**

Most suggested a component on 'what to expect when seeing someone'. Professionals suggested introducing 'talking therapies' in particular, such as CBT, mindfulness and interpersonal therapy (IPT). Medication was also suggested as another issue to cover. However, professional 3 wanted to stress this was not the first or only option, and young people should not be left to think:

*'When you've done the 'four hygies' and it's not working, 'it's a tablet next for me' (Professional 3: female: general practitioner).*

One professional recommended stressing that medication was in general non-addictive. One parent suggested that information on medication should only be in the parents' section or

covered superficially, whilst another parent suggested describing what to expect if admitted to hospital. Professionals recommended links to NICE guidelines on assessment and treatment.

#### **4.6.6 Section for parents, carers, friends, professionals**

Young people proposed a separate section or 'tab' for friends, families, carers and professionals, with possibly a different design to the section for young people. Parents and professionals stated that young people can get a great deal of support from friends as well as parents and carers.

Parents suggested there should be information on signs of depression, what to look out for, and the possible effect of others on the young person, and vice versa. They also stated that parents should be advised to be patient, not to push it too far, not to attribute blame, to take young people out where appropriate and not to isolate them. Parents should also inform young people that they're not alone, and there's someone there for them. Tips on how to talk to young people were also discussed. One parent suggested personal stories from parents.

Content suggested by professionals included definitions of mood, mental health, wellbeing, and advice on how to support the child and where to get help and further information, such as from YoungMinds. Professional 1 suggested that adults might be more interested in NICE guidelines than young people. Professional 4 urged caution regarding advising on parenting, as it might be 'too judgemental' and could increase anxiety. Professional 1 suggested there was a need for reframing for the parent:

*'There's a risk - a child wants to concentrate on positives, parent wants to say why it's not perfect yet – child is then more depressed' (Professional 1: male: psychiatrist).*

It was suggested that professionals also need information on how to use the site, and to encourage its use. Participating professionals urged consistency with what is taught at school. Professional 1 also suggested putting things in context and reframing for professionals.

*'Tier 1 professionals are often alarmist – OMG this person needs CAMHS – but need to reframe things...They have little experience of risk management etc.'* (Professional 1: male: psychiatrist).

## **4.7 Key theme 4:**

### **Integration and context**

#### **4.7.1 Use of the package with others, e.g. parent, friend, professional**

Many of the participants discussed how the package could be used with parents and others, including another trusted adult or friend. One young person and two parents proposed three versions or sections – one for the young person only, one for use with a parent or other person, and another for use by the parent only. Professional 3 suggested that the young person could access it separately, but then key words would be flagged and codes would be given to a trusted adult to monitor issues.

He proposed that the young person invites an adult to work with them, with initial self-assessment or self-reflection work, such as *'How do you feel? How's it been this week? Would you like the adult to put in any comments?'*, possibly with marks out of ten.

*'Young people will share with whoever they feel it's safe to share with – teachers, social workers, specialists concerned about youth mental health'* (Professional 1: male: psychiatrist).

Professional 4 was sceptical, and suggested asking young people whether they would be happy to sit with their parents, or whether they would prefer independence. Professional 3 suggested another option was not to give access to an adult, and state:

*'I might come back to you in a month to see how you're doing...It's important not be too invasive – but got a handle on who's asking for help'* (Professional 3: female: general practitioner).

#### **4.7.2 School/education services**

Nearly all participants suggested that this package should be used and promoted in schools and educational services, especially through teachers and pastoral staff:

*‘This is essential...teachers see you every day for five years!’ (Young person 2: female: under CAMHS).*

One young person referred to its possible use in personal, social and health education (PSHE) lessons, as this would ensure that the package was available to adolescents who did not have internet access at home. All parents also referred to its use in PSHE lessons, possibly as a module. Professional 4 suggested integrating it into these lessons, as mental health was not a significant component of current PSHE lessons. Professional 1 proposed the package could be linked with the ‘emotional and wellbeing agenda’.

Links with other school-based professionals were also proposed, including primary health care workers (professional 3), and educational psychology services, school counsellors/nurses and SENCO (professional 1). Professional 4 also recommended signposting to the educational psychologist and pastoral support team or the headmaster.

#### **4.7.3 Health and other services**

Professional 3, a GP, stated she would be ‘overjoyed’ to have the package in her surgery. She thought that GPs, primary care counsellors and interested clinicians could engage with this. However, she also questioned its role in the NHS.

*‘I’m not sure if parking the software in healthcare is a good idea – this should be in education, social, youth services’ (Professional 3: female: general practitioner).*

Professional 1 suggested links to CAMHS and primary care, as well as social services, National Assembly of Wales groups (Funky Dragon and the Children’s Commissioner), and the voluntary



sector, including Barnardo's, Action4Children, NSPCC, YoungMinds, RCPsych and Welsh language contacts.

#### **4.7.4 Name, branding and promotion**

Young people preferred names that were non-stigmatising, fairly universal (e.g. my feelings, YoungMinds) and did not refer overtly to depression (e.g. not 'depressed.com', but 'Moody Ville', 'Cheerup Town'). One referred to the drug information site 'Talk to Fred' as a good example of an ambiguous but interesting name. Suggestions from parents were 'Helping your mood', 'The Paradise' and 'Airport', using the analogy of escaping or flying away from the depression.

Professional 2 also suggested the name should not be associated with depression, anxiety and anger, because of stigma and the difficulty of having a 'label'. Terms such as 'mental' were perceived as unhelpful. It was suggested that a long-winded name should be avoided. Mood was proposed by many (as in MoodGym), although some said it was vague, too neutral (losing specificity) and difficult to understand; 'low mood' though was preferable to anger or anxiety.

Young people proposed a range of individuals to promote the package, such as rugby players, musicians, and suggested using posters in schools. All parents thought that promotion and marketing was important, for example through websites, emails and television – and that this could be found on Google when searching, for example 'teenage depression'. Professional 3 suggested that GP noticeboards might be a place to advertise.

Professionals suggested a striking logo and ambassador to help with advertising and promotion. When promoting the package, young people thought it would be important to highlight the research and user input underpinning it, particularly the consultations with young people.

## **4.8 Discussion**

### **4.8.1 Summary & key issues taken forward to the focus groups**

The interviews were a valuable exploration of the views of young people, parents/carers and professionals on how the online package should be developed. To some extent, the interview discussions focused on what the research team wished to explore, to help develop the package, particularly its content and design. These issues became the key themes of the interviews, although other sub-themes emerged from the conversations as well. The ideas were carried forwards to the focus groups, by bringing them up as questions or discussion points and presenting them on slides in these groups. Diagrams and images were also developed from the interviews to present in the groups, for example possible structural frameworks for the package and moodboards (see methods chapter 3, and focus group chapter 5). Table 6.1 in chapter 6 demonstrates how the themes from the interviews and groups influenced the online package.

All participants described how there was a need for this package, especially given the lack of CAMHS and online resources. Participants noted that using digital technologies was a valid approach to engagement, as young people use these in everyday life, although there were concerns about those without internet access. The package could promote self-management, address the diversity in the target group, and help those who find it difficult to talk to others. It was clear that there was a need to cater for parents, carers and others concerned about a young person.

Overall design was discussed the most in interviews, especially by young people, and how multimedia should engage users and communicate information, and that there should be a 'multiplatform' approach and an 'app'. There should be clear structure and navigation, the tone should be at the level of the young person, and visual and other representations could illustrate various issues. Most recommended tailoring the design and content according to the user, and there should be mood monitoring and other interactive elements. Security and confidentiality were key issues, and there were concerns about including a forum or links with social media.

Regarding the content of the package, participants state there should be different 'levels' of information, and a clear explanation of the package and its aims. There should be information on mood, the signs, symptoms and effects of depression, the difference with 'normal sadness', and related issues, such as anxiety. Possible reasons for depression should include environmental and biological factors, and how there were sometimes no clear reasons. Self-management approaches should build on existing strengths and attributes. A personalised tool-kit was suggested, to include short-term measures, dealing with stress and healthy living. Information should be included on where to get help, from trusted friends and family, school and health services, and on possible treatments. There should also be information for parents/carers, professionals and others. Accounts of personal experiences were recommended.

To help with adherence and encourage support, participants suggested it would be helpful for the young person to be able to use the package with others, including family/carers, friends or professionals, as well as independently. Schools were considered an important setting for the intervention, particularly PSHE sessions, as well as health and other services. Participants discussed possible names for the package, although there was no consensus on this.

#### **4.8.2 Comparison of the views of young people, parents, professionals**

The young people talked more about the overall design and multimedia, compared to the parent and professional groups, and how this could determine the effectiveness of the package in engaging and communicating information. Young people may have the greatest insight into what will engage their peers.

Parents and professionals focussed more on the content of the package, although they also recognised the importance of investing in its design. Professionals proposed more detailed information and underlying theory, reflecting their expertise in the area. However, all the parents were also knowledgeable, perhaps because of their personal experiences of mental health issues. With regards the content, young people seemed particularly interested in an

explanation of mood and the difference between 'normal sadness' and 'depression', and in the help sections.

The main concerns raised by young people were whether the package would be user-friendly, and whether the general tone would be youth-friendly. They acknowledged that consulting them in this process would help with this. Another reservation was related to security and confidentiality, and links with forums and social media. Parents seemed concerned particularly about the information presented, for example on medication, and on the mood-monitoring component. They suggested that the young person might need to be supervised at times, when using the package. A couple of professionals, however, noted there should be 'reframing' for parents and professionals (as well as young people), particularly where there was excessive anxiety.

In general, all participants seemed interested in and enthusiastic about the project, which was reflected in the way in which they engaged with the interviews and spoke at length about their ideas. They were all selected because of their experience of or expertise in mental health difficulties, and they all identified the need for and supported the development of this package.

### **4.8.3 Conclusions**

There is a lack of resources and research evidence regarding the development of online interventions for youth mental health. The interviews were essential in gathering the views of a range of potential users of the online package for adolescent depression, at an early stage in its development, to help create a package that is usable, acceptable and engaging. This is consistent with the guidelines on the development of complex and digital health interventions (Craig et al. 2008; Yardley et al. 2015), which recommend consultation at each stage of development.

The main themes discussed in the interviews were 'design issues', 'content issues', 'need/aims for the package' and 'integration with daily life'. Design issues were especially prominent, and this is consistent with findings in other studies (e.g. Barnes et al. 2011). The extensive insights that emerged were helpful in informing the preparations for the

subsequent focus groups. Specific issues were taken on as discussion points and questions to pose in the groups, and initial diagrams (e.g. a structural framework for the package), designs, images and moodboards were developed to present and explore (see chapter 5).

## **Chapter 5: Co-design phase**

### **Results of focus groups with users to inform the development of the package with the multimedia company**

#### **5.1 Introduction**

This chapter gives an account of the qualitative study involving focus groups during the second stage of the overall research plan to develop an online psychoeducation package for adolescent depression (figure 5.1, stage 2). This included a series of focus groups with potential users of the package – adolescents, families, carers and professionals who work with this age group, from health, social, education and youth services.

The aim of the focus groups was to build on the findings from the literature review (chapter 2) and interviews (chapter 4), and gather and analyse views of potential users of the package (young people, parents, professionals), to inform the development of the initial prototype of the online package (figure 5.1, stage 3; chapter 6). Discussions in the focus groups were guided by the themes from the interviews, and groups were iterative - whereby discussions were informed by findings from previous groups. Initial designs were developed with the multimedia company to present as the focus groups progressed, most of which are presented in this chapter, whilst others are documented in the next chapter on the development of the package (chapter 6).

There were also discussions to complement these findings, with the research team, and a range of advisors from the fields of adolescent depression, resilience, psychoeducation/education, psychological approaches, electronic media and public engagement.

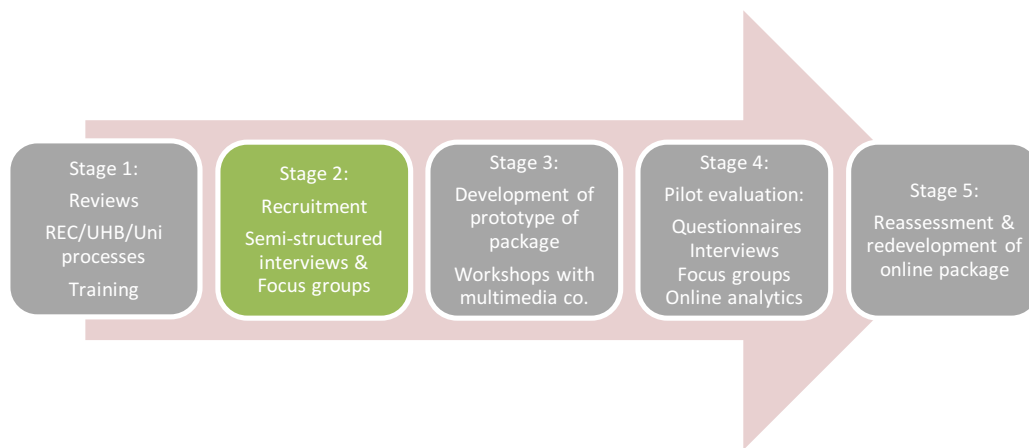


Fig 5.1: Broad stages of the research plan

## 5.2 Focus group participants

There were six focus groups conducted; three with young people (total N=29), one with parents/carers (N=7), two with professionals (N=22, including one group of researchers with a special interest in child and adolescent mental health). Of those interviewed earlier in stage 2, one young person and one professional also participated in the focus groups in stage 2. Further information about the composition of the groups is provided in tables 5.1a-d.

### 5.2.1 Adolescents

The mean age of the participants in the young people focus groups was 16 years (range 13-19 years). The majority (69%) were female.

**Table 5.1a: Participants in the three focus groups for young people**

	<b>Focus group 1 (EPAD group)</b>	<b>Focus group 2 (CAMHS group)</b>	<b>Focus group 3 (EPAD &amp; CAMHS)</b>
EPAD group	15		2
CAMHS		8	3
Volunteer			1
Female	18 yr old 17 yr old x 2 16 yr old x 5 15 yr old x 2 13 yr old	17 yr old x 2 15 yr old x 2 14 yr old	19 yr old 18 yr old 17 yr old 16 yr old
Male	19 yr old 18 yr old x 3	17 yr old 16 yr old 15 yr old	16 yr old 15 yr old
<b>Total</b>	<b>15</b>	<b>8</b>	<b>6</b>

## 5.2.2 Parents

**Table 5.1b: Participants in the focus group for parents**

<b>Source of recruitment</b>	<b>Number of participants</b>
EPAD study	5 (all female)
CAMHS	2 (both female)
<b>Total</b>	<b>7</b>



### 5.2.3 Professionals

**Table 5.1c: Participants in the focus group for professionals who work with young people**

Profession	Number of participants
Psychiatrist	2 (both male)
Mental health nurse	2 (1 female, 1 male)
Educational psychologist	3 (2 females, 1 male)
School nurse	2 (both female)
Teacher	1 (female)
Youth worker	2 (both female)
<b>Total</b>	<b>12</b>

**Table 5.1d: Participants in the focus group for researchers (with a special interest in child & adolescent mental health)**

Profession	Number of participants
Academic child & adolescent psychiatrist	2 consultants (1 female, 1 male) 2 trainees/fellows (2 females)
Academic GP	1 (male)
Research psychologist	1 senior lecturer (male) 2 postdoctoral (both female) 1 doctoral (female)
Medical student	1 (male)
<b>Total</b>	<b>10</b>

## 5.3 Key themes identified in the focus groups, and how they informed the designs

As noted previously, it became clear during the interview process (chapter 4) that the key themes were related to the issues the research team wished to explore to develop the package (see topic guide, chapter 3). These themes then informed the discussion guide and presentation slides for the focus groups, and the key themes were consistent across the interviews and focus groups. These were i) the need/aims for the package, ii) design issues,

iii) content issues, and iv) integration and context (table 5.2). Each of these will be discussed in turn; particular focus is given to new ideas and areas of discussion that differed from, or did not overlap with, the findings from interviews.

**Table 5.2: Themes arising from the focus groups**

<b>Key theme 1: Why do we need this package? What are the aims?</b>	
5.4.1	Increasing awareness and tackling stigma
5.4.2	A lack of resources for young people
5.4.3	Embrace digital technology as a medium that's relevant for young people
5.4.4	Diversity
5.4.5	Need to target parents/families
<b>Key theme 2: Design issues</b>	
5.5.1	Harnessing multimedia to engage the user
5.5.2	Multiplatform use and 'app'
5.5.3	Clear structure, navigation, and distribution of information
5.5.4	Language
5.5.5	Characters & avatars
5.5.6	Imagery and metaphors
5.5.7	Moodboards
5.5.8	Gaming element
5.5.9	Personalising the space
5.5.10	Monitoring tool
5.5.11	Technical aspects - security and confidentiality and the use forums/social media
<b>Key theme 3: Content issues</b>	
5.6.1	General approach
5.6.2	What are mood, well-being and depression?
5.6.3	Other difficulties related to low mood/depression
5.6.4	Causes/reasons/risk factors
5.6.5	Prevention & self-management strategies
5.6.6	Where to get help
5.6.7	Information for parents, carers, professionals
<b>Key theme 4: Integration and context</b>	
5.7.1	Use with parent, carer, friend, professional
5.7.2	Use within education and health services
5.7.3	Name, branding, promotion

The themes and findings from the interviews and focus groups were discussed with the research team and multimedia company in meetings/workshops, along with the findings from the systematic review and other sources (see section 3.5: Development of initial prototype & fig 3.11). From these discussions, the specifications for the content and design of the online package were refined according to the level of importance given to them by the participants, and the potential effect on the acceptability, feasibility and ease of use of the package. Other considerations were the technical difficulty, time required and development costs.

Chapter 6 (especially section 6.2) gives an account of the process of development and translation of findings, from the initial sketches through to the final designs for the prototype. Many of the initial designs shown in the focus groups are included in this chapter. Designs and components were drawn by the participants, doctoral student, multimedia company and animator during (and between) focus groups and research meetings/workshops. For example, for the characters that featured in the illustrations and animations, the student developed initial drawings based on the interview/group discussions (and drawings by some participants), then the animator refined these so that they could be animated and they would be clear on small screens. Elements of the characters were refined further by the student and multimedia company from feedback from later focus groups (see subsection 6.6.3 for more detail on character design).

## **5.4 Key theme 1:**

### **Why do we need this package? What are the aims?**

For this key theme, the areas highlighted by the focus groups were generally similar to those from the interviews. These included: increasing awareness and tackling stigma; a lack of resources for young people; embracing digital technology; diversity; and the need to target parents/families/others.

### 5.4.1 Increasing awareness and tackling stigma

As with the interviews, all focus groups felt there was a need to increase awareness of depression and reduce stigma around mental health issues in young people.

*‘Educating them...there’s a lot of stigma attached to mental health and depression’  
(Parent FG).*

*‘It’s important that people know about mental health information...there’s not much out there...it would be pretty revolutionary if it works’ (Young person FG3).*

### 5.4.2 A lack of resources for young people

Clinical and research professionals stated that depression, emotional problems, and low mood in young people were becoming increasingly common but that resources had been reduced and were insufficient.

*‘As a GP – I see a lot of young people with difficulties, but resources are limited’  
(Clinical professional FG).*

The groups also commented on the long waiting lists and difficulties in getting help, and suggested the package could help with this.

*‘Lots of little steps until you get support’ (Young person FG3),*

*‘If they’d been able to nip something in the bud, it might have been better. This will provide immediate support – there’s such a long waiting list for CAMHS etc!’ (Parent FG).*

*‘There’s not much between GP and CAMHS, and that’s a big jump...we need something to make young people accept what they have’ (Parent FG).*

The lack of reliable online mental health resources also emerged as an important issue across all groups. Professionals noted there was a lack of ‘evidence-based’, ‘good quality’

online resources, and that something was needed to refer young people to at the first point of contact. Although there was reference to some other online resources, many were more appropriate for adults, or were not generally well received. One young person referred to an existing online CBT package, which was suggested by his doctor, but stated it was unhelpful, 'boring' and 'generalised'. Another young person agreed:

*'Everything out there's too generalised...nothing is personal to you...one tone fits all...doesn't feel like something you're confident in' (Young person FG2).*

### **5.4.3 Embracing digital technology as a medium that's relevant for young people**

As in the interviews, the use of digital technologies was highlighted as being particularly relevant for young people, and a useful resource for parents/carers and professionals. All young people used the internet daily or almost daily, and most had looked up health information online. Use of smartphones and tablets was common and all young people used desktop computers at home and in school/college. Nine out of twelve participants from the clinical professionals group used the internet in their work with young people, and all stated they would refer young people to the package in development.

Digital technologies were thought to be particularly important for young people as they can find it difficult to talk to adults.

*'It's easier than plucking up the courage to talk to someone'.*

*'Would rather go on internet, rather than face to face...anonymity is important'.*

*(both Young people FG2)*

### **5.4.4 Diversity**

The main sources of diversity discussed by participants across the focus groups were age and gender. There was agreement that the package should be accessible for both males and

females from a range of ages. Although one young person suggested that personal preferences could be more important.

*‘Age doesn’t make a difference – it depends on the person’ (Young Person FG2).*

Research professionals noted that the information should help young people with a diagnosis of depression, as well as those with subthreshold symptoms, and those ‘at risk’.

#### **5.4.5 Need to target parents/families**

Parents in the interviews felt that the package could be helpful for them as well as for young people. This was echoed in the focus groups, with young people and parents suggesting that there should be a section for them within the package. Clinical professionals noted that families and parents were asking for a resource like the one in development, and there should be information for friends of those with mental health difficulties. Research professionals agreed there was a need for such a resource.

### **5.5 Key theme 2: Design issues**

Design issues taken forward from the interviews were developed further before and during the focus groups, through the development of diagrams to convey the overall structure and functionality, and images and moodboards to reflect on the visuals of the package. This meant that the interview ideas were discussed in more depth, although new ideas also emerged from the group discussions, and this section focuses primarily on these.

Many of the design issues highlighted by the focus groups were again similar to those from the interviews. Subthemes included: Harnessing multimedia to engage the user; Multiplatform use and ‘app’; Clear structure, navigation, and distribution of information; Language; Characters and avatars; Imagery and metaphor; Moodboards; Gaming element; Personalising the space; Monitoring tool; Technical aspects - security, confidentiality and the use of forums/social media and the package name.

### 5.5.1 Harnessing multimedia to engage the user

The range of possible media to engage the user was discussed at length in all groups. Approaches suggested by participants included using animations, quotes, songs, music and videos to show aspects of depression. Research professionals suggested that a welcome screen could include a video of a young person who experiences stressors, to help explain who the package is for and to demonstrate its flexibility. Parents also noted the need for various media and approaches.

*‘You need an awful lot there to keep their attention – to see them through the whole package’ (Parent FG).*

Clinical professionals suggested that the approach should be ‘stylised’, and the design should be ‘in line with youth culture’. One suggestion was to reflect the design of social media, as young people were familiar with this. Parents raised similar ideas, and recommended that the package should be engaging, contemporary and current.

*Up to date ...not have pictures of Freud all over it...it’ll scare them off...Got to entice them to keep wanting to have a look, and go further’ (Parent FG).*

Clinical professionals also stated the importance of interactivity.

*‘It would be good to be able to give something more interactive, rather than a bunch of leaflets’ (Clinical professionals FG).*

### 5.5.2 Multiplatform use and ‘app’

In line with the findings from the interviews, all participants agreed the package should work across platforms (phone, tablets, desktops, laptops), and that there should be a mobile application.

*‘What I really liked was the ‘app’, an up-to-date, modern idea’ (Parent FG).*

While there was a general acceptance that young people use mobile phones more than computers, some young people stated they would prefer to use other devices, such as desktops and laptops for the package in development.

### **5.5.3 Clear structure, navigation, and distribution of information**

In line with the findings from the interviews, participants in the focus groups highlighted the need for the package to be simple, user friendly, visual, easy to read (without large chunks of text) and streamlined. The young people in group 1 emphasised the need for balance in terms of the functional and aesthetic. Participants in this group suggested that everything should be compartmentalised, so as not to be *‘overwhelming’*. A clear structure that was easy to navigate was also considered to be important.

*It should be clear what’s going on – clear where to go, what to do, clear that what you answered leads to this’ (Parent FG).*

The overall design of the package was considered in greater depth in the focus groups and diagrams were used to facilitate discussion. A broad structure for the content of the package was developed based on the interview findings, and was shown to the groups in the form of a ‘hub and spoke’ model (see fig 5.2).



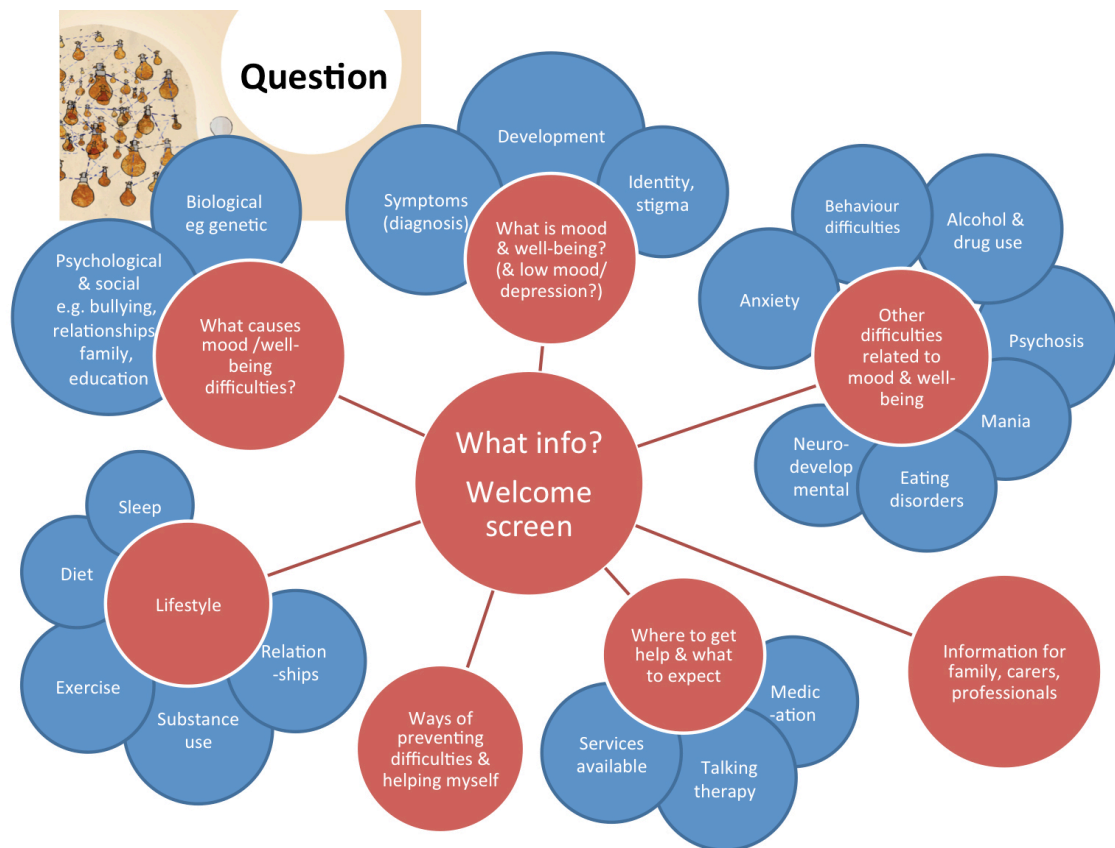


Fig 5.2: Slide shown in young person focus group 2  
to show the overall structure of the package

Young people in group 2 suggested using the bubbles/circles for the welcome screen to represent the different sections of the package. Both young people and professionals thought it would be good to use icons or characters to signify the different sections. One young person in group 2 proposed having separate options for different users; the young person worried about him/herself, and someone else who is worried about a young person. This idea was incorporated into the designs which were shown to subsequent focus groups (see fig 5.3). The designs were greeted with favourable responses. Comments from young person group 3 included: *'looks positive'*, *'inviting'*, *'really good'*, *'quite cool'*, *'makes sense'*, *'breaks everything down nicely'*, and *'it's not massively overwhelming'*. One young person stated, *'It felt like it could actually do something'*. Parents were also in general positive about the designs, and all agreed that the layout and navigation was clear.

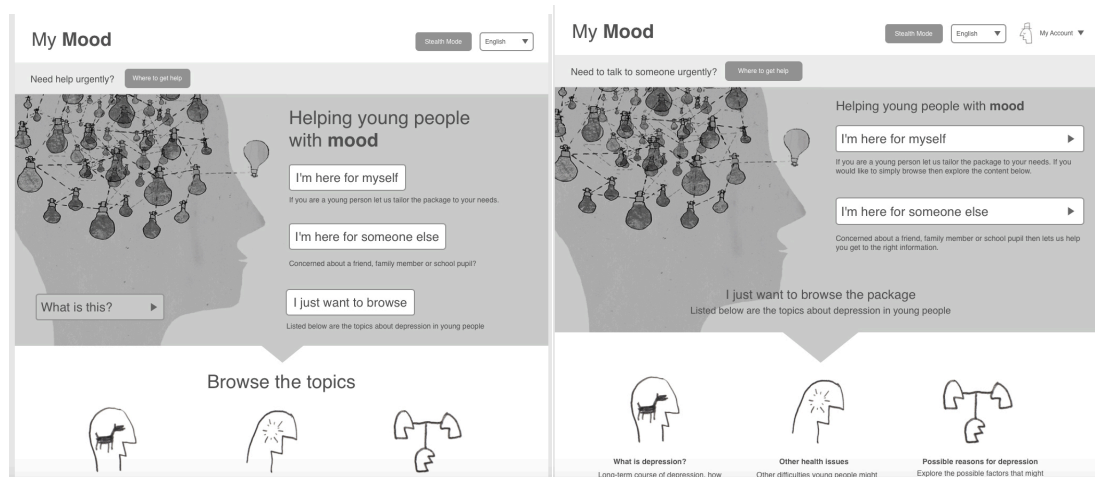


Fig 5.3: Welcome screen in the initial prototype for the young person and parent focus groups, showing the different options for the user

## 5.5.4 Language

As with the interviews, both the type of language used, and its tone were highlighted as important by participants in the focus groups. Language should be plain, but not patronising or insulting for older adolescents:

*‘Treating you as a mature person – not talking down’ (Young person FG2).*

There was also discussion about specific words and phrases which were considered unhelpful or hard to understand, such as ‘stigma’ and ‘causes of depression’, and alternatives to these were suggested. There was general agreement across all groups that the package should be bilingual – in Welsh as well as English. One young person in group 2 suggested it could start in English, but have a ‘Welsh button’ at the top so the user could change the language if desired. The Welsh-speaking participants in group 3 (n=2) stated they would be confident to use it in this language.

## 5.5.5 Characters and avatars

The use of characters was discussed particularly by young people. There were debates regarding the use of animation versus live action, and of the use of actors versus ‘real

people'. When asked initially, most preferred 'live action' characters compared to animation.

*'Characters...might be hiding behind something...live action might be more believable' (Young person FG2).*

However, when discussed further, they noted it would be difficult to find young people who would be happy to talk about their experiences, and felt that that live action could make the package 'depressing'. In contrast, participants thought that having some animated characters might 'lighten' the mood, and would appeal to a range of users. Others suggested there was a place for both 'live action' and 'animation'. Young people in group 3 suggested that the characters could have different features, and be up-loadable, for example for the profile picture.

There were also mixed views on the use of avatars and guides for the package. Some saw an avatar as a good idea, possibly when 'logging-in'. However, others in young person group 3 made comparisons with the '*annoying paperclip character*' in Microsoft programmes. Four out of seven of the young people in group 2 liked the idea of a character guide. In contrast to professionals from the interviews, who were particularly positive on the use of characters as guides/avatars, professionals in the focus groups did not have a strong opinion on the issue.

### **5.5.6 Imagery and metaphors**

In general, there was support for the use of illustration, graphic imagery and visual metaphors throughout the package, particularly from young people. Several visual themes were discussed to bring together the components of the package, based on findings from the interviews, and developed further in the groups. These included the use of colour, maps, and heads.

Overall, participants particularly liked the use of heads, and this was discussed in the greatest detail. An image entitled '*Metaphors of the mind*' was shown to some groups as an illustration of how heads could be incorporated into the design (figure 5.4). This print was

developed by asking several people how they visualise the mind, and the metaphors they use. The response to the image was generally favourable from young people:

*'I like the colours – natural earthy colours – stand out enough, but not overwhelming' 'they're really cool' (both Young person FG2).*



Fig 5.4: 'Metaphors of the mind' illustration

Young people suggested the use of icons within heads could be used to navigate through the different sections of the package, for example doors (YP FG1), speech bubbles, or buildings (YP FG2). Although others noted it was important not to 'over complicate' the package. Some young people in focus group 2 suggested that different heads could be used to represent the young person and others (parents etc). Parents and professionals were also generally in favour of using heads in the package, and felt they could be useful to show 'what's going on in the mind' and illustrate how 'everyone's mind is different'. However, some research professionals were cautious about using only head imagery in the package.

*'One of the features of depression is that it is introspective and situates all problems in the young person – there should be other factors e.g. schools, buildings, other people, body' (Research professional FG).*





One of the metaphors mentioned in the interviews was a 'black dog'. This idea came up again in the clinical professional group and an image of a black dog was incorporated into sketches for the welcome screen of the package (figure 5.3) and shown to later focus groups. Whilst not all young people understood the reference initially, most thought it was appropriate. Other metaphors were also discussed by young people, for example a lead weight.

### 5.5.7 Moodboards

A series of moodboards were developed based on the interviews and early focus group discussions (figure 5.6). These boards differed in terms of colour and style and were shown to later groups for discussion. The first moodboard included images of the head, body and mind, created through illustrative or printmaking techniques with warm, pastel colours. The second moodboard presented similar subject matter, but had more graphic imagery, with flat and brighter colours. The third included 'darker' imagery related to the mind and body, but also mental states and illness. The colours were also darker, and had greater contrast. The final moodboard had photographs of young people and families, related to mental health.

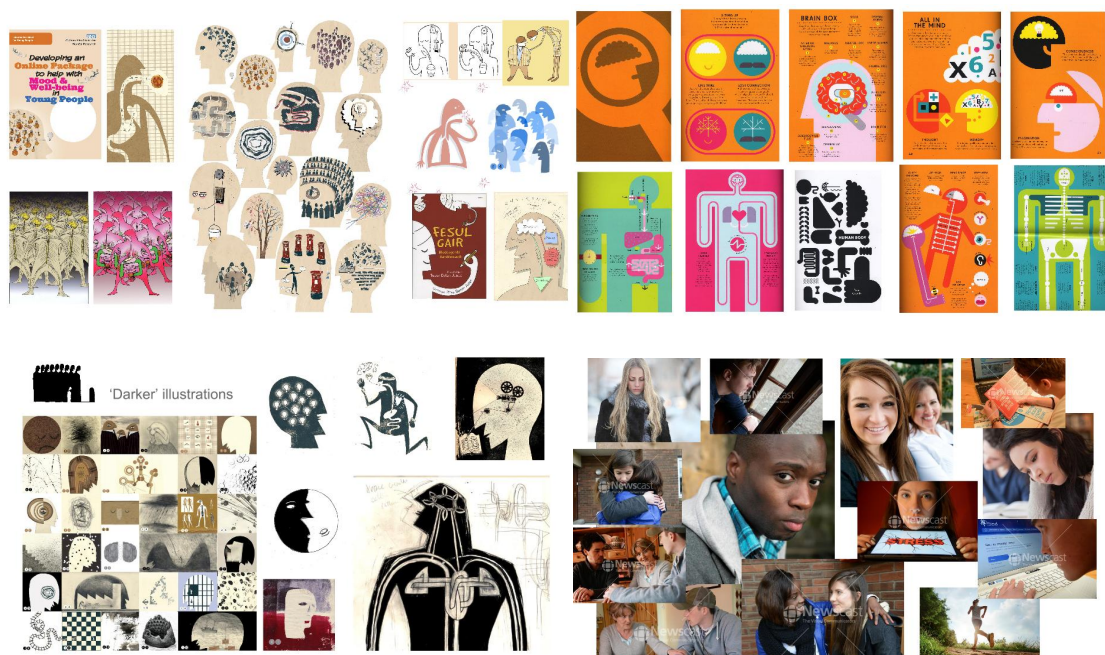


Fig 5.6: Moodboards presented in the focus groups (1-2 on top row, 3-4 on bottom row)

In young person group 3, all stated they particularly liked the illustrations and colours of moodboard 1. They noted the colours in the second moodboard were 'too bright', but they liked the combination of text and image. The darker illustrations of the third moodboard were not considered appropriate ('too dark', 'aggressive', 'depressing') for the overall design. However, they suggested they could be used for some aspects of the package in the right context, particularly to 'validate' difficult user experiences. All the young people preferred the illustrations to photographs. They thought the photographs were 'too staged'.

*'They should be real, not posed or pretending to be sad, cheesy...type of thing you'd see in a school slideshow' (Young person FG3).*

They suggested that the user could upload their own photograph, for example to a personal profile, and that photographs of (real) young people should be used only for case studies. Parents commented that the first moodboards were 'quite complex' and 'quite surrealist'. However, there were some positive comments about the illustrations, including those involving the heads. The darker illustrations in moodboard 3 were criticised as '*dark, not giving hope*' and were not considered suitable by this group. In contrast to the young people, parents preferred photographs to illustrations.

*'Young people want real people...they can relate, connect with them...everyone wants faces' (Parent FG).*

### **5.5.8 Gaming element**

The idea of including a quiz was originally suggested in the interviews. Clinical professionals in the focus group suggested a quiz would be a good way to get to know oneself – for example using personality tests. Research professionals added there could be a quiz with true or false questions. A quiz was incorporated into the initial designs, both at the start of the package, and within the sections (figure 5.7).

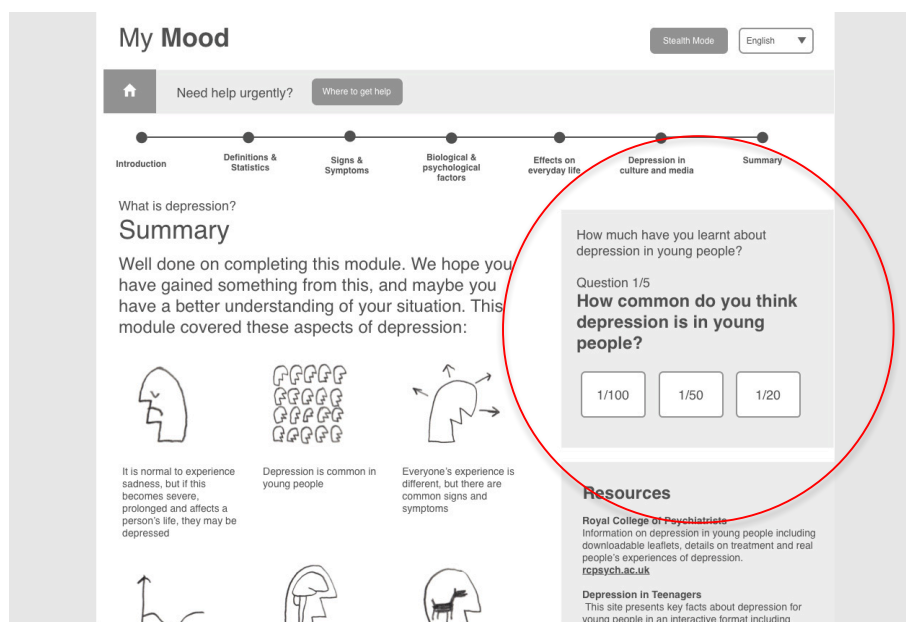


Fig 5.7: Screenshot of young person section, with quiz on right side

Most young people in group 3 agreed there should be a quiz at the start and end of each module.

*'You feel like you've learnt something' (Young person FG3).*

However, there were mixed views regarding whether the questions at the end should be the same as those at the beginning.

*'I'd probably memorise answers – Why are you asking me again?' – Should have different questions at the end' (Young person FG3).*

Parents discussed the quiz in detail in response to the designs presented (figure 5.8). Whilst some felt it could be a useful way to inform parents, there were many reservations. Most felt it would be more appropriate for young people.

*'It sounds academic to me...as a parent you just want to go through, get the information, get it straight away'.*

*'I don't see the relevance of a quiz, when I'm trying to find out something to help my daughter'.*



*'It's a bit patronising...Then we're going to analyse, big-brother is watching you'  
(All Parent FG).*

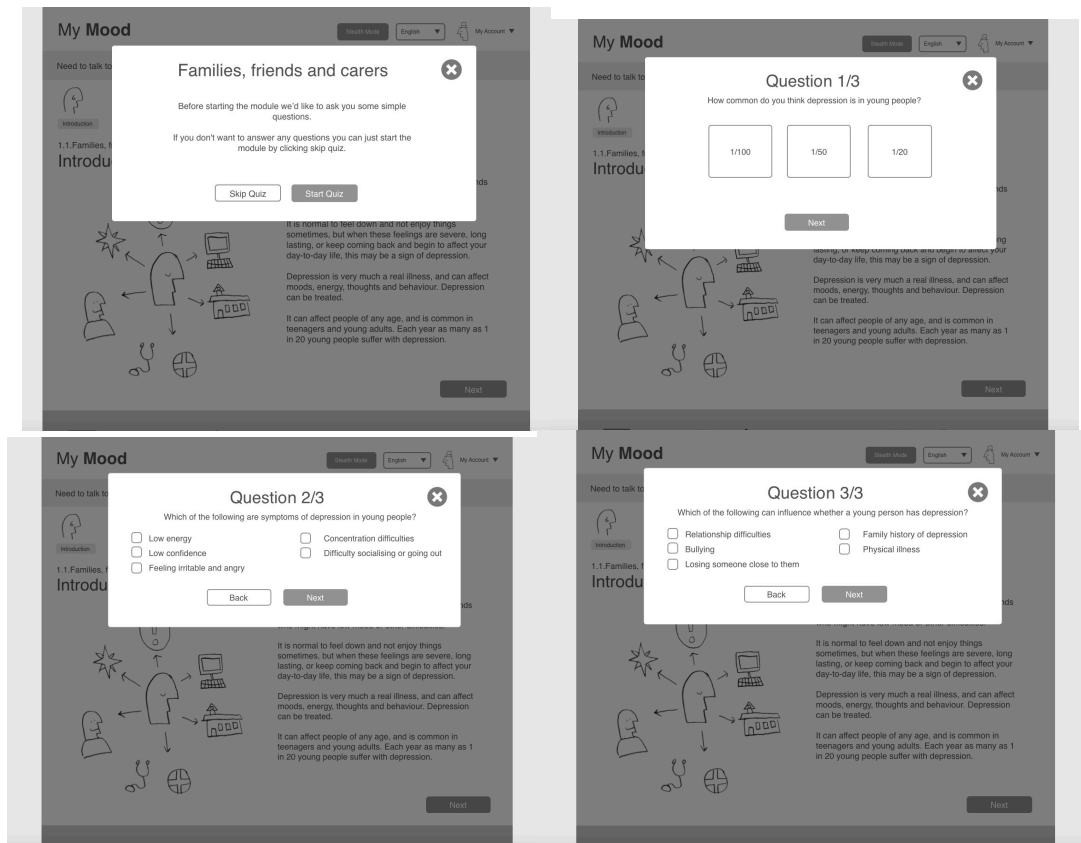


Fig 5.8: Screenshots of part of parent section of the package, with quiz questions

### 5.5.9 Personalising the space

The importance of personalising the package was a recurrent theme in the interviews and the focus groups. Participants discussed several different ways personalisation could be achieved, including use of a login, tailoring/modifying the content according to the needs of the user, allowing the user to save/upload information, and to set personalised goals.

*'It feels more personal, about you, and not the general public...Would I be interested in knowing about bereavement, if say my child had a totally different reason?'  
(Parent FG).*

Research professionals stated that not all issues are important for everyone, and users should be able to select which sections to access. Clinical professionals suggested the content could be modified according to answers to questions and this idea was incorporated into initial designs which were presented to later focus groups (figure 5.9). Questions were designed to help the user to monitor their mood and other issues, as well as help to guide them to the most relevant sections of the package. Parents and young people in group 3 responded favourably to this, and stated it was clear, although some modifications to the wording were suggested.

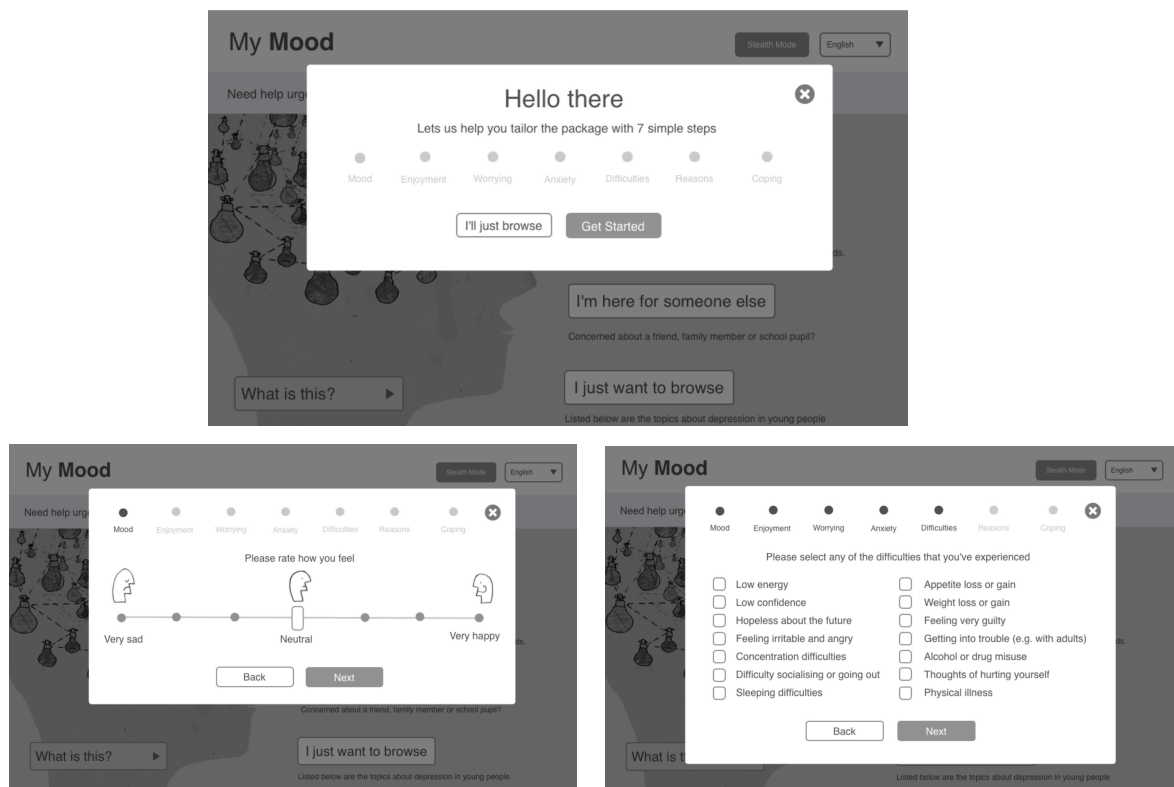


Fig 5.9: Examples of initial questions in the prototype presented in the latter groups

Another suggested a way of personalising the package was to enable users to save links to websites, which could give a short-term lift (figure 5.10). The idea was based on discussions in the interviews and early focus groups. It was entitled 'Stuff I like', and was well received in young person group 3.

*'A place where you can save things basically' (Young person FG3).*

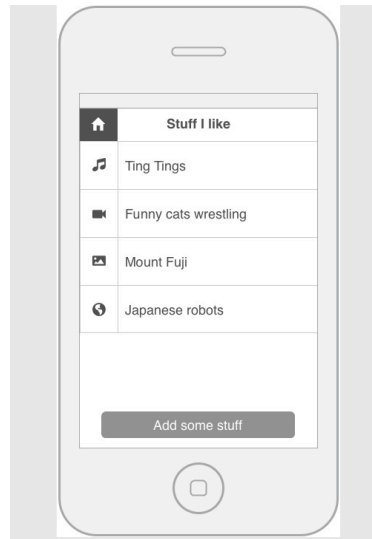


Fig 5.10: Screenshot of 'Stuff I like'

Young people in group 3 were also supportive of a section on goal setting although there was some debate regarding the optimal number of goals and the timeframe. Other suggestions included adding regular activities such as eating breakfast, and introducing positive responses, such as a face with a smile, when a goal was completed.

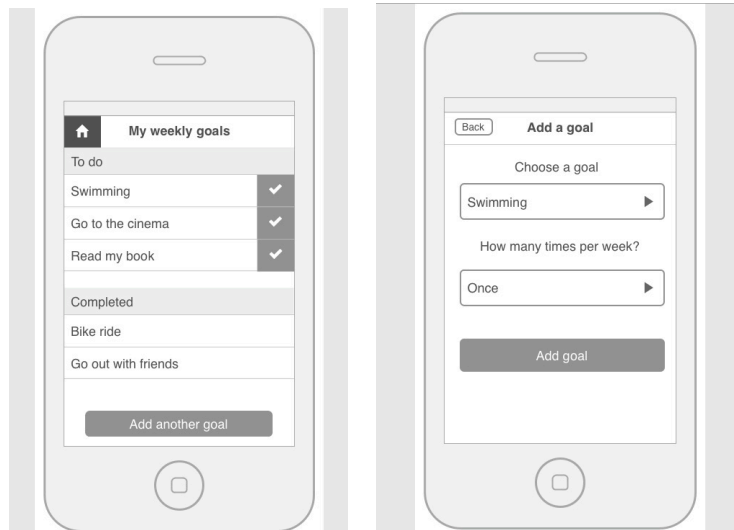


Fig 5.11: Screenshots of goal-setting option

### 5.5.10 Monitoring tool

In the interviews, parents and professionals were generally positive about including a tool to monitor mood, and other issues. Images were developed to explore this idea further in the focus groups (figure 5.12). In contrast to the interviews, parents in the focus groups had

mixed responses to the monitoring component. On the positive side, they noted that it could help identify triggers, and felt it would promote self-management.

*‘Being proactive, taking ownership’... ‘It’s easy for them to say ‘I’m feeling miserable’ – so why and how do you get out of this?’ (Parent FG).*

However, there was also some concern that the monitoring tool could provoke anxiety or encourage rumination.

*‘It could induce paranoia... Is it going to exacerbate? Let’s see how I am today...become quite obsessed with how I am, a preoccupation’ (Parent FG).*

As found in the interviews, clinical and research professionals were generally in support of a monitoring component, and suggested this would encourage self-reflection.

*‘Only when writing down, things become obvious’ (Clinical professional FG).*

They suggested including ‘alerts’ or ‘flags’ if the young person experienced severe difficulties such as suicidal thoughts and including prompts to encourage help-seeking if there were ‘high mood scores’. This idea was echoed by people in group 3, who suggested there should be programmed responses according to the scores (e.g. a recommendation that the user seeks help).

Young people in the focus groups responded favourably to the idea of a mood monitor. Participants in young person group 2 stated that this would help to show progress and deterioration, identify triggers, and indicate when to do something.

*‘One of the main parts of the ‘app’ should be ‘monitor yourself, identify your trigger’...If you can identify triggers – you can do something about it earlier, before letting it get to the bad points’ (Young person FG2).*

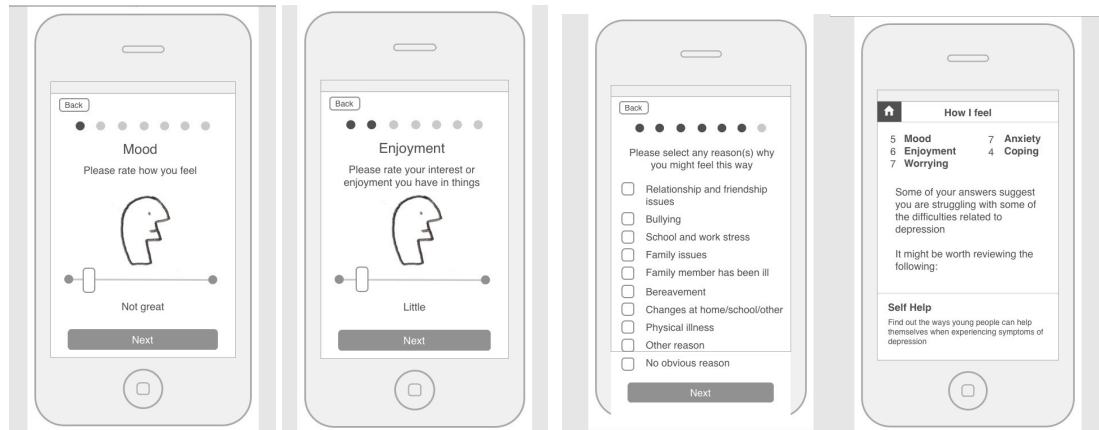


Fig 5.12: Screenshots of an initial prototype of the ‘app’ for monitoring experiences (e.g. mood), shown in the latter focus groups

The design of the monitor was also discussed, particularly in the young people focus groups. Young people debated how mood was rated, the range of scores, and how results should be presented. Those in group 3 recommended that the results could be presented visually, for example using a graph. Participants were in favour of colour coding the displays, with red to signify if someone is worried, and green if they were ‘ok’. Some parents had reservations regarding the use of emoticons and faces on the mood monitor - one stated they reminded her of scales she would fill for CAMHS, and did not think they were helpful.

### 5.5.11 Technical aspects - security, confidentiality and the use of forums/social media

Similar to the interviews, participants in the focus groups were cautious about linking to forums and social media, and suggested this would need to be monitored and moderated.

*‘I don’t think it should be on social media – it can be so toxic’ (Young person FG2).*

In addition, several new discussions emerged in the focus groups concerning technical reliability and security. Young people in the second group stated it was important the package did not ‘crash’, that the ‘links’ worked and that other technical aspects functioned well. Clinical professionals suggested it needed to be designed outside statutory services to ‘work well’ and proposed a mixture of online and offline components in case of poor internet access.

The security of the content was deemed crucial, particularly who supervised this and what was uploaded. Anonymity was considered an important issue, and most young people thought there should be a login for personal and monitoring information, but that some areas could be open access. Clinical professionals also supported the use of 'log-ins' and 'portals', in which diaries could be entered. A 'flick-off' button was also recommended, for example if a user wanted to leave the package quickly. One professional referred to its use on the 'ChildLine' website (childline.org.uk). This feature was added to the initial designs and shown to later focus groups (Fig 5.13). The young people in focus group 3 supported the 'stealth mode' option in the initial prototype. However, there were mixed feelings regarding its name, and 'hide this' was suggested as an alternative.

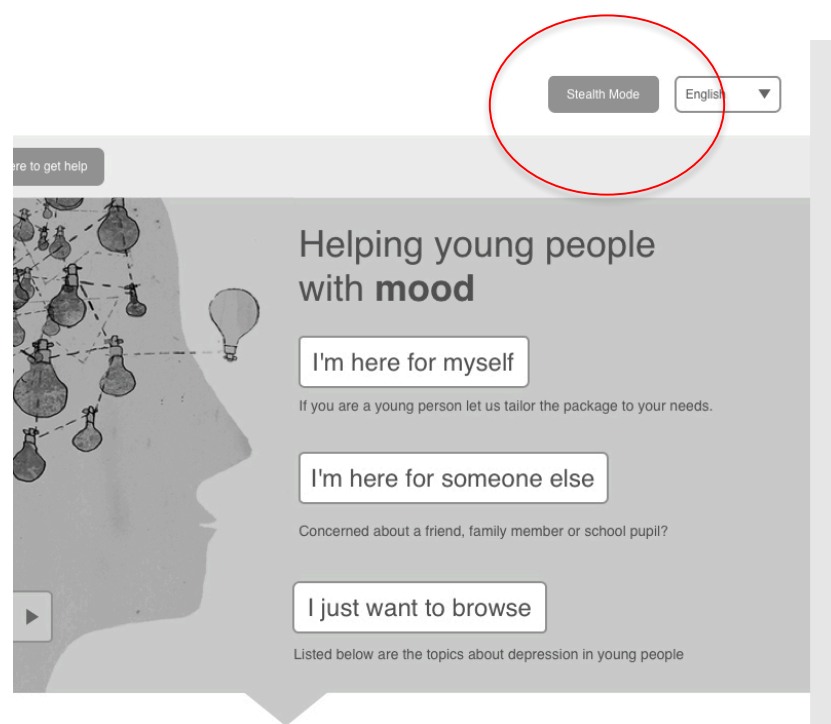


Fig 5.13: Welcome screen shown in young person focus group, with 'stealth mode' button (top right)

## 5.6 Key theme 3: Content issues

Key messages to be included and an outline of the sections emerged in the interviews (chapter 4), and these were elaborated upon in the groups, with some new ideas. Group discussions on content issues were centred around the main sections of the package. These included: What are mood, wellbeing and depression; other difficulties related to low mood/depression; prevention

& self-management strategies; where to get help; and information for parents, carers, and professionals.

In all groups, different levels of information were proposed to accommodate diversity in user characteristics (such as learning abilities/difficulties, prior knowledge, age, personal preferences, and level of depressive difficulties).

*'It should not be one type fits all.'* (Young person FG1).

One clinical professional suggested the use of three levels, and information could be simplified with links:

*'Quick guide, want to know more, and test the professionals'*  
(Clinical professional FG).

### **5.6.1 What are mood, well-being and depression?**

All participants who were interviewed suggested including information on the signs and symptoms of depression. This was echoed throughout the focus groups, however there was some disagreement amongst young people on whether the package should include a list of symptoms.

*'I don't think there should be an outline of symptoms... it should focus on what to do'.*

*'It's important to list difficulties, especially severe ones, so people can go and get help if needed – teenagers might miss something'.*

*(Both Young person FG2)*

Young people also proposed including information on self-esteem, confidence, stress and anxiety and to explain how the experience of depression can differ in adolescents and adults.

Both clinical and research professionals recommended that statistics were useful, but should be used selectively. They also noted the ‘big problem’ was that some people have ‘set views’ about depression, and proposed a ‘common myths’ section to help with this. Other issues professionals thought important to include were the quality and duration of episodes, severity, and prognosis (‘what will happen in future?’).

*‘It’s not all or nothing – as some teenagers might think’ (Research professional FG).*

In the interviews, professionals recommended explaining the distinction between depression and ‘normal’ sadness. Professionals in the focus groups also suggested highlighting that ‘it’s quite normal to feel sad sometimes’ but also noted that it can be a problem when depressive symptoms are normalised.

*‘A common theme...the biggest problem is that we don’t see teenagers with depression – all we see is the tip of the iceberg – a lot of normalising is going on, for example when identifying triggers etc. – although we don’t want to go too far the other way’ (Research professional FG).*

There was also discussion about what is ‘normal’ in the young people focus groups. In response to the phrase ‘depression is very much a real illness’, one participant asked, ‘Would you say that about cancer?’. However, another preferred to see it included:

*‘I’ve family members say ‘pull yourself together’...sometimes it’s nice to be told that [it’s an illness]’ (Young people FG3).*

In line with findings from the interviews, all groups suggested that it was important that the young person should not feel alone, and that statistics could be used to emphasise this.

*[You could say] ‘1 in 10 children experience depression...just so they don’t feel like freaks’ (Research professionals FG).*

Initial designs – ‘What is depression’ section: A prototype of the ‘what is depression’ module was developed and shown to later focus groups (figure 5.14). Young people in group 3 were generally happy with the content of the early prototype. They liked the progress bar, the



quiz and links to other resources. Most were in favour of including case studies of young people with depression, particularly those which are recovery oriented to give hope.

*‘This would show all sorts of people suffer, different genders’ (Young person FG3).*

It was suggested that users could upload their own experiences, to share with others. Half of the participants stated they would be happy to do this, although they were unsure about being filmed.

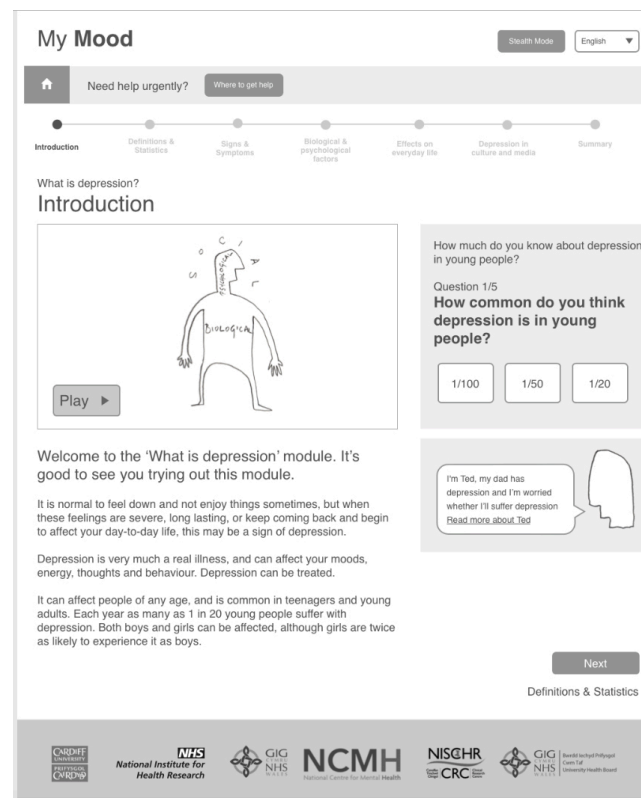


Fig 5.14a: Screenshot from ‘What is depression’ module

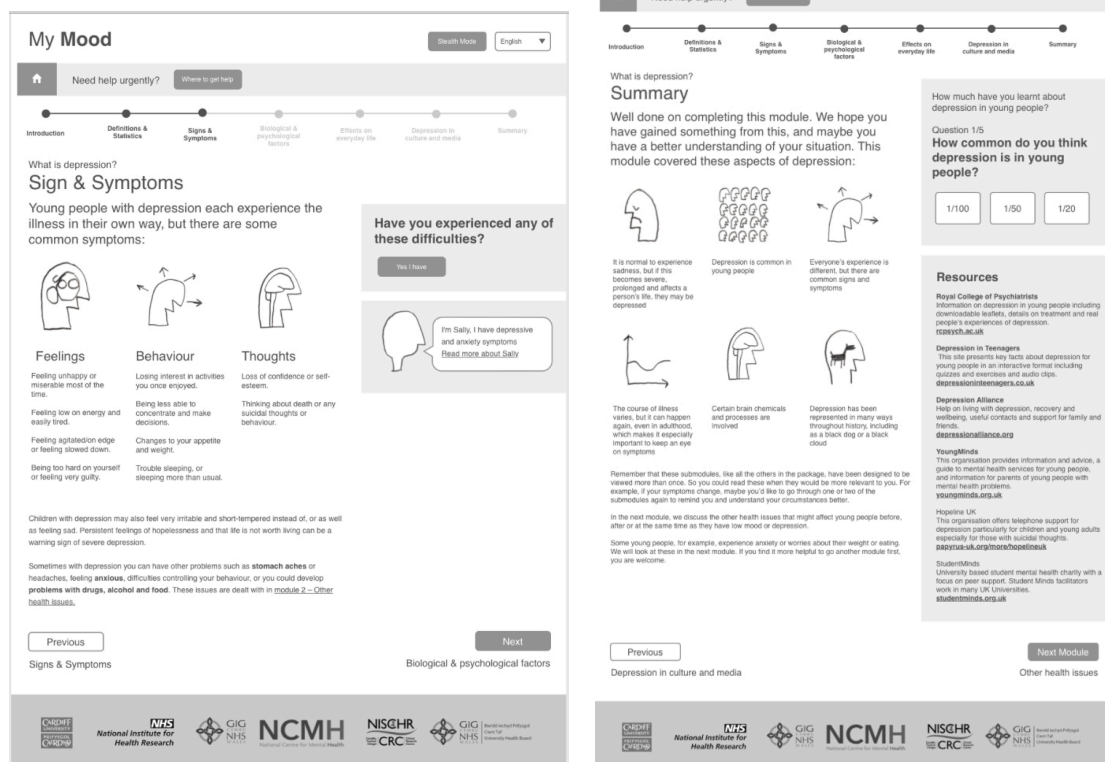


Fig 5.14b: Screenshots from 'What is depression' module

## 5.6.2 Other difficulties related to low mood/depression

There was a lot of discussion about other difficulties related to depression. These centred on i) what should be included, and ii) whether there should be a separate section/module devoted to this topic.

Young people in groups 1 and 2 suggested that the package should include information on other conditions including anxiety, substance use, and self-harm, and group 3 suggested this section could also include schizophrenia, bipolar disorder, and obsessive-compulsive disorder (OCD). Clinical and research professionals recommended covering self-harm, sexuality, gender identity, abuse and possibly information for young carers. They noted that the young person might suffer with these other difficulties, even though they might present with depression.

There was debate, particularly amongst young people and professionals, regarding whether other issues should be a distinct module. Some young people in group 2 thought that a separate section could *'scare someone off'*, and would be *'a lot to take in'* – especially if using the package *'to pick yourself up'*. Further risks of highlighting other difficulties included:

*'The power of suggestion – 'I might have that' danger'.*

*'You might miss something if you focus too much on some of these difficulties'.*

*(both Young person FG2).*

However, others in young person group 2 and most in group 3 were in favour of a separate section. There was also disagreement amongst professionals. Some were concerned that a separate section would increase anxiety, and that there was a risk of trying to cover too much.

*'It's easy for the package to become an 'all mental health problems' package'*  
*(Research professional FG).*

Others felt these issues could be covered as a sub-module of the initial 'what is depression' section, or within the 'possible reasons and risk factors' section. Links to other sources were recommended, including more specialist packages/sites, and information on where to get help, for example from Samaritans.

*'Name the other problem, then show where to go next' (Clinical professional FG).*

### **5.6.3 Causes/reasons/risk factors**

Similar to the interviews, both environmental and biological risk factors were highlighted. Environmental factors raised included bullying, relationships, school, anxiety, stress over exams, and drug and alcohol issues. In addition to the neurochemicals mentioned in the interviews, professionals in the focus groups also highlighted genetics as an important biological factor. Professionals felt it was important to state that brain changes and other

factors are not fixed, and that some issues (such as bullying and depression) can be bi-directional. It was also suggested that the section could be divided into modifiable and non-modifiable (e.g. genetic) factors.

The inclusion of psychological and thought processes – such as cognitive approaches was also advised in the focus groups. One young person in group 2 explained:

*‘One of my main problems was overthinking, then I went the other way, where I wasn’t thinking anything’ (Young person FG2).*

Research professions were cautious about presenting a cause/effect structure, and suggested explaining how moods, thoughts, and behaviours affect each other (CBT approach). Another young person noted that there is not always an obvious reason for depression, and that an ‘I don’t know’ category might be appropriate in some cases.

*‘It can just happen...some people don’t know why they have it’ (Young person FG2).*

#### **5.6.4 Prevention & self-management strategies**

There was some discussion amongst the focus groups regarding whether content related to ‘prevention and self-management’ and ‘where to get help and treatment’ should be distinct sections within the package. Most young people in groups 1 and 2 thought they should be kept separate, and that it would be ‘overwhelming’ to have both together. Research professionals suggested there should be two self help modules; one on ‘staying well’ and one on ‘managing difficulties’.

Quick and easy strategies: Participants suggested the package should include quick and simple strategies that can help the young person to improve their mood, and manage or prevent difficulties.

*‘Actual things psychiatrists do for you, you could do to yourself...without having to go to see someone’ (Young person FG3).*

In addition to the ideas that were suggested in the interviews, young people in the focus groups discussed including coping mechanisms for specific situations, e.g. with panic, stories or tips from people who have recovered from depression, and things to do between therapy visits. They acknowledged that young people who were particularly depressed, might lack motivation, and suggested that advice could be separated into simple, manageable steps, for example to help people to socialise more. They noted that the package should not be 'pushy' or 'too forceful'.

Dealing with stress: As with the interviews, professionals in the focus groups discussed approaches to help young people identify and deal with stressors. They recommended CBT approaches, especially for modifiable factors. Others suggested asking the young people to rationalise how they cope with problems, and asking questions such as '*what you would say to a friend*' [in your situation] and '*what can you do now and this week*'.

Healthy living/hygienes of life: Lifestyle issues, including diet, exercise and sleep, were raised by in both the interviews and focus groups. While all participants in the groups agreed on the importance of a healthy lifestyle, there were concerns regarding how best to communicate this information in the package. Clinical professionals raised concerns that advice might seem judgemental or irrelevant, and carried the risk of disengaging users. One young person noted that diet and weight can be particularly sensitive issues and that changes should be suggested lightly and subtly. Research professionals agreed the language should not be too directive. There was also discussion amongst young people and professionals about the extent of the evidence-base underlying lifestyle approaches, and that it was stronger for some aspects (e.g. exercise) than others.

### **5.6.5 Where to get help**

Young people advised there was a need to stress how '*there's someone there for you*'. They discussed how they would prefer a package, '*that doesn't just give information, but shows how you can be helped*' (Young person FG3). One participant also noted that young people '*don't need to know everything*', as this could be overwhelming, and the information would need to be selective. The main areas discussed in the focus groups were the same as the

interviews, and included talking to others, signposting to services, and the different treatment approaches.

Talking to others: Young people in group 1 and parents thought talking to someone trustworthy could be a major source of help.

*‘It’s good to talk – you don’t have to internalise everything, there are people there to approach’ (Young person FG1).*

Clinical and research professionals suggested including information on 'how' the young person could talk and describe their difficulties to others, including parents, teachers and GPs. Research professionals suggested that issues could be linked to literature on mental health literacy.

Signposting: Participants suggested a variety of places to signpost to services and charities, online resources, school, GP, and CAMHS. They also recommended including advice on *when* young people and families need to get help. Clinical professionals suggested including subsections on 'what to expect from services' and on the transition from CAMHS.

Treatments: The participants in the focus groups generally felt that the package should include an outline of different depression treatments (psychological and pharmacological). However, as with the interviews, there was some caution amongst professionals with regards to the medication section. Whilst they agreed that information on medications should be included, it was suggested that there should be an explanation that they are a possibility 'down the line'. Some young people in group 3 also suggested including a medication section.

*‘Simply - what they are, how they work - make it more likely that they’re used’ (Young person FG3).*

## 5.6.6 Information for parents, carers, professionals

All groups agreed there should be a section for parents and others concerned for the young person. Parents discussed this in depth, and generated several ideas for this section, including how it could link with the young person sections. For example, they suggested a 'where to get help' subsection could link to the section of the same title for the young person. Figure 5.15 shows some initial designs which were presented to the parent focus group.

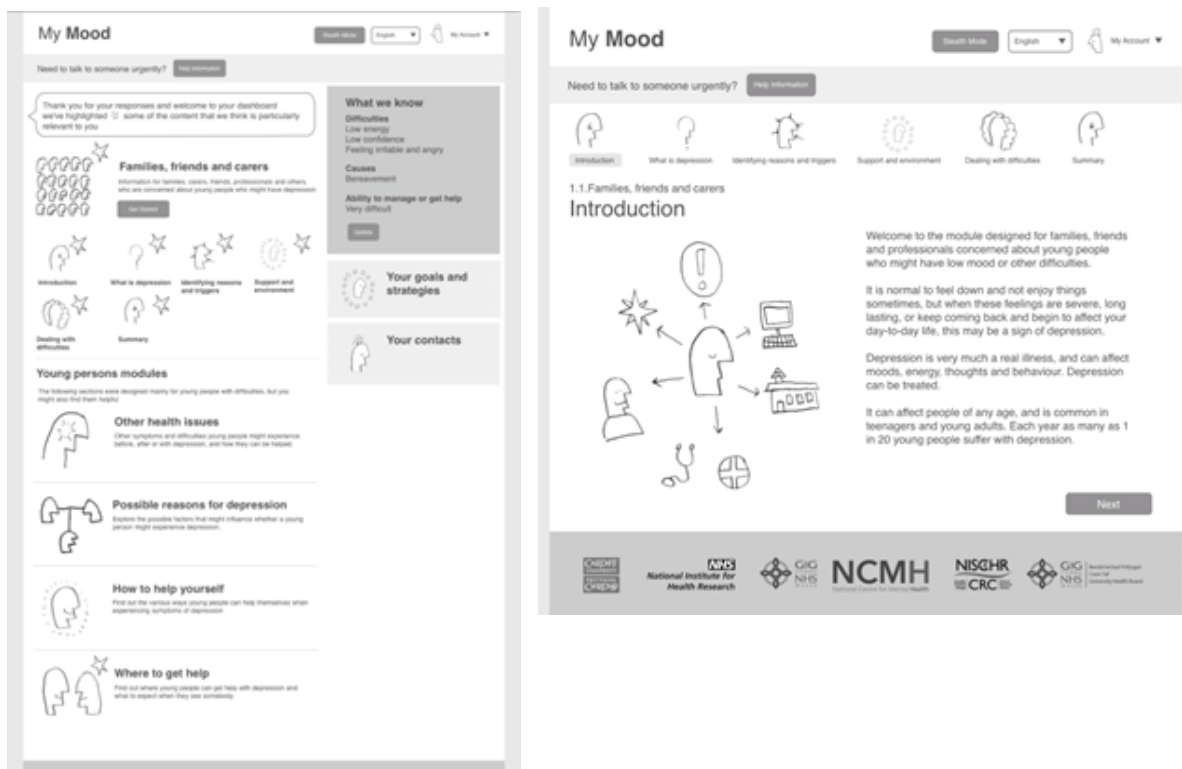


Fig 5.15: Initial designs for parents, carers, and professionals' package

Parents suggested that the format could be like the young person's version of the package, beginning with questions to help identify the most relevant sections to explore. Recommended sections including an overview of depression and identification of reasons and triggers. Parents also stressed that families should be urged to help the young person to attend school, and to develop goals and self help strategies. With regards to symptoms, parents felt it was important to highlight the range of presentations associated with depression.

*‘When taking your child to hospital for numerous illnesses, when nothing’s severely wrong - for example stomach problems, lots of minor issues, non-specific issues – it can be down to depression’ (Parent FG).*

When responding to some of the initial prototype screens, parents noted that whilst adults might be more inclined to ‘read’ through the package than young people, there might still be too much text.

Dealing with difficulties: There was some discussion amongst parents on whether the package was primarily ‘to look at your convenience’ or whether it should help in a crisis. When reflecting on the initial designs for a ‘dealing with difficulties’ subsection (fig 5.16), parents proposed it needed to be clear which services were available at what times, especially for urgent matters.

There were reservations about waiting times, both for ‘out of hours’ services such as casualty and ‘working hours’ services such as the GP, with a further wait if referred to CAMHS.

*‘We waited in casualty for 11 hours after being referred by the GP out of hours...by the time you go to casualty, you need to prepare for the wait...then refer to the psychiatrist’.*

*‘Totally inappropriate support...by the time they refer you, you wait to see a psychiatrist...you’re not likely to go through it...you’ve dealt with it’.*

*(Both Parent FG)*

Parents suggested noting other sources of help, including helplines and websites, such as the Samaritans, to encourage young people to talk to someone.



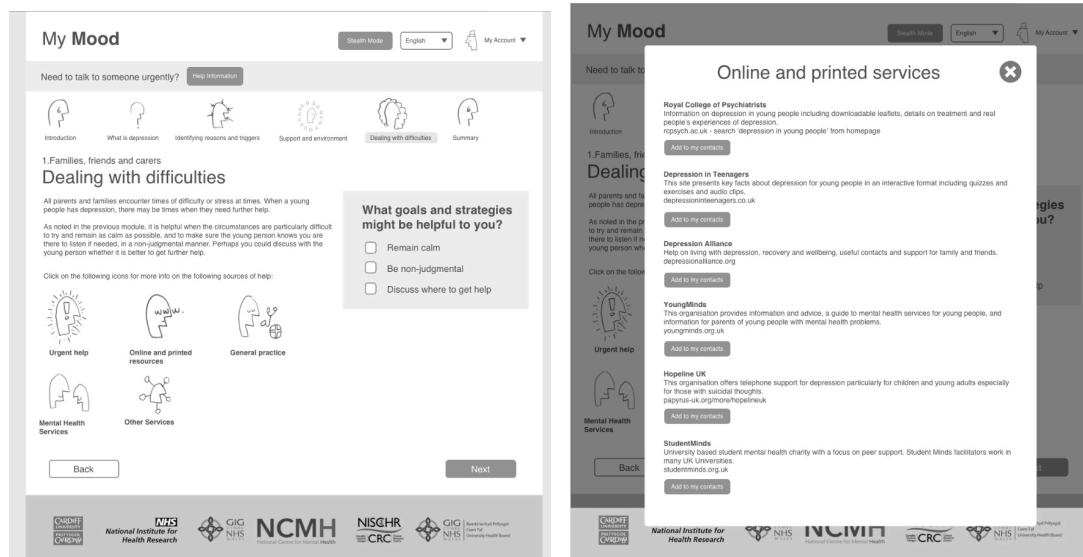


Fig 5.16: Dealing with difficulties and online resources subsections in the initial prototype

## 5.7 Key theme 4: Integration and context

### 5.7.1 Use with parent, carer, friend, professional

There were mixed feelings in the young person groups on whether young people would use the package with their parents or others. However, overall they noted they would like the option of doing so.

### 5.7.2 Use within education and health services

Findings from the focus groups were consistent with those from the interviews. Most recommended the use of the package in schools, including school nurses and counsellors, school pastoral support teams, and in personal, social and health education (PSHE) sessions. Clinical professionals noted the lack of mental health information in the current school curriculum and felt the Introduction of the package in PSHE lessons would help to 'normalise' mental health difficulties.

On the other hand, they noted that teachers' time was limited, and that there was a risk the package might be perceived by young people as 'naff' if it was 'school-related'. There was also some concern that much of the information in the package might be too specific for school curricula.

All groups suggested that the package could be offered by professionals in primary care and mental health services.

### 5.7.3 Name, branding, promotion

Participants were asked to generate ideas for and comment on possible names for the package. Young people in group 1 stated that the term 'mood' was 'ok', but that 'wellbeing' was not helpful, and there was a need for a more specific term. Several possible names were presented to group 3, based on ideas from earlier interviews and groups (fig 5.17). Some names were preferred over others, but there was no consensus.

#### **Possible names for package??**

- MoodSpace (GofodHwyliau), MoodHelp (HwylHelp), MoodMap
  - YoungMood, YouthMood, YPM (Young People & Mood)
  - KnowLow, MoodInfo, DownInfo, iKnow
  - Sails(Hwyliau), MoodSails, BlueSails (HwyliauGlas)
  - Hwyl, Who-eel(Hwyl), Soar, Huile, Who-III
  - Glas(Blue), Glass, BlueGlass
  - Help!
  - Head+ (Pen+), MyHead (FyMhen), HeadPen (diary)
  - oPAD (Online Package for Adolescent Depression)
- (\*Hwyl/hwyliau is the Welsh translation of mood – also the Welsh word for sails (for boats))

Fig 5.17: Slide presented in the latter focus groups on possible names for the package

To promote and increase awareness of the package, young people in group 2 suggested that leaflets could be left in doctors' waiting rooms. Clinical professionals noted that it would need to be 'sold' to professionals as well as young people. An endorsement by institutions such as the Welsh Government could help with this.

Young people in group 2 suggested links to online health resources, and parents suggested it could be found on search engines such as Google, and linked to NHS sites. Clinical professionals suggested there should be links *to and from* other sites, including mental health sites.

Clinical professionals also proposed asking a celebrity to promote this, such as Lady Gaga. However, they recognised it could be ‘dangerous to pin on one person’, as celebrities can get into difficulties, and they would need to be ‘fresh’ and part of youth culture at the time.

## **5.8 Discussion**

### **5.8.1 Summary of findings and development from interviews**

The greater breadth of discussion in the focus groups (particularly given the range of participants), helped to develop the ideas from the interviews (chapter 4), as well as generate new ideas. This was also aided by presenting images, moodboards and designs (created with the multimedia company) to the groups, based on the interview data. Therefore, the group discussions were more guided, and responsive to the slides projected on the large screen compared to the interviews. Whilst the earlier focus groups discussed the broad ideas and designs developed from the interviews, the later focus groups were more focused as participants interacted with prototypes of the package on mobile devices provided to the groups, and gave feedback on these.

The accounts of the need for and aims of the package were similar across interviews and focus groups, and related to addressing the increasing mental health difficulties in young people, and the lack of adolescent mental health resources. There was a call for greater awareness and understanding of depression in young people, and the use of online and digital technologies to engage young people, as they are used so much in their daily lives, and can address the diversity in the potential users. This might be especially relevant as young people often do not wish to talk to adults or professionals.

As was the case with the interviews, overall design was the key theme discussed the most in the groups, and the introduction of designs for the package helped to guide discussions. It was confirmed that that package should be multi-platform, include an 'app', allow the user to personalise the space, have a clear structure and navigation, and not link to forums or social media. Design elements were developed further in the group, for example with regard the illustrations, characters, metaphors, moving images and audio. There was guidance regarding the amount of text, and how the language and terminology should be at the level of the young person – in line with the general approach of the package. Whilst young people noted that phrases in the initial designs were 'well-meaning', some could be interpreted as condescending. The mood monitor was developed further, and 'Stuff I like' and 'My goals' were new ideas developed in the groups.

As with the interviews, group participants agreed there should be levels of information, for example with a hierarchy of sections and subsections within the package. The overall structure and content of the package evolved with each interview and focus group, and this is demonstrated in figure 5.18 below, and included sections on mood and depression, possible reasons, self help and where to get help. Whilst there were differing views, overall it was felt there should be a separate section on 'other health issues', such as anxiety, bipolar disorder and physical illness. The content within each section was refined, to include, for example, tips on how to talk about difficulties with others.

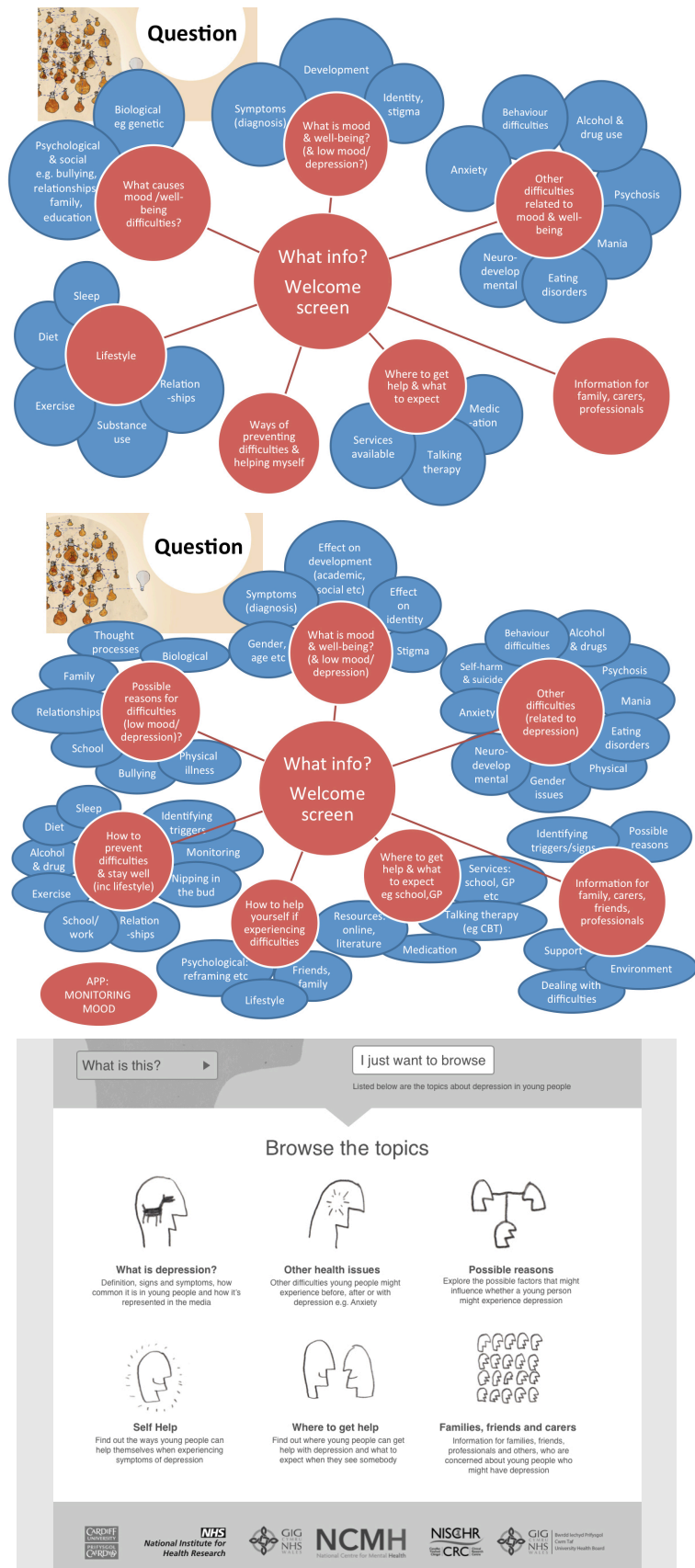


Fig 5.18: Structure of the package changed from the first young person group (top), to the second group (middle), to the initial prototype in the third focus group (below)

The creation of a separate user pathway and section, for parents/carers, friends and professionals, was supported by all groups – with information on signs, symptoms and triggers, supporting the young person and dealing with difficulties. As in the interviews, participants suggested that the package could be used with others (e.g. families), at homes, in schools (e.g. PSHE sessions), and health and other services. As with the interviews, there was no consensus on the name of the package, although the term ‘mood’ was considered more acceptable than ‘wellbeing’.

Table 6.1 in the next (development) chapter shows how themes from the interviews and focus groups translated into elements of the package. A comparison of the package with other online resources and interventions, an account of the strengths and weakness, and a discussion on its integration in the young person’s life, can be found in the discussion chapter (chapter 8).

### **5.8.2 Comparison of focus groups (and other approaches in stage 2)**

All groups were enthused about the package on the whole. As with the interviews, young people were as interested, if not more so, in the design as in the content. Whilst parents and professionals also stressed the importance of design aspects, they were particularly interested in the content. Health professionals and researchers stressed the underlying evidence base and guidelines for assessment and management (e.g. NICE 2005), and suggested that the designs should be guided more by the young people.

Some possible differences emerged in how ‘adults’ perceived adolescent depression, compared to the actual adolescent experience. Suggested reasons included the ‘normalising’ of depressive symptoms and episodes, how some might not consider this to be a ‘real illness’, and the changing experience of young people with each generation, for example in relation to stressors such as exam pressure and expectations, social media and cyberbullying, and parental divorce rates.

There was a mixed response to the ideas and formats presented in the groups, including online resources, still and moving images, and interactive components. Generally, parents were more

cautious, for example some noted that mood monitoring might encourage a preoccupation and rumination. To address these concerns, there could be alerts when the mood was particularly low, and links to sources of help could help. With regards the moodboards, young people preferred the graphic and illustrative imagery, whilst parents considered the photographs more appropriate, and thought that is what the young people would prefer.

As noted previously, whilst they were guided by ideas from the interviews, the discussions in the initial focus groups were more open (on the ideas for the design and content), and the participants' views of current mental health resources. The latter group discussions were based more on the refined designs of the initial prototype - with comments on the strengths and weakness of the designs, and on their functionality on mobile devices made available to the participants. In the latter groups, therefore, there was sometimes praise or criticism of the research and design teams, whilst the discussions of earlier groups were more general.

There were also different challenges to the recruitment for the various groups. For group 2 and 3, young people seemed less reluctant to attend and some cancelled shortly beforehand or did not attend. This may have been because most recruited for those groups had experience of depressive difficulties, and they did not wish to discuss anything related to their difficulties with people whom they did not know. It is possible that their depressive or anxiety symptoms made it difficult for them to attend. This was a challenge to some extent as well for the parent/carer groups, all of whom had experienced depression themselves, or had a child with depression. For the first young person group, more attended than expected, possibly because they had been recruited mainly via their parents, who were enthusiastic about the project. Sufficient numbers of professionals also attended. These issues are discussed further in the strengths and limitations sections of final (discussion) chapter.

As noted in the methods chapter (section 3.4.6), other consultations in stage 2 of the project included informal one-to-one discussions and group discussions, for example with the youth national assembly group 'Funky Dragon', and in public engagement events (e.g. exhibitions, workshops). In general, similar issues were raised in these consultations as those discussed in the interviews and focus groups, without any significant differences. Everyone highlighted the advantages of multimedia given that it is a significant feature in the lives of young people, and that if used in the right manner, it can be used to engage users and communicate information in various ways. They all noted the importance of developing the

package for those concerned about young people as well, and that it should be integrated across a range of settings, not only healthcare.

### **5.8.3 Conclusions**

The focus groups helped to gather the views of a range of young people, parents and professionals on the online psychoeducation package, and develop ideas taken from the interviews. The key themes related to the needs/aims of the package, design issues, content issues and integration with the young person's daily life. The findings from these groups informed the workshops and discussions with the multimedia company, and played an important role in influencing and enriching the designs for the online package, so that it would be usable, acceptable and engaging. The following chapter gives an account of the further development of the package, based on the findings from the reviews, interviews, groups and other consultations.



## Chapter 6:

### Development of the initial prototype of the online package

#### 6.1 Introduction

This chapter describes the development of the initial prototype of the online package for adolescent depression (figure 6.1, stage 3). The content and design were informed by the literature review and qualitative work. The initial development of the package began in parallel with the focus groups. Some early designs were created based on the findings, and were shown to later groups for discussion. A prototype of the package was then developed for use in the evaluation phase (chapter 7). The site can be accessed at <https://www.moodhwb.org>.

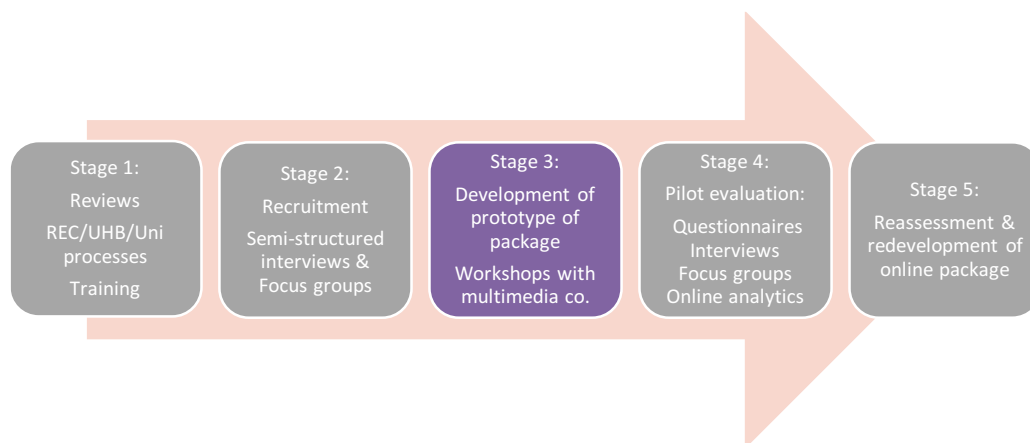


Fig 6.1: Broad stages of the research plan

This chapter first outlines the process of development, including the project management and the translation of the qualitative findings. This is followed by an overview of relevant theories/approaches, and the logic model for the intervention. The design elements and package content are then discussed. Although design and content are outlined separately here, there was interplay between these areas – for example the content determined aspects of the design, whilst design issues influenced what and how much information was presented.

## **6.2 Project management**

### **6.2.1 Consultation and collaboration**

Regular meetings were held with the design team, which consisted of the 'Made by Moon' multimedia company and an animator (who was brought in to help with the animations). Meetings began during the focus group stage so that initial designs could be created and presented to the groups.

A variety of digital tools were used to aid project management. These included the 'Basecamp' programme which was used for communication and to organise files, 'Trello', which was used to prioritise and allocate tasks, 'Team Gantt' which was used to manage the project timeline, and 'Bugherd' which was used in the latter stages of development to record technical or other issues that needed attention. The team also communicated using 'Google Drive', email, 'Skype', 'Facetime' and the telephone – this enabled effective collaborative working 'at a distance'.

Regular consultations were held with experts in adolescent mental health, complex interventions, and online and multimedia design as the package was developed (in supervision and departmental meetings). Preliminary ideas for the design and content were also discussed with several experts in adolescent depression, youth mental health and e-health during an overseas visit to New Zealand and Australia.

During the final stages of development, several components of the prototype, for example the animation scripts and storyboards, were reviewed by participants who had taken part in the focus groups. This was done to ensure the package material was clearly presented, and was age appropriate. The script for the content of the package was peer reviewed by a senior researcher with expertise in adolescent depression (Dr Frances Rice, Cardiff University).

### **6.2.2 Process of development: From initial sketches to wireframes to prototype**

There was a staged approach to the development of the package, from the initial ideas to the creation of the prototype. This ensured that the package evolved in response to the qualitative work, and discussions with experts.

In early meetings with the multimedia company, 'post-it' boards and sketches were created based on user and project requirements (fig 6.2), and black and white and some colour designs were shown in the focus groups. Wireframes (skeletal framework or blueprints) were then constructed showing the layout and functionality of each screen within the package. These further evolved into the initial digital prototype ready for the evaluation phase (chapter 7).

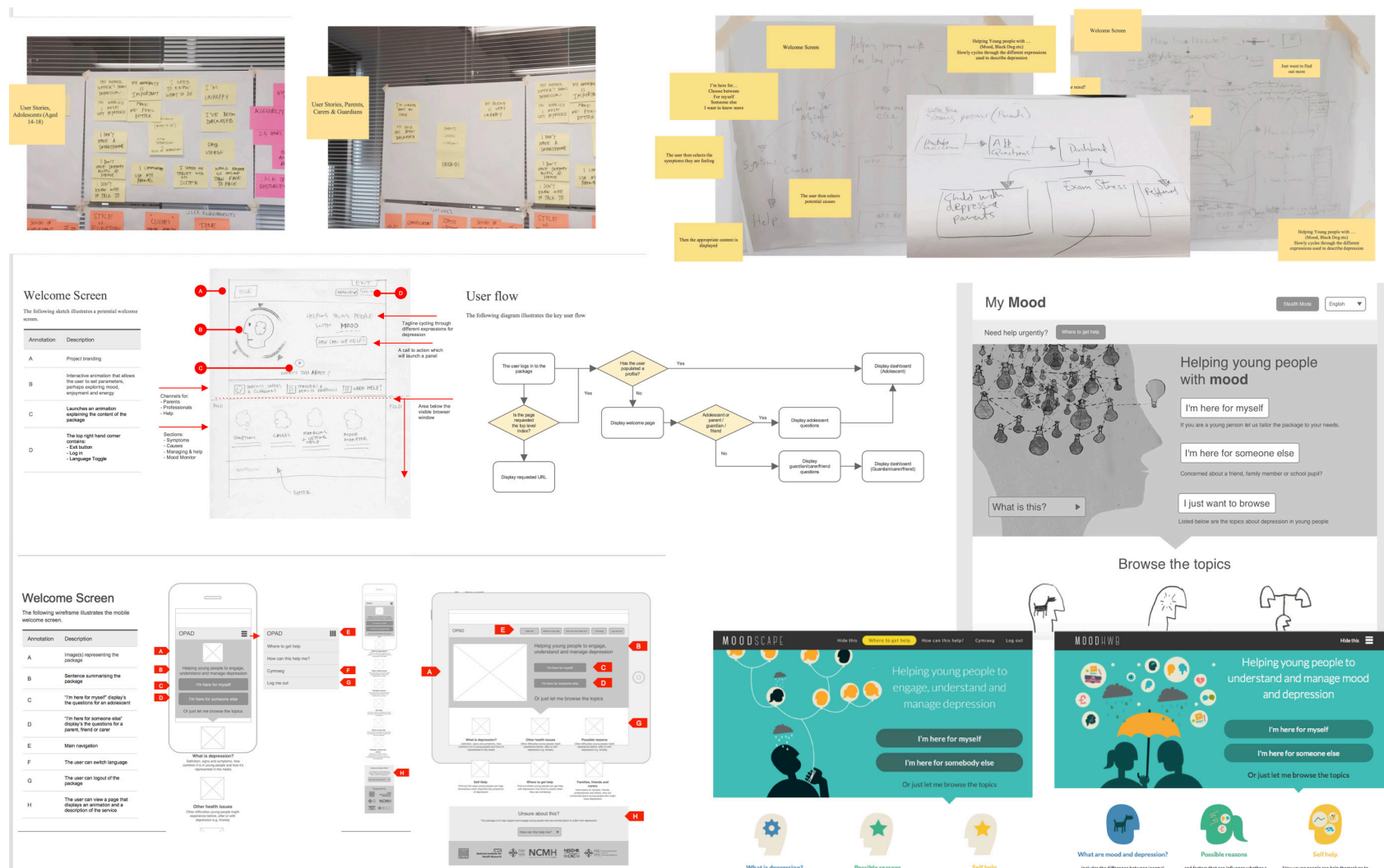


Fig 6.2: Development of welcome screen/user flow: 'Post-its'/sketches (above, centre left), wireframes (below left), black /white and colour designs (centre/below right)

### **6.2.3 Translation of findings from interviews and focus groups**

Several themes emerged from the qualitative work with young people, parents, and professionals. Table 6.1 outlines each of the main themes, and how they influenced the design or content of the package. Whilst the package was primarily influenced by the findings of the interviews and focus groups, the possible theories and approaches underlying the individual themes and examples are also provided where relevant. Many theories/approaches in the table were suggested in the interviews and focus groups with professionals, and by advisors and supervisors. Some theories/approaches were also mapped onto the suggestions for the design/content made by young people and parents/carers, with reference to relevant literature, especially from the systematic review (see also 'Theory and approaches' section, 6.3).

**Table 6.1: How findings from the interviews and focus groups influenced the development of the online package**

Findings from interviews/focus groups	Examples of how themes were addressed in the online package	Possible underlying psychological & behaviour change theory/approach
<b>Key theme 1: The need for, and aims of the package</b>		
Accessible for a diverse range of users	Introduce 3 broad user pathways: i) young person, ii) parent/carer/other, iii) browse option; Develop design elements (e.g. character design) which are not specific e.g. to gender, age, culture; Implement different levels of information and personal stories from a range of perspectives	
Increase awareness/knowledge/understanding; Reduce stigma	Communicate information on mood and depression at an accessible, youth-friendly level; Explain that low mood and depression is common in young people, and it can affect everyone	IMBT
Embrace how young people use digital technologies	Develop the package so that it can be used on a range of platforms, especially portable devices; Develop an accompanying 'app'	SDT, SRT
Promote self-management/autonomy	Give opportunities for the user to relate the content to their experiences e.g. through interactive features; Develop a 'Self help' section	SDT, SRT
Young people find it difficult to talk to adults	Develop the package so that it can be used alone or with someone the user trusts; Provide a diverse list of resources for the user and highlight a variety of different sources of help	IMBT
Help for parents, carers and professionals working with young people	Develop user pathways specifically designed for families/carers, friends and professionals; Develop a separate section for them as well	SCT, IMBT, Resilience theory, Family systems theory

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**Key theme 2: Design issues**

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Harnessing multimedia to: i) <i>engage</i> the user, ii) <i>communicate</i> information	Use a range of imagery and multimedia formats such as animation and audio	
Clear structure and navigation, multiplatform use	Develop clear user pathways from the welcome screen, use drop-down and side menus; Keep the structure of the modules consistent; Use colour to easily distinguish between sections and aid navigation	
Language	Create a bilingual package (English and Welsh); Ensure the general tone and wording are age-appropriate; Avoid use of jargon and ‘unhelpful’ words/phrases	
Characters	Develop engaging characters with some ambiguity, so that they are not specific to gender, age, culture; Ensure that facial expressions are used sparingly in the illustrations/animations	
Imagery, metaphors, moodboards, colour	Use images and visual metaphors to help illustrate aspects of mood and depression throughout; Take a graphic illustrative approach throughout, rather than photography and live-action video; Ensure the colours are bright and uplifting, and appropriate for the general design, colour contrast etc.	CB theory
Gamification	Introduce a quiz at the start and the end of each section	
Personalising the space, monitoring tool, interactive elements	Ask the user to answer questions at the start of the package (and throughout) to: i) help monitor mood and other issues, ii) highlight relevant subsections within the package; Encourage self-monitoring, in a helpful manner; Develop a ‘My profile’ component, including answers to questions, allow user to select profile picture; Develop a ‘Stuff I like’ component and ‘app’; Develop a ‘My goals’ component and ‘app’	SRT, SDT, CB theory, Behavioural activation

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Security and confidentiality (Forums/social media)	Ensure the user's account is password-protected; Encrypt account data on servers; Do not link to forums or social media, or allow users to share information with one another	
<b>Key theme 3: Content issues</b>		
General approach <i>Levels of information</i>	Communicate general information to young people & others regarding aspects of mood and depression; Introduce levels of information to the sections: i) animations (and intro/summary subsections) for key messages, ii) subsections to include text and image, iii) further details via collapsible blocks, feature blocks, iv) links to further resources	IMBT
<i>Positive/validating approach</i>	Emphasis on strengths and positives throughout, not only possible difficulties; Subsections in 'Self help' section e.g. 'Believe in yourself'	SDT, SCT, Resilience theory, Positive psychology
Mood, depression, its symptoms and effects	Communicate information on: what are mood and depression in young people; Take a bio-psycho-social / cognitive behavioural approach – identify links between thoughts, feelings, actions; Include personal experiences – diversity in case studies, recovery oriented	IMBT, CB theory
Possible reasons for depression	Communicate information on: possible reasons/triggers, how to appreciate strengths, focus on modifiable factors; Include a diverse range of possible reasons for depression, taking a bio-psycho-social approach	IMBT, CB theory
Prevention and self-management	Communicate information on: range of self help strategies; For self-efficacy – subsection on 'Believe in yourself'; Include some information on sleep, exercise, diet and drugs/alcohol	SDT, SCT, IMBT, CB theory, Resilience theory, IP theory, Family systems theory



Where to get help	Communicate general information on: range of sources of help (e.g. in an emergency); Include information on what to expect from services; Links to helpful resources; Information on psychological treatments and medication	SDT, IMBT, IP theory, Family systems theory
Other health issues	Build a separate section for other health issues e.g. anxiety, self-harm; Communicate general information for each and provide links to further resources	SDT, SRT, IMBT, CB theory
Parents, carers, friends, professionals	Develop a section specifically for parents/carers/friends; Link this section to the adolescent sections for further information; Develop personal stories from perspective of others	SCT, IMBT, Resilience theory, IP theory, Family systems theory
<b>Key theme 4: Integration and context</b>		
Use of the package with others	Develop the package so that it could be used with someone else	SCT, IMBT
School/education services	Develop the package so that it could be used independently by pupils, or with school counsellors / in lessons	SCT, IMBT
Health and other services	Develop the package so that it could be used with health professionals	SCT, IMBT
Name, branding	Use a name and approach that resonates with young people, with no negative/stigmatising associations	

Abbreviations: Cognitive behavioural theory (CB theory); Interpersonal theory (IP theory);  
Information, motivation, behaviour theory (IMBT); Self regulation theory (SRT); Self determination theory (SDT); Social cognitive theory (SCT)

## 6.3 Theories and approaches

The online package brings together the fields of psychoeducation, e-health and multimedia, and psychiatry. The package was influenced primarily by the qualitative work, but the development was informed by a range of theories/therapeutic approaches (design, educational, psychological and behaviour change), as well as evidence-based knowledge and guidelines. A logic model was developed for the programme (fig 6.4).

### 6.3.1 Design and educational theories/approaches

Several possible design and learning/educational theories were suggested to underpin this package by advisors and supervisors (such as Ms Cath Camps and Dr Clare Kell, Lecturers in Education, Cardiff University), and in interviews and focus groups with professionals. They advised that it was not enough to create a 'bright and beautiful' package, but it should have sound pedagogy and philosophy of education, communication and design behind it.

A key issue relating to the package, was that it should be 'person-centred' or 'person-based'. This approach is advised by guidelines for digital health-related intervention (Yardley et al. 2015), which focus on understanding and accommodating the perspectives of the users. Firstly, this approach embraces a developmental process involving qualitative research with a wide range of individuals from the target user populations, at every stage of the intervention development. This is not only to help to assess acceptability, usability, and satisfaction, but also to appreciate the context, to anticipate usage and outcomes, and modify the intervention to make it persuasive, feasible and relevant. Secondly, the approach helps to identify underlying 'guiding principles' to address the aims of the intervention.

The general approach to the development of the online package was also influenced by elements of the framework for e-health and m-health interventions by Mohr et al. (2014). This describes considerations for the theoretical approaches (aims ('why'), conceptual/behaviour change strategies ('how')), as well as the instantiation and technical approaches (elements ('why'), characteristics ('how'), workflow ('when')). The theoretical and technical approaches to the current package are discussed in this chapter. Another design approach considered was the 'Persuasive System Design' (Oinas-Kukkonen & Harjumaa 2009), which is also referenced by Mohr et al. This approach identifies four general design features. These

are listed here with examples of how they were addressed in the current package: i) primary task support, including tailoring/personalisation, self-monitoring; ii) dialogue support, including positive reinforcement and suggestions; iii) credibility, by conveying trustworthiness and expertise, in the general tone and references to evidence/guidelines, supporting institutions and user-input in the development process; iv) social support, by encouraging use/discussions with a trusted person, and providing links to other sources of help.

The package was personalised where possible, so that engagement was a two-way process, whereby the participants could interact with and take 'ownership' of the programme, rather than be a passive recipient of information (Samuelowicz & Bain 2001). Other PI programmes identified in the systematic review (e.g. Beardslee et al. 2003), stressed how relating information to the user helped to ensure lasting improvements. For the current package, this was done with the use of questions at the start and throughout, tailored messages, and signposting to relevant subsections (see later). Personal stories were suggested in the interviews/groups, and have been used in other PI programmes (Demaso et al. 2006) to help to contextualise the content.

Diversity and learning preferences are key considerations in education. The package was developed to be accessible, inclusive and to address diversity, such as regarding age, gender, language, culture, degree of depressive difficulties, and other difficulties and disabilities (e.g. learning, physical, sensory). Multimedia (and a range of potential media), helped to engage and adapt to the user's learning style or preference. As with other PI programmes (e.g. Beardslee et al. 2003), key themes and messages were repeated in various ways to help the user. This linked in with the VARK approach, which states that individuals prefer to learn through different sensory modalities: visual, auditory, read/write, kinaesthetic (vark-learn.com), as the package included text, illustrations, animations, audio and interactivity.

A blended learning approach was discussed on several occasions with project advisors. This approach combines several formats to aid the learning process, including online digital media and more traditional forms of learning (Singh 2003). This was an approach taken by studies in the review, which showed that PIs can adopt several formats, sometimes within the same programme, including 'individual' and 'family', and 'in person' and 'long distance' approaches (chapter 2). Whilst the current intervention was predominantly an online programme, there were various multimedia elements across many platforms, as noted

above, and opportunities to use it with someone else. The user could learn from discussions with another user or trusted person. The package could go beyond the digital interface, through printed versions, or by incorporating it into presentations and group meetings.

Consistent with the proposal in interviews/groups that the user could access different levels of information, there was a requirement for 'active and deep' (not only 'superficial') learning, which would make the user experience more meaningful ('Bloom's taxonomy' (Anderson & Krathwohl 2001)). This meant that the user could not only gain knowledge and understanding, for example by reading the text or watching the animation, but also apply and analyse the content, for example through completing the exercises, reflecting on their personal profile, and use of the 'app' (e.g. mood monitor, goal setting).

Kolb's experiential learning theory and design principles were also considered (Kolb & Kolb 2005), which state that the impetus for learning and developing new concepts is through new experiences, typically through the four stages of a cycle (fig 6.3). There was an opportunity for the user to build on the knowledge and experiences from the online package, for example, by answering questions throughout, completing tasks and planning activities (e.g. with the goal-setting 'app'), and reflect on the content with others.

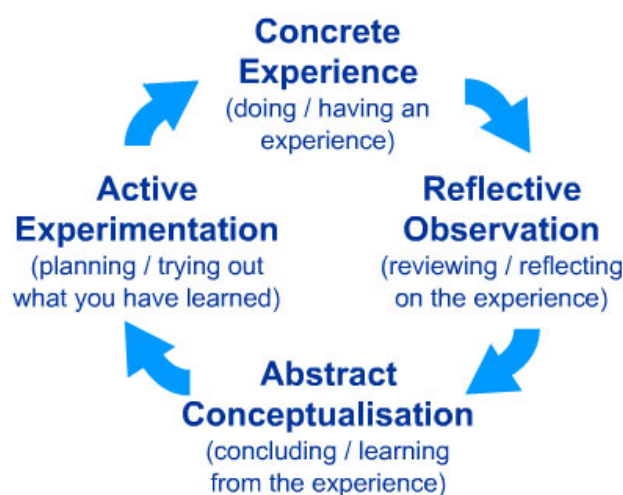


Fig 6.3: Kolb's theory ([simplypsychology.org/learning-kolb](http://simplypsychology.org/learning-kolb))

The package would also take a constructivist orientation, which states that individuals are actively involved in finding meaning and constructing knowledge (often building on existing knowledge and addressing gaps and inaccuracies in understanding), rather than passively

receiving information (Biggs & Tang 2007). This was done in the package by contextualising the information (e.g. asking questions related to the content, and personal stories) and allowing the user to learn from experience (e.g. by suggesting activities). To help with this, the package was designed so that it could be flexible and 'non-linear' in its approach, for example allowing the user to 'backtrack', 'revisit' and 'consolidate' their knowledge and experience, although it could be a linear approach if the user preferred.

There was also consideration of the length and number of the sections of the package, as studies of online interventions have shown differences in outcomes due to these factors (Calear & Christensen 2010). Levels of concentration and performance tend to dip around 20 minutes into a presentation (Biggs and Tang 2007), and approaches were introduced to help maintain concentration, such as breaking up sections and incorporating interactive elements. A quiz before and after each section of the package aimed to test and consolidate knowledge of aspects of depression. The user experience was designed to be intuitive, so that an instruction manual was not needed, although there was an introductory animation.

### **6.3.2 Psychological and behaviour change theories/approaches**

As noted in the review chapter, there can be 'blurry' boundaries between 'simple' interventions (such as PIs) and 'skilled' approaches (such as CBT) (Colom 2011). The findings from the review and consultation phases of the project, suggested that a range of approaches should inform the overall development of the package. As one of the child and adolescent consultant psychiatrists in the interview stage stated, there could be 'a mishmash' of approaches. Information on possible 'talking/psychological therapies' for depression (such as CBT and IPT) was presented in the help sections, although it is important to distinguish between this and elements which could promote change in the user (see table 6.1).

Elements of cognitive behavioural theory was suggested as part of the online package in the professionals focus group, possibly because many practiced CBT and it is recommended in NICE guidelines (2005). This theory was referred to in the package when discussing the symptoms and effects of, and possible reasons for depression (and other health issues). The user was encouraged to group symptoms according to thoughts, feelings, actions, or

sensations, and to appreciate how they can affect one another. There were also references to addressing 'negative thoughts', and metaphors related to mood and depression, which can be used in CBT (Stott et al. 2010). The goal-setting component and self help subsections (e.g. 'Plan ahead', 'Life healthily') used elements of behavioural activation theory to help the user. The research teams behind the computerised CBT packages, SPARX (University of Auckland, New Zealand), and 'Think, Feel, Do' (University of Bath) were consulted.

Aspects of positive psychology were incorporated in the general tone of the package, particularly where the user was encouraged to think of their 'strengths and positives', and how they can help them to overcome difficulties. The developers of Bite Back ([biteback.org.au](http://biteback.org.au)), an online site based on positive psychology, were consulted at the Black Dog Institute (Australia). Interpersonal and family systems theories were also referenced, particularly in the help sections, where encouraging the user to consider their relationship and roles with friends and family, and where advising others to support the young person.

The development and content of the package was influenced by several behaviour change theories. These are specified in table 6.1 and influenced the development of the logic model (figure 6.4), and include information, motivation, behaviour theory (IMBT), self regulation theory (SRT), self determination theory (SDT), and social cognitive theory (SCT) (Abraham & Michie 2008; NICE 2007, 2014). Some of the key concepts of these theories overlap and are relevant to the package. IMBT promotes change by providing information to support the behaviour change, motivating the user, and encouraging a favourable attitude towards (and to try out) the new behaviour. The online package presented health information (and attempted to assess/consolidate knowledge through quizzes and other questions) in an acceptable and engaging way, and related this to the user's life through exercises, which fed into their personal profile. The user would be asked to try certain behaviours, for example using the goal-setting component.

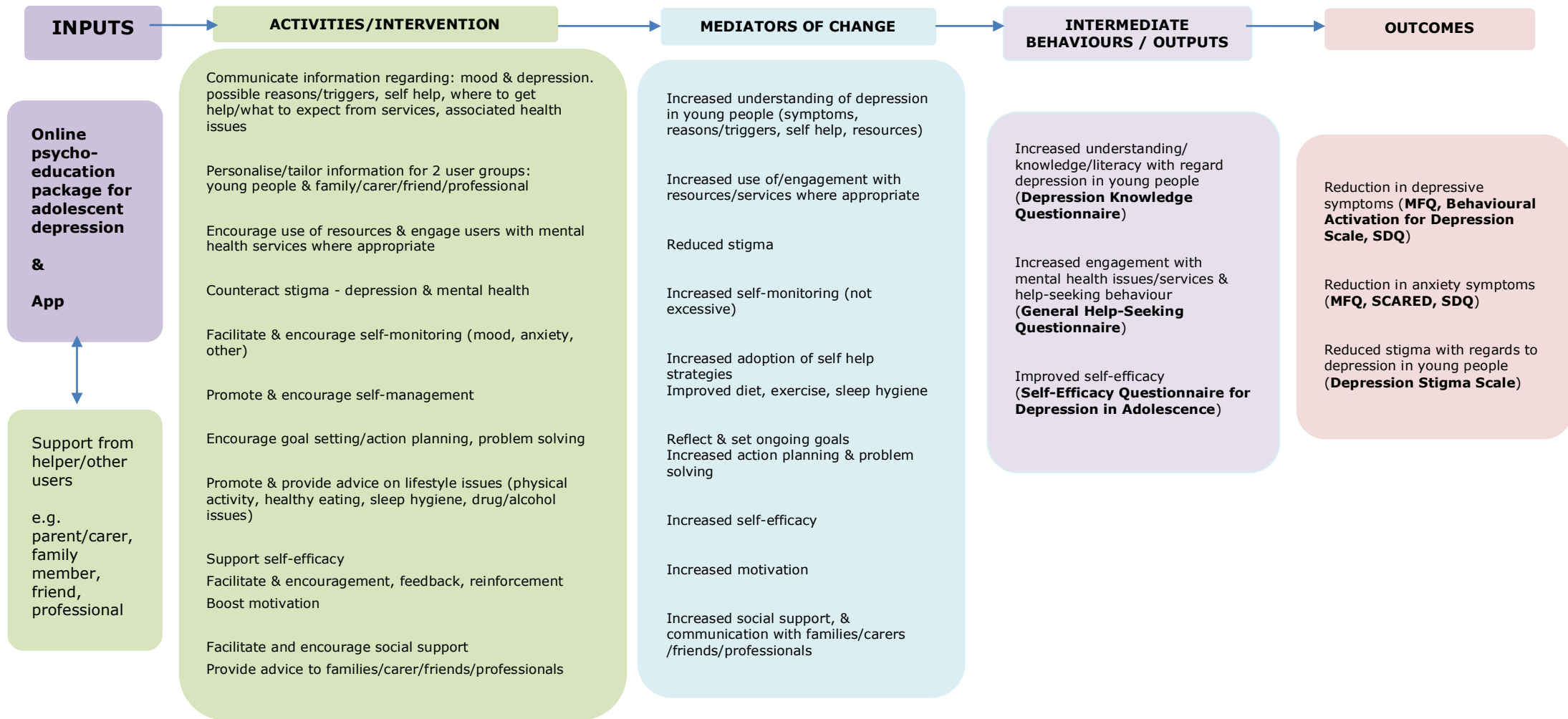
SRT is concerned with goal setting and monitoring or self regulation, whereby the individual compares their progress against the goal and adjusts their behaviour appropriately. It relates to the person guiding their own thoughts, behaviours, and feelings to reach certain goals. There are four components: i) standards of desirable behaviour, ii) motivation to meet standards, iii) monitoring of situations, and iv) willpower. The online package encouraged the user to identify and monitor their thoughts and feelings, and possible underlying

factors/triggers (e.g. with the mood monitor), and use self help approaches. SDT is also related to motivation and engagement, and how this could be improved by supporting an individual's experience of autonomy, competence, and relatedness. The online package promoted these experiences, for example by making it accessible on a range of devices, tailoring/personalising the space, identifying personal strengths, and encouraging self-management skills (and help-seeking when appropriate).

SCT emphasises the importance of learning from others, social support, self-efficacy and knowledge and skill as well as regulating goal directed behaviour. The online package incorporated elements related to these concepts, including identifying personal strengths, and promoting helpful self-management approaches and goal-setting, as well as the individual's observations of others in the context of social interactions and experiences. This was particularly relevant in the package when discussing approaching trusted friends and family/carers, encouraging its use with others, and in the section for families/carers, friends and professionals.

### **6.3.3 Logic model (fig 6.4)**

A logic diagram was developed based on the findings which emerged from the early research stages (stages 1 and 2) as well as relevant theory. There were a range of possible areas of change which could be targeted by the online package, and a range of possible outcomes. The logic model described the inputs in terms of intervention components, the mediators of change and the intermediate and longer term outcomes, as well as contextual factors which might influence the effectiveness or otherwise of the intervention.



CONTEXTUAL FACTORS				
Participants/other user availability of computer/smartphone, and access to internet Understanding & knowledge of how internet & app work Quality and design of app/website Ease of use & acceptability of app/website Quality of intervention content Privacy & security of app/website data Other apps/programmes are more appealing	Availability of family/carers/friends to act as helper(s) Characteristics of helper(s) Characteristics of family/social network Integration of family/social network	Access to resources to help with self-management Physical activity opportunities e.g. gym Access to healthy food Socioeconomic factors Everyday barriers and facilitators e.g. school/exam, family/peers or work commitments	Intrinsic or biological factors e.g. family history of depression (genetics), other mental health difficulties, physical health difficulties, learning difficulties/disabilities	Integration with approaches in health, education, social, youth services/charities



## 6.4 General design and technical specifications

### 6.4.1 Multiplatform use

A design specification established early in the project, was that the central package would need to run over several platforms, including desktops, laptops, tablets and smartphones. The package would need to be responsive to all the screen formats, with regard to size and proportions. This flexibility is seen with websites such as those of the BBC (bbc.co.uk), which were referenced often during the development process. Careful consideration was given to colour and text, and to design features such as animations and characters, so that they would be clear on different formats.

The central platform was designed to link with an 'application' or 'app' (peripheral platform) for use on mobiles/smartphones and tablets. It was clear from the qualitative work that young people use smartphones and 'apps' to access information, including health information, and this is evident in recent ONS statistics (ONS 2016).

### 6.4.2 Security and confidentiality

Participants in the interviews and focus groups stressed that security and confidentiality should be a key consideration when designing the package. It was agreed that data (such as mood and other variables) entered into the package would be stored securely in an encrypted database on the Cardiff University server. The user's account would also be password-protected. It was decided not to link the package with social media or online forums, due to concern raised in the interviews and focus groups. To do so safely would require regular moderation, which was beyond the scope of the current package.

### 6.4.3 Language issues

**Bilingual approach:** The package was developed as bilingual - in English and Welsh. This requirement was supported by findings from interviews and focus groups. Adolescents and

families whose first language is Welsh might find it more comfortable to deal with sensitive issues such as mental health difficulties if the package was bilingual, and NICE guidelines recommend that children and young people are engaged in their first language (NICE 2005). Approximately 20% of the population in Wales speak Welsh (ONS 2011), and the bilingual approach meant the package was compliant with the Welsh Language Act in the provision of information to participants, given that both Welsh and English are official languages in Wales (HM Government 1993).

This specification also meant that the package would be developed so that it could be translated to other languages in future. This was a consideration for example when developing the illustrations and animations, so that there was no text, and the icons were not culture-specific.

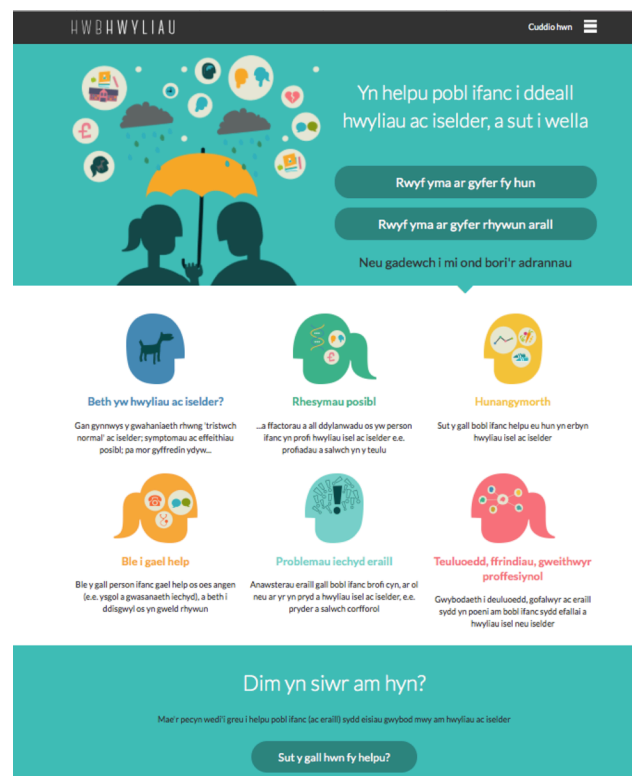


Fig 6.5: Welcome screen for 'HwbHwyliau', Welsh language version of the package

**Style and tone:** Participants in the interviews and groups emphasised that the information in the package should be age appropriate, and the use of jargon should be avoided. Information presented should be clear, factual, and comprehensive, but not patronising. It was also considered important not be too alarmist, for example when describing the risks and effects of depression. The third person was used for most of the package, so that the

user did not feel singled out, but the second person was used in the help sections, as this could be considered more motivating.

The language and tone used in the package was also guided by information from other resources. Information on adolescent depression and its communication is similar in resources from around the world for young people and families, including NICE guidelines and AACAP practice parameters, and mental health institutions and groups such as the National Centre for Mental Health (Wales), YoungMinds, Royal College of Psychiatrists (RCPsych) (UK), Black Dog Institute, Headspace (Australia) and the Lowdown (New Zealand). This may be because their information is based on national and international guidelines, and the best available evidence on depression.

#### 6.4.4 Name of package

There was no consensus on the preferred name for the package in the interviews and focus groups, but 'mood' seemed appropriate and has been used for other programmes related to depression (e.g. MoodGym, Mastermymood). Early names considered included OPAD (Online Psychoeducation for Adolescent Depression), 'Moodscape' ('Hwylwedd' in Welsh) and 'Moodspace'. The university legal department advised that certain names could not be used because they were similar to existing titles.



Fig 6.6: Initial designs and typography for the name, including final choice (below)

The name 'MoodHub' was chosen, because the package is a 'hub' of different elements. This evolved into 'MoodHwb' ('HwbHwyliau' in Welsh), which incorporates 'hwb', a Welsh translation for 'hub', and also means a 'lift' or 'boost'.

## **6.5 Design elements: structure and functionality**

### **6.5.1 General structure and components (primary level)**

In conjunction with the multimedia company, an 'Information Architecture' file was created (figure 6.7) which provided an overall framework for the package. The primary level gave an overview of the initial screens (welcome, dashboard), and the main sections of the package, whilst the secondary level (discussed next) outlines the different subsections within each of these. It might be helpful to navigate the site, at <https://www.moodhwb.org>, whilst reading the remainder of this chapter.

The final package consisted of six main sections. These were: what are mood and depression?, possible reasons, self help, where to get help, other health issues, and friends, families and professionals. There was also a welcome screen, a dashboard, and three interactive elements (mood monitor, stuff I like and my goals). This section describes the user's journey through the primary level of the package, with a focus on design features, as well as a description of the secondary level (subsections). Whilst there could be a linear progression through the package, there was also flexibility, so that the content could be tailored according to the needs of the user – and they could 'dip in and out' of relevant subsections as they wished.

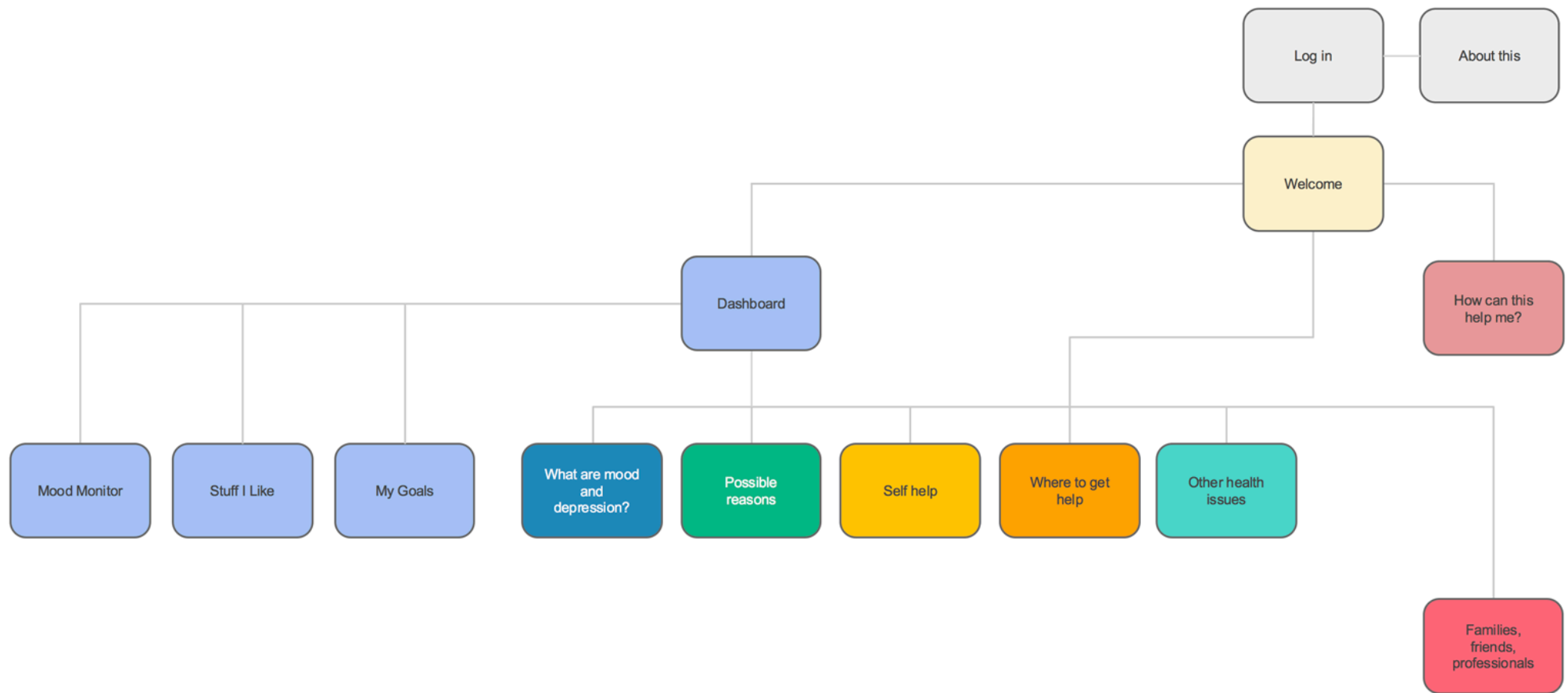


Fig 6.7: 'Primary level' user flow diagram from the 'information architecture' document

## 6.5.2 Welcome screen

As was stressed in the interviews and groups, it was important to design an engaging, clear and user-friendly welcome screen, which the user could use intuitively to navigate the package. The designs for the welcome screen (figure 6.8) consisted of:

- a clear layout with a clear title and tagline;
- a minimalist but engaging illustration to the left;
- a choice of user pathway options ('I'm here for myself', 'I'm here for someone else', and 'Just let me browse the topics');
- 'hide this' selection (if the user wished to leave the package quickly);
- menu icon (including links to dashboard, login, interactive elements, package information and language options).

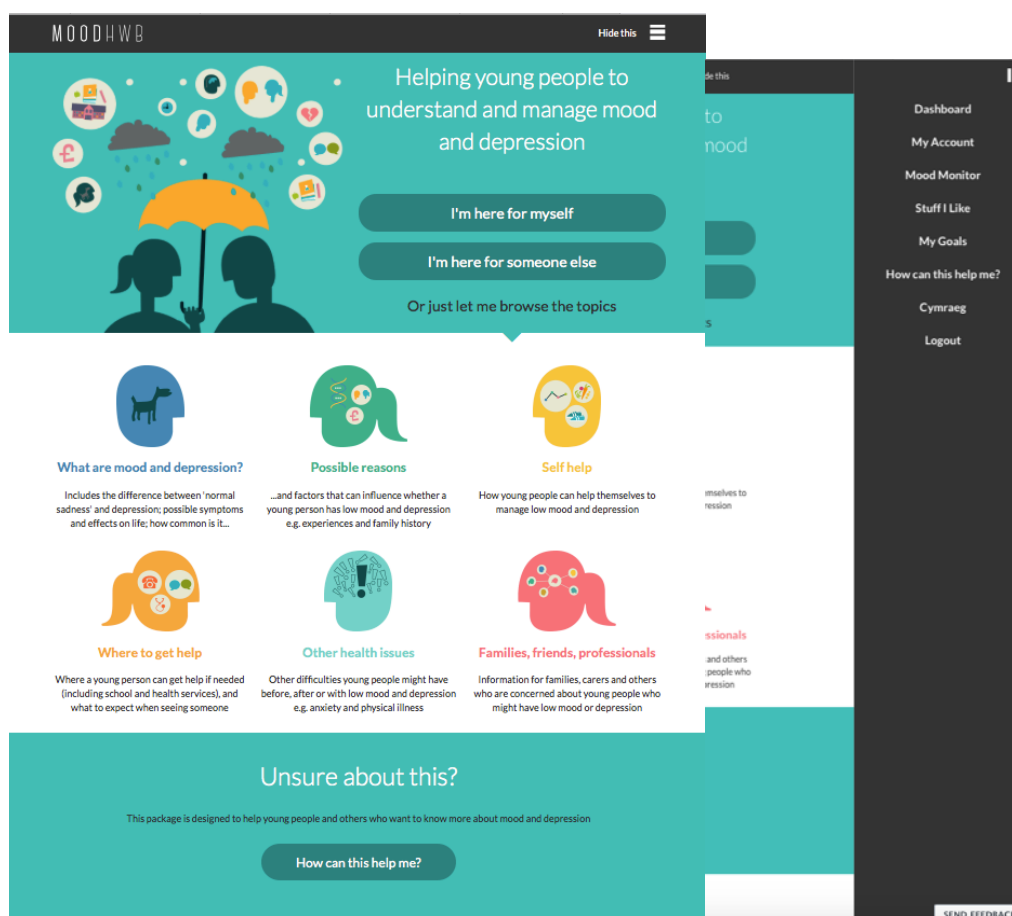


Fig 6.8: Welcome screen and menu (right)

### **6.5.3 User pathways**

The package was designed so that it could be used independently or with another person (family/carer, friend, professional), and this meant that whilst it would be appropriate primarily for the young person, it could be used by others to provide information and advice. Three different user pathways were designed, to accommodate different user needs (see previous subsection).

This was a requirement from the interview/group findings, and from the review, which revealed that family interventions (e.g. Beardslee et al. 2003) seemed to be the most effective form of PI for adolescent depression. Guidelines (e.g. NICE 2005, AACAP 2007) also stress the importance of the family in the management of adolescent depression. As noted in the review, the support and skills of a facilitator (whether family member or other) and therapeutic relationship (Green 2006) could be key factors in the success of a PI. Guided self help is recommended in NICE guidelines (2005) for adolescent depression.

After selecting one of the three options from the welcome screen, the content was tailored to the different user pathways. Users who selected the first or second options were presented with a set of initial questions asking them about their mood and other issues. Users who selected the second option were presented with the same questions, but asked to respond in relation to the young person about whom they were concerned. Users who selected the third option were not presented with any questions, and were free to browse the package content.

### **6.5.4 Initial questions**

The purpose of the initial questions was to help the user to:

- 1) Personalise the package, by tailoring the content so that it was relevant to them – different subsections would be recommended, depending on the responses provided.
- 2) Monitor their progress. These questions also served as the mood monitor, which the user could access at any time to rate their current mood/other issues, and monitor changes over time.

Ideas for the style and content of the initial questions/mood monitor were discussed with participants during the qualitative work, and with the design and supervision teams. A range of questionnaires and scales were considered, including the Patient Health Questionnaires (PHQ) (Richardson et al. 2010) and Moods and Feelings Questionnaire (MFQ) (Goodman 1997). The style (e.g. tick box vs sliding scale) and range of the scale were also discussed.

The final design included nine questions which focused on the young person's mood, level of interest/enjoyment, ability to control worries, anxiety and ability to cope. The initial four questions were broadly based on the PHQ-4, which is used especially in primary care to assess depression and anxiety (Kroenke et al. 2009). Additional multiple-choice questions were then asked about the user's difficulties, possible reasons for these, strengths, and what might be helpful for them. Initial questions were presented in a Likert-style format, with response options ranging from 1-7. This is the approach taken by several other programmes, including SPARX (Merry et al. 2012). Head icons were used to make the design more visual and engaging. The expressions and colours changed depending on the response selected, to increase clarity.

The figure displays four screenshots of the MOODHWB interface, arranged in a 2x2 grid. Each screenshot shows a progress bar at the top with steps: Mood, Enjoyment, WorryCope, Calmness, Difficulties, Reasons, Strengths, Help, and Coping. The current step is highlighted.

- Top Left:** "Please rate how you've been feeling over the past 7 days". A yellow head icon is shown with a score of 5 on a scale from "Very sad" to "Very happy".
- Top Right:** "Please rate the interest or enjoyment you've had in things, over the past 7 days". A red head icon is shown with a score of 2 on a scale from "None at all" to "Very much".
- Bottom Left:** "Please rate how easy you find it to cope or get help with your difficulties". A green head icon is shown with a score of 6 on a scale from "Very difficult" to "Very easy".
- Bottom Right:** "Please select any of the difficulties you've experienced". A list of 12 difficulties is shown with checkboxes. The selected difficulties are: Low energy/tired, Low confidence, Hopeless about the future, Feeling irritable and angry, Concentration difficulties, Difficulty socialising/going out, Sleeping difficulties, Appetite loss/gain, Weight loss/gain, Feeling very guilty, Getting into trouble (e.g. with adults), and Alcohol or drug use.

Fig 6.9: Questions when entering the package and when monitoring mood/other issues



## 6.5.5 Dashboard

Once the user completed the initial questions, they were directed to the 'dashboard'. This screen was designed so that the user could easily navigate through the different sections of the package, and keep track of their progress. This key screen would be referred to repeatedly by the user and displayed:

- the results from the initial questions, with a 'traffic lights' colour coding system (red, yellow, green);
- tailored messages in response to the initial questions, depending on the severity of the difficulties;
- link to the 'my profile' section, where answers to multiple-choice questions in the package would be stored, and where the user could reflect on strengths, difficulties and self help;
- links to the six sections available (and their respective subsections) and other components of the package.

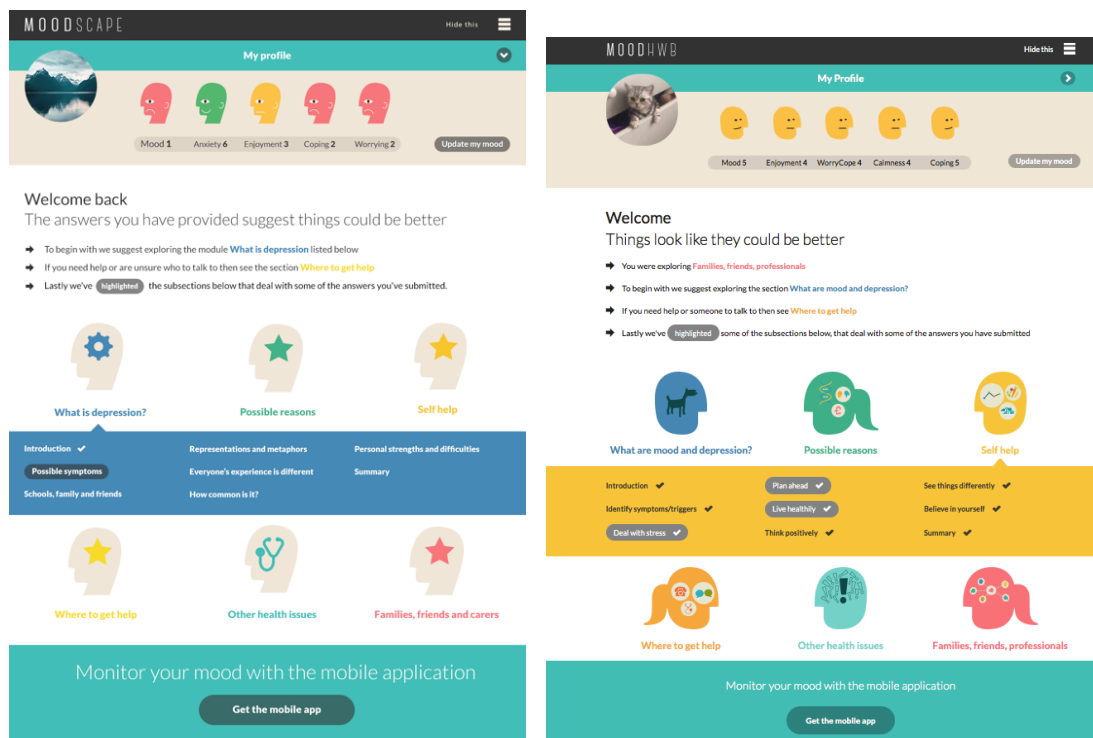


Fig 6.10: Dashboard: Early design (left) and latest design (right) showing sections and subsections (with some highlighted)

### 6.5.6 'My Profile' section

The 'My profile' section, accessed from the top of the dashboard screen, offered another way in which the package could be personalised. This section contained a summary of data collated from responses to the various questions and interactive elements of the package (e.g. difficulties, strengths/positives, preferred resources). It was automatically populated, but the user was also able to edit as required.

This was a database of all the answers to the questions and interactive aspects throughout the package. There would be a balance of questions about the user's strengths/positives and links to help/resources, as well as their difficulties, so as not to encourage the user to worry excessively and ruminate about their difficulties.

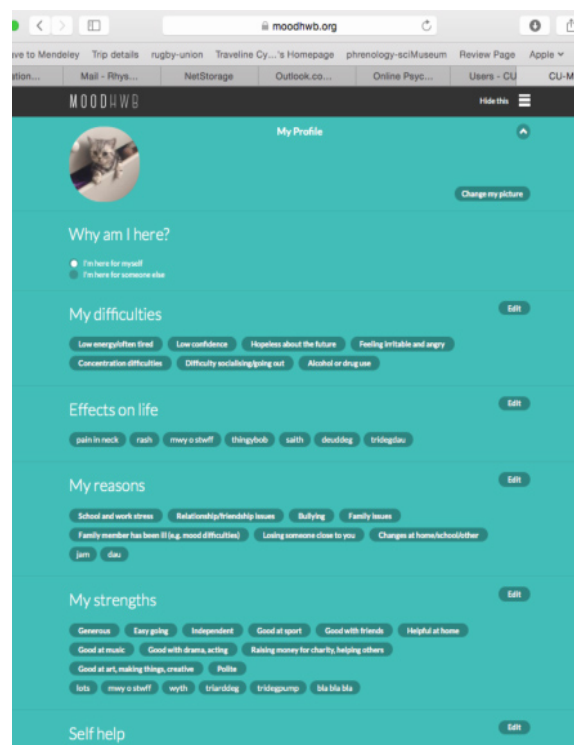


Fig 6.11: Designs for the 'my profile' section

### **6.5.7 General structure and components (secondary level)**

Early in the development of the package, it was decided in the focus groups that the content of the package should be divided into categories, to help with the clarity and navigation, and not to overwhelm the user. The layout and structure of each section followed a similar framework. This helped ensure the package looked cohesive, and enabled the user to become familiar with and easily navigate the package. The sections were built so that they could be 'scrolled' or 'wiped' up and down, consistent with the navigation of content on mobile phones and tablets. This also followed the example of educational sites, such as the BBC's iWonder sites ([bbc.co.uk/iwonder](http://bbc.co.uk/iwonder)). Other approaches were considered, such as placing the subsections in individual 'pages' (clicking 'next' and 'back'), although this was not considered to be as user-friendly by participants in the interviews and focus groups, particularly if using the package on a mobile device.

Each of the six main sections was divided into subsections or 'content blocks' which consisted mainly of text and illustrations. These were followed by one or more 'feature blocks', which helped to give context and engage the user. Examples of feature blocks include case studies (personal stories); questions for the user (e.g. 'have you experienced these difficulties?'); quizzes; and links to the 'app', other subsections, or resources. Figure 6.12 shows how the initial sketches for the content sections evolved into the wireframes and colour designs.

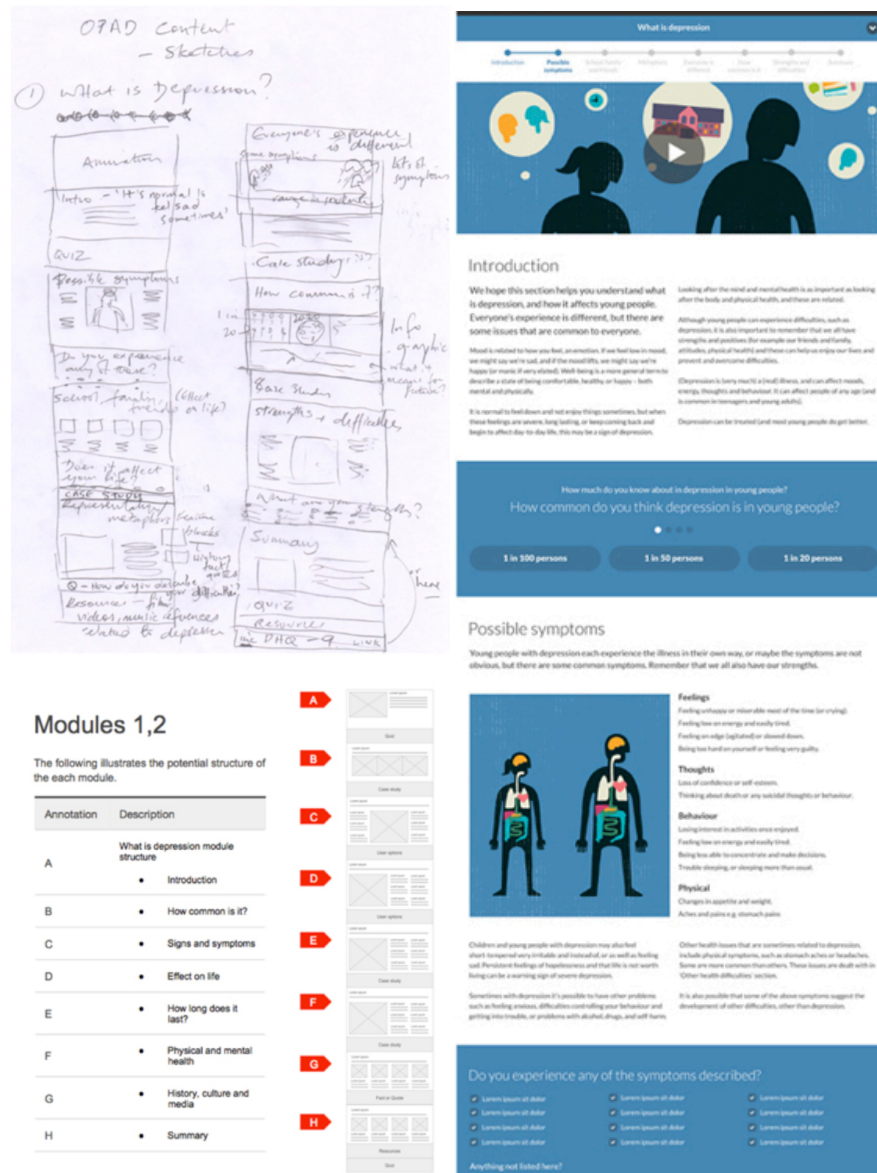


Fig 6.12: Sketches (top left), wireframes (bottom left) and early colour designs (right) showing the structure of the 'what are mood and depression?' section

## 6.5.8 Levels of information

Several approaches were taken during development of the package to address user diversity. One approach, as discussed in the interviews and groups, was to introduce various levels of information in each section. This was done in several ways:

- 1) animations at the start of each section gave an overview of the content;
- 2) the introductory subsection, and summary subsection at the end, included the key messages;

- 3) the text and illustrations in each subsection (the content blocks) gave more detail, and the ‘feature blocks’ gave more context (e.g. providing a case study, or asking the user to relate the content to their own experience);
- 4) the user could select ‘collapsible blocks’, which presented more information;
- 5) further details could be found by choosing the links to other relevant websites and resources.

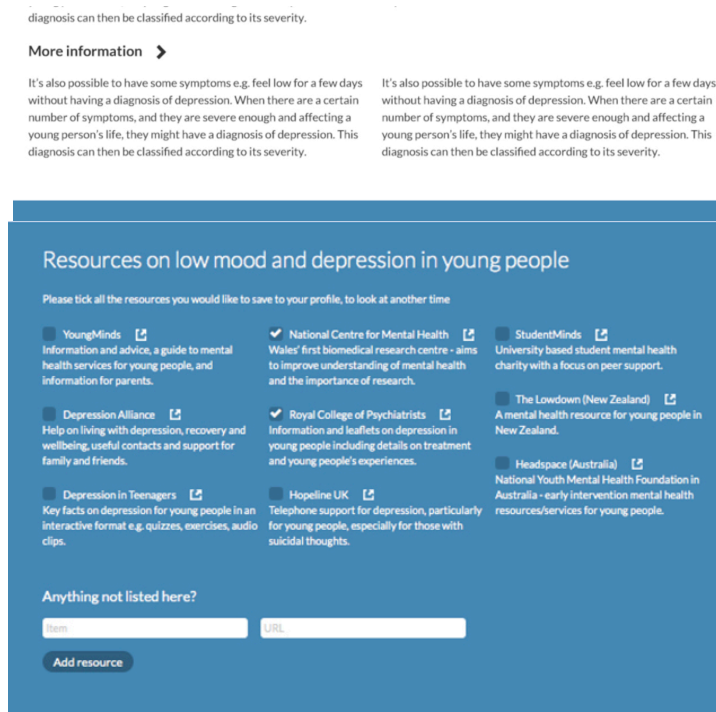


Fig 6.13: Collapsible block (top), and feature block (bottom)

### 6.5.9 Interactive sections & ‘App’

There were three interactive sections included in the design of the package. These sections not only provide the user with useful strategies to help them manage depression, but also enable them to personalise the package (an important theme from the qualitative work). The three sections are i) Mood monitor, ii) ‘Stuff I like’ and iii) Goal setting.

An ‘app’ was developed to accompany the package, comprised of these three interactive sections. The purpose of the ‘app’ was to provide the user with greater flexibility, and enable them to monitor their mood, or enter information ‘on the go’. The ‘app’ could be installed

on a mobile device or tablet, and is linked to the user's account, so that any information entered is automatically uploaded, and assimilated into their profile.

*Monitoring mood & triggers ('Mood monitor'):* The 'Mood monitor' could be accessed by the user at any time when using the package or the 'app'. The nine questions that comprise the mood monitor were the same as those asked at the start of the package, and have been described previously. Scores to these questions were stored and presented to the user in graphical format (Fig 6.14), enabling them to easily monitor progress and changes over time. This information could be accessed via the main menu on the dashboard.

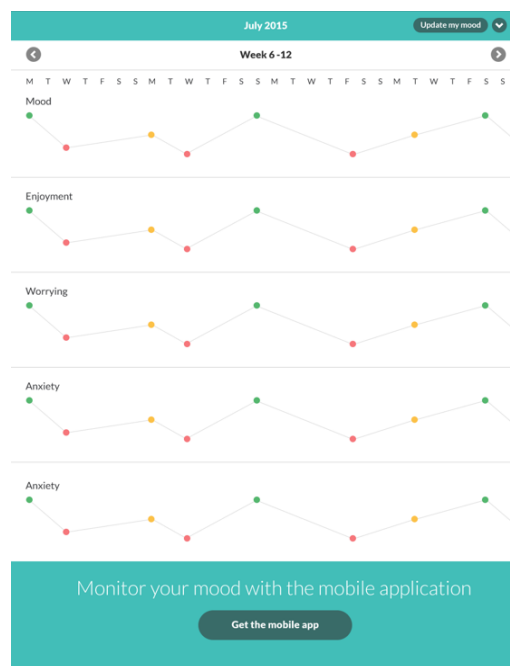


Fig 6.14: Colour design for the mood monitor

*'Stuff I like':* The findings from the qualitative work suggested it would be useful to have quick and short-term measures as a form of self help. The 'Stuff I like' interactive section was designed to enable the user to store links to helpful online resources such as websites and videos (with individual icons), which could provide them with a short-term lift in mood.

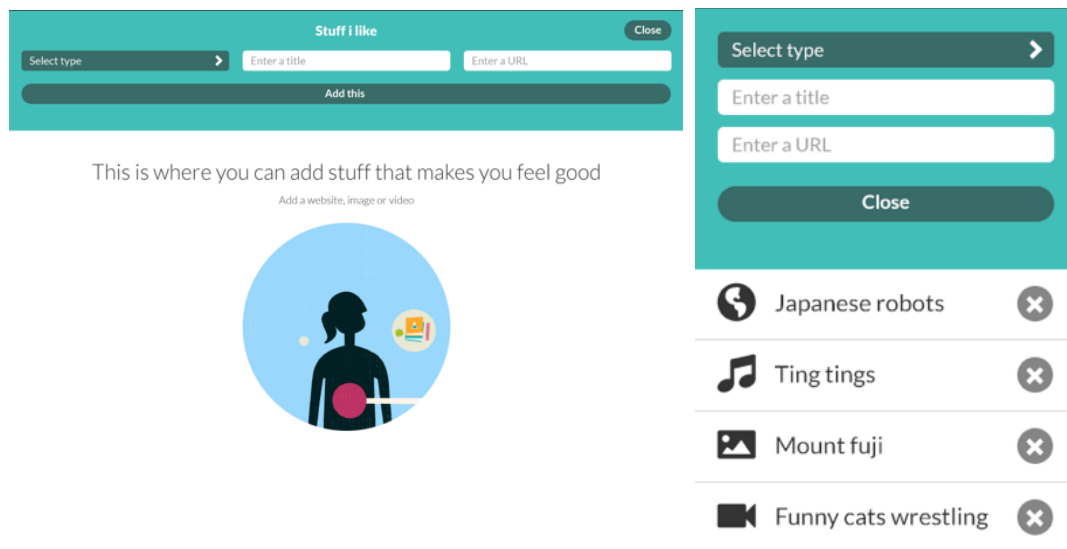


Fig 6.15: Designs for 'Stuff I Like' introductory screen on a desktop (left), and 'app' (mobile device, right)

Goal setting ('My goals'): Thirdly, a goal-setting section was developed, which allowed the user to plan activities over the following days and weeks. Tick and cross icons were used to indicate whether goals had been completed, and completed goals were saved and could be reintroduced in the 'to do' section.

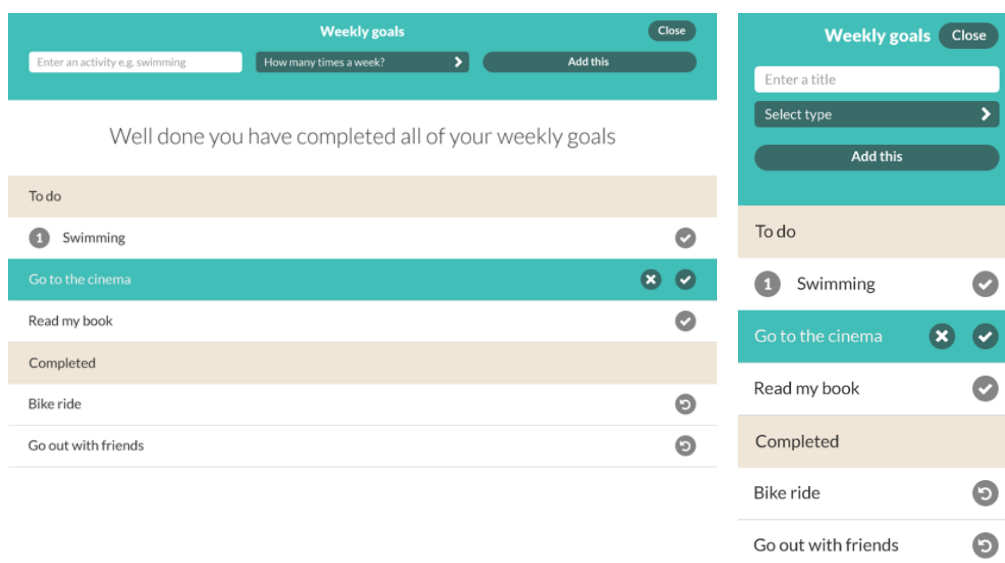


Fig 6.16: Designs for 'My goals' on a desktop (left), and 'app' (mobile device, right)

## 6.6 Design characteristics: graphics, colour, moving image

### 6.6.1 General stylistic approach

***Illustrations:*** A graphic illustrative approach was taken in response to the findings from the interviews and groups. Illustrations were clear and simple - clear lines, figures and icons, based on vectors (use of polygons to represent images in computer graphics). This helped to ensure the package would appeal to a diverse range of users, especially compared to the use of photographs.

***Colour:*** Whilst there was an appreciation of the colours traditionally associated with low mood and depression, such as blue and black, these were considered too dark, and participants in the interviews/groups stressed the need for a colourful approach to engage young people and help to lift their mood. Other considerations when choosing a colour palette included how the colours would be perceived in different formats online, for example when converted to monochrome and by those with visual impairments (Caldwell et al. 2008). The final designs for the package adopted a flat-colour, warm 'pastel' palette.

Colour was also used as a tool to aid navigation. Each of the six main sections were represented by a different colour. For example, blue represented the section 'What are mood and depression?' and the warm colours, yellow and orange, represented the 'help' section ('Self help' and 'Where to get help').



Fig 6.17: The colour-coded sections of the package



*Typography, text:* Several approaches to typography were considered to communicate the information clearly but also to engage and interest the user, and complement the graphic approach. There were also design considerations regarding the layout of text, and the balance with the imagery. Bullet points and briefer paragraphs were used where possible.

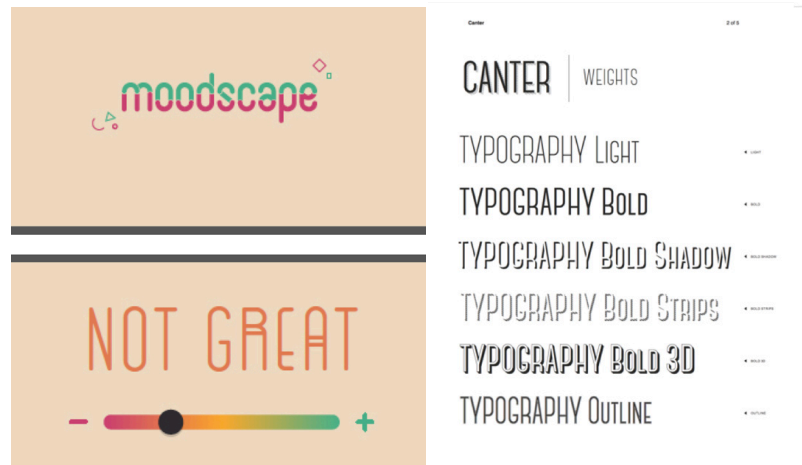


Fig 6.18: Examples of the typography considered, including the final choice (right)

## 6.6.2 Representations and metaphors

Findings from the qualitative work suggested there was a role for metaphors in the package. These could be incorporated in still and moving imagery and interactive components, to help engage the user and communicate ideas. Suggested metaphors to help understand low mood included 'being weighed down', 'a black dog' and the use of nature and weather. These were incorporated into subsections of the package for example in 'What are mood and depression?' and 'Self help' sections (Fig 6.19). The use of heads was viewed particularly favourably by participants, and were often featured in the designs for the package, including for the six main sections.

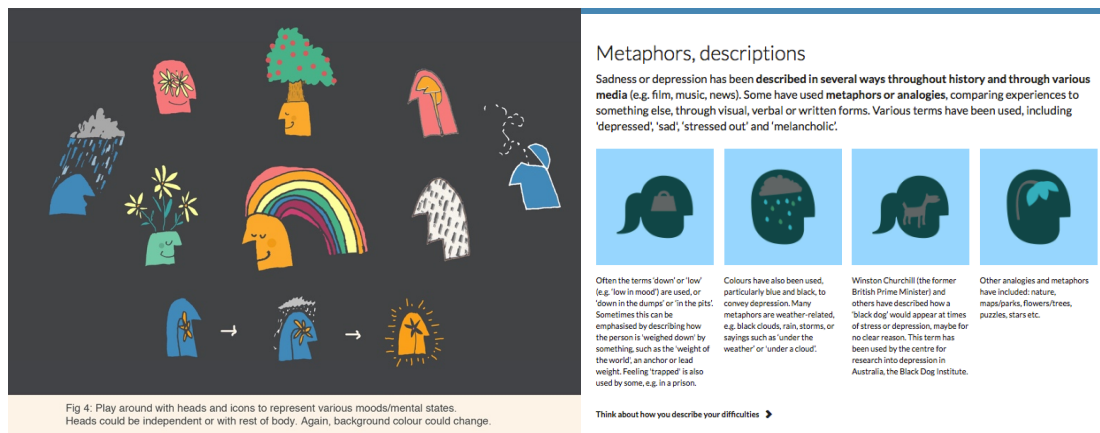
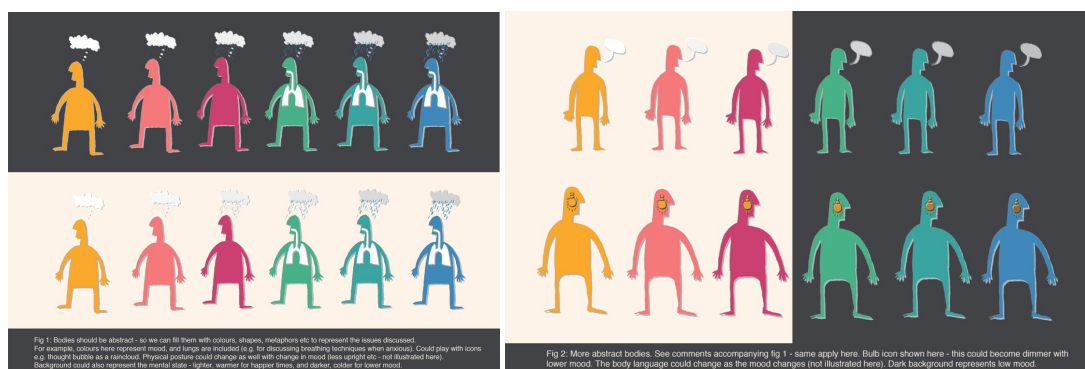


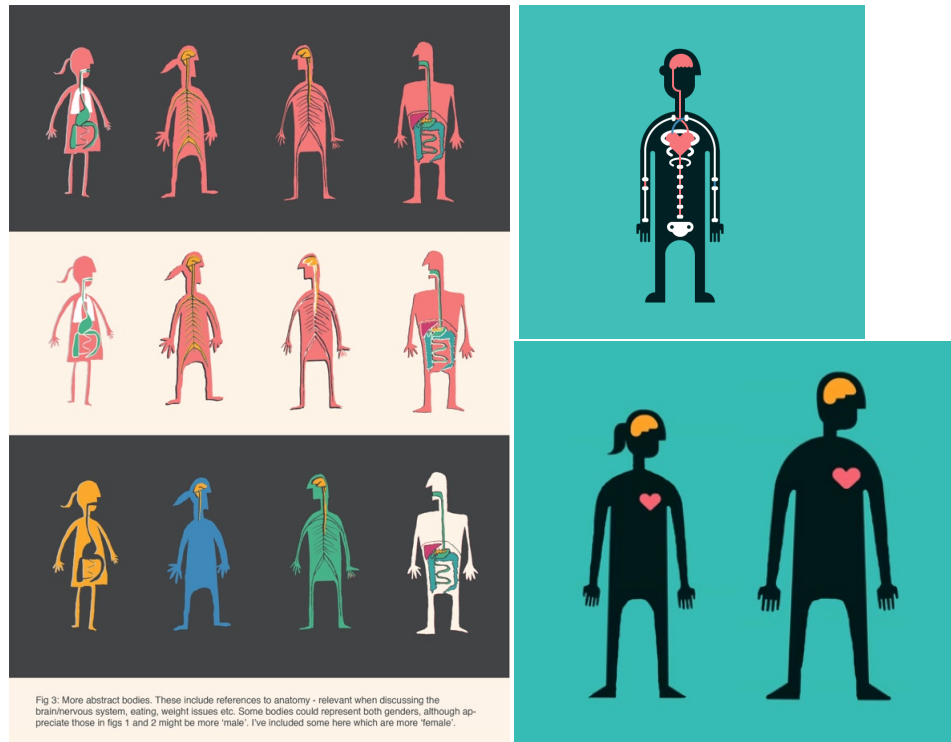
Fig 6.19: Initial ideas for metaphors (left) and metaphors subsection in the 'What are mood and depression?' section (right)

### 6.6.3 Character design

The characters used in the package were developed to be appropriate for a diverse range of users, for example, by avoiding elements which would make them age or culture specific. A silhouette approach was deemed appropriate for this. The simple figures also allowed for graphic representations of the interior as well as the exterior of the body, for example when describing symptoms of depression (Fig 6.20). They also needed to be clear when reducing the screen size, for example on smartphones.

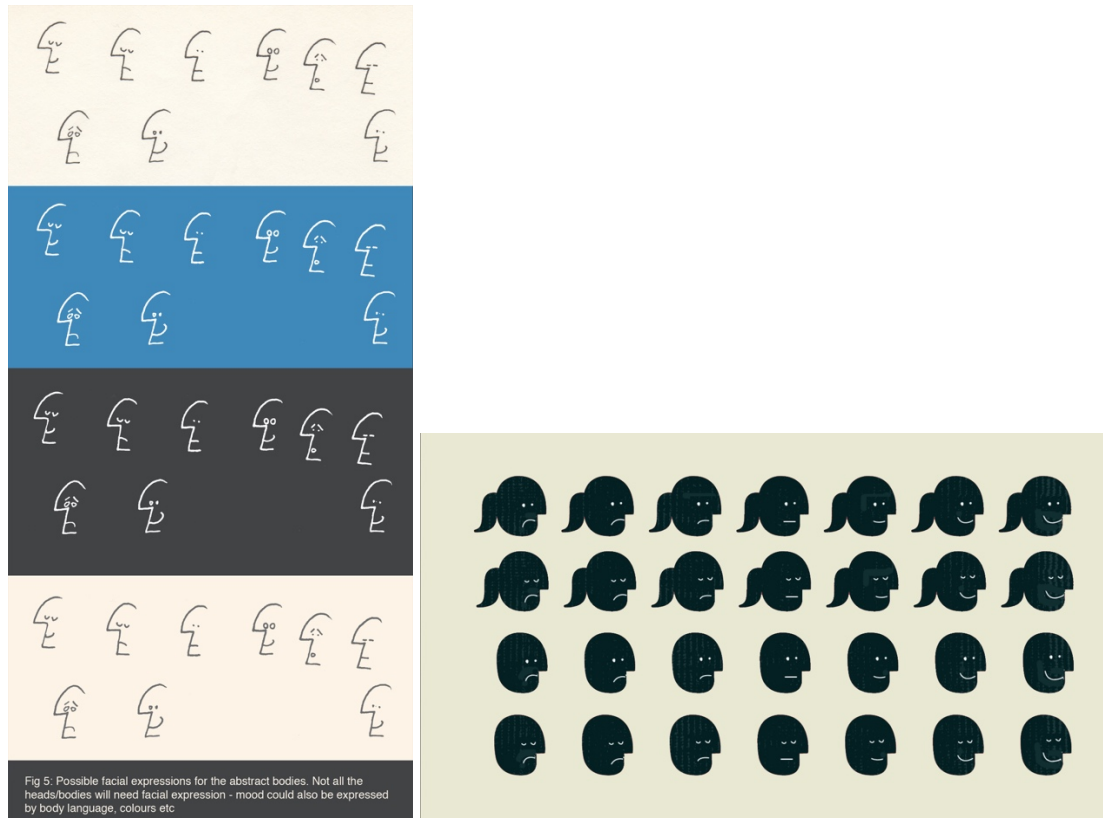


Figs 6.20a: Experimental character designs



Figs 6.20b: Experimental character designs including the final versions (bottom right)

A recurrent concern was whether the silhouetted figures might appear too dark (fig 6.20), and might induce low mood in some users. Alternative approaches were considered, such as changing the colours of the characters, for example according to their mood or context. For the final design, the dark silhouettes were softened into grey/green figures (see figures in section 6.6). Separate figures were created to represent a male and a female character. Facial expressions were not generally used (except for the mood monitor), and instead body language was relied on to convey certain behaviours and mental states.



Figs 6.21: Designs for facial expressions, particularly for the mood monitor

#### 6.6.4 Moving imagery – animations

In the interviews and focus groups, participants explained that it should be clear from the start what is covered by the package. Several animations were created, including one to introduce the package, and one for each of the six main sections to communicate the key messages. The purpose of the introductory animation was to engage the user from the start, and to communicate the aims of the package, how to use it, and how it could help the user. Written scripts, sketches and then storyboards (images to map the key frames) were developed for each animation. There was a great deal of collaboration between the student and the animator in developing the package animations.



## 6.7 Content

The final sections for the package were, in order, 'What are mood and depression?', 'Possible reasons', 'Self help', 'Where to get help', 'Other health issues' and 'Families, friends, professionals'. The number of subsections were limited to around six per section (not including the introduction and summary), so that it was not overwhelming for the user, and to limit the overall file size, which affected the loading speed.

The sections of the package are consistent with NICE guidelines (2005), which in general state that the information should cover '*the nature, course and treatment of depression*'. Similarly, in Rutter's Child and Adolescent Psychiatry (2015), Brent and Maalouf recommend providing the patient and family with all the requisite information about depression and its treatment, and then making treatment decisions collaboratively. They list the following key points with regard the content of psychoeducation in adolescent depression (fig 6.23).

**Figure 6.23:**

**Key points for parents & patients in psychoeducation for depression**  
(Rutter's Child & Adolescent Psychiatry, 2015)

1. Depression is an illness and not the fault of the patient or family.
2. How to recognize and monitor depressive symptoms, detect early relapse and recurrence.
3. Modal course, in order to have reasonable expectations for pace and extent of recovery.
4. Risks and benefits of different treatment options, in order to make an informed decision.
5. How to collaborate in development of a plan for relapse prevention, continuation, and maintenance treatment.

The content was guided by existing resources and guidelines (e.g. NICE guidelines), the literature review of existing programmes, the qualitative work, and discussions with the design and research team. There was a balance to be struck between communicating an adequate amount of information, and not overwhelming the user. The package did not give an exhaustive account of the presentation, risk factors/aetiology, prevention and management approaches in adolescent depression, but rather gave a comprehensive but manageable amount of information for the young person and family/carer. As suggested in the interviews and groups, there were personal stories throughout the package, related to the information in the sections. These were written from the perspective of a range of

young people of difference ages, genders and ethnicities, and from the perspective of parents and siblings in the section for families, friends and professionals.

### 6.7.1 Section 1: What are mood and depression?

Figure 6.24 shows the structure of this section of the package. Participants in the interviews and focus groups emphasised the need for the package to state the difference between depression and ‘normal’ changes in mood. This approach is consistent with many other sources of information for young people and families/carers on depression, which start by comparing it to the ‘normal’ emotional experience of sadness (e.g. understanding NICE guidance 2005; RCPsych; YoungMinds).

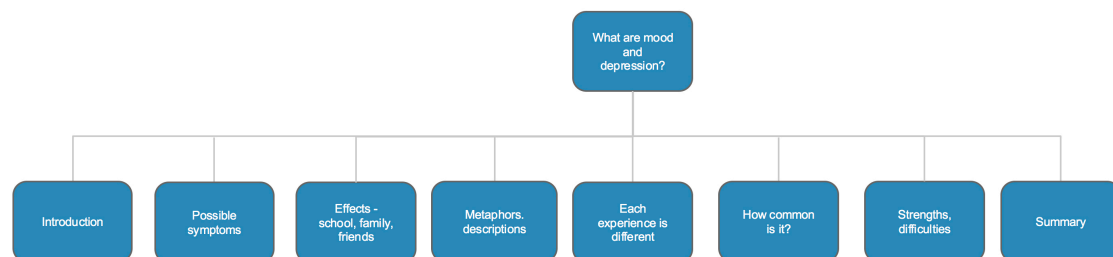


Fig 6.24: ‘Information architecture’ for the ‘What are mood and depression?’ section

Participants also advised adding information on the possible range of symptoms of depression, and not only the psychological aspects. Symptoms were presented in the package using a cognitive-behavioural approach – feelings, thoughts, behaviours, and physical sensations (Stallard 2002). A similar structured approach was taken with the ‘possible effects of depression’ subsection, by including effects on school, relationships/social life, identity, and physical health (fig 6.25).

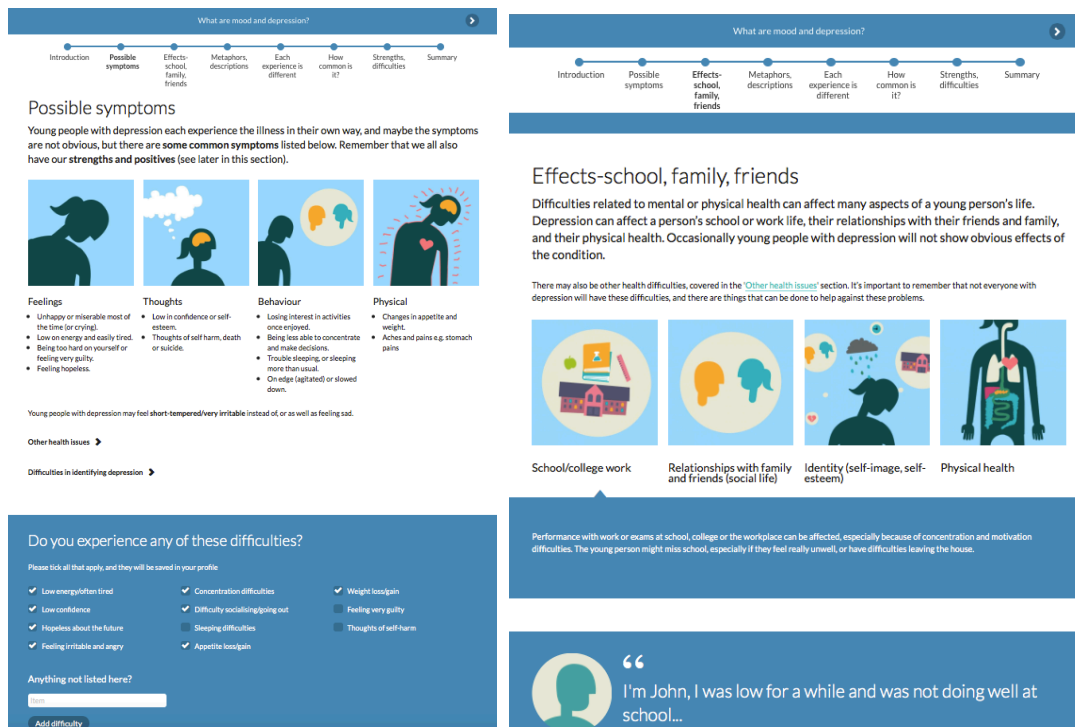


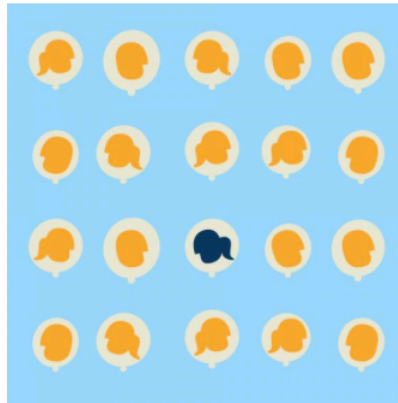
Fig 6.25: Subsections on the possible symptoms (left) and effects (right) of low mood and depression.

Other key messages emphasised in this section were: i) depression is a spectrum of severity rather than a category, ii) depression is a cluster of symptoms, and symptoms sub-threshold to a diagnosis can cause impairment (Pickles et al. 2001), and iii) each experience of depression is different. The qualitative findings also suggested that the package should include some statistics but that use of these should be limited. A subsection 'How common is it?' was developed which included statistics about depression and mental health. Wording was carefully chosen so that it was understandable by the young person and family/carer, rather than presenting a list of percentages and fractions.



## How common is it?

It is **common** for young people to feel low sometimes, or even to feel anxious, confused or angry. This is because there's a lot going on during teenage years and early adulthood, related to school, social and family life, as well as physical development. When these feelings are severe, don't go away and affect a person's life a lot, this might be a sign of depression.



Depression can affect people of any age, and is common in teenagers and young adults. Each year as many as **1 in 20** young people, or **5%**, have depression. It is more common as a young person gets closer to adulthood. The number of young people with some symptoms of depression, but not enough for a diagnosis, would be higher.

In fact, 1 in 10 children and young people (aged 5-16) have mental health difficulties, including depression – around 3 in every class at school. So if you have difficulties, you are not alone!

Both boys and girls can be affected, although **girls are twice as likely** to experience it as boys. Depression is common in **all countries**, and is predicted to be 2nd highest cause of disability in the world by 2020.

What does it mean for the future? ➔

Fig 6.26: Subsection on statistics on depression and mental health difficulties

As well as noting possible difficulties, the findings from the earlier stages of the research suggested that it was important to stress the positives, and the individual's strengths. A subsection 'strengths, difficulties' was developed to reflect this (figure 6.27). Resilience theory was a consideration here, and is discussed further in the section on 'Self help'.

## Strengths, difficulties

Although everyone will go through difficult times at some point, it's important to remember that everyone has **strengths and positives**.



For example, we all have aspects of our personality and things we are good at or we enjoy doing. These can include being considerate of others, being kind/helpful to others, being good at fixing/mending things or being creative. We might also have the support of people who care about us. These strengths can help us to enjoy our lives and to prevent and overcome difficulties.

When a young person experiences depression, it's helpful for them to focus on their strengths and positive aspects. This is one of the self help approaches described in the [Self help](#) section.

Listed below are some possible strengths and positives, although there are many more. If someone is feeling low in mood, it might be difficult to see these clearly. It might be better to discuss this with someone they trust as well.

What are your strengths and positives?

Please tick all that apply, and they will be saved in your profile. If you're feeling low, this might affect how you see these things.

<input checked="" type="checkbox"/> Generous	<input checked="" type="checkbox"/> Good at sport	<input checked="" type="checkbox"/> Good at art, making things, creative
<input type="checkbox"/> Outgoing, sociable	<input checked="" type="checkbox"/> Good with friends	<input checked="" type="checkbox"/> Polite
<input type="checkbox"/> Nice personality	<input checked="" type="checkbox"/> Helpful at home	<input type="checkbox"/> Good at school work
<input type="checkbox"/> Reliable and responsible	<input checked="" type="checkbox"/> Good at music	<input checked="" type="checkbox"/> Good at fixing/mending things
<input checked="" type="checkbox"/> Forgiving	<input type="checkbox"/> Well liked	<input checked="" type="checkbox"/> Trustworthy/friendly

Fig 6.27: Subsection on 'strengths, difficulties', with elements of resilience theory

## 6.7.2 Section 2: Possible reasons (Why do I feel this way?)

Figure 6.28 shows the structure of this section of the package. As noted by the participants (especially the professionals), the risk factors and possible causes of adolescent depression are diverse and comprise individual, family, social, biological and psychological factors. In line with most existing resources, the package adopted a bio-psycho-social approach when explaining the risk factors and possible causes of depression. The complexity was further emphasised with a subsection entitled 'It's complicated' (figure 6.29). It was also considered important to note that there may not be a clear reason for depressive episodes and to stress to the young person and family that it was not their fault (Brent & Maalouf 2015; NICE 2005).

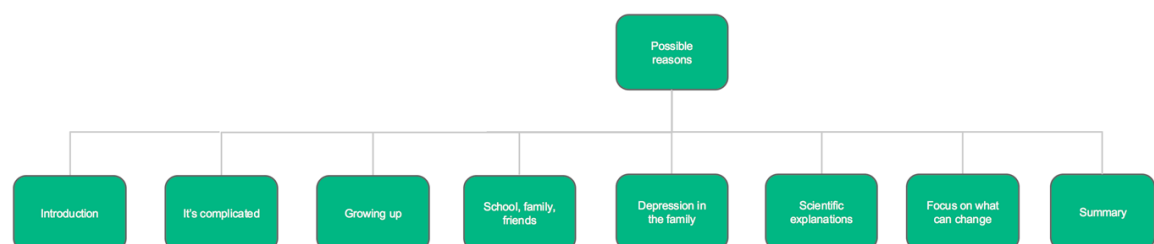
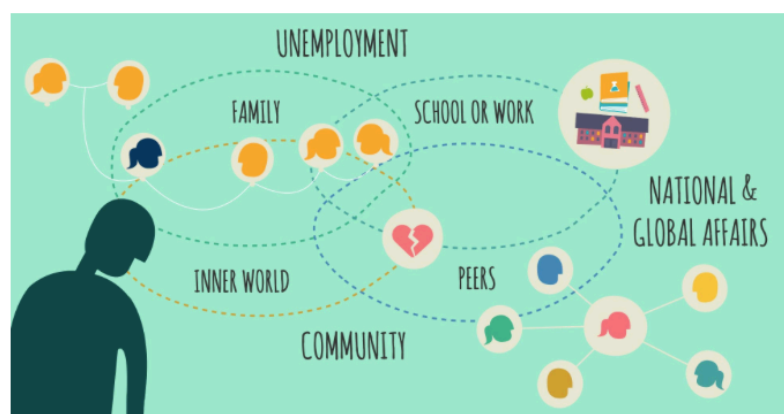


Fig 6.28: Information architecture for the 'possible reasons' section

### It's complicated

Each person's experience of low mood and depression is unique and personal, and the reasons behind it are usually complicated. Studies show that depression usually results from a complex mix of life experiences and genetic factors (it can be described as 'multifactorial').

The two main factors are 1) psychological or social stress (especially if it's been going on for a long time, e.g. bullying or family issues), and 2) a family history of depression. Here is one possible way to show how factors can overlap to increase the possibility of depression:



Possible factors related to depression ➤

Fig 6.29: Subsection and illustration on the complex relationship of risk factors

The section's structure followed other authors' approaches to psychoeducation. For example, Schotte et al. (2006) proposed a 'biopsychosocial diathesis-stress model of depression' as a guide for psychoeducation and treatment of depression. This model referred mainly to adult depression, and a more developmental approach was needed for adolescents, including a recognition of factors relevant to this age group, such as family, school/education and peer-relationships. This was acknowledged in the subsections 'Growing up' and 'School, family, friends' (see fig 6.30).

Exposure to psychosocial stress, including both acute stressful events and chronic adversity, is a strong risk factor for adolescent depression (Thapar et al. 2012). The stressors/life experiences included in this section were informed by the qualitative work, the literature and resources (e.g. NICE 2005). It was considered important to emphasise that some stress or low mood would be expected in reaction to these events, and this is not necessarily a sign of depression.

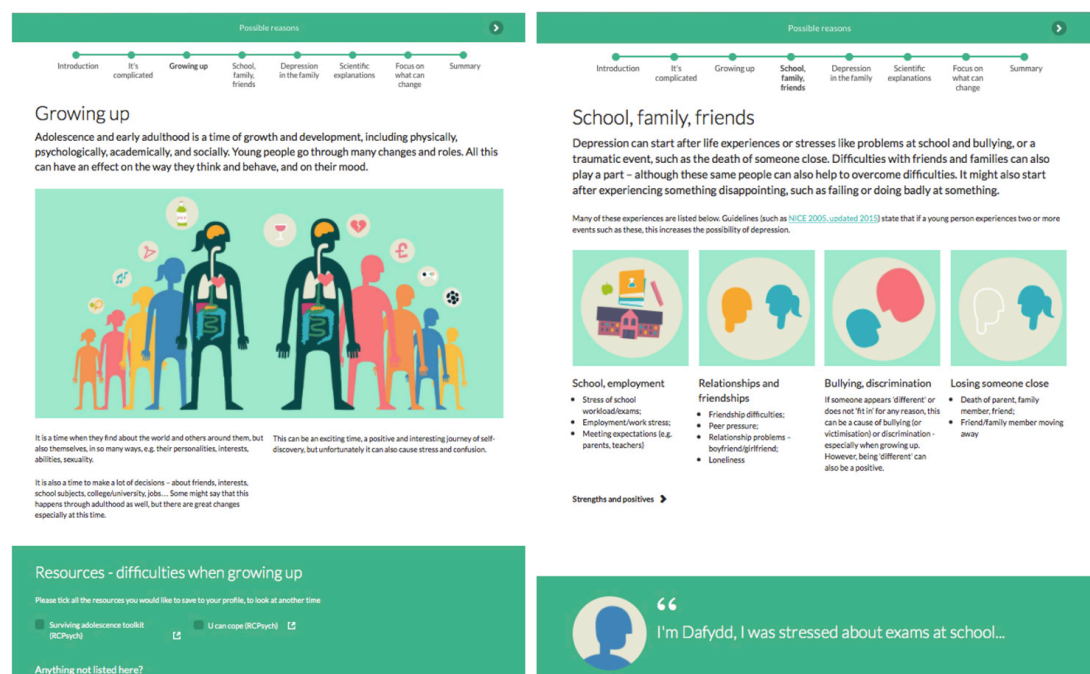


Fig 6.30: Subsections on developmental issues (left) and psychosocial risk factors (right)

In line with a bio-psycho-social approach, biological risk factors, such as having a family history of depression, were also included in the package. However, it was stressed that many children of depressed parents will not experience mental health difficulties. A subsection on 'scientific explanations', included information on changes in the levels of

chemicals (neurotransmitters) in the brain, and cognitive factors. Adolescents with poor coping mechanisms, a negative cognitive style and low self-esteem are thought to be more vulnerable to depression (Gladstone 2011).

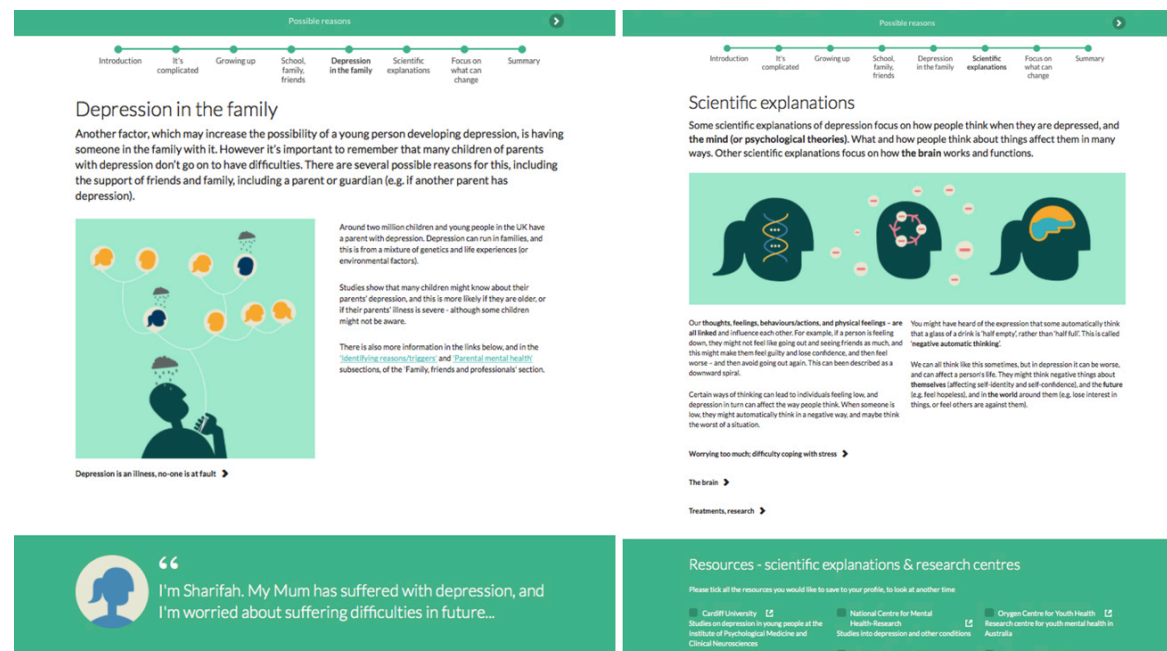


Fig 6.31: Subsections on depression in the family (left), and scientific explanations (right)

Overall, it was considered more helpful to attempt to deal with risk factors/reasons that are modifiable. This was discussed in one of the final subsections 'Focus on what can change'.

### 6.7.3 Section 3: Self help approaches (prevention, management, monitoring)

Figure 6.32 shows the structure of this section of the package. There was a lot of discussion by participants in the interviews and focus groups about self help strategies, and many of their suggestions are reflected in this section.

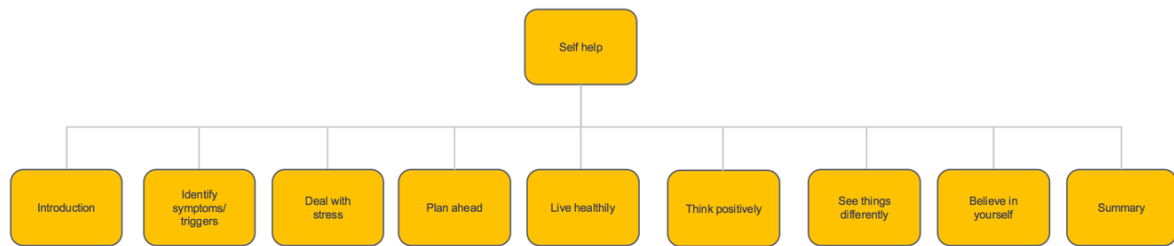


Fig 6.32: Information architecture – self help section

Similar to the section on ‘What are mood and depression?’ the self help section started with a subsection entitled ‘Identify symptoms/triggers’. The purpose of this section was to promote the user’s awareness of their symptoms and possible triggers, and help them to identify when to introduce self-management strategies or get further help. To help with this, there was a link provided in this subsection to the ‘Mood monitor’ component.

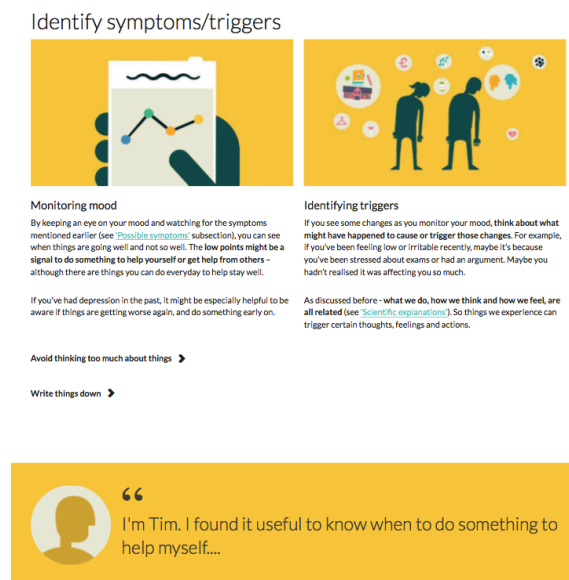


Fig 6.33: Identifying symptoms/triggers subsection

Participants in the interviews/groups recommended including advice on ‘quick and easy’ short-term approaches, such as dealing with stress. Two sub-sections were developed to help with this - ‘Deal with stress’ and ‘Plan ahead’. A link was provided in these subsections to the interactive components described earlier in this chapter (‘Stuff I like’ and ‘Plan ahead’), which could also be assessed via the ‘app’, for help strategies ‘on the go’.

NICE (2005) recommends a young person with depression should be offered advice on the benefits of regular exercise, sleep hygiene, anxiety management, and nutrition/diet. Findings from the qualitative work agree with this guidance, and participants suggested that lifestyle factors should be discussed in the package. When writing the content, attempts were made not to be too directive or give specific targets, as this might encourage feelings of failure if targets were not reached - especially with perfectionist 'black and white' thinking which can be seen with depression.



Fig 6.34: Subsection on living healthily

Whilst an awareness of risk and causal factors is important, the package also introduced the concept of protective factors and resilience. As noted in chapter 1, resilience is not merely the opposite of risk, but rather better than expected functioning across psychosocial outcomes over time, in the context of known risk factors (Rutter 2006). Guided by literature in this field (e.g. Collishaw et al. 2016), the package promoted supportive peer and parent relationships, a healthy lifestyle/exercise, self-efficacy (figure 6.35), and the expression of positive emotions by the parent about the child (family/professionals section), which can help to increase resilience. Elements of CBT were also incorporated into this section, including the use of 'reframing' and metaphors.

## Believe in yourself

Believe in yourself and in your ability to get over things. This might sound easier to say than to do, but there are studies to suggest that this can help with depression.



Think about all your strengths and positives in your life, not only the negatives and difficulties. Build on your strengths – and use them to help yourself, especially through difficult times. Talking to someone you trust about this could help – it might be difficult to think of positives when you're low.

It might be helpful to think about how you cope with day to day problems, and what's worked during difficult times in the past. Praise yourself for getting through that. Whilst others can help, you might know more about yourself and what works for you!

Also think about what you'd like to change right now (e.g. at school, home, or with friends), and what you could do about it.

What you would tell a friend in the same situation? ➤

### What are your strengths?

Please tick all that apply, and they will be saved in your profile. You may have answered this already.

- |  |   |  |
|--|---|--|
| <input checked="" type="checkbox"/> Generous | <input checked="" type="checkbox"/> Good at sport     | <input checked="" type="checkbox"/> Good at art, making things, creative |
| <input type="checkbox"/> Outgoing, sociable  | <input checked="" type="checkbox"/> Good with friends | <input checked="" type="checkbox"/> Polite                               |

Fig 6.35: Subsection on self-belief

### 6.7.4 Section 4: Where to get help

Figure 6.36 shows the structure of this section of the package. Whilst self help strategies are important, there are times when young people should seek further help from others. Informed by findings from the focus groups, the package distinguished between urgent and non-urgent sources of help.



Fig 6.36: Information architecture for the 'Where to get help' section

The content of this section was also informed by NICE guidance. If depressive symptoms are



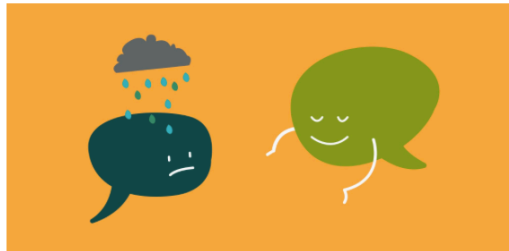
severe or persistent, NICE recommend talking to a parent or a friend in the first instance (if possible), or a teacher, family doctor, or another trusted adult. They recommend that if the feelings do not go away, adolescents should be offered further help and treatment, not only in health services, but also schools and other centres. The subsections in the package were designed to reflect the wide range of services and resources available, with reference to both formal and informal sources of help. Information was also provided on what to expect from services, as suggested in the focus groups.

Fig 6.37: Subsections on getting help from family and friends, and from services



### Talking/psychological therapy

The first treatments recommended to help against depression are usually education about mood and depression in young people (or 'psychoeducation'), self-help approaches (see [Self-help](#)), and psychological or 'talking' therapies.



Listed below are the main psychological therapies available. These range from one-to-one to group therapies, as well as therapies using various media, such as art and online technologies.

There is some evidence for their effectiveness in depression in young people, but more research is needed. More information on these can also be found in the resources below.

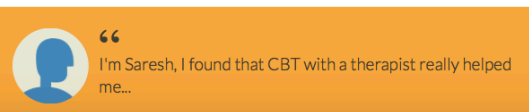
Cognitive Behavioural Therapy (CBT) ➤

Interpersonal Therapy (IPT) ➤

Family Therapy ➤

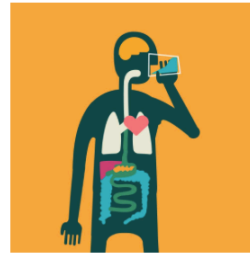
Counselling ➤

Creative therapies ➤



### Medication

For some young people, especially those dealing with more severe forms of depression, mental health workers and other professionals might discuss with them whether to prescribe medication, such as antidepressants. This could help to lift the mood.



Guidelines in the UK (such as NICE guidelines) say that medication should only be prescribed in the case of moderate or severe depression - and alongside talking therapy.

The professionals would discuss with the young person and family all the details, including how the medication works, how it is taken, and any possible side-effects. Not all medicines that work well for adults with depression are suitable for young people, but some have been shown to be effective.

Fluoxetine (Prozac) is the only licensed antidepressant medication for young people in the UK. Other medications e.g. Citalopram are sometimes prescribed. Medication usually helps with the brain chemicals which can be affected when someone is depressed (see [Scientific explanations](#)). It might take a couple of weeks for them to work.

Are there possible side-effects? ➤

Myth busting about antidepressant medication ➤

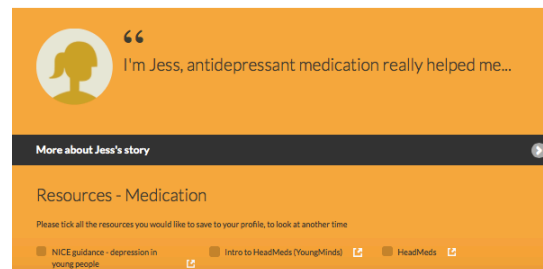


Fig 6.38: Subsections on psychological therapies and medication

## 6.7.5 Section 5: Other health issues (associated with depression)

Figure 6.39 shows the structure of this section of the package. As discussed in chapter 1, co-morbidities are common amongst adolescents with depression (Ford et al. 2003). It is important to be aware of possible co-morbidities, as if they go unrecognised or untreated, this may affect recovery following a depressive episode (Thapar et al. 2012). There was consensus from the qualitative work that the package should include information on other difficulties, however there were also concerns of overwhelming, or alarming the user. Therefore, these difficulties were not covered in great depth. For each difficulty/disorder considered in the package there was a subsection with information on its presentation and a personal story. Links to more specialist resources were provided to give further information and help.

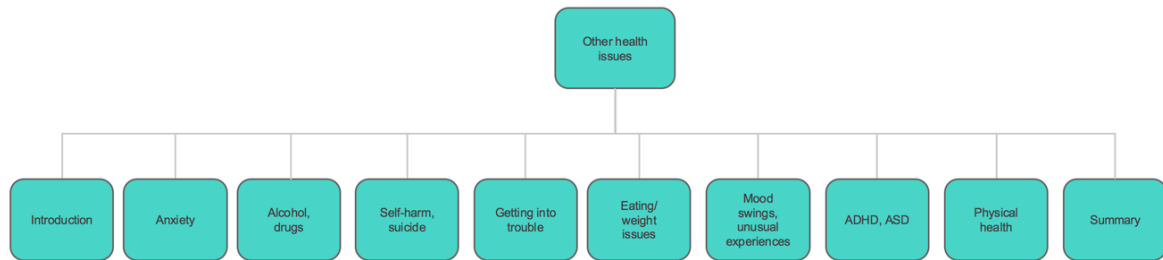


Fig 6.39: Information architecture – ‘Other health issues’

There were subsections on some of the most common co-morbidities of adolescent depression, including anxiety disorders, substance misuse, self-harm/suicide, disruptive behaviour disorder, eating disorders, bipolar disorder, psychotic experiences, and neurodevelopmental disorders (autistic spectrum disorders, ADHD). The section ended with a subsection on the physical co-morbidities with a focus on the relationship between mental and physical health (Thapar et al. 2012; WHO 1992).

### Anxiety

Depression and anxiety can often happen together. It is normal to feel worried at times. Sometimes this can be too much, and it can start to affect a person's life (e.g. schoolwork, friendships, avoiding situations). Anxiety can range from feeling slightly nervous to feeling panicked, and affects us all in different ways.

**Possible signs and symptoms**

**Thoughts and feelings:**

- Nervous, fearful or worried all the time
- Tired or unable to relax and switch off
- Irritable and impatient
- Finding it hard to concentrate or pay attention
- Low self-confidence or shyness
- Having trouble sleeping

**Physical:**

- Feeling the heartbeat is racing
- Breathing faster
- Feeling physically sick
- Shaking or trembling
- Feeling dizzy and faint or getting headaches
- Muscle pain

**Types of anxiety** ➤

**Help for anxiety** ➤

**Possible reasons**

Anxiety is common and can affect anyone. Sometimes there may not be any clear reason, and it is no-one's fault. However the things listed below can make it more likely:

- Under a lot of stress – especially when things are out of our control, such as starting a new school, moving home or being bullied.
- Some are more likely to worry about things, or find it hard to cope, especially if they are with other people who are anxious a lot.
- Genes – as with depression, feeling anxious can run in families.

### Alcohol, drugs

Young people sometimes drink alcohol, smoke or use drugs as a way of coping with stress or depression. There are lots of other reasons why young people might do this – including trying to fit in with peers, friends or family.

However, this can cause difficulties and make things even worse, especially if the person is already depressed. If someone is 'intoxicated' (or 'drunk' or 'high') from one of these substances, it can affect how clearly they think. It can also make them more likely to take risks and become more vulnerable.

If someone uses these substances regularly, and has difficulty in controlling how much they use, this is a sign they might have a dependence or an addiction.

Alcohol, smoking or drugs can have many effects on life, including on schoolwork or other work, and relationships with friends and family. Sometimes they can lead to other mental health difficulties, including depressive symptoms, and physical health problems, such as liver, kidney and heart problems.

**Where to get help** ➤

**More about Mary's story**

**Resources - alcohol, drugs**

Please tick all the resources you would like to save to your profile, to look at another time

☐ Talk to Frank ☐ Drugs & alcohol (RCPsych)

Anything not listed here?

Fig 6.40: Subsections in ‘Other health issues’

### 6.7.6: Section 6: Information for family/carers/guardians, friends, professionals

Figure 6.41 shows the structure of this section of the package. As recommended in guidelines (e.g. NICE, ACAAP), and from discussion in the interviews/groups, it was important for the package to encourage the involvement of the family and others concerned about the young person, from an early stage - but that parents/carers should not be made unduly anxious or guilty about their children's difficulties. A section was therefore developed specifically for use by families/carers, friends and professionals.

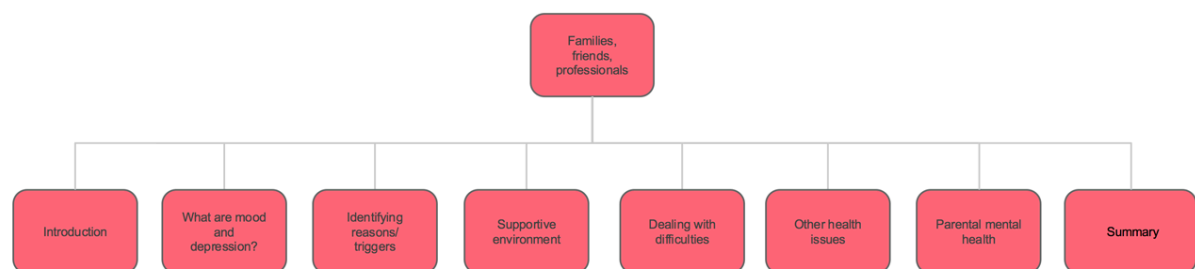


Fig 6.41: Information architecture – 'Family, friends, professionals'

The subsections covered the same broad topics as the youth version of the package, however they were written from the perspective of a concerned parent/friend/professional. As with the child sections, case studies were used to provide context and help to engage the user. Due to the large overlap in content, links were provided in each section to the equivalent section in the youth version. This ensured that the package dealt with issues from the perspective of someone concerned about a young person, but unnecessary repetition was avoided. For example, the supportive environment section in the parent/friend/professional version linked to the main 'Self help' section. Similarly, the 'Dealing with difficulties' section linked to the 'Where to get help' section.

## Supportive environment

If you're worried that your child may be depressed, let them know that it's ok to talk to you about it. In fact, you can use this package with the young person, if they are happy with that, or you can explore it on your own. One of the aims of the package is to help promote and mobilise social support in this way.



Avoid trivialising problems. Avoid relating everything to depression ➔

Let them know of other sources of help ➔

It's important to support the young person, not to blame anyone, and to encourage them to find ways to help themselves - see the [Self help](#) section for suggestions.

Spend time with your child doing things you both enjoy. Try to support them in having a healthy lifestyle and feeling good about themselves. Encourage them to exercise and help them to eat healthily and get enough sleep. This can help to lift their mood.

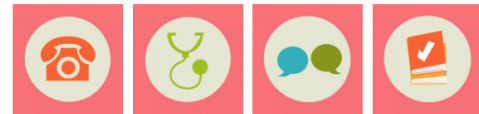
Encourage them to talk to people they trust - for example family members, close friends or even teachers - and to be social (don't isolate them).

Be patient, don't push it too far or too quickly.

## Dealing with difficulties

There are lots of things that the young person and family can try to do to help themselves. However, there are times when it's better to get help from professionals who work with young people. This could be from someone at school, or the family doctor/GP. Other services can help, such as youth or social services, or charities such as Mind. See the [Where to get help](#) section for more details.

All parents, carers and families encounter times of difficulty or stress. As noted in the previous section, if the circumstances are particularly difficult, it is helpful to try and remain as calm as possible. Make sure the young person knows you are there to listen if needed, in a non-judgmental manner. Perhaps you could discuss with the young person whether it is better to get further help.



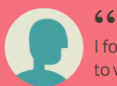
Urgent help

School, GP

Mental health & other services

Online/printed resources

- The first step is for the young person to talk to someone they trust e.g. family member or friend. They can approach someone at school e.g. a teacher, nurse or counsellor. They can also make an appointment to see their GP or practice nurse at the local surgery. The school team or GP might talk to them about whether to refer them to child and adolescent mental health or other services.
- Outside school or working hours, in case of emergency, a family doctor/GP is usually available, as are helplines and emergency services. If they are already seeing a professional, such as a mental health nurse or counsellor, and things are getting particularly bad, it is usually best to contact them - during daytime hours if possible - as they will know the young person best and will be well placed to know what might help.
- See the 'Urgent help' subsection in 'Where to get help' for more details and resources.
- Remember, it's important to get help sooner rather than later, especially if the difficulties are severe and affecting the young person's life. With the right help, they can get through these times.



“

I found it best to give my son space, but to be there to talk to when needed...



“

My son went to see the family doctor...

Fig 6.42: Subsections in the 'Family, friends, professionals' section

The results of the initial review and qualitative work suggested that a subsection on 'parental mental health' should also be included. As noted previously, there is an increased risk to the child if there is a family history of depression or other mental health difficulties. It was stressed in the package that parental mental health problems (particularly depression) should be treated in parallel with youth mental health problems, possibly including liaison with primary care, adult mental health services and other services (NICE 2005; AACAP 2007). However, there was an attempt to communicate this in a sensitive and helpful manner. Links to resources for parents/others concerned about a young person were also provided.

## 6.8 Summary and discussion

### 6.8.1 Initial prototype

The initial prototype of the online psychoeducation package was created following a prolonged development phase (lasting over two years) which included a review of the literature (stage 1), an analysis of findings from the interviews and all focus groups (stage 2), and consultations with the multimedia company and research team (stage 3). The package was developed from initial sketches, through to wireframes and into the initial prototype. A model of the intervention was developed, with several underlying design, educational, psychological and behaviour change theories/approaches. The package was designed so that it could be used across platforms, using a range of multimedia.

The user of the package could personalise the content by choosing the relevant user pathway. Answering the initial questions after the welcome screen helped to determine which subsections were highlighted on the dashboard, and enabled the user to monitor their mood and other issues – the data was stored in their profile section. They could update their responses ('Mood monitor') at any stage, as well as save links to helpful resources ('Stuff I like') and set goals ('My goals'), through accessing the package or using the accompanying 'app'.

Intensive work was also completed on the overall design, and a graphic illustrative and colourful approach was taken. The typography chosen was clear but also had a distinctive character. Other concepts were incorporated to make the package more engaging, including the use of metaphors, characters and animations.

Each section of the package was structured in a similar manner, so that the user could 'scroll' through the subsections, and menus and bars to navigate the sections. There were levels of information to help communicate to a diverse audience, with animations (and introductory and summary subsections) to deliver the key messages, text and illustrations in each subsection, and collapsible blocks of text and links to further resources for further detail. Feature blocks helped to illustrate the key information and engage the user further; these included quizzes, case studies, questions to relate the content to the user, and links to other sites and resources. The sections or content blocks were built so that the information

could be easily updated and changed, and so that the structure itself could be reformatted as required.

Participants in the interviews and focus groups stressed that security and confidentiality should be a key consideration when designing the package. This was reflected in the password-protected log-in, encryption of the data, and other functions in the wireframes/designs below.

### **6.8.2 Conclusions and next phase**

The initial prototype of the online package for adolescent depression was completed following consultations with young people, parents, professionals, designers and researchers, and with careful analysis of each component at each stage. The package was also informed by literature and guidelines in this field, as well as psychological, educational and design theories and approaches. The work done could also help inform the development of other youth mental health interventions in future, particularly given the lack of literature in the field. The following chapter (chapter 7) describes the findings from the evaluation phase, which was an important part of the overall development of the package.

## Chapter 7:

### Results of early evaluation and consultation phase

#### 7.1 Introduction

This chapter describes the results of the evaluation phase of the 'MoodHwb' prototype. This is the fourth stage of the overall research plan to develop an online psychoeducation package for adolescent depression (figure 7.1). The purpose of the evaluation phase is to assess whether the package and user assessments are acceptable, feasible, clear and easy to use. Findings from this phase will also be used to further develop of the package (stage 5) and inform a future feasibility trial.

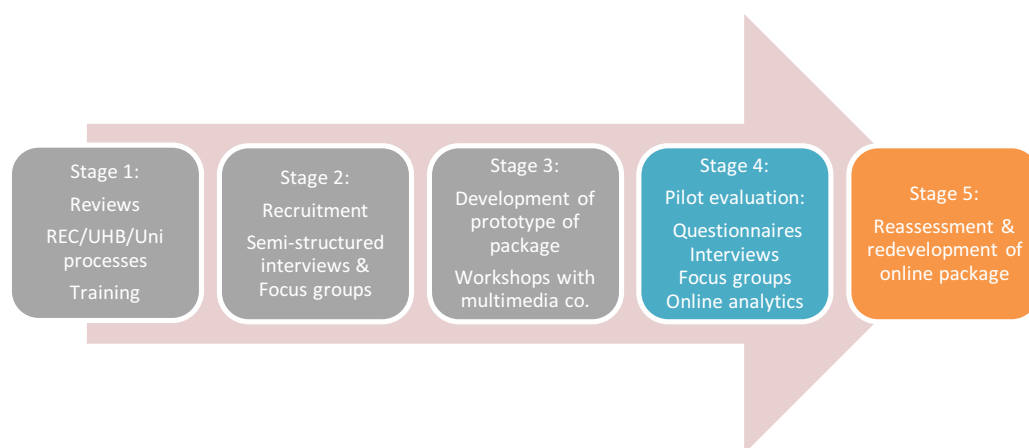


Fig 7.1: Broad stages of the research plan, with stages 4 & 5 highlighted

A mixed-method approach was taken to evaluate the package, involving questionnaires and further qualitative work. The evaluation period lasted approximately seven months. This chapter describes the main findings, beginning with the quantitative analysis.

## 7.2 Questionnaires & online usage (quantitative results)

Questionnaires were administered at baseline and post intervention to assess levels of depression and anxiety symptoms, depression literacy and stigma, help-seeking behaviour, behavioural activation and self-efficacy. Participants were also asked to complete a feedback questionnaire to provide their views on the package and the questionnaire assessments. Further information on the questionnaires, recruitment, and methods of assessment can be found in the methods chapter (Chapter 3).

### 7.2.1 Participants

In total 59 families expressed an interest in participating in the evaluation phase. Forty-four out of the 59 adolescents consented to participate (75%). Post-intervention questionnaires were completed a minimum of two months after the baseline assessments (mean 4.5 months) to allow the user sufficient time to work through the package. Response rate was good (82%), with 36 of the 44 young people completing either the post-intervention or package feedback questionnaire. One participant did not complete the feedback questionnaire, and one participant completed the feedback questionnaire, but not the pre or post-intervention questionnaires. Of the 32 young people who participated in the development phase (stage 2), 17 (53%) also consented to participate in the evaluation phase, although four of these did not complete post-intervention questionnaires.

In addition to the young people, 31 parents/carers provided consent to participate in the evaluation phase. Each participant was a parent of a child who was also participating. The response rate was lower than for young people with 21 of the 31 parent participants (68%) completing either the post-intervention or feedback questionnaire. Of the 11 parents/carers who participated in the development phase, six participated in the evaluation phase. In total, both pre and post-questionnaire data were available for 35 adolescent and 20 parent participants. Package feedback data was available for 35 adolescent and 21 parent participants (fig 7.2).

Table 7.1 provides information about the young people who participated in the evaluation phase. Young people were recruited from a range of sources and varied in terms of age,



gender, and treatment history. The ratio of females to males was around 4:1. Twenty-nine of the 31 parents who participated were mothers (93.5%); the remaining two participants were fathers (6.5%). Fourteen of the parents (45%) were currently being treated for depression themselves and nearly three quarters (72%) had been treated for depression during their lifetime.

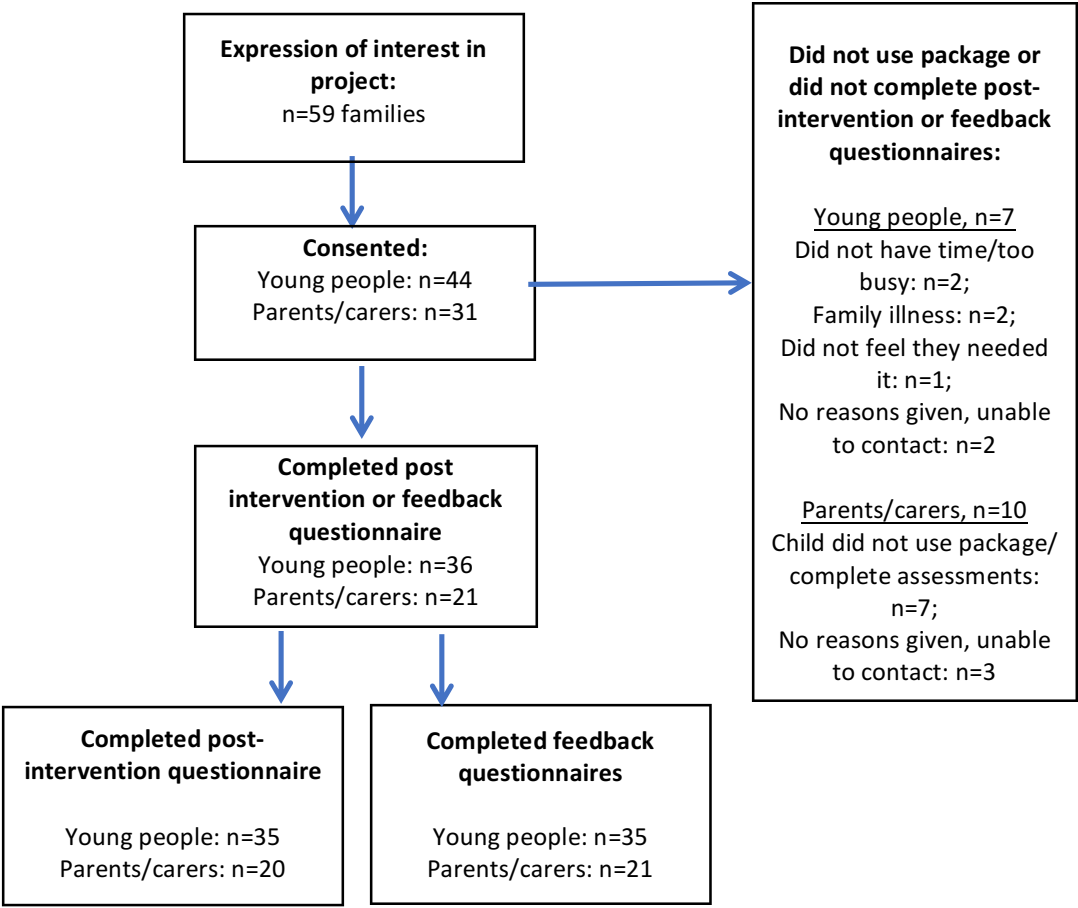


Fig 7.2: Flow chart of participants in the quantitative evaluation phase

**Table 7.1: Characteristics of young people participating in study at baseline (N= 43) <sup>a</sup>**

<b>Characteristic</b>	
Recruitment source, N (%)	
<i>School counsellor/nurse</i>	8 (18.6%)
<i>Primary mental health</i>	6 (14.0%)
<i>Secondary CAMHS</i>	10 (23.3%)
<i>EPAD study</i>	13 (30.2%)
<i>Volunteer</i>	6 (14.0%)
Age	
<i>Mean (SD)</i>	16.3 (2.4)
<i>Median</i>	16
<i>Range</i>	13-23
Gender, N (%)	
<i>Female</i>	34 (79.1%)
<i>Male</i>	9 (20.9%)
Currently getting help, N (%)	
<i>School counsellor/nurse</i>	14 (32.6%)
<i>GP</i>	9 (20.9%)
<i>Youth worker</i>	3 (7.0%)
<i>Social worker</i>	1 (2.3%)
<i>Mental health worker</i>	14 (32.6%)
<i>Other</i>	3 (7.0%)
Baseline depressive symptoms (MFQ), mean (SD)	34.4 (1.5)
Currently attending sessions for psychological therapy for low mood/depression, N (%)	21 (61.7%)
Currently prescribed medication for depression, N (%)	13 (38.2%)
Past treatment for depression, N (%)	9 (22.0%)

<sup>a</sup> one participant did not complete the pre-package questionnaire

MFQ: Mood and Feelings Questionnaire

Number with missing data was 9 for psychological therapy; 9 for medication and 2 for past treatment

## 7.3 Use of the package

### 7.3.1 Online usage data

The overall online usage data of the package (provided by the multimedia company) was analysed, for the period of the evaluation phase. This was based on its use by all those with access to it over that time, and data on individual or groups of users was not available (see chapter 3). Figure 7.3 shows use of the package. The most common section accessed was the 'What are mood and depression?' section (27%). The other sections were accessed approximately half as often (range 12%-17%). 15.6% of use was in Welsh and 84.4% was in English. Most people used the package for themselves (77.9% of use) and 22.1% for another person.

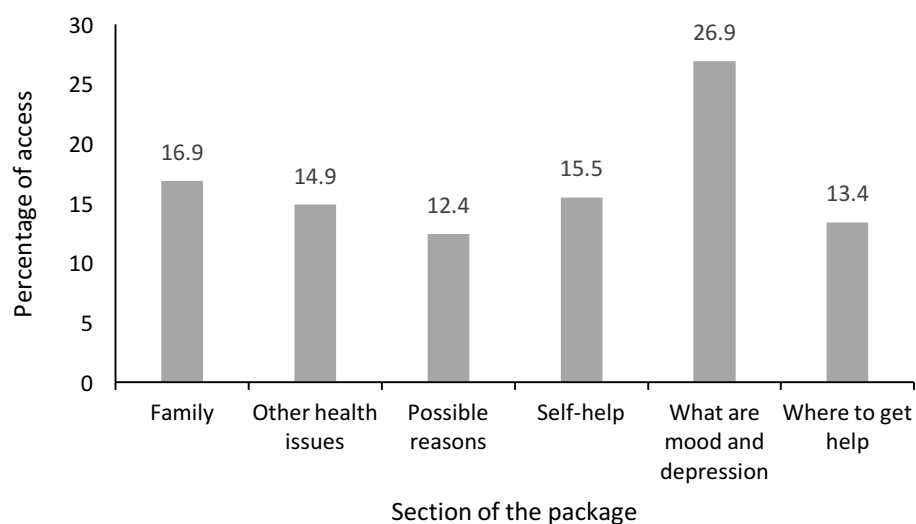


Fig 7.3: Use of the package

### 7.3.2 Questionnaire data

Young people and parents were asked about their use of the package as part of the post-intervention assessments (table 7.2). Data was available from 35 young people and 21 parents. In terms of frequency of use, approximately a quarter of the young people in the sample used the package at least once a week (26%). Most young people (44%) used it once

or twice a month (figure 7.4). Parents used the package less frequently with most (55%) using it only once or twice. Only 10% of parents (n=2) used the package regularly. Table 7.2 provides information about patterns of use. Most people used the package for half hour at a time and most young people used it alone (88%). Parents were more likely to use the package with others (37%).

The sections looked at the most were similar for young people and parents. These included ‘Self help’, ‘What are mood and depression?’ and ‘Possible reasons’. Young people also said they looked at the ‘Mood monitor’, and parents the ‘Families friends and professionals’ sections. Two young people and 1 parent used the package only in Welsh, however most participants were not Welsh speakers.

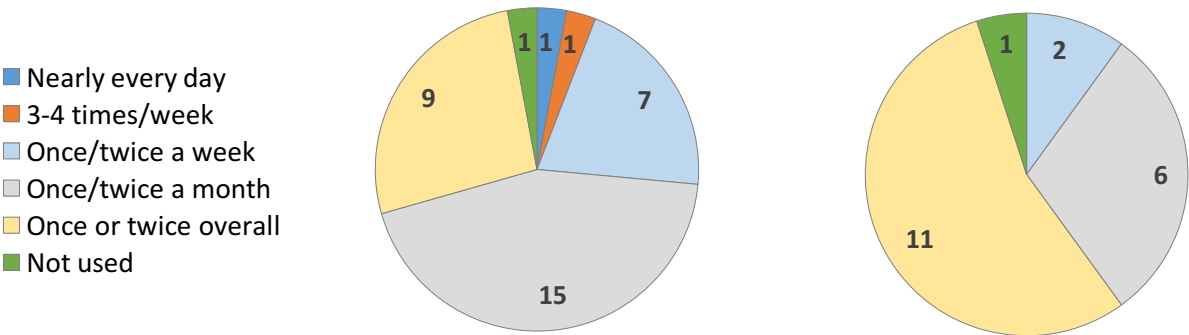


Figure 7.4: Frequency of use by young person (left) and parent (right)

**Table 7.2: Use of package – by young people (n=35) & parents/carers (N=20) <sup>a</sup>**

<b>For how long package used each time? <sup>b</sup></b>	<b>N (%)</b>	<b>N (%)</b>
Several hours	1/35 (2.9)	0/20
About an hour	10/35 (28.6)	4/20 (20)
About half an hour	19/35 (54.3)	12/20 (60)
Few minutes	7/35 (20.0)	4/20 (20)
Not used	2/35 (5.7)	2/20 (10)
<b>Sections looked at the most <sup>b</sup></b>		
My profile	16/34 (47.1)	3/19 (15.8)
What are mood and depression?	17/34 (50.0)	13/19 (68.4)
Possible reasons	15/34 (44.1)	10/19 (52.6)
Self help	23/34 (67.7)	10/19 (52.6)
Where to get help	8/34 (23.5)	6/19 (31.6)
Other health issues	9/34 (26.5)	3/19 (15.8)
Families, friends, professionals	7/34 (20.6)	8/19 (42.1)
Mood monitor	22/34 (64.7)	4/19 (21.1)
Stuff I like	9/34 (26.5)	1/19 (5.3)
My goals	7/34 (20.6)	1/19 (5.3)
The 'app'	10/34 (29.4)	3/19 (15.8)
<b>Language</b>		
English	27/34 (79.4)	18/19 (94.7)
Welsh	2/34 (5.9)	1/19 (5.3)
Both	5/34 (14.7)	0/19
<b>Use with others <sup>b</sup></b>		
Used with others	4/33 (12.1)	7/19 (36.8)
Parent/guardian/carers	3/33 (9.1)	-
Friend	1/33 (3.0)	0/19
Professional	0/33	0/19
Young person	-	7/19 (36.8)
Partner	-	0/19
Other	0/33	0/19

<sup>a</sup> one parent participant did not complete this part of the feedback questionnaire

<sup>b</sup> participants could select more than one response option

For young people, the number with missing data was 1 for frequency and 1 for use with others. One young person and one parent participant were missing information as they did not use the package

## 7.4 Acceptability of questionnaires

Data on acceptability of the questionnaires was available for 43 young people and 30 parents at baseline, and 34 young people and 19 parents at follow-up. Most participants felt the number of questions was ‘about right’ (figure 7.5 and 7.6). Young people at follow-up were somewhat more likely to rate the questionnaires as having a ‘few too many questions’. This is likely due to the additional burden of the package feedback questions.

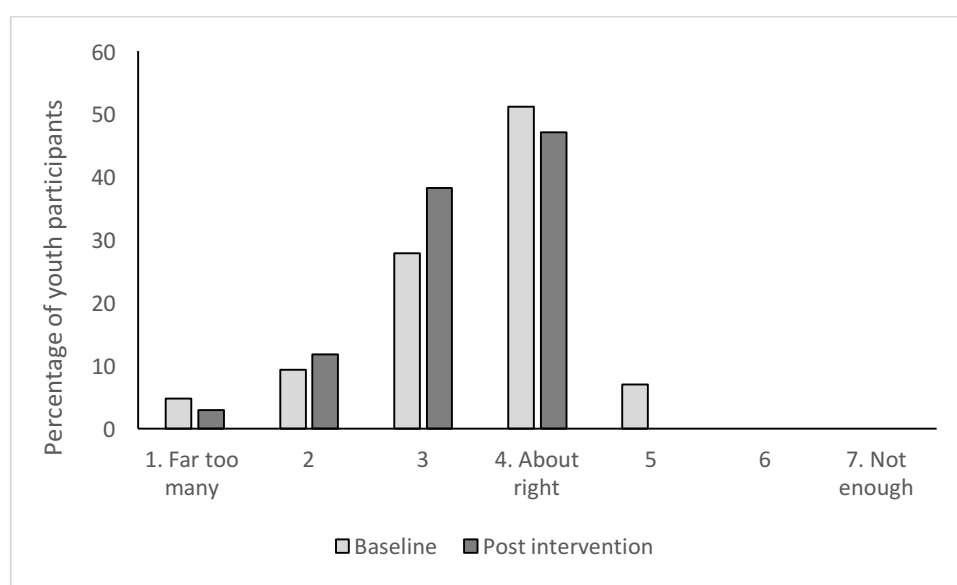


Fig 7.5 Acceptability of questionnaires (young people)

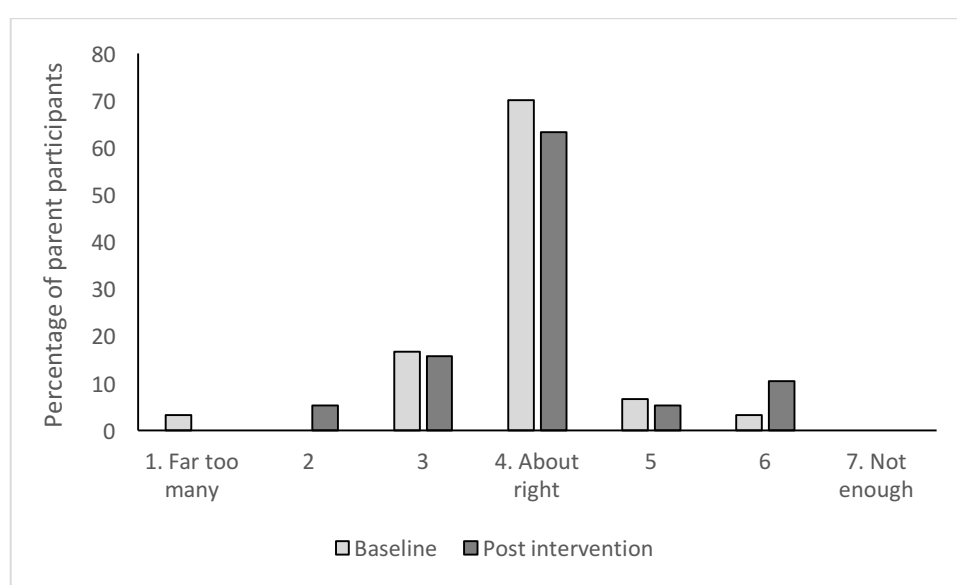


Fig 7.6 Acceptability of questionnaires (parents)

Participants were asked whether they had any additional comments they would like to make about the questionnaire. Twenty-five children provided a response to this question at baseline and ten at follow-up. The number of parents who provided a response was 15 at baseline and ten at follow-up.

*1) Young people:* Ten young people at baseline and five at follow-up commented that they found the questionnaires 'interesting', 'helpful', or 'therapeutic'. Many said that completing them had encouraged them to think more about what they were feeling. Two participants (1 at baseline and 1 at follow-up) found them 'comforting' and said they made them feel like they were not alone. Four participants at baseline and one at follow-up commented that there was a good range of questions, however two young people felt that they were too focused on depression. Three people at baseline said they would have liked the questions to be more in depth. Five young people (four at baseline and 1 at follow-up) were less positive, and found the questions to be a little repetitive, confusing or hard to answer.

*2) Parents:* Seven parents at baseline and three at follow-up commented that they found the questionnaires straightforward and interesting. Many commented that they had been thought provoking, and had encouraged them to think more deeply about their child's and their own mental health. Four parents at baseline and two at follow-up noted that they found it difficult to answer some questions, as they did not always know how their child was feeling. Three parents (2 at baseline and 1 at follow-up) thought that some of the questions/language would be more suitable for younger children.

## **7.5 Comparison of pre- and post-intervention questionnaires**

Questionnaires were administered before and after using the package to assess changes in depression literacy and stigma, self-efficacy, help-seeking behaviour, depression symptoms, behavioural activation, anxiety symptoms and behaviour.

*Young people:* Thirty-five adolescents completed both the baseline and post-intervention questionnaires. Levels of depression literacy were significantly higher after using the package (table 7.3). Although the differences were small, there was a trend for several of

the other scores to improve after using the package, particularly with regards to self-efficacy and depressive symptoms. The sample size for these analyses was small, and confidence intervals were wide with most including the null value. Due to the small sample, it was not possible to conduct further analysis, and explore whether results were moderated by factors such as initial depression score, or frequency of use.

**Table 7.3: Comparison of pre-and post-intervention questionnaires (young person)**

	<b>Pre- intervention Mean (SD)</b>	<b>Post- intervention Mean (SD)</b>	<b>Difference in means (95% CI)</b>	<b>t</b>	<b>p value</b>
Depression Literacy (ADKQ)	9.1 (1.95)	10.8 (2.24)	1.7 (0.8, 2.6)	3.82	<0.001
Depression Stigma (DSS)	30.3 (6.39)	29.4 (5.89)	-0.7 (-3.2, 1.7)	-0.62	0.540
Self-efficacy (SEQ)	30.3 (6.67)	32.0 (8.85)	1.7 (-1.0, 4.5)	1.28	0.211
Help seeking (GHSQ)	69.2 (15.2)	71.8 (14.04)	2.6 (-3.1, 8.4)	0.95	0.352
Depression (MFQ)	36.5 (15.13)	33.9 (16.48)	-2.6 (-7.2, 2.0)	-1.15	0.256
Behavioural activation (BADs)	71.9 (24.07)	72.7 (29.1)	0.8 (-8.5, 10.2)	0.18	0.860
Anxiety (SCARED)	42.2 (18.04)	40.6 (18.46)	-1.6 (-5.4, 2.2)	-0.87	0.392
Behaviour (SDQ)	17.4 (6.33)	17.4 (6.63)	0.06 (-1.5, 1.7)	0.08	0.939

ADKQ = Adolescent Depression Knowledge Questionnaire; DSS = Depression Stigma Scale; SEQ = Self-Efficacy Questionnaire; GHSQ = General Help-Seeking Questionnaire; MFQ = Mood and Feelings Questionnaire; BADs = Behavioural Activation for Depression Scale; SCARED = Screen for Child Anxiety Related Disorders; SDQ = Strengths and Difficulties Questionnaire.

*The number with missing data was 5 for the ADKQ, 2 for the DSS, 1 for the SEQ, 6 for the GHSQ, 1 for the MFQ, 0 for the BADs, 0 for the SCARED, 1 for the SDQ.*

**Parents:** Twenty parents completed both the baseline and post-intervention questionnaires. As found for young people, parents' own depression literacy improved significantly after using the package (table 7.4). Overall parent-rated scores of their child's depression, anxiety



and behaviour were considerably lower than children's self-rated scores. In contrast to the young people, parent-rated scores of their children's mood and behaviour were similar or slightly worse after using the package. However, findings are difficult to interpret give the small sample.

**Table 7.4: Comparison of pre-and post-intervention questionnaires (parent)**

	<b>Pre- intervention Mean (SD)</b>	<b>Post- intervention Mean (SD)</b>	<b>Difference in means (95% CI)</b>	<b>t</b>	<b>P value</b>
<b>Parent rated about their child</b>					
Depression (MFQ)	21.8 (15.47)	24.2 (14.3)	2.4 (-2.1, 7.0)	1.13	0.273
Anxiety (SCARED)	22.3 (15.41)	23.5 (12.32)	1.13 (-2.9, 5.1)	0.60	0.558
Behaviour (SDQ)	12.8 (7.24)	13.3 (5.14)	0.5 (-1.4, 2.4)	0.55	0.588
<b>Parent rated about themselves</b>					
Depression Literacy (ADKQ)	9.6 (2.11)	11.0 (1.74)	1.3 (0.4, 2.2)	3.07	0.006
Depression Stigma (DSS)	30.4 (8.24)	30.2 (7.71)	-0.2 (-1.7, 1.4)	-0.23	0.824
Depression (HADS)	14.4 (8.61)	15.6 (8.79)	1.2 (-1.1, 3.5)	1.13	0.274

MFQ = Mood and Feelings Questionnaire; SCARED = Screen for Child Anxiety Related Disorders; SDQ = Strengths and Difficulties Questionnaire; ADKQ = Adolescent Depression Knowledge Questionnaire; DSS = Depression Stigma Scale; HADS = Hospital Anxiety and Depression Scale.

*The number with missing data was 1 for the ADKQ, 3 for the MFQ, 2 for the SCARED, 0 for the SDQ, 2 for the DSS, 1 for the HADS.*

## **7.6 Questionnaire feedback on the package (young people & parents)**

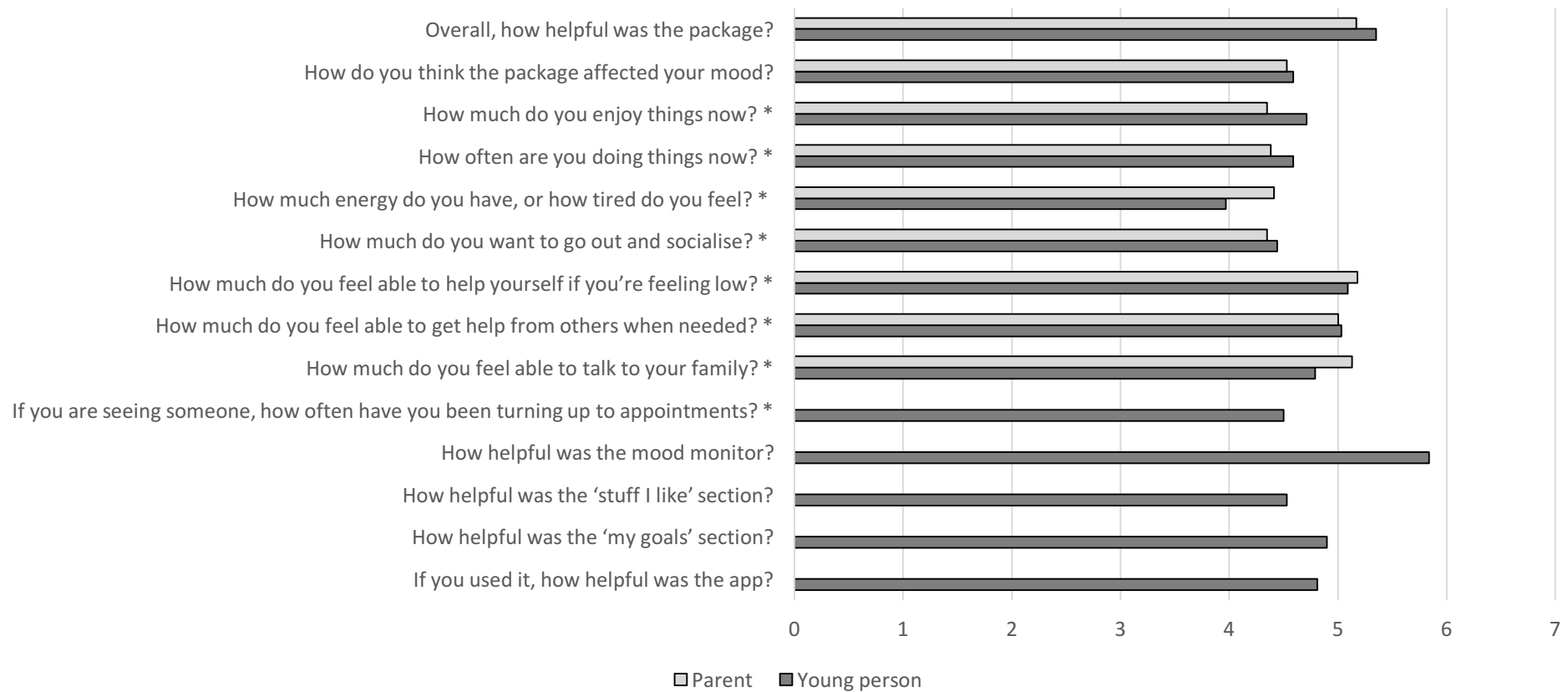
### **7.6.1 How helpful was the package?**

Overall, young people found the package helpful, in particular with finding ways to help themselves (figure 7.7). Of all the sections in the package, most young people identified the 'Self help' section as the most helpful (74%) followed by the 'Mood monitor' (60%), 'What are mood and depression?' (54%) and 'Possible reasons' (54.3%) sections. The sections identified as the least helpful were 'Stuff I like' (37%), 'Families, friends and professionals' (20%) and 'My goals' (20%). Half of the young people (51%) downloaded the 'app' and 14% felt this was one of the most useful elements of the package. Findings were similar for parents; they also felt that the young person found the package helpful overall (figure 7.7) and selected 'Self help' (43%) and the 'Mood monitor' (38%) as the most useful sections for the young person.

Parents were also asked to rate how helpful they found the package for themselves. Overall parents found the package helpful (figure 7.8). The sections they identified as most helpful were 'Possible reasons' (62%), 'What are mood and depression?' (52%), 'Where to get help' (43%), 'Family, friends, professionals' (38%), and 'Self help' (38%).

Overall, young people and parents/carers noted that the amount of information for each of the different sections was adequate (figure 7.9).

**Figure 7.7: Feedback on how helpful the package was for the young person**

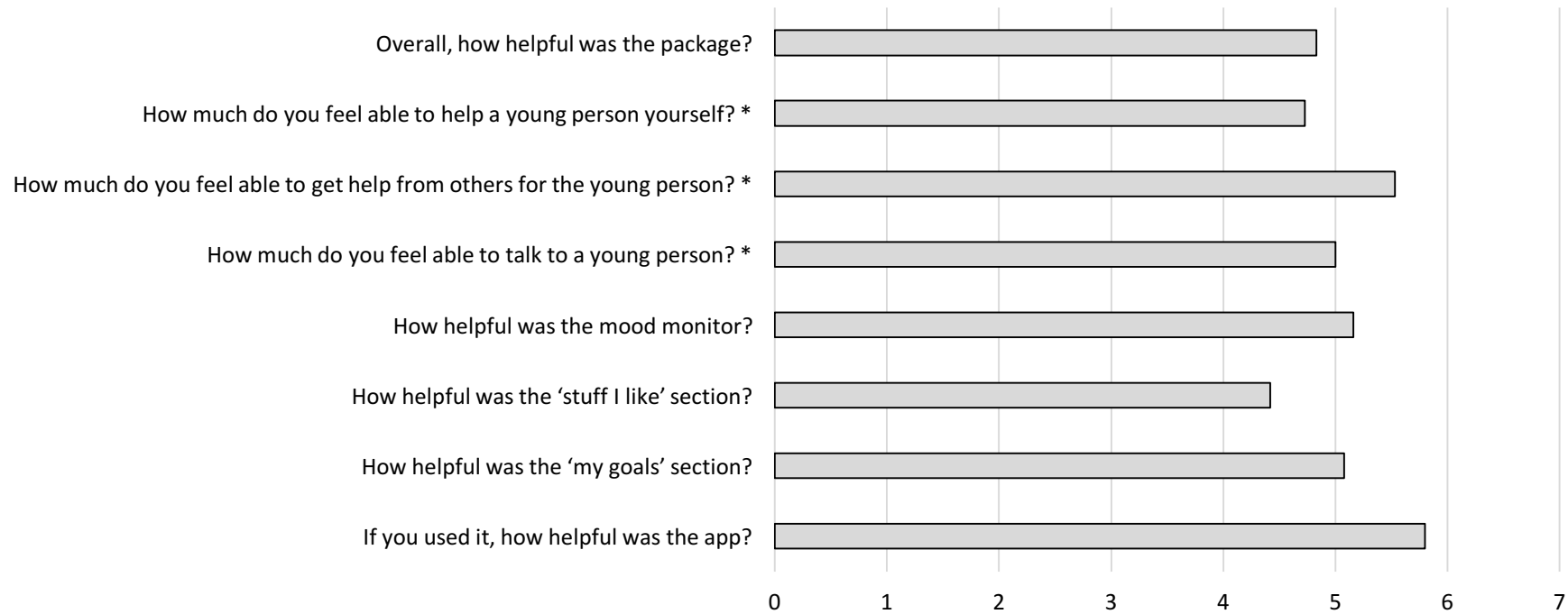


\* Compared to before using the package

Parents' responses were about their child

Ratings range from 1 (lowest/least improved) to 7 (highest/most improved); 4 = no change /made no difference

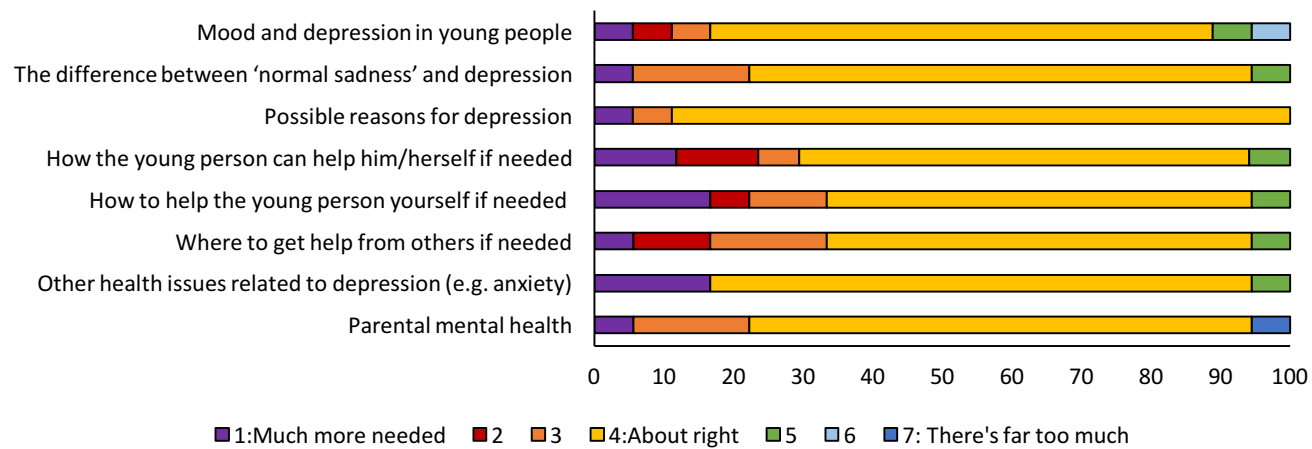
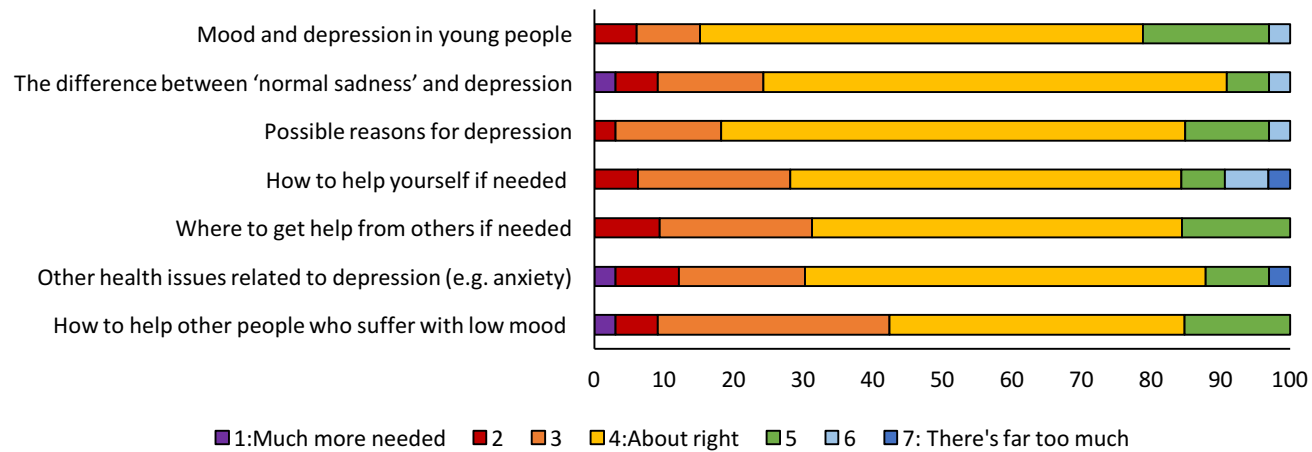
**Figure 7.8: Feedback on how helpful the package was for parents**



*\* Compared to before using the package*

*Ratings range from 1 (lowest/least improved) to 7 (highest/most improved); 4 = no change /made no difference*

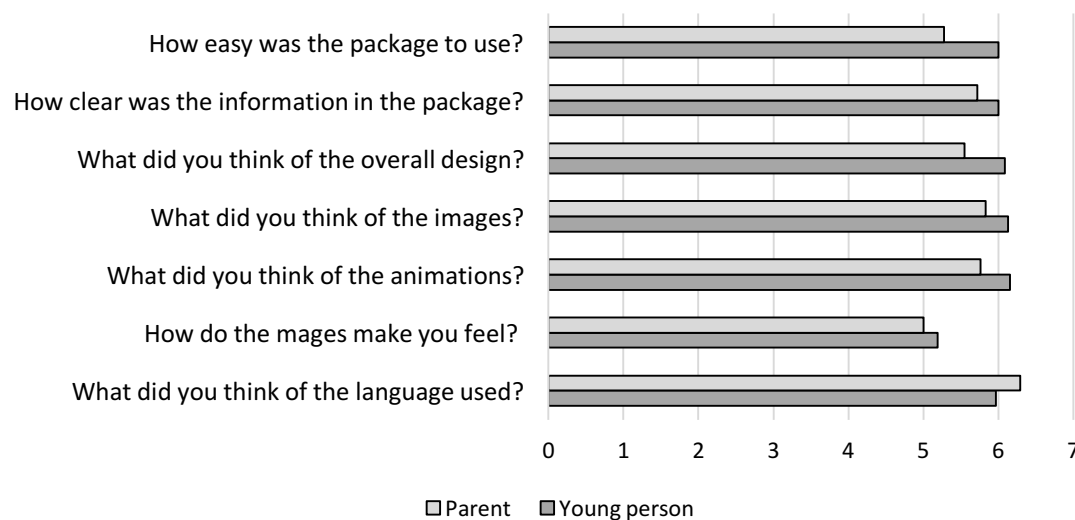
**Figure 7.9: Feedback on the amount of information in the package**



## 7.6.2 Design and language

Young people and parents approved of the design elements of the package, although parents were slightly less positive than young people. Both groups rated the words and phrases used in the package very highly.

**Figure 7.10: Feedback on design and language**



*Ratings range from 1 (lowest) to 7 (highest)*

## 7.7 Interviews with young people & parents (qualitative results)

### 7.7.1 Participants

Table 7.5 provides information about the 19 young people who were interviewed. The young people included those who had been under CAMHS for depression/depressive symptoms, those who had been seen by primary mental health workers and school counsellors, and those 'at-risk' because of a family history of depression. The young people varied with regards to age, gender and ethnicity. The ratio of females to males was around 3:1. Around two thirds were interviewed along with their parents (11 mothers and 1 father). Nine of those interviewed spoke Welsh fluently, and had used the package in this language.

**Table 7.5: Characteristics of young people who were interviewed**

<b>Characteristic</b>	
Recruitment source, N (%)	
<i>Mental health service/school counsellor/nurse</i>	13 (68.4%)
<i>EPAD group (parent with depression)</i>	6 (31.6%)
Age	
<i>Mean (SD)</i>	16.5 (1.78)
<i>Median</i>	16
<i>Range</i>	14-19
Gender, N (%)	
<i>Female</i>	14 (73.7%)
<i>Male</i>	5 (26.3%)
Ethnicity, N (%)	
<i>White</i>	18 (94.7%)
<i>Other</i>	1 (5.3%)
Seen alone, N (%)	
	7 (36.8%)
Seen with parent, N (%)	
	12 (63.2%)
Interview location, N (%)	
<i>Home address</i>	12 (63.1%)
<i>Cardiff university</i>	6 (31.6%)
<i>School</i>	1 (5.3%)

### 7.7.2 Key themes

As with the interviews and focus groups in stage 2, the interviews of the evaluation phase (stage 4) were guided by issues the research team wished to explore to help develop and evaluate the online package. The three key areas of interest explored in the interviews: design features, sections and content, and integration and context, and these became the key themes.

## 7.8 Key theme 1 (interviews): Design features

### 7.8.1 Overall design and use of colour

In general, all participants made favourable comments about the package, and stated that it seemed helpful for young people, families and carers. Some commented that they were surprised by the high quality of the package, and that they had reservations about using it previously.

*I was really pleasantly surprised with it...I thought it was great and I can definitely see people using it and wanting to use it. I was, yeah I was very impressed with it. Yeah, I wish I could criticise a bit more, but I can't (19-year-old female).*

*I really liked it overall... I really liked most things about it (Mother of 15-year-old female).*

The colours and palette impressed several participants. The palette was described as 'simple', 'not too boring', 'not overloading', 'eye catching' and 'positive'.

The colour used for the background of the welcome screen and profile section was discussed. Whilst a few young people suggested changing this to a brighter colour, such as orange, the majority liked the existing teal colour, describing it as 'calming', 'soothing', 'tranquil', 'neutral', 'subtle' and 'professional'. Participants also liked that the different sections were colour-coded.

The approach of the package was contrasted with that of existing resources such as websites by the NHS and charities. The design of the current package was more interesting, or more appropriate than other designs. Most found the overall design attractive, and not overwhelming. The design also made some young people feel they could 'trust' the package.

*It looks nice. It looks professional and quite sleek...you'd think it was official and quite, you know a lot of work has been put into it ...Yeah you kind of trust it and the information more (18-year-old female).*



The 'My profile' section was well-liked and described as helpful, particularly to pool and 'bookmark' links to interesting resources. The option to choose the profile picture was approved by all participants, in that it helped to personalise the package. One young person noted the similarity to social media websites, which made it more relevant to the target age group. One participant felt that the profile section would only be helpful if the package was used frequently.

There was consensus that the current name for the package (MoodHwb) was appropriate, memorable and original. Most did not appreciate that 'hwb' was a Welsh word for 'boost' or 'lift' as well as 'hub', and many liked the name even more when they learnt this. They stated that this meaning should be made more explicit.

*Yeah, it's not too serious and it's not too childish, so I think it's quite good for this age group... It's quite catchy as well, so you just felt, you don't forget it (16-year-old female).*

### **7.8.2 Navigation and ease of use**

Overall, participants felt that the package was clearly structured, easily navigated and user-friendly. They noted that the layout of the dashboard, and the way in which the titles of the subsections were highlighted made it easy to identify the sections that were most relevant to them. However, some participants felt the highlighted sections should be brighter/clearer.

*I thought it was quite easy to use and it was nice that you've got those little options about, you can go at your own pace as well which is quite nice (18-year-old female).*

*[It's] accessible to a whole range of people ... [They] very quickly understand where they needed to go, which section they needed to access (Mother of 15-year-old female).*

Suggestions included some additional links from the welcome screen (for example to the urgent help subsection and Welsh language option) and adding a clear 'home' button

throughout the package to link to the original screen. Parents had some difficulty identifying the menu icon in the corner of the screen and suggested this could be made clearer, although young people did not report any problems with this. There were also some suggestions on additional ways to find sections of interest, such as using a search term.

### 7.8.3 Illustrations and animations

Young people and parents were particularly positive about the illustrations and animations in the package, and commented that they were ‘friendly’, and ‘sophisticated’ without being ‘patronising’. Some noted that they were pleased to see both genders represented.

*I think the illustrations that you use, I think they're very good cos they make it less serious maybe, so if they feel like, it's not like a chore to go and look at the website ... It's not that it's childish, but it's less, you know just black and white, it's just, it's less serious, I think it's easier to use (16-year-old female).*

The characters were designed to be appealing to a diverse audience, with clean lines and minimal features. Participants approved of the abstract nature of the characters.

*Mother: I quite like the people...Quite generic...*  
*Daughter: Yeah the characters are fine and it doesn't make it feel as if it's you that they're representing... it's not like a particular person or particular type of person, it's just a person (18-year-old female & mother).*

When asked, all young people stated they preferred the current illustrative approach to a more ‘photographic’ one. Parents also agreed with this, which contrasted with their discussions in the parent/carer focus group during the development phase.

With regards to the animations, a few participants noted that they found them useful, as they helped to deliver the key messages and acted as ‘refreshers’. Most participants made favourable comments about the introductory animation noting the design was clear, minimalist, uncomplicated, engaging, and helped to explain what to expect from the package and how it can help. However, a few participants had not seen this animation, and

felt that the link needed to be more obvious on the welcome screen. One young person noted that there might be too much repetition in the introductory animations in each section.

#### **7.8.4 Interactive elements**

Initial questions/Mood monitoring: Nearly all participants praised the questions at the start of the package (which could also be answered subsequently), particularly for their functionality, ease of use, and 'fun' element. Some noted that this was their favourite aspect of the whole package.

*That was one of my favourite things actually, it was good to be able to see how you've been each day and the graphs were good, yeah... It's just helpful to track, I mean that's not something I would usually do, I just wouldn't even think about it (19-year-old female).*

All participants thought the colour coding 'traffic light system' (green for a high score, red for low, and yellow for middle-ground) was appropriate and 'universal'. Everyone felt that the questions were relevant, clear, and easy to use and understand. Participants also liked the mix of rating scales and multiple-choice questions. Some participants felt that the monitoring tool could be developed further; one person suggested introducing a 'free text' area to write entries, and a few others suggested adding in additional questions to make it even more specific to the user. Most participants commented favourably on the graph/chart of the mood. However, a few did not find it, and suggested it could be better signposted. Some noted that their use of the monitoring tool phased out over time, and that reminders could be sent to help with this.

'Stuff I like': Some young people had used it to add songs and images and felt that it helped make the package feel more personalised. However, others stated that they probably would not use this feature because they tended to bookmark sites they found interesting already. Suggestions to develop this further included adding images and icons to the links.

Goal setting: Most noted that 'My goals' was helpful and motivating. They liked how it was possible to add the number of activities, and how they would count down after they were achieved.

*I thought that was really helpful for myself because I've been trying to like get out of the house and do more. So I wrote that down, I thought that was really good...Cool, I liked that that was my, one of my favourite parts of the thing... It's quite motivating I think (16-year-old female).*

One young person warned about the association with schoolwork, as this component reminded her of when teachers would ask her to write her 'targets' for the academic year. As with mood monitoring, participants suggested adding reminders for this component (for example 'remember to walk'). Other suggestions included adding rewards, and more colour and interest.

### **7.8.5 Technical issues**

There were some comments about the compatibility of the package with certain computers and operating devices, such as Windows phones and old PCs/Windows 98. Some participants stated they did not receive the emailed link to the 'app', even though the multimedia company had stated this had been done, sometimes more than once. Users also needed to have Wi-Fi or phone data to use the package, and some had experienced difficulties with the internet provision at home or on their mobile device. A few noted that the package was slow to load. Two of the young people suggested that some of the information from the package could be installed into the 'app', so that an internet connection would not be required. A few commented that it looked markedly different on the phone compared to the laptop/computer, and that the computer should be recommended for some sections.

All participants felt that the log-in screen was simple, clear and easy to use. However, three young people noted that they only logged in once or twice because they had forgotten their password. Whilst there was already a 'forgotten your password?' option, they suggested having the additional option of remembering their password on their device. However, they appreciated that there may be confidentiality issues with this approach.

### **7.8.6 Scroll-down versus separate pages**

The main issue on which the participants were divided, related to the way in which the sections were structured. Participants were asked whether they preferred the current approach of ‘scrolling’ to each subsection, or whether the sections should be spliced so that each subsection could be opened on a separate page from a menu. At least half of the participants preferred the current approach, especially if using a tablet or phone device. Others felt that splitting the pages would be more appropriate.

*[It might] ‘make it less daunting to read and easier to digest’ (16-year-old male).*

## **7.9 Key theme 2 (interviews): Sections and content**

### **7.9.1 Structure of sections**

The general structure of the sections and flow of information was noted by many as a strong feature of the package. Participants commented on the importance of continuity and consistency – so that all sections followed the same approach. The progress bar and quiz (present in every section) were particularly popular.

*I like how the sections are all quite, it’s laid out in the same way, so it’s once you know how to navigate through one, you know how to navigate through all of them, it just makes it smooth (14-year-old male).*

### **7.9.2 Language, tone and amount of information**

On the whole, participants agreed that the language used in the package was appropriate, in that it was accessible, simple and jargon-free, but at the same time not ‘too dumbed down’.

Many also stated how they approved of the general tone of the package, stating it was 'sensitive' and 'affirming'.

*I like the style of the writing because it's not too complicated, so teenagers can like, can understand it and relate to it. It's not too... you know there's not ridiculously big words and the scientific, you know. It's a good style of writing to keep teenagers reading (17-year-old female).*

However, participants did suggest some minor changes to the terminology, for example in the wording of the personal stories, the initial questions, and the tailored messages; one participant felt the phrase 'we suggest that you talk to someone as soon as possible', might cause stress and anxiety.

When discussing the Welsh language option, nearly all stated that this was worthwhile. Those who spoke the language stated that the Welsh version had made it easier for them to relate to the content. One family stated they weren't aware of the Welsh language version, and suggested adding a Wales flag to the menu to make it clearer.

Amount of information: In general, participants were pleased with the content of the package, and found it comprehensive.

*I didn't expect that amount of information; the depth is incredible (Mother of 17-year-old female).*

Whilst a couple of participants thought there might be too much text in the package, the majority felt that the amount was acceptable. Participants stated this was helped by the structure of the sections and how the text was broken up by illustrations, animations and interactive components. Participants described the text as 'succinct', 'bite size', and 'short and snappy'.

*That is quite short and sharp and it's broken up... it's not as intimidating as it, especially if somebody is perhaps not as academic, you know having the balance of pictures and text means that it's catering for all of the spectrum (14-year-old female).*

### 7.9.3 Personal stories

All participants made favourable comments about the personal stories, in particular how the user could relate to and identify with them.

*I do like the personal stories as well because then you feel like you're not the only person that's going through a hard time. You can maybe like relate as well (16-year-old male).*

Suggestions included having some stories from those in the public eye (celebrities), creating animations to accompany the stories, and adding videos or audio files, instead of (or along with) the text. Some young people thought that some of the terms used in the stories were not what a young person would say, for example the term 'low mood', and suggested reviewing them.

### 7.9.4 Sections of the package

What are mood and depression?: Participants agreed that it was important to include accurate information about the difference between sadness and depression, how to identify difficulties, and the range of symptoms and experiences. Some made favourable comments on the section on metaphors of low mood and depression, and many liked the reference to the 'black dog'.

*I've used it a lot since being diagnosed and it helps me to understand what depression is and some of the reasons I guess that it might get bad or better (15-year-old female).*

*It can help you ... start to identify if you do [have depression], if there is actually a problem so you can then go and seek help... [It helped me understand that] it's not like being sad, it's other stuff as well (18-year-old female).*

Some noted that those with depression and other mental health difficulties might be reluctant to engage with the package, because of the subject matter.

*I think it's quite difficult because the subject itself...it's not something, especially if you're in a really low mood, you particularly want to sort of think about...it's just talking about things that you try and avoid basically... I don't know in what way you can improve that but I think that's maybe the reason why I wouldn't have gone on it so much (16-year-old female).*

Help sections: Several participants stated that the 'self help' section was their favourite part of the package.

*The sections I went to is perfect, it's exactly how I imagined it to be, like self help, I particularly like that section (16-year-old male).*

*Daughter: The self help part could help people find ways to feel better, yeah. Mother: Yeah, I felt its stance was quite motivational throughout so there was very much a focus on ways in which you can improve .... the way you're feeling or coping with things (15-year-old female & mother).*

However, some others felt that the information on self help was too general at times, and it was suggested that there could be more specific and personalised approaches – for example 'breathing techniques for panic attacks'. One participant noted that it could be particularly difficult to help oneself when depressed.

Several people commented favourably on the information in the 'Where to get help' section. Some suggested there could be even more information included in this section, for example on CAMHS, and different treatments.

Other health issues: Everyone noted that this section was important, relevant and comprehensive, particularly the sections on anxiety, eating/weight issues and physical health. However, a few were concerned that this could cause some people to worry unnecessarily.



*My only concern with that is you run the risk then of the people who are a bit paranoid is self-diagnosis... That's something else for me to worry about and become panicky and anxious (Mother of 17-year-old female).*

Family, friends, professionals: Parents/carers found the 'family, friends, professionals' section and its general approach helpful.

*I thought, in terms of the content, I thought it was good, a good holistic approach to it from a parent's point of view (Mother of 15-year-old female).*

One young person suggested it could help to prepare young people if they meet someone with mental health difficulties in future, and suggested there could be more information on how to talk to or approach friends.

*From a friend's perspective, it's quite difficult to start a conversation about depression (14-year-old male).*

## **7.10 Key theme 3 (interviews): Integration and context**

### **7.10.1 Targeted versus Universal**

Most participants thought the package would be helpful for anyone who was interested, and that it should be 'open access'. They also noted it would be especially helpful for those with difficulties, and their families/carers – particularly those starting to experience difficulties.

*Son: Yeah, get the widest range of coverage and I think the more people who use something like this the better really, and if there's people out there having issues then if they can get used to something like this it's brilliant.*

*Mother: I don't see why there needs to be a barrier ... why you should have to go to somebody to suggest you use it (16-year-old male & mother).*

*I think it's been done in such a way that I think it's, whoever looks at it it's gonna be beneficial. I mean there's a lot of information on there that even if you haven't got a mental health problem or maybe you know someone or whatever it is or even if you're just curious (19-year-old female).*

However, there were some participants who had reservations about making it open access, and suggested being referred to it in the first instance, and then opening it up if it is well-received. One young person suggested having an open access package, but with the option to create an account.

Some stated that the package could help counteract stigma, and making it accessible would help with this.

*Having something like that would bring mood and depression into more of, more light if that makes sense, would reduce the stigma people have on it and they wouldn't feel so bad about talking to other people about it (16-year-old male).*

### **7.10.2 Use with families and friends**

Most young people had separate accounts to their parents, and those who did not noted that, on reflection, they would have asked for different accounts. One young person felt that the package could help with the communication between the young person and the family/carer/friend.

*It's probably, in mine and my friends' experiences the hardest people to talk to would be parents so I like this because it's a way that you can use the account separately, but learn the same things (15-year-old female).*

Suggestions for improvement included adding more options, such as being able to monitor someone else's mood, by partially linking accounts, or by having 'a mood common room' where a young person and parent/carer could share information. However, some families noted that young people would not be comfortable using the package with parents and others.

### **7.10.3 Integration with schools and health services**

Many participants felt there was a place for the package to be used in school, particularly PSHE lessons, as a way of introducing the programme. A teacher area or package was also suggested. However, it was noted that there was a risk that associating the package too much with schools might make the package less appealing.

Some noted that the package could be used with counsellors, GPs and CAMHS therapists, either in or between sessions.

*It's there to back it up at home...So it's like between the sessions you've got this at home to use.... A safety net or if like, when I stop CAMHS sessions then it's just there as something for when I need it (14-year-old female).*

Participants commented that the dashboard, mood monitor, and my goals sections could be useful to reflect on with a professional. Suggestions included being able to send results to a professional, and adding in a diary element, so that it would be possible to record entries and discuss them in sessions. This might be particularly helpful if the young person had difficulties talking to others.

*I find it really hard to tell people so that's why I have the diary... If I just showed her on my phone...it's better because you know it also saves time in the meeting then, instead of spending half an hour explaining (15-year-old female).*

## **7.11 Focus group with professionals**

### **7.11.1 Participants**

Thirteen professionals participated in a focus group at Cardiff University to ascertain their views of the package prototype. Participants were from a range of disciplines including

health, education, social and youth services and charities (table 7.6). Of the 12 professionals who participated in the focus group in the development phase (stage 2), four participated in the professionals' group in the evaluation phase.

As described in chapter 3, the professionals were provided with a link to the package a couple of weeks before the focus group. During the focus group, the package was projected onto a screen, and participants were given the opportunity to discuss each component.

**Table 7.6: Participants in the focus group for professionals**

<b>Characteristic</b>	
Profession, N (%)	
<i>Psychiatrist</i>	2 (15.4%)
<i>Mental health nurse (secondary care)</i>	1 (7.7%)
<i>Primary mental health worker</i>	2 (15.4%)
<i>Social worker</i>	1 (7.7%)
<i>Educational psychologist</i>	2 (15.4%)
<i>School nurse</i>	1 (7.7%)
<i>School counsellor</i>	1 (7.7%)
<i>Teacher</i>	1 (7.7%)
<i>Youth worker/Community wellbeing officer</i>	1 (7.7%)
<i>Charity worker (Emotional wellbeing &amp; mental health manager)</i>	1 (7.7%)
Gender, N (%)	
<i>Female</i>	10 (76.9%)
<i>Male</i>	3 (23.1%)
Ethnicity, N (%)	
<i>White</i>	13 (100%)

### 7.11.1 Key themes

The same three key themes were explored in the focus group as the interviews: design features, sections and content, and integration and context.

## 7.12 Key theme 1 (focus group): Design features

### 7.12.1 Overall design

As with the results from the interviews, the feedback in general from the professionals' focus group was favourable.

*Overall I think it's a really excellent resource...It is a brilliant tool, I think I've got to say, just making that link from the research place and putting it out there (Psychiatrist: female).*

*I mean to be honest with you know, if you put this package out now as it is... it is fantastic and all this is like all the nitty gritty you know of it, and again all personal preferences (School counsellor: female).*

Professionals were pleased to see the efforts to personalise the package, particularly where they could save links to sources of help in the personal profile.

*I like the fact that there was space for the young person to add their own contacts on there so they then had ownership of it, you know it's given them a bit of responsibility (Primary mental health worker: female).*

Professionals also commented on how the package was easy to navigate.

*So the fact that it's like all the same colour and you've got the top bar running through like, so it's almost, you're not going to get lost (Educational psychologist: female).*

In general, the professionals liked the appearance of the welcome screen.

*I think it engages the young person straight away...You get a lot of information in a short space of time...It's fresh I think (School nurse: female).*

They approved of the 'hide' button, and how it diverted the user to Google. As with the interviews, one of the participants suggested adding a 'home button' to easily return to the welcome screen if desired. There were more calls from the professionals than the young people/parents to change the teal background to a brighter colour, as it was described as 'a bit drab' and 'muted', although many noted it would be preferable to ask young people. Other suggestions for improvement included having the main menu on both the bottom and top of the screen, and including more information on how the package was developed, possibly with an animation.

Participants also remarked positively on the 'dashboard', and particularly the display of the scores from the initial questions. They felt this allowed the user to reflect on their situation and group strengths and difficulties together.

*I think it's really positive showing the three areas that are going well because it just helps to kind of see them, to kind of have thresholds for things and give the young person kind of perspective, which makes it feel a lot more manageable (Primary mental health worker: female).*

Unlike young people who felt the traffic light system was 'universal', some professionals felt this required some explanation.

### **7.12.2 Illustrations and animations**

The aesthetics and illustrative approach was praised by most who attended the focus group. Professionals agreed that the use of the graphic illustrative approach was appropriate, compared to photography.

*I thought the graphics were really good because they weren't too old, they weren't too young, I just thought that they were spot on (Primary mental health worker: female).*

As with the interviews, many professionals stated they had missed the introductory animation, possibly due to the incompatibility of their computer. A screenshot or icon was suggested to accompany the link to the animation, so as to make it clearer, positioned at the top of the screen rather than at the bottom. Other new suggestions by the professionals included proposals to add subtitles to the animations. They noted that young people were unlikely to read the written script in the 'How can this help me?' section, and felt that the text could then be taken out or collapsed. Subtitles would also help those with hearing impairment. One participant suggested making it clearer that headphones might be required.

### **7.12.3 Interactive elements**

Professionals generally liked the mood monitor. Unlike the young people, who found this simple to use, some professionals reported difficulties using the sliding scale and suggested there could be an explanation on how to operate this. Several professionals agreed that it was important that there was a 'red flag' when the user indicated they had thoughts of self-harm.

With regards to the goal-setting component, one professional approved of how it was possible to see a record of how many goals were completed, and how much the user had achieved. Professionals agreed with the young people that reminders would increase use of this feature.

### **7.12.4 Technical issues**

Some participants noted that the package was slow and that some links did not respond, especially on some NHS desktop computers. They noted it had worked better on their home computers, suggesting that the difficulties may be related to an incompatibility with old versions of operating systems. Log-ins and passwords were discussed at length, because of the concern regarding confidentiality, and participants stressed that users should be automatically logged out if they closed the page.

### 7.12.5 Scroll-down versus separate pages

Similar to the interviews, there were mixed views regarding the way in which the sections were structured. In general professionals preferred a segmented approach, as opposed to the scrollable sections. One noted this was the approach taken on NHS websites. Others suggested the segmented approach might not be ideal as it might take a long time to load each page.

## 7.13 Key theme 2 (focus group): Sections and content

### 7.13.1 Package content

Professionals praised the extensive, authoritative, and reliable information delivered in the package; one described this as ‘a wealth of information’.

*What’s really good is it’s relevant, you know, you’ve identified that it can be due to all sorts of different things so... you know for a young person coming to realise actually it’s not just about me and now and just one thing, and realising that’s linked to so many other things, and opening it up rather than then kind of shutting it down, and it’s an exploratory thing which I think is really great (Psychiatrist: female).*

Overall, participants were positive about all the different sections of the package. The interactive quizzes were described as ‘engaging’, although one teacher noted they reminded her of lesson plans. Participants praised the family and systemic approach of the package, and highlighted the subsection on parental mental health as particularly important

*What I really liked about it is that the fact that it’s talking more about the family so it’s not about just the child it’s about saying, you know how are your parents doing?, to the parents, how are you doing?, so it’s recognising that the children’s mental*



*health difficulties don't come in isolation and you know I like that kind of, finding that sort of systemic kind of approach (Psychiatrist: female).*

Professionals generally approved of the help sections, and liked that there was an explanation of the services and professionals. Some commented favourably on the signposting to other resources and sites.

*I like the fact that it's got, it's got links to other good sites as well so it's not trying to be all things to all men (Psychiatrist: male).*

However, several others thought the package could go further and link to more resources, within services and charities. There was also some discussion on the need to regularly update the 'Where to get help' section, because of concerns that the information may change over time. Other suggestions included adding links for the local area. With regards to the 'Possible reasons' section, professionals suggested adding in more specific information on bereavement, loss and trauma.

### **7.13.2 Language and text**

Participants approved of the Welsh language option but also felt that it could be used outside of Wales. One noted that there should be a more prominent Welsh language option on the welcome screen, and possibly use of the Welsh flag. This was also suggested in the interviews. Unlike in the interviews, professionals did not comment as much on the appropriateness of the language/terminology used in the package.

At the early stages of the discussion, some professionals were critical of the amount of text in the sections, suggesting it might be 'wordy' or 'overwhelming' at times. This was different to the interview findings, where most felt the amount of text was appropriate.

*There is so much information it is really good, there's so much information it's overwhelming...I'd got so far and I just thought I can't be arsed reading any more of this (School counsellor: female).*

However, some people had been unable to access some of the illustrations and animations because of technical difficulties on their work computers, leaving a more text-heavy package. Other professionals disagreed and thought the amount of text was suitable.

*I don't feel the text is all that much if you're talking 14-18 years' olds we've got to be careful not to lower it too much because they've actually got onto this website because they're needing information (Educational psychologist: female).*

### **7.13.3 Personal stories**

Participants made especially favourable comments about the personal stories, as they showed users they were not on their own.

*One of the things I liked especially was the personal stories that were injected after each section; I just thought they would really help a young person kind of identify with it in more of a grounded way so that it wasn't just theoretical talking (Social worker: male).*

The participants agreed that it was important to have stories from a range of perspectives. In general, they thought the stories were realistic. As suggested in the interviews, one or two of the professionals thought that these could take a more visual approach, and be accompanied by an animation, photo, video, or comic strip, to help 'bring them to life'.

## **7.14 Key theme 3 (focus group): Integration and context**

Several participants referred to how they are expected to deliver information and to signpost, and they were keen to see a reliable resource which they could use in their work with young people. All professionals suggested the package could be open-access.

*A big part of our work I think is psychoeducation and so it would be great to know that there's a reliable, like you say, moderated place that you can kind of send them for all of the things, because at the moment we tend to use sites that are lots of*

*adult based and we're having to cut and paste or omit language (Psychiatrist: female).*

#### **7.14.1 Integration with schools and health services**

The school-based professionals noted the importance of using the package in schools, especially PSHE sessions, as there was 'a big gap' in resources and lack of training for teachers. Professionals seemed to have fewer reservations than the young people about using it in schools.

*I've done PHSE based on sort of depression and it was just a sheet of paper and ... it wasn't very appropriate and I don't have any training in this area, so if I had a resource like this to use then it would have been much, much more successful (Teacher: female).*

All healthcare professionals in the group felt that the programme would fit in with their work, and could be used across all tiers, especially in primary mental health and CAMHS. However, they felt it might be especially helpful for those whose difficulties are not severe enough to fit the criteria for primary mental health. Some participants noted that it could also be a helpful resource for young people who are no longer in services, and those who are waiting for an appointment.

*They might come for 4 or 5 counselling sessions and then they say 'no I'm fine now', and they'll go off, and then they might want to come back, but they might have to wait, so at least if there's a resource they're like that, they've already started they can just dip in and remind themselves maybe of some stuff (School counsellor: female).*

One educational psychologist noted that she worked a great deal with children in care, and thought the package was relevant for them, especially as 'they're moving around a lot'.

### 7.14.2 Challenges in implementation

Many professionals highlighted the challenge of keeping the package up to date. There were also some concerns about how young people might use the package, and whether they would engage with it, despite all the user-involvement.

*My worry would be that people might use it quite superficially or lose motivation (Educational psychologist: female).*

Some of the participants had been involved in recruiting young people for the project, and had encountered difficulties, but were unsure why this was the case. Parental consent was proposed a possible reason, particularly where the young person's difficulties were related to issues at home.

Convincing professionals to recommend the package was also suggested as a possible challenge.

*It's a pre-IT literate professional group, trying to recommend something they might not feel comfortable with, we've had the opportunity to play around on it and think actually this is really good ... we need to make sure all the professionals who are likely to recommend it have the same opportunity (Psychiatrist: male).*

## 7.15 Discussion

### 7.15.1 Summary of quantitative results

Forty-four young people and 31 parents/carers consented and completed pre-intervention questionnaires for the evaluation phase, and 36 young people and 21 parents/carers completed post-intervention questionnaires. This gave an 82% retention rate in the young people, and there was little missing data. Overall, participants found the questionnaires acceptable and many were very positive about completing them. There may have been too

many questions, especially at the post-intervention stage, and this is a consideration for a future trial.

According to the online usage data, the sections of the package viewed the most were 'What are mood and depression?', 'Family, friends, professionals', and 'Self help'. This was similar to the questionnaire results, although they showed that the 'Possible reasons' was more interesting to young people and parents than the online data suggested. The mood monitor was also popular with young people. Parents/carers used the package less frequently than young people. Most participants used the package for half an hour at a time. Most young people (88%) used the package independently of others, whilst parents were more likely to use it with others.

According to the rating scales completed by young people, there was some improvement after using the package, which gave limited support to the outcomes noted in the logic model (subsection 6.3.3). Depression literacy was significantly higher after using the package, and there was a trend of improvements in other scores such as self-efficacy and depressive symptoms. Parents' own depression literacy also improved significantly after using the package.

Parent-rated scores of their children's mood and behaviour were similar or slightly worse after using the package, and were also much lower than the children's rating in general. This might suggest they may not be as accurate when rating internalising symptoms, and some parents commented in the free-text questionnaire sections that they were often unsure or guessing responses. The findings are limited by the small sample, which prevented further analysis, including subgroup analysis, and a larger feasibility trial is required (see also limitations section, chapter 8).

Overall young people and parents/carers found the programme helpful, from the results of the questionnaires, especially in finding ways for the young person to help themselves and for getting help. Again, this gave some support to the logic model (subsection 6.3.3). Young people found the 'Self help' and 'Mood monitor' particularly helpful, whilst parents/carers found 'Possible reasons', and 'What are mood and depression?' most helpful. In general, the feedback from the questionnaires was in line with that of the interviews.

### 7.15.2 Summary of strengths of package (qualitative results)

Nineteen young people and 12 parents/cares participated in interviews, and 13 professionals participated in a focus group. The strengths of the package according to the findings of the evaluation phase, are presented here. The areas of the online package which need attention and further development are discussed in chapter 8.

Everyone in the interviews and focus group liked the **general design** of the package. Some families noted they had reservations about using it previously, and were pleasantly surprised by how engaging it was. Those who had participated earlier in the project confirmed that ideas had been carried forward from previous interviews and groups. Most noted that the package was easy to use and navigate, and well-structured – and the person-centred approach to the development of the package and its design was commended. Participants, especially young people, stated that the overall content and design was relevant to them. They also stated it was engaging and persuasive in helping them to change their understanding, views and behaviour related to mental health, mood and depression (Oinas-Kukkonen & Harjuma 2009).

The illustrations, animations (especially introductory animation) and colours were considered engaging, and the characters were appropriate, and not too abstract. The overall graphic approach was supported by everyone, even though parents in the development phase focus group had preferred photographs.

Many noted the **welcome screen** gave a positive and trustworthy gateway to the package, and liked the illustrations. Most preferred to keep the ‘teal’ colour of the welcome page. The initial questions/mood monitor (and colour-coded icons) was one of the most popular sections of the package, and ‘My goals’ and dashboard were also praised. The **structure of the sections** was approved by over half of families, and most approved of the consistent approach to the sections. The balance between text and image was considered appropriate by most.

In general, participants approved of the **information** in the package, and professionals highlighted the systemic/family approach, and use of signposting. The general tone with regard the language, as well as the general design and approach, was commended. The

comprehensive range of information was praised as well. The self help section was some users' favourite section. Nearly all agreed there should be a Welsh option, and those who used it stated that it helped them relate to the subject matter.

Most considered that the package should be available **universally**, but that it would be most relevant for those starting to experience depression/depressive symptoms, and those concerned about a young person. Most young people preferred to use the package independently but some used it with parents/carers/others. Many families suggested introducing the package in PSHE lessons, but only for one or two sessions, and the package could then be used by adolescents in their own time if they wished. Some suggested it could be used with counsellors, primary care/CAMHS and charity workers, and professionals agreed it could be integrated into their work – in schools, health, youth and social services, charities, and with children in care. They also noted it could help those on waiting lists, those who had difficulty talking to others and who had not accessed any services. There was consensus that the name should be kept as 'MoodHwb'/'HwbHwyliau'.

### **7.15.3 Conclusions**

In general, the responses of all groups of participants to the package were favourable, although there were some suggestions for change. When comparing the responses of young people and parents/carers, there were fewer differences between these groups compared to in the development phase. Young people found the package easier to use overall, and were better able to understand the graphic language than the adults (although parents and professionals also found it acceptable). Parents discussed the graphic approach more favourably this time. Professionals were more in favour (than the families) of splitting the sections into separate pages.

The evaluation phase helped to show that the initial prototype of the online package was acceptable, feasible, clear and easy to use for young people with, or at risk of, depression and their families/carers and professionals. There were promising results on potential efficacy regarding depression literacy, self-efficacy, and depression symptoms, which gave some support to the logic model. However, a randomised controlled trial, which is properly powered, would be required to explore this further. The findings are consistent with the

limited number of studies in the field of psychoeducation for adolescent depression, which show that these programmes can be acceptable and feasible for young people with mental health difficulties, and have a positive effect on range of outcomes (see chapter 2). The findings also help to address the gap in the literature on online PIs, as identified in the review.

The evaluation helped to inform the further development of the package in the short and medium term, and the longer-term plans for the development and evaluation of the package, and this is discussed further in the final chapter of the thesis (chapter 8).



## Chapter 8:

# Discussion: Development and evaluation of an online psychoeducation package for adolescent depression

### 8.1 Introduction

Depression is common in adolescence, and leads to distress and impairment for individuals and families (Thapar et al. 2012). However, adolescent depression is difficult to recognise and treat, and engaging young people in prevention and early intervention programmes is a challenge for health and other services. Guidelines stress the need for good information and evidence-based psychosocial interventions for individuals and families (NICE 2005; Birmaher et al. 2007). Over recent years there has been growing interest in psychoeducational interventions (PIs), which are broadly about delivering accurate information about health issues and self-management.

The aim of the doctoral project was to develop and evaluate a user-friendly online psychoeducation multimedia package for young people with (or at high risk of) depression and their families, as part of a NIHR/HCRW fellowship. The research plan was guided by the initial phases of the MRC framework for complex interventions, and digital health guidelines. This involved both qualitative and quantitative methods (see stages below).

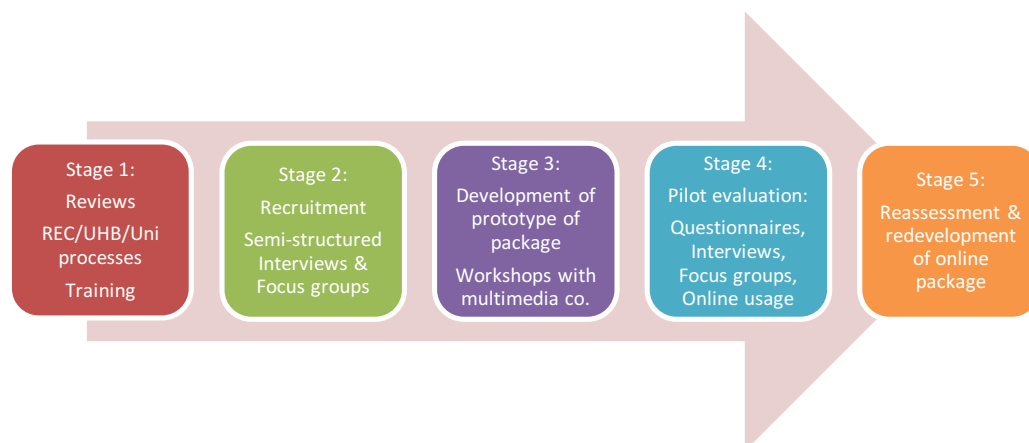


Fig 8.1: Broad stages of the research plan

This chapter discusses the findings from the project and the future directions. Firstly, a summary of the project and its key findings is presented, followed by a reflection of the possible strengths and weaknesses. The chapter then focuses on the integration of the package in the lives of young people and in the context of services. The chapter concludes by examining the direction for future research, and describing plans for the online package.

## **8.2 Summary of project and findings**

For the review of psychoeducation in adolescent depression, searches were undertaken independently in PubMed, PsycINFO and EMBASE by the student and a fellow researcher. The results showed there were a range of approaches to psychoeducation, and most programmes involved content presented to groups/families facilitated by a professional. The limited number of studies (especially in less economically developed countries), heterogeneity in their formats and approaches to evaluation, and variable methodological quality, made it difficult to compare programmes and measure the overall effectiveness. However, the studies available suggested that psychoeducation had some effect on a range of outcomes including understanding of depression, family communication, engagement with services, and health outcomes.

A series of twelve semi-structured interviews and six focus groups were conducted with adolescents (with a history of depression or at high-risk), parents/carers, and professionals from a range of services. Participants were recruited from CAMHS teams in South and West Wales, and from families involved in the Cardiff EPAD study. Thematic analysis of the interview transcripts was performed using the software 'NVivo'. The key themes were 'aims of the package', 'design issues', 'content issues' and 'integration and context'.

Findings from the review and qualitative work informed the development of the initial version of the package. The package was designed so that it would be engaging, informative, and personalised according to the needs of the user. The package included sections on mood and depression, possible reasons for low mood/depression, self-management and finding help, and other issues such as anxiety. There were also multiple user pathway options and a section for families/carers, friends and professionals. It was designed to engage users through illustrations, animations and interactive components – including

profile-building, mood monitoring and goal setting components. It was 'multi-platform', and there was an accompanying 'app' that could be downloaded.

Young people, parents/carers and professionals were recruited for the early evaluation of the initial version of the package from primary mental health services and school counsellors/nurses, as well as secondary CAMHS and the EPAD sample as before. Young people and parents/carers completed questionnaires before and after using the package. Some participants were interviewed, and there was a focus group for professionals. Online usage was also monitored. The results showed that the prototype was acceptable, feasible, clear and easy to use for young people, parents/carers and professionals, and that the assessment process itself was acceptable. The results also supported, to a limited extent, the outcomes noted in the logic model, particularly improved depression literacy, self-efficacy (especially regarding self help strategies and knowing where to get help), and depressive symptoms.

The evaluation phase informed the further development of the package (currently in progress), which included modifications to aspects of its design and content. This stage also informed plans for a future larger feasibility trial of the package. The evaluation phase results were consistent with the findings of the review (chapter 2), which showed that whilst the evidence is limited, PIs can influence a range of outcomes. Overall the development and evaluation of this programme helps to fill the gap identified in the review on the literature on PIs, particularly online PIs, in adolescent depression. In particular, this study shows how a PI programme can be developed using rigorous methods - following extensive mixed-methods approaches with user input, and for a wide range of settings or services, in line with recognised frameworks and relevant theory (Craig et al. 2008; Yardley et al. 2015).

### **8.3 Implications for redevelopment phase (stage 5)**

Several suggestions were made to improve the design during the evaluation phase, although only a few major revisions were suggested, and no-one suggested wholesale changes. The suggestions were discussed with the multimedia company and research team. The issues were prioritised according to the level of importance given to them by the participants, and whether they would improve the acceptability, feasibility and ease of use of the package.

Other considerations were the technical difficulty, time required and cost of making the changes.

Table 8.1 lists the changes suggested in the interviews and focus group, and the proposals to address these (right column). Due to limited funding, certain tasks were prioritised. Remaining tasks could be addressed when applying for funding for the further development and evaluation of the package.

**Table 8.1: Further development of package (stage 5)**

Suggestions by participants (by young people and parents/carers unless stated otherwise)		Plans to address suggestions
<b>Specific design issues</b>		
<b>Login screen</b>	Add a 'remember me' option (which might make it more likely for some to re-enter), although possible confidentiality issue	Add this option
<b>Welcome screen (or home screen)</b>	<p>Elements could be clearer on this screen:</p> <ul style="list-style-type: none"> <li>- Introduce a link to 'urgent help'</li> <li>- Clearer reference to the Welsh language option (for example with a flag)</li> <li>- Add an explanation of 'hide me'</li> </ul> <p>There could be a link to the welcome/home screen throughout the package, and an option to return to the welcome screen instead of the dashboard.</p> <p>The meaning of 'MoodHwb' could be more explicit, especially the translation of 'hwb'.</p> <p>There could be a brighter, lighter background colour for the welcome screen, such as a light orange, although most preferred keeping the teal</p> <p>Suggestions by professionals:</p> <p>Design a clearer 'home' button, and the menu could go at the bottom as well as the top of the screen.</p> <p>A new idea was that there could be information on how the package was created.</p> <p>A brighter colour to the welcome screen, but should also consult young people.</p>	<p>To explore how to optimise 'signposting' and 'navigation', and revise the design of the dashboard in line with the welcome screen.</p> <p>Footnote to be introduced at the bottom of each screen to explain the name.</p> <p>Background colour to remain teal</p> <p>Page to be introduced on how the package was developed</p>
<b>Menu icon</b>	Most parents/carers did not understand this icon, and this could possibly be clearer.	Explore how to make this clearer e.g. add term 'menu'
<b>Introductory animation</b>	<p>It could be made clearer there was an introductory animation, by introducing a link at the top of the welcome screen, possibly with a video/animation icon.</p> <p>The script could be condensed or hidden in a collapsible block.</p> <p>Professionals: As with the interviewees, many had missed the introductory animation, and it was suggested this could be better signposted, for example with a screenshot or icon at the top of the screen (rather than the bottom). Professionals were even more keen for the animation script to be reduced or hidden.</p> <p>Another new suggestion was for subtitles to be added, and to make it clear that headphones were needed.</p>	<p>Add 'watch video' on welcome screen, and launch in 'modal' (i.e. self-contained box)</p> <p>Animation script on 'How can this help me?' to be placed in a collapsible block, with 'read more' link. Add a subtitles option.</p>

<b>User pathway</b>	<p>There were some reservations about using the package with others, and another user pathway was proposed – a ‘mood common room’ where the young person and parent/carer could use the package together. A ‘teacher area’ was also proposed.</p> <p>A few asked for a ‘free text’ box to be added to the initial questions, as a form of diary, and possibly links to messages as the person answered the questions. The mood chart could also be better signposted. Reminders were suggested by many for the mood monitor and the other ‘app’ components.</p> <p>Professionals: Although it was not an issue raised by the young people, a few professionals had difficulties operating the initial questions/mood monitor. They suggested there could be more explanation for this and for the scores, and more specific guidance on how to help with each aspect, such as mood and enjoyment. Professionals agreed that reminders would be helpful.</p>	<p>Explore how to improve functionality of the initial questions, e.g. progress indicators should not appear ‘clickable’, and add instruction to drag mood indicator.</p> <p>Explore feasibility of ‘mood common room’.</p> <p>Add ‘free text’ option.</p> <p>Add reminders.</p> <p>Add ‘skip this’ if users do not wish to answer questions.</p>
<b>Dashboard/profile section</b>	<p>On the dashboard/profile section, the teal colour was considered a little overwhelming by some for the profile page, and it was suggested there could be more variation and images (possibly the user could choose a colour).</p> <p>The head icons for the scores could be linked more strongly with suggestions for help, some dashboard messages could be reworded (for example to be less alarmist).</p>	<p>Separate out the subsections within the profile section to make it appear more interesting.</p> <p>Explore how to link the recommendations with the scores for mood, enjoyment etc.</p>
<b>Tailoring /personalising</b>	<p>Participants also suggested that the package could be tailored and personalised further, for example in the presentation of subsections/content on the dashboard (also noted by professionals), and by giving more specific guidance in help sections. Workbooks or worksheets were also proposed. A search engine was also suggested.</p>	<p>To change colour of highlighted subsection titles &amp; explore tailoring /search engine options.</p>
<b>Section/Content issues</b>		
<b>Information within sections</b>	<p>There were specific additions suggested for the content, for example there could be more information on CAMHS, treatments and other conditions (although the programme was mainly for depression), and on how to help friends who were experiencing difficulties. There were concerns that the package might cause unnecessary worry, and that some would not want to think about their difficulties. The tone and information therefore needed to be accurate, proportional and engaging – and some titles needed rewording e.g. ‘think positively’.</p> <p>Professionals: It was suggested there could be more information on bereavement, loss and trauma, and links to local resources/services and other resources. There was a call for the use of the term ‘carers’ throughout, and for some of personal stories to be from their perspective.</p>	<p>More information will be added on these issues, and wording to be reviewed.</p> <p>The term ‘carers’ will be used more frequently, and personal stories will be added from their perspective.</p>

<b>Structure of sections</b>	<p>The main possible design change related to the restructuring of the sections. Whilst many young people preferred the current approach, especially on mobile devices, others stated the sections should be spliced into separate subsections. Some suggested the text could be cut down a little, for example with the use of bullet points.</p> <p>Professionals were stronger in their opinion that the sections should be divided into separate screens/subsections, rather than as one scrollable unit, although again there was no consensus. They commented far more than the young people on the excessive blocks of text, particularly in the introductory subsections and personal stories, although this view was based in part on using the package on old operating systems.</p>	<p>The text will be reviewed, and cut down where possible.</p> <p>The company will review the text size throughout.</p>
<b>Personal stories</b>	<p>Young people suggested the personal stories would need to be reviewed to ensure it was at the level and using age-appropriate terminology.</p> <p>Professionals: They called for a more visual approach, especially for the personal stories, through comic strips, 'student art' or photographs/videos. Worksheets, printed resources and elements of gamification were also suggested. There may also be a contrast issue with black and red/pink in the family/friends section.</p>	<p>Young people, and an author for young people, will be asked to review the personal stories.</p> <p>The company will review the colour contrast throughout the package. Explore adding more visuals.</p>
<b>'App' and technical issues</b>		
<b>Stuff I like / goal setting</b>	<p>The 'stuff I like' and 'goal setting' sections could be developed further, with more explanation, colour and engaging aspects, such as images/icons to represent links.</p>	<p>Explore how to make these more engaging e.g. colour/images.</p>
<b>Language</b>	<p>The 'app' would also need to be translated into Welsh, to be consistent with the rest of the package.</p>	<p>The 'app' will be translated into Welsh.</p>
<b>Technical issues</b>	<p>To address issues where giving access to the user to the 'app', and related to compatibility with devices and operating systems. Some found it difficult to access the internet, and wondered whether some information could be stored within the programme. The package was slow to load.</p> <p>Professionals: Programme was slow, or the animations did not appear – especially on older NHS computers. They wanted to ensure that users would be logged out if they closed the package.</p>	<p>The multimedia company will investigate the technical performance, check compatibility with operating systems etc. – and make improvements.</p>

## 8.4 Comparisons with other online packages

As noted previously, there is a lack of online interventions for adolescent depression, particularly with regards to psychoeducation. Available packages tend to target adults (see chapter 2). Therefore, there is little literature on the development of such interventions to give context to the current study.

There was some overlap in the content of 'MoodHwb', and the online/computerised PI programmes identified in the review. For example, the programme described by Stasiak et al. (2012), also covered depression, 'mental health hygiene' and stress reduction. In line with findings from this thesis, Demaso et al. (2006) found that personal stories were well-received in their feasibility trial of the 'Depression Experience Journal' website. This online programme, and one described by Stjernswärd and Hansson (2014), stressed the importance of supporting the families and carers of those with depression. This was also highlighted by participants in this study. Whilst a forum might be an option for parent/carers, young people only felt comfortable in sharing personal experiences through anonymous personal stories.

Some of the key issues raised in the qualitative work, such as design issues and the need for self-management strategies, were also raised in the focus groups conducted during the development of Beating Bipolar (Barnes et al. 2011); an online psychoeducation for mood disorders for adults referred to previously. There was a greater emphasis on relapse prevention for the latter project, given that this was designed for those already with a diagnosis. Participants in both studies felt that an overly formal design could disengage the user, and appreciated the benefits of a mood monitoring component (BipolApp in the case of Beating Bipolar). In this study, however, participants had reservations about applying some features of Beating Bipolar for the adolescent package, describing the former as 'clinical', 'adult' and 'cold'. Participants also concluded that young people would not be comfortable with forums or blogs, unlike Beating Bipolar, where a forum was included, although this was targeting a different age group and disorder.

The graphic illustrative and animated approach chosen by the research participants in this study is different to the approach taken by many sites dealing with youth mental health (e.g. youngminds.org.uk, thelowdown.co.nz, childline.org.uk), which are based largely on photographs of young people. When showing examples of other sites to the young person



groups, they noted that the most attractive online resources were those that were clear, colourful, graphic, uplifting, and positive in their design and content, such as ‘Headspace’ (headspace.com); a mindfulness resource primarily targeted at adults. This site also uses characters, imagery and visual metaphors, which were also found to be engaging for the young people in this study.

Whilst there are few PIs for depression in young people, there are some online CBT packages – although there is little literature on their development. Some of the themes discussed in the interviews and focus groups for this project have been applied to some existing online CBT interventions. For example, characters, avatars and gamification have been used with some success in SPARX, described previously (Merry et al. 2012). The researchers behind this intervention also consulted young people in its development.

A child-centred CBT and mindfulness programme for depression and anxiety, Pesky gNATs (NAT: negative automatic thought) (Tunney et al. 2016), also uses a game format, whereby the user learns CBT approaches whilst exploring a land. It has strong anti-stigma messages. As with Pesky gNATs, a multi-platform and ‘app’ approach, and audio-visual representations and components, were considered key features of this project, although there was less enthusiasm on incorporating games, other than quizzes.

## **8.5 Strengths and limitations**

### **8.5.1 Strengths**

One of the main strengths of the project relates to the rigorous methodology, which followed the MRC guidance for complex interventions, and the consultative and person-based approach (Yardley et al. 2015). A range of potential users of the package were involved from an early stage in its development, which will help to ensure that it is used in future. Interviews and focus groups progressed in an iterative fashion, so that participants could guide the development of the package. The interview and focus group transcripts were all analysed and double coded.

Another strength was the diverse range of participants in the development and evaluation phase (stages 2 and 4). Participants included young people from mental health services (primary and secondary care), schools and volunteers, many of their parent/carers, and a mix of professionals. 'At risk' young people were also recruited from a previous study sample. There were a range of recruitment centres in urban and rural areas across south and west Wales, including in areas with several ethnicities and areas of deprivation. Participants were also recruited from communities and schools where Welsh was spoken widely, so that the Welsh-language option could be used.

The results from the systematic review, interviews and focus groups were complemented by other investigations, including advice from experts in various fields related to the project, visits to centres of excellence in youth mental health and e-health in the UK and overseas, and workshops with multimedia professionals. The development of the package was strengthened by basing this on design, educational and psychological/behaviour change approaches, and on current research evidence and guidelines. The detailed description of the components and the development of the logic model also demonstrated how the intervention would be expected to work, and gave a framework which could be tested with mixed methods approaches. In all, this helped to create an accessible, engaging and informative package, which the user could personalise, which fits with the increasing interest in 'precision (or personalised) medicine' (Bahcall 2015).

A rigorous evaluation of the initial version using a range of methodology helped to develop the package further and inform its future direction. This stage used mixed methods and collected data from a range of approaches, including online usage data, pre- and post-intervention questionnaires, interviews and a focus group. The questionnaires used to assess adolescent outcomes were valid and reliable, and have been used in previous studies on adolescent depression. Efforts were made to engage the young people and families/carers by offering to see them where convenient to discuss the project and to complete assessments, including at their home, school and at the university. There was also contact afterwards to promote retention and adherence, including by email, text and phone message. The recruitment target of between 30 and 40 young people set at the outset was met, and there was a good retention rate (82% of young people). An amendment was made to the project so that parental consent was not required for those over 16, and this helped with recruitment for the evaluation phase.

Nearly all participants who completed post-intervention questionnaires used the online package with most young people using it for around half an hour or more at a time, which is a favourable response in terms of adherence for an e-health intervention (Hollis et al. 2015). A key aim of the evaluation phase was to assess feasibility, acceptability and completeness of data, and this was achieved – showing that the process of evaluation, as well as the package, was acceptable and feasible. Participants noted that the package was engaging, easy to navigate, and well-structured, and they praised the graphic and animated approach. The package and information included were considered helpful by most.

## **8.5.2 Limitations**

### **8.5.2.1 Development phase**

It is possible that the personal views of the student and research and multimedia teams could have influenced the process of development, as they were involved throughout the project, and the student led the interviews and groups. However, as noted previously, a range of groups were consulted in the development and evaluation of the package, which would help minimise bias. Certain decisions regarding development had been made prior to the interviews and groups. For example, that this would be an online resource targeting adolescent depression. The key themes that emerged may have been influenced by the consultations and topic/discussion guide. However, it was necessary to have some focus to the discussions to help develop the online package, and this was not an open ‘scoping’ exercise. Prior decisions were based on a review of literature and practice and expert clinical opinion.

As with all methods of data collection, there are limitations to the interview and focus group approach, especially with regards to the generalisability of the findings given the small number of participants, and the possibility that they are not representative of the population of adolescents at risk of depression or experiencing depression. There was an under-representation of certain groups, such as ethnic minorities, those from poorer backgrounds, and those with learning and other difficulties and disabilities. Given the inclusion criteria for the interviews and focus groups, it is possible there was some ‘self-selection’, in that participants were more likely to have an interest, and less likely to have

reservations about the development of the package.

However, a range of participants were recruited, reflecting the diversity of the possible user group, as noted previously, across a large geographical area. Efforts were made to make the focus groups balanced, and this was achieved to an extent with characteristics such as age, gender, and experience of mental health difficulties. The aim of qualitative research is also not generalisability in the statistical sense but to generalise to, and provide insights about, individuals in the same situation or context (Pope & Mays 2006).

It may be argued that the number of initial interviewees (n=12) at stage 2, was small, and that data saturation may not have been reached. However, many ideas and themes were repeated as the interviews progressed, indicating that saturation might have been reached, at least in part. The participants were purposively chosen at this early stage of the project to offer a range of viewpoints and generate initial ideas to guide later focus groups.

The number of those who attended the focus groups also varied across the study. Recruitment for young person group 2 and 3, where the majority had experience of mental health difficulties, was particularly difficult. Many did not attend because they were reluctant to discuss sensitive subjects with others, especially those whom they did not know, or because of their depressive and anxiety symptoms. The stigma and embarrassment associated with mental health issues could account for some of the recruitment difficulties. Other young people did not attend because of difficulties in travelling, or because they had other activities, such as examinations.

Some young people and parents had agreed to attend beforehand, but cancelled within a day of the meetings or did not attend, although this is not unusual for focus groups (Greenbaum 1998). At the start of one of the young person groups, one participant left early because she knew one of the other participants, and there may have been some conflict between them previously. Three fathers had stated they would attend the groups but did not, leading to an all-female parent group. This is consistent with other depression studies involving parents and their children, where most participants were mothers (Mars et al. 2012).

Several attended the first young person group without confirming beforehand, partly because of the enthusiasm of their parents (who had participated in the EPAD study). Perhaps it could have been made clearer there were only a certain number of places available. In fact, many of the young people in the study may have participated in the study because of the interest of their parents/carers – whilst at other times parents/carers were not aware of their child's participation.

With regards to group dynamics, some participants were more confident and vocal than others, especially in the young person groups, and there were also occasional disagreements between participants. This is to be expected to some extent in focus groups, where participants may be influenced strongly by dominant participants or 'opinion leaders'. There could also be 'groupthink' and 'public', rather than 'individual' and 'private' accounts of views, meaning that views can be censored and conform (Sim 1998).

All this might indicate that interviews are potentially a preferable format over focus groups in this context, although the group setting has advantages, for example for getting varied viewpoints (see chapter 3). To attempt to address the above issues, it was stressed beforehand that individuals would not be asked about their personal experiences, but rather their views on the online package, and that their participation would be confidential and efforts would be made to make the groups informal and harmonious. Gift vouchers were also provided as a thank you and to help cover travel expenses.

In general, all adolescents who attended the interviews and focus groups appeared enthusiastic and engaged, and seemed to appreciate the opportunity to contribute. Everyone followed the ground rules set at the start of the sessions, for example to respect the opinions of others. Several methods were used to encourage participation, including responding to designs on the screens, encouraging elaboration and appropriate interjections of humour. The writing and drawing of ideas were also encouraged in the groups, especially if participants did not want to discuss them verbally.

There may be limitations with generalisability in that the project was developed in south and west Wales, and it may be argued that there might be difficulty in rolling it out beyond these areas. However, other studies, programmes and expert advisors from around the world were consulted in its development – and it was developed to be helpful in general,

especially in the UK. The bilingual approach ensured that it was designed so that it could be translated into other languages in future. Further development and evaluation work could involve other centres outside of Wales.

Finally, the intensive development meant that the approach was time-consuming, particularly considering that most of the work was done by the student in consultation with the multimedia team, and several other agencies/university departments.

#### **8.5.2.2 Evaluation phase**

There were several difficulties in recruitment for the evaluation phase. Considering the number of centres visited, only a small number of potential participants were proposed for the project by the professionals based at the recruitment centres, which may have led to a biased sample. Several of those who initially showed interest in the project, did not go on to participate, and often no reason was given. This might reflect the difficulty in engaging young people in mental health research in general, or that the online package might be more useful for certain subgroups and contexts (such as schools, primary care or CAMHS). Some participants also required several prompts (email, text, phone) to use the package and complete the questionnaires.

There was the further difficulty in making the sample representative (for example in terms of ethnicity). However, we addressed the limitations in the same way as stated in the development phase (see previous subsection) by recruiting as diverse a range of young people as possible for the evaluation phase. More females than males participated in the research, although this might reflect in part how depression is more common in females in this age group (Thapar et al. 2012).

There could have been some bias with regards to the results of the evaluation. Participants might have reported more favourable responses because they were seen by, or in more regular contact with, the student, as participants had variable contact with the student or research team. Response bias could be an issue, for example where participants provide socially desirable answers. Young people might also have been less likely to give candid

responses in the presence of their parents/carers, although they were given the option of being seen alone.

Some of the online usage data generated by Google Analytics could be misleading, as it might include contamination by those who were not participating in the study and who viewed the log-in page (but were not able to access the package), such as 'fishing robots', or the researchers/designers who were involved in the development of the package. This data could therefore not be analysed effectively. Online usage data provided by the multimedia company could have been more refined, to allow separating of usage, for example of young people, parents/carers and professionals. With regards to the quantitative outcomes, the sample size was small and not powered to assess efficacy, and this meant that there were limits to what could be concluded from the questionnaire data. It also meant that the exploration of subgroups was not possible. However, we obtained useful information on feasibility, acceptability and completeness of data. Future research with a much larger sample is needed to explore whether outcomes are moderated by patient characteristics or factors such as amount of use.

Many of those who had improved may have done so in any case over time, or due to other interventions or factors, although data was collected on other sources of help received by the participants. Some had difficulties with access, for example due to technical difficulties in emailing links to the 'app', or related to more proximal factors such as Wi-Fi/broadband issues or mobile phone coverage in their area. This is linked to the general concern in e-health regarding the 'digital divide' between those with access to the internet and those who do not (Hollis et al. 2015).

## **8.5 Integration and context**

The integration of the online package into the lives of young people and families/carers and in services, was a theme discussed in the interviews, focus groups and other consultations during the development and evaluation phases. The findings suggest that the online package could help with the prevention and management of adolescent depression (including relapse prevention), potentially improve resilience, and help with other difficulties in this age group. In particular, it meets the need outlined in guidelines for depression in young

people (e.g. NICE 2005, and AACAP (Birmaher et al. 2007)) for good information and evidence-based psychosocial interventions for the young person, family and carer. The review of psychoeducational interventions in adolescent depression (chapter 2), concluded that there were few programmes, particularly online, which had been developed and evaluated according to rigorous methods, and this package helps to fill this gap.

In all, the project could also benefit the NHS and other services because it could help to raise awareness of adolescent depression, and engage young people with mental health issues and services. The package is also in line with how commonly the internet, smartphones and computers are used by young people (ONS 2016). It is also an opportunity to implement a novel intervention widely and at low cost compared to face-to-face therapies, and to fit with the drive towards self-management and autonomy (NICE 2005, AACAP 2007). Online interventions also address issues of accessibility, waiting lists and times, and treatment flexibility. Overall, the package fits with the UK government's push to provide access to online therapies to young people, through 'information and communication technology' (ICT) (CMO 2014, HM Government 2011, NIB 2016, Kelsey & Cavendish 2014).

The findings from the evaluation phase suggested the online package might be particularly helpful in the early stages of depression when a young person starts to experience difficulties. This could be when they first present to professionals, such as to primary care/mental health, school workers (teachers, counsellors, nurses, educational psychologists), or youth or charity workers. With regard the NICE guidelines for depression in young people, the intervention might be most appropriate at the initial (lower) levels of the stepped care approach – tier 1 and 2 (see fig 1.2, chapter 1). This would include an introduction to psychotherapies, and guided self help.

The package fits with the guided self help approach as it has been designed so that it can be used with another person such as a parent or professional if needed, as well as used independently. As noted in the review chapter, PIs could be delivered by a range of professionals, and Colom (2011) states that facilitators need to be an expert on the 'disorder' not the 'technique', and this would avoid the 'complex training' and associated funding required, for example for CBT. PIs could therefore help in areas where there is a lack of skilled alternative approaches, particularly in lower-middle income countries (LMIC).



The package could introduce the user to more specific psychological approaches, such as CBT, and they could even advance to online approaches which use this, such as SPARX (Merry et al. 2012). However, a recent RCT showed no evidence for the superiority of CBT or short-term psychoanalytical therapy compared with a brief psychosocial intervention in maintenance of reduced depressive symptoms 12 months after treatment (Goodyer et al. 2017). In addition, the package could complement (and be an adjunct to) other approaches, for example in the management of more severe or chronic difficulties. The package could also fit with the Improving Access to Psychological Therapies (IAPT) programme in England, which provides evidence-based treatments for depression and anxiety, implementing NICE guidelines (NICE 2005). It is also aligned with the increased interest in and calls for further resources and research in youth mental health, shown by the establishment of the International Association for Youth Mental Health (IAYMH) ([iaymh.org](http://iaymh.org)).

The evaluation phase also showed that the package could be used in other services and settings as well as the healthcare setting, including education services. Young people, parents/carers and professionals working in schools stressed the lack of mental health literacy provided, for example in PSHE sessions. It was suggested that aspects of this package could be shown in one or two sessions, and then it could be used by (and targeted at) those who needed it most. The package could also be used by and complement other services such as youth services and the work of charities.

Parents/carers, particularly those with a history of depression, conveyed their concern about the risk of mental health difficulties in their children, and were keen for this programme to be available for them and their children as well. Other individuals, such as friends or siblings, could also refer to the package if they were concerned about another young person. For this reason, and because many young people with difficulties don't present to services (Potter et al. 2012), the consensus from the evaluation phase was that the package should be 'open access'. However, they thought it would be most helpful for those starting to experience difficulties.

## 8.6 Future research

### 8.6.1 Research in the field in general

Further research is required in this field to determine the most appropriate methodology for developing and evaluating e-mental health interventions, especially for young people.

Organisations such as MindTech are exploring this area ([mindtech.org.uk](http://mindtech.org.uk)). This may be a focus for future NICE guidelines and research recommendations specific to e-mental health. There may, for example, be more appropriate methods for further developing/evaluating the online package, for example by incorporating more online feedback, triangulation, and by involving the multimedia company in the process from the outset, even when developing the research plan.

This and other similar projects are inevitably bound by the technology and resources available at the time, and therefore the findings and programme may seem 'dated' as this field advances further (Hollis et al. 2015); especially considering the long timescale of this development/evaluation phase (over 3 years), and any future trials needed before the package can become more widely available. The package will likely need to be reviewed regularly and the programme updated to help with 'future proofing'.

As discussed in the review chapter, there are other possible directions for further research in e-health for young people and psychoeducation. For example, there could be the establishment of an agreed definition of psychoeducation, as opposed to general health information and psychological approaches (see chapter 2). It will also be important to explore how best to personalise programmes and engage users through multi-modal interventions, and how to address the 'digital divide'. The review and interviews/groups also revealed the need for online PIs for difficulties other than depression, such as anxiety, and online programmes could be developed in these areas as well. Risk factors other than family history, including psychosocial factors, could also be used to identify possible participants for future research involving online and other interventions for adolescent depression.

## 8.6.2 Research for the online package

The further development and evaluation of the current online programme should follow the next phase of the MRC guidance for complex interventions (Craig et al. 2010), which would include a feasibility trial of the package. This would again take a mixed methods approach, but with a greater emphasis on quantitative data collection and trial methods than the development phase. The following research plan (see fig 8.2) has been developed in consultation with the research team and consultations with the South East Wales Trial Unit (SEWTU) (Cardiff University), and UK Child Psychiatry Research Society (CPRS). It has also been presented to (and discussed with) the Section of Child Psychiatry, the Division of Psychological Medicine and Clinical Neuroscience, and the 'Advice Leading to Public Health Advancement' (ALPHA) young person group, at the Centre for the Development and Evaluation of Complex Interventions for Public Health Improvement (DECIPHer), all at Cardiff University.

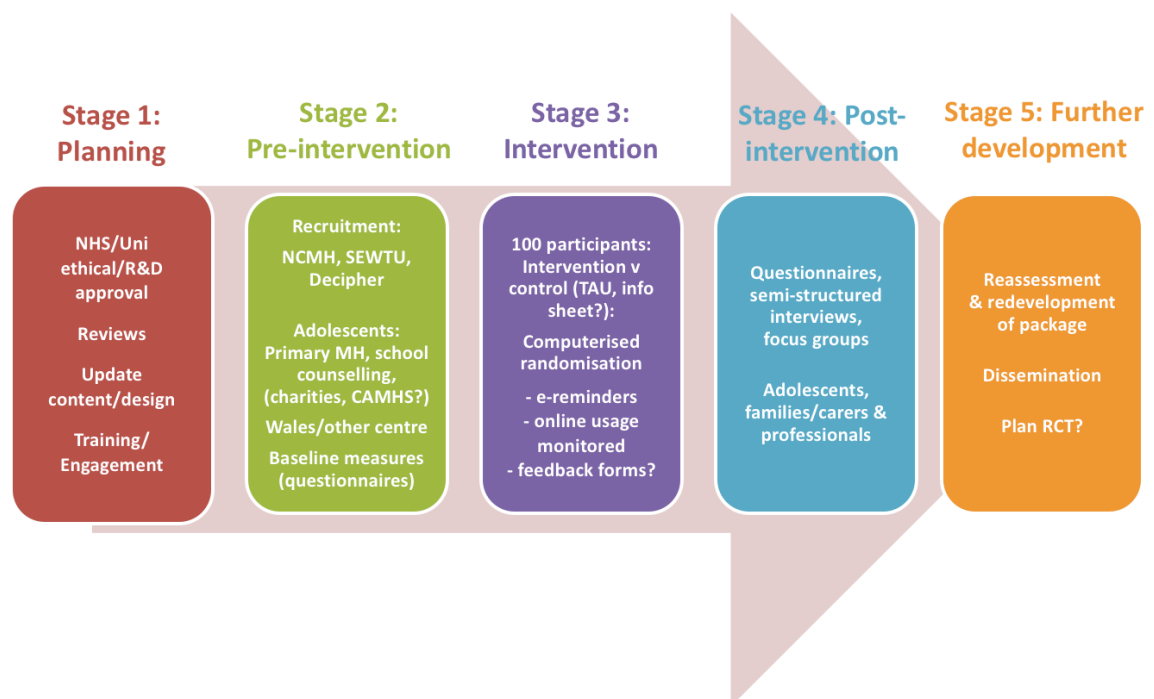


Fig 8.2: Possible research plan - further development and feasibility trial of online package

#### **8.6.2.1 Stage 1: Planning**

After securing appropriate funding, the first stage would include an application to NHS and university research ethics committees (because of the participation of schools), and approvals from health board research and development departments. A review of the current literature and guidelines in the field would help to update the content of the online package. Workshops with the multimedia company would be required to update the content, design and technical specifications, for example to conform with the latest devices and operating systems, and the university IT department would be consulted to upgrade the database capacity.

The evaluation data from the development phase would help to inform the approach taken in the trial, for example with regards to adherence, recruitment, and retention. The research team would seek to improve these, compared with the completed early evaluation, and assess whether in the feasibility trial pre-specified progression criteria were met in relation to these three areas (as well as feasibility and acceptability criteria), to progress to a full trial.

#### **8.6.2.2 Stage 2: Pre-intervention**

The second stage would involve recruitment of young people with depressive symptoms (and possibly those 'at risk'). As noted above, the most appropriate setting for the package could be the time when difficulties start and the young person first presents. Therefore, school counsellors/nurses and primary care/mental health centres could be the focus of recruitment. Youth services and charities could also be involved, as well as secondary CAMHS. Participants could also be given access to the package whilst waiting for services, such as secondary care. Further engagement meetings with professionals from these groups would be needed to build on the links created during the development phase. The ALPHA group also suggested advertising the project online, for example on social media, to help with recruitment.

Schools and services across Wales could be targeted, with the help of the National Centre for Mental Health (NCMH), SEWTU and DECIPHer – all of whom have shown an interest in

being involved in this project further. Another centre in the UK could also be involved, particularly to increase numbers, and to assess the package in another setting outside Wales. Participants could be asked to complete similar pre-intervention questionnaires to those used in stage 4 of the project on: depression literacy, stigma, help-seeking behaviour, self-efficacy, depression and anxiety symptoms and wellbeing. This could be via paper questionnaires as before, or online questionnaires, as suggested by the ALPHA group. The primary outcomes would need to be determined (e.g. depression and anxiety symptoms), as well as the secondary outcomes (e.g. depression literacy, stigma, help-seeking, self-efficacy).

### **8.6.2.3 Stage 3: Intervention**

Participants would be allocated to 1) the online package (possibly plus Treatment as Usual (TAU)), OR 2) TAU plus an information sheet on adolescent depression (such as those of the NCMH or RCPsych). Those in the control group could be given access to the package after the study. As advised by the trials unit, we would aim to recruit 100 participants, plus their parents/carers, considering the potential attrition, and ensuring that more would participate than in the early stage evaluation (chapter 7). Participants would be randomised 2:1, allowing for more information to be gained about those receiving the intervention. This is important, as the main aim of the study would be to assess the feasibility and acceptability of the intervention. Other outcomes of interest, such as recruitment and retention rates, and acceptability of outcome measures, could still be assessed using this allocation approach.

There would be liaison with the multimedia company to ensure participants can access the package and 'app'. Young people and families/carers would then use the package for around 3 months, and text/email reminders would be sent at regular intervals to encourage use of the package. The package would still be accessible to intervention participants beyond three months but we would not send reminders. Participants could write comments on the package as they use it, via a 'comments tab', or by contacting research team. Online usage data would also be recorded, possibly with more specific data than was available for stage 4 of the current project.

#### **8.6.2.4 Stage 4: Post-intervention**

Participants would then be asked to complete the same questionnaires post-intervention as were completed pre-intervention, as well as a further questionnaire on the participant's use and views of the package. This could be at two time points, such as after 3 months and then 6 months. Up to 40 young people and parent/carers would be interviewed, the number would depend on data saturation. There could also be focus groups with young people, families/carer and/or professionals, and further workshops. A key focus would be to further develop and test the logic model to examine the mechanism of action, and active components of the intervention.

#### **8.6.5 Stage 5: Further development and plan for next phase**

The data from stages 3 and 4 would inform the further development of the package with the multimedia company, and the findings would be disseminated. If the study met the pre-specified progression criteria, then we would look to plan a larger-scale trial (RCT). This could be alongside other therapies such as CBT, which would be in line with the latest NICE research recommendations (NICE 2015), which advise trialling online CBT with another online self help intervention. The full RCT could assess the package as a stand-alone intervention or as an adjunct in services.

### **8.7 Summary and conclusions**

An online psychoeducation package for adolescents with (or at risk of) depression/depressive symptoms and families/carers and professionals, was developed following a rigorous development approach. This included a systematic review of the literature, interviews/groups with potential users, consultations with experts in the field and with a multimedia company. An early evaluation revealed that the package was acceptable, feasible, clear and easy to use, and its assessment was acceptable, and results from this stage informed the final development phase of the project. This will also inform the future development and feasibility trial of the package. This is important to establish effectiveness,

so that it can be rolled out in health, education, youth and social services, and charities to help young people, families/carers, friends and professionals.

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## Appendix 1: Recruitment and consent documents

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**CARDIFF UNIVERSITY**  
PRIFYSGOL CARDIFF

**NHS**  
National Institute for Health Research

ID number.....(for office use)

## Assent form for Young People

• Version 4, November 2013

**Developing an Online Package to help with Mood & Well-being in Young People**

Young person (or if unable, parent on their behalf) to circle all they agree with:

Have you read (or had read to you) the information sheet for Children and Young People?	Yes	No
Has someone else explained this project to you?	Yes	No
Do you understand what this project is about?	Yes	No
Have you asked all the questions you want?	Yes	No
Have you had your questions answered in a way you understand?	Yes	No
Do you understand it's OK to stop taking part at any time?	Yes	No
Are you happy to take part?	Yes	No
Do you agree for the interview to be audio recorded for research purposes only, and the recordings to be typed by a professional company?	Yes	No
Do you agree for us to let your GP know you are taking part?	Yes	No

If any answers are 'no' or you **don't** want to take part, **don't** sign your name!

If you do want to take part, please write your name and today's date

Your name	Date	Signature
-----------	------	-----------

Your parent or guardian must write their name here too if they are happy for you to do the project

Parent's name	Date	Signature
---------------	------	-----------

The researcher who explained this project to you needs to sign too

Researcher	Date	Signature
------------	------	-----------

Name of person taking consent (if different from researcher)	Date	Signature
--	------	-----------

**When completed:**  
1 for patient, 1 for researcher site file, 1 (original) to be kept in medical notes

**CARDIFF UNIVERSITY**  
PRIFYSGOL CARDIFF

**NHS**  
National Institute for Health Research

ID number.....(for office use)

## Consent form for Young People

• Version 4, November 2013

**Developing an Online Package to help with Mood & Well-being in Young People**

Please initial boxes

For example: R B J

I confirm that I have read and understand the information sheet for young people dated November 2013 (version 3) for the above study

I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily

I understand that my participation is voluntary and that I am free to withdraw

- At any time
- Without having to give any reason
- Without my medical care or legal rights being affected

I agree for the interview or discussion group to be audio recorded for research purposes only, and the recordings to be typed by a professional company

I agree to take part in the above study

I agree to my GP being informed of my participation in the study

Name of participant	Date	Signature
---------------------	------	-----------

Name of person taking consent (if different from researcher)	Date	Signature
--	------	-----------

Researcher	Date	Signature
------------	------	-----------

**When completed:**  
1 for participant, 1 for researcher site file, 1 (original) to be kept in medical notes

**CARDIFF UNIVERSITY**  
PRIFYSGOL CARDIFF

**NHS**  
National Institute for Health Research

ID number.....(for office use)

## Consent form for Parents/Guardians of Young People participating in research

• Version 4, November 2013

**Developing an Online Package to help with Mood & Well-being in Young People**

Please initial boxes

For example: R B J

I confirm that I have read and understand the information sheet for parents/guardians of young person participating in the research, dated November 2013 (version 3) for the above study

I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily

I understand that my child's participation is voluntary and that they are free to withdraw

- At any time
- Without having to give any reason
- Without their or my medical care or legal rights being affected

I agree for the interview or discussion group to be audio recorded for research purposes only, and the recordings to be typed by a professional company

I agree for my child to take part in the above study

I agree to my child's GP being informed of their participation in the study

Name of parent/guardian	Date	Signature
-------------------------	------	-----------

Name of person taking consent (if different from researcher)	Date	Signature
--	------	-----------

Researcher	Date	Signature
------------	------	-----------

**When completed:**  
1 for participant, 1 for researcher site file, 1 (original) to be kept in medical notes

**CARDIFF UNIVERSITY**  
PRIFYSGOL CARDIFF

**NHS**  
National Institute for Health Research

ID number.....(for office use)

## Consent form for Parents/Guardians

• Version 4, November 2013

**Developing an Online Package to help with Mood & Well-being in Young People**

Please initial boxes

For example: R B J

I confirm that I have read and understand the information sheet for parents/guardians dated November 2013 (version 3) for the above study

I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily

I understand that my participation is voluntary and that I am free to withdraw

- At any time
- Without having to give any reason
- Without my medical care or legal rights being affected

I agree for the interview or discussion group to be audio recorded for research purposes only, and the recordings to be typed by a professional company

I agree to take part in the above study

I agree to my GP being informed of my participation in the study

Name of participant	Date	Signature
---------------------	------	-----------

Name of person taking consent (if different from researcher)	Date	Signature
--	------	-----------

Researcher	Date	Signature
------------	------	-----------

**When completed:**  
1 for participant, 1 for researcher site file, 1 (original) to be kept in medical notes

Consent forms for the development phase (English versions)



## Appendix 2: Focus group discussion slides

### Selection of slides shown during a focus group

#### Slide 1: Welcome screen:



NHS  
National Institute for  
Health Research

CARDIFF  
UNIVERSITY  
PRIFYSGOL  
CARDIFF

Welcome!  
Croeso!

Facilitators:  
Rhys Bevan Jones  
Harriet Beeching

#### Slide 2: Aims

##### Aim of project:

To develop an online package for mood & well-being in young people (aged 14-18 years) & their families/carers

##### Aim of group meeting:

To discuss ideas for the content & design of the package & related issues

##### Why should I help?

- Package will benefit young people & families
- Opportunity to develop a package rolled out across the UK
- £25 gift voucher for taking part

#### Slide 3: Some points

- Refreshments
- Toilets, emergency exits
- Confidentiality
- Digital recording & using the information
- Information sheets & consent forms
- Name badges
- Post-box
- Duration - maximum 1.5 hour
- We'll be around afterwards

#### Slide 4: Ground rules

Everyone to contribute (some more familiar with study than others)  
One person to talk at a time  
Respect each other's comments  
No wrong answers  
Not asking about personal experiences  
Discussion not to go outside of the group  
You may leave at any time (please let us know)  
Any questions?

#### Slide 5: Final check

Refreshments  
Completed consent form  
Name badge  
Paper & pencil/pen  
Any more questions?  
Start recording...

#### Slide 6:



#### Slide 7: Initial questions

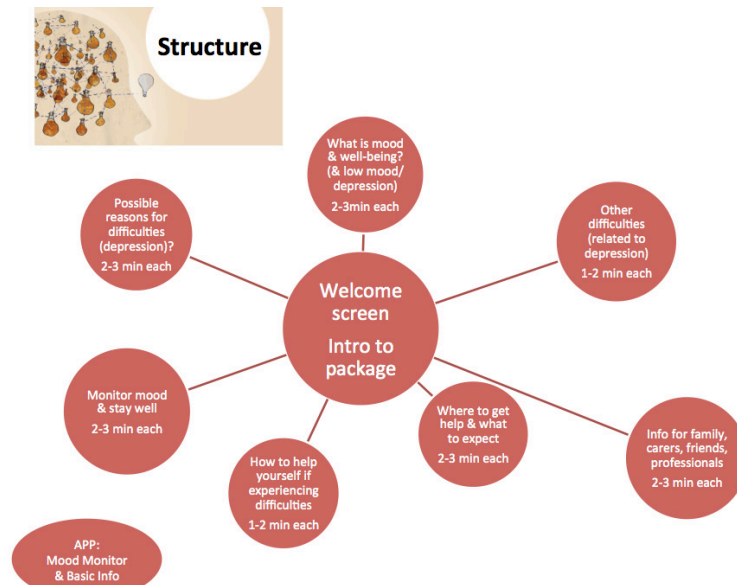
How many here access the internet regularly?  
How many use the internet to look up information on health & mental health?  
How many would use an online package for mood and well-being?

Briefly explain:

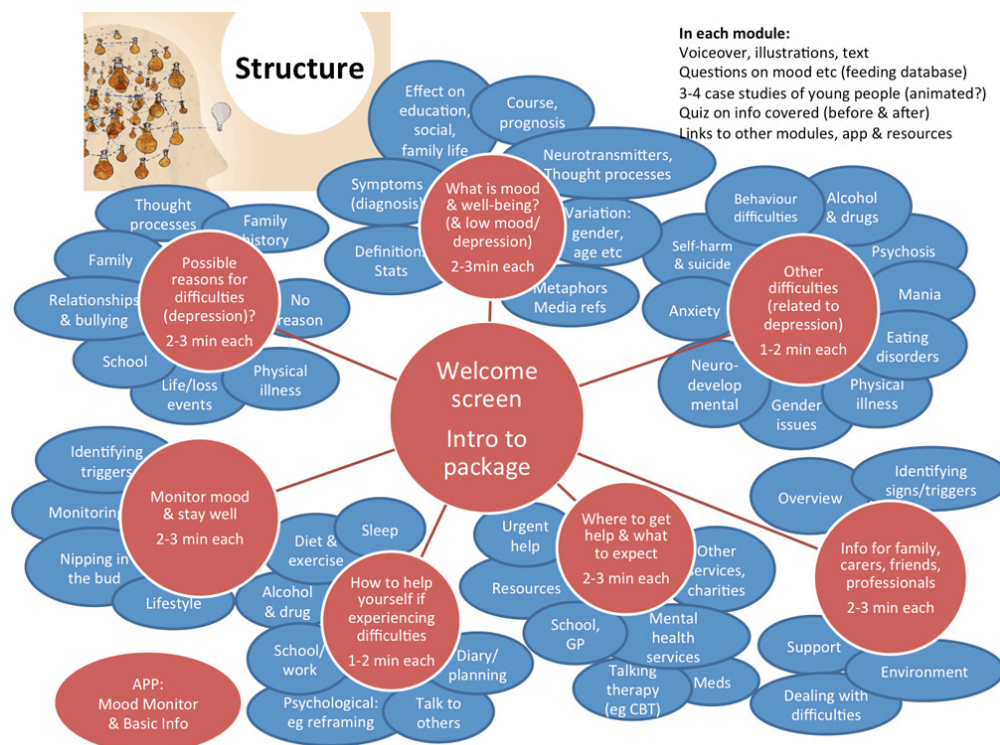
why you are interested in this study  
&/or whether this package is needed and why (or any general comment about the study)

## Slide 8 & 9: Structure and content of package

The content and structure was discussed, with a general initial question on 'what information should be included in the package?' – then each of the modules or circles below would appear in sequence.

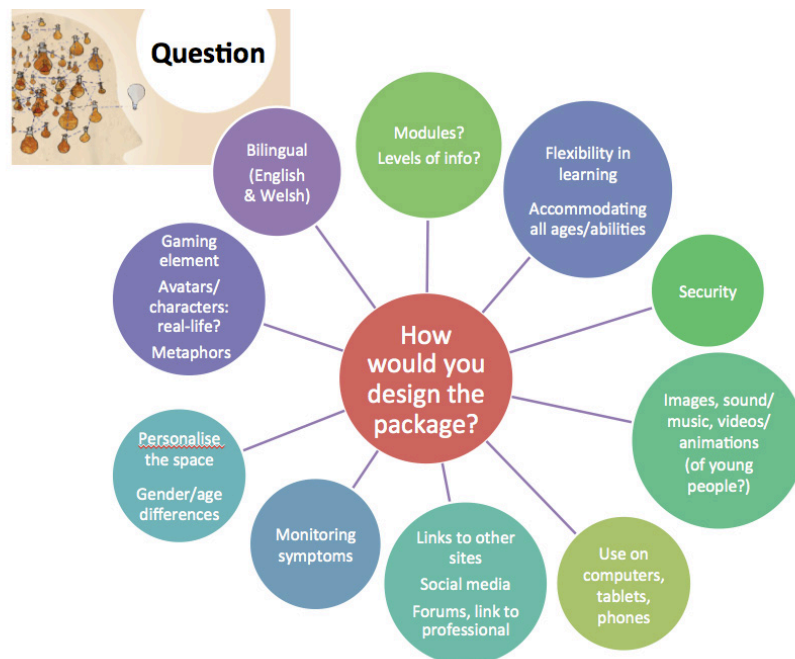


For each module of the package, we then discussed the specific information which should be included. The structure evolved with each focus group, and participants were asked to comment on this.



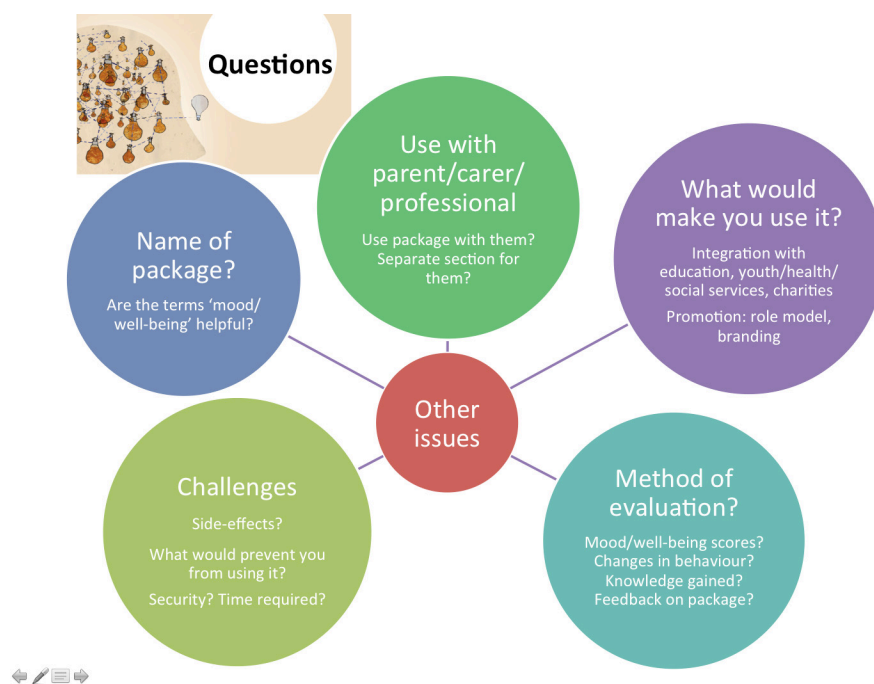
## Slide 10: Design issues

The specific design issues of the package were then discussed in sequence.



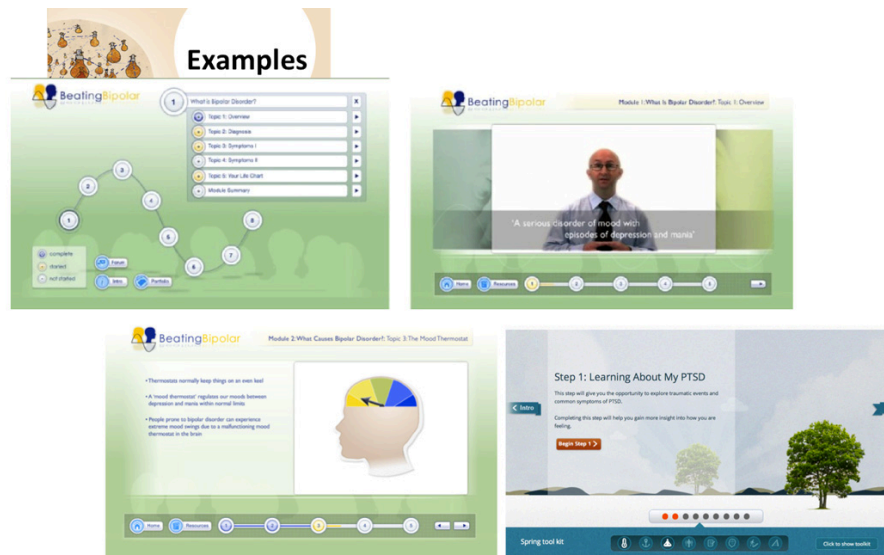
## Slide 11: Other topics

Finally, there were additional questions regarding the package's use with others, what would make the person use the package, how would it be evaluated, the challenges and side-effects and the potential names of the package.



## Slides 12-15: Examples of educational packages

Examples were then shown of educational healthcare packages and websites to help inform the current project, with certain components of the packages shown, and participants asked to respond to aspects of these.



### Online (adult) healthcare packages

Beating Bipolar Education for Bipolar Disorder [www.beatingbipolar.org](http://www.beatingbipolar.org)

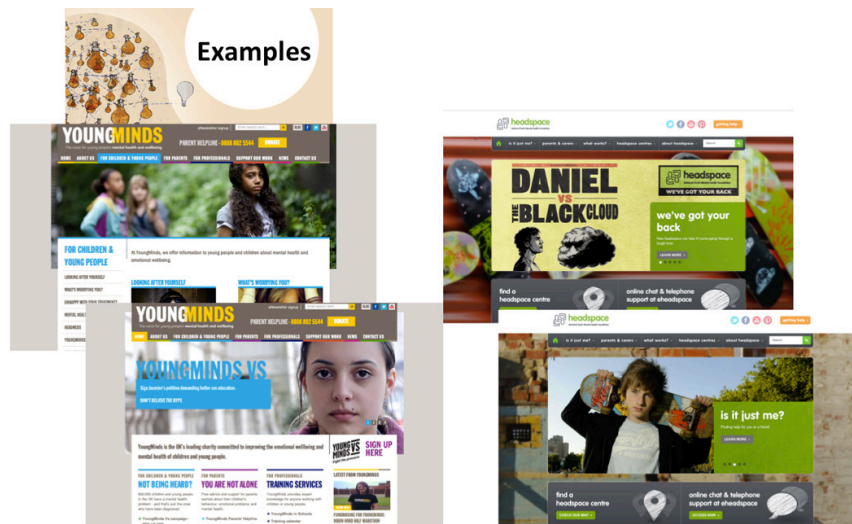
Spring Education for Post-traumatic Stress Disorder [www.mypstd.co.uk](http://www.mypstd.co.uk)



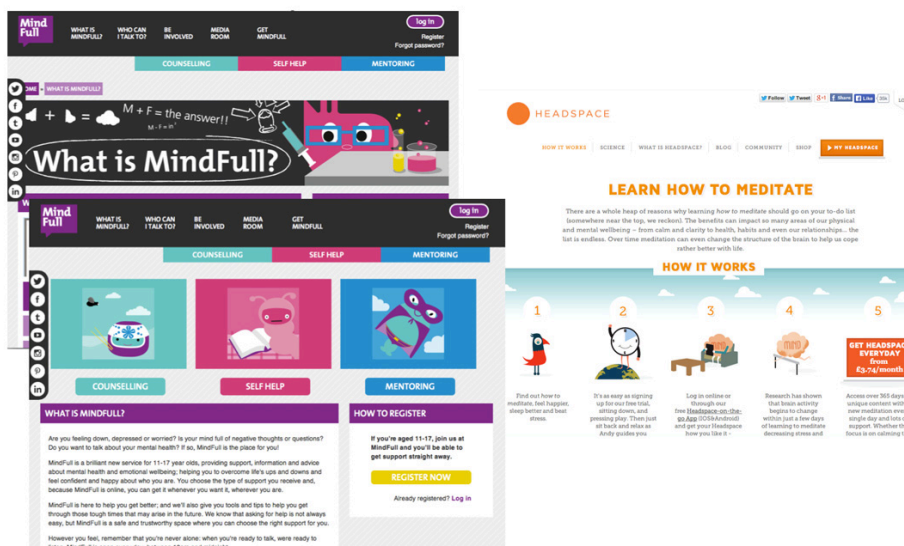
### Online package on depression in young people:

The Lowdown (New Zealand) [www.thelowdown.co.nz](http://www.thelowdown.co.nz)





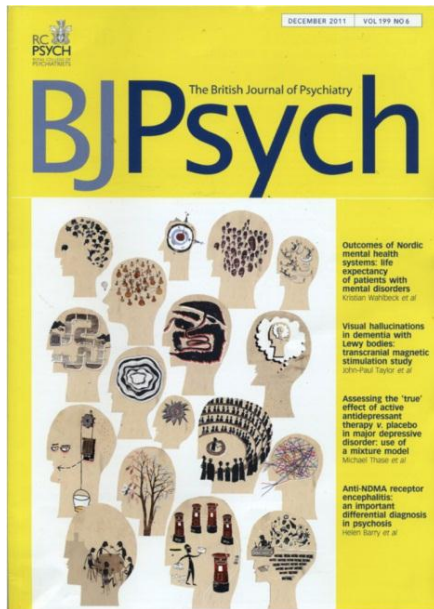
Mental health websites for young people:  
 YoungMinds [www.youngminds.org.uk](http://www.youngminds.org.uk) (UK);  
 Headspace [www.headspace.org.au](http://www.headspace.org.au) (Australian)



Online (illustrated) healthcare packages:  
 Mindfull [www.mindfull.org](http://www.mindfull.org); Headspace [www.getsomeheadspace.com](http://www.getsomeheadspace.com)

## Slides 16-20: Examples of images which could inform the design of the package

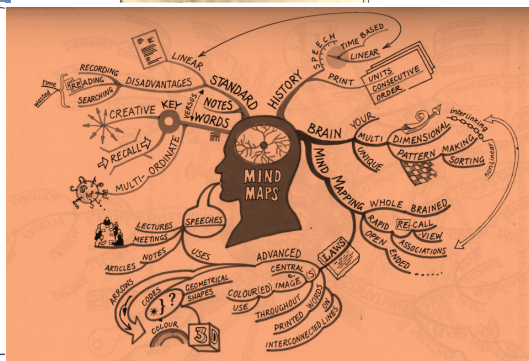
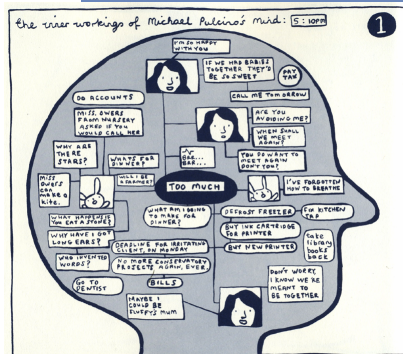
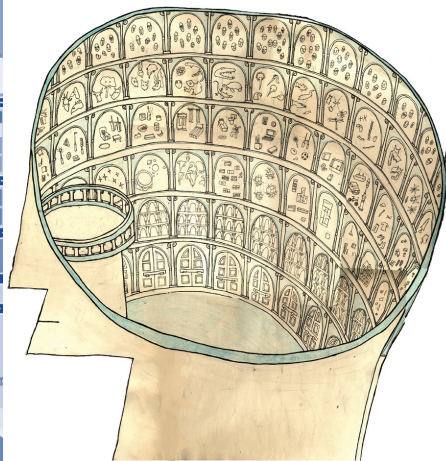
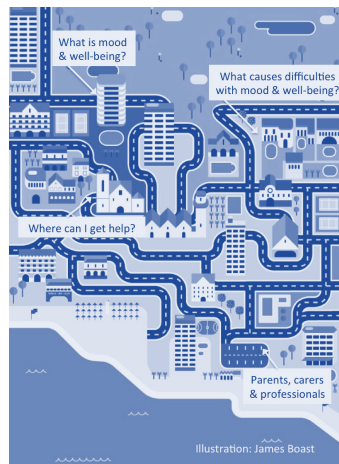
The following images (unless credited) were developed by the student after asking young people and others how they 'see' the mind/mental states. These images/characters - and the idea that the user could go on a journey around a map - were discussed in the interviews and groups. A range of approaches to the imagery were discussed, including a graphic illustrative approach, which might engage/accommodate a range of ages and backgrounds (compared to photographs). We developed these ideas further with the multimedia company.



Figs: 'Metaphors of the mind' – how individuals 'see' the mind



Figs: 'Drawing depression' – images based on responses to the question 'how do you see depression?'



Figs: The user could go on a journey around a map e.g. in a head/mind-map, town, park, tree (Illustrations - top left: James Boast; lower left: Simone Lia; lower right: Tony Buzan)

The final slides allowed participants to raise any other issues and ask questions. Participants were also thanked, and directed to resources on depression and other difficulties. They were also informed that they could write any comments (or draw any images) if they did not feel able to do so during the focus group itself, and leave them in a box in the room. They were also informed that the group facilitators would be available after the meeting to discuss any issues, particularly if they felt distressed or concerned about any issues arising from the meeting.

### Appendix 3: Further themes from the interviews (stage 2)

The following themes in appendix 3 and 4 emerged from the discussions in the interviews and focus groups of stage 2. They were not included as part of the main thesis because they were not considered as relevant as the other issues for the development phase of the package.



## Location/town as a metaphor

Several participants suggested the online package could have a central theme, of a location such as a head, town/village, landscape, or park, with the ability to personalise and click on certain aspects, such as stations/buildings/snack bars and go inside them. A mind-map was a related suggestion by professional 4.

Young person 4 was particularly enthusiastic about having a town populated by young people as a framework for the package. She suggested calling this 'MoodyVille', with characters such as 'Moody Margaret' and 'Rude Ralph'. She suggested certain buildings could house sections of the package, for example a school could hold the school-based issues related to depression, and the university holds the research and evidence in this area. One parent suggested there could be a family section within this town.

Parents were generally in favour of a town metaphor, although parent 1 was concerned that there was a risk of representing someone going around in circles, or '*bumbling along in a maze*'. Professional 4 also urged caution:

*'It needs to be explicit, not too convoluted...There's a fine line between the interesting and fascinating or weird' (Professional 4: female: educational psychologist).*

However, the metaphor of a journey (or map/path) was a popular idea among interviewees, and an element of achievement, continuation and progress within the package.

*'I know personally I'd prefer the journey approach, the feeling of having progressed and...I'm beginning to understand this' (Professional 3: female: general practitioner).*

Parent 1 found it better to show a more linear user experience. A young person described a more abstract approach.

*'It's like an analogy that I saw that really resonated with me was, if you imagine life is like an arrow, which it kind of is, it's that when you're going back into all the crap, that's because life is about to propel you into the good stuff' (Young Person 3: male: under CAMHS).*

## **What can we learn from other sites and packages?**

During the interviews, existing online packages were discussed, and what could be learnt from them with regards the content, design and other aspects – including positive and negative aspects. It was suggested there could be links to some of these sites in the package.

### ***Beating Bipolar***

One of the most frequently discussed was the 'Beating Bipolar' package, which was developed to help adults diagnosed with bipolar disorder (Barnes et al, 2011). Whilst a few liked it, all felt that the design was not appropriate and too 'clinical', 'uniform' and 'adult' for the current project. Professionals also noted that it was too detailed:

*'Having looked at the Beating Bipolar site that strikes me as that there is only a few teenagers that would want that kind of detail' (Professional 2: male: psychiatrist).*

### ***SPARX***

SPARX was discussed a great deal, particularly by the professionals, in the context of online resources for adolescent depression. This is a gamified CBT-based package, which is based in a fantasy land, and was developed in New Zealand by Merry et al (2012). Professional 2 particularly liked how the player could choose a male or female avatar, and how they could change their dress, hairstyle and body shape, and encounter guides on their journey. Professional 3 described the game as '*clever and arresting*', and particularly liked learning aids within the game, such as the 'sword of truth'.

However, some cautioned that it might not be the ideal model to follow. It was felt that it could overwhelm or distract, and may not be suitable for those with anhedonia or concentration difficulties.

### ***Other health related resources***

There were mixed feelings about 'Beat bullying' and 'ChildLine' sites, with some thinking they were too 'serious' and 'grim'. Young people liked the 'Mindfull' site in general, as it was thought to be 'personal', especially because of the ability to log in, and 'nice' and 'organised'. Young person 4 liked its 'straight lines', but did not like the abstract cartoons, 'girly' colours, and preferred more figurative drawings and less text. Three parents favoured the 'Mindfull' website, stating it was 'visually better for the age group' and had 'nice colours' and was 'fun'.

Young person 2 liked 'Headspace' because it appeared youth-friendly and activity-based. 'Talk to Frank' was described as 'useful', but had possibly too much information. Professionals suggested MoodGym (Australia), The Lowdown (New Zealand) and YoungMinds as good resources. Another professional referenced a self-harm forum. Professional 3 referred adults, to 'Getselfhelp.co.uk', because she was familiar with it, but described it as 'unfriendly, boring, unclear, cluttered with advertising', 'overloaded on the front page' and 'needing guidance'. She did not recommend it for young people for these reasons.

### ***Non-health related websites***

Professionals liked the sites of 'Welsh Water' and 'WWF', and described them as friendly, bright, animated, moving, arresting, colourful, and inviting interactivity – and engaging for young people. Professional 3 stated that young people expected this 'cool, good' look. The website of the S4C children's programme 'Cyw' was shown as well. One professional found this 'very young'.

*'Maybe a half-way house between Cyw (lovely, fun, busy) and Beating Bipolar (cold, sterile, clear)' (Professional 4: female: educational psychologist).*

'Minecraft' was cited by one parent as an example of a popular online game with young people.

## Evaluation of online package

All parents thought this package should be assessed, with young people, parents and others, for example with those accessing therapy. Some proposed evaluating it in schools and youth clubs, as only a small number present to GPs. The results would be used to improve the package:

*'If the right information is there, it's going to work' (Parent 3).*

Professionals offered a range of evaluation approaches, especially qualitative feedback by young people on content and design. Professional 1 proposed asking the user *'What do they want to get better? Has it?'*. To ensure that components such as the language were appropriate, professional 2 suggested asking the young person: *'Is this really representative of you?'*. One parent stated there could be a 'pop-up' questionnaire every fifteen minutes or so as the package is used.

Professionals suggested using formal evaluation tools before and after using the package, such as MFQ and SDQ for depressed mood, demographic and psychological profiles, and wellbeing measures (from the EMBAR project (class/school) or PASS survey (feelings about themselves) (Professional 4)). Careful screening was recommended by professional 3, in case the person was too unwell, using BPA, HADS, and MFQ.

*'I'd need to see if this isn't working...we need to move on and do something else' (Professional 3).*

One parent suggested a focus on depression awareness and mood. Online usage, such as number of clicks or hits, and duration of use, was also suggested. Three questions were proposed by professional 1:

*'1) Does the young person feel they've had an improvement in their life that enables them to cope with/get rid of problems? 2) Are you doing a good job as a professional? 3) Government / public health priorities – admissions for self-harm, referral rates, school engagement, literacy, sex, drink, arrests etc. – multifactorial approaches...figures for Wales' (Professional 1).*

## Challenges and potential side-effects

A major challenge identified was *'pin pointing it all...communicating things simply'* (Young person 2). Challenges identified by parents included addressing all the target audience, especially as: *'everybody suffers differently'* (Parent 2). Professionals suggested looking at barriers to engagement.

*'Like all these sites, setting them up is really difficult and hard, but it's much easier than keeping them going...Disengagement could be because 1) they're better or 2) it's rubbish'* (Professional 1: male: psychiatrist).

The time taken to complete the package was seen as a possible obstacle. Professional 3 was concerned about the possible lack of supervision – and suggested that school counsellors could help implement this. One parent stated that it was important it was user-friendly, as some are not computer-literate.

## Appendix 4: Further themes from the focus groups (stage 2)

### What can we learn from other sites/packages?

Several existing resources were discussed in the groups. **Beating Bipolar**, an online psychoeducation package for bipolar disorder for adults, was shown in some groups. Favourable descriptions from young person group 2 included 'really tidy', 'appealing', and negative comments included: 'square' and 'manufactured'. Young people noted a need for balance in terms of content and design, to make the structure engaging.

A similar package '**Spring**' (a CBT-based package for PTSD in adults) was also shown. Both Beating Bipolar and Spring were described as 'a bit generic'. Young people liked the navigation and progress bars in both packages, and preferred the option to take a 'linear progress' or 'jump around'.

Research professionals had mixed feeling about Beating Bipolar. The package was described as 'clear', 'nice and simple, not too daunting', with a logical way of progressing. The graphic presentation of information was considered potentially helpful for young people, and not

patronising. They also appreciated the option of reading the content as text, as well as through video and animation. However, the package was described as 'a little boring' for young people, and 'heavy' with too much information and 'talking'.

Young people in group 1 referenced the websites of the charities **Mind**, **Samaritans** and **YoungMinds**. Clinical professionals discussed **Doc Ready** (information to help a person before seeing a health practitioner), **SPARX** (gamified CBT-based programme for adolescent depression), **Think Good Feel Good** (CBT-based CD-ROM for depression and anxiety) and **'Living with a Black Dog'** ('app' - information on depression).

The **YoungMinds** UK youth mental health site was described as 'too much, samey'. Young people in group 2 described the Australian youth site, **Headspace**, as 'better for young people, more personal', although many also thought it was 'too much'.

**Mindfull**, a website for depression in children and young people (which was later taken down because of a lack of funding) was shown in some groups. Young people in group 1 commented that it was 'a bit childish, like primary school', whilst group 2 noted the characters were 'really cute', and approved the bright uniform colours. There were reservations about the links to social media, such as Facebook, Twitter, for the reasons discussed earlier. Some clinical professionals liked the imagery, describing this as 'trendy', whilst others were concerned that the characters were too 'child-like' for teenagers, and the site was 'a bit text heavy'.

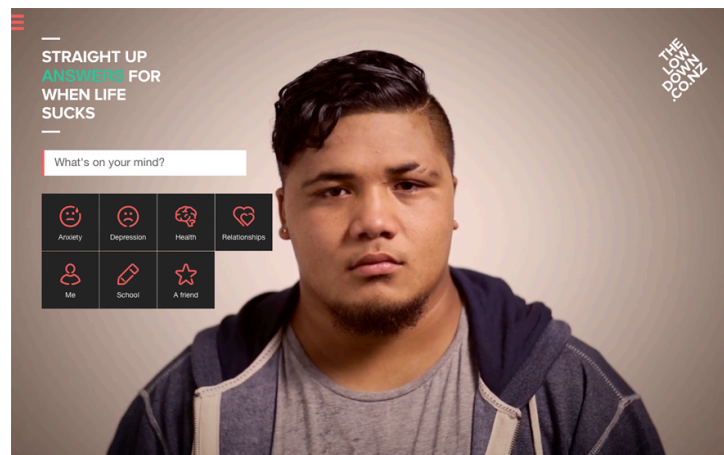
Nearly all in young person group 2 liked the illustrated, creative and colourful approach another site named **Headspace**, which introduced meditation and mindfulness. However, one participant stated that the characters 'look so sad'.

**The Lowdown**, a youth mental health site from New Zealand, received a mixed response in young person group 2. On this site, it was possible to choose a celebrity to guide the user through the package. One described this as 'more personal', whilst another stated that aspect was 'a waste of time'. This site was revamped by the time of young person group 3, with more photographs of young people, and videos of 'real life' case studies.

*'I like that they're obviously real people ...although they're not all real' (Young person FG3).*

*'It's a bit offensive really, what's wrong with normal people' (Young person FG3).*

One described it as 'really cheesy'. All preferred the illustrative approach of Mindfull and Headspace, and the moodboards.



Screenshot from the latest version of The Lowdown

The language used in The Lowdown also drew a mixed response from young people, with phrases such as 'straight up answers'. One person stated:

*'It makes it quite real – although it could seem too 'down with the kids' – and can sound a bit stupid' (Young person FG3).*

All stated they were more likely to use the package prototype we had presented (in development).

*'It's better for what the aim of it is – more suitable and organised' (Young person FG3).*

Research professionals commented that the site of the **Royal College of Psychiatrists** was 'just black and white, generic'. **Talk to Frank** (information for young people on drugs) was generally well received by the young people. Non-health related websites were also discussed, for example that of **Welsh Water**, and the graphics were generally well received.

### **Difficulties/challenges in the development of the package**

Parents stated that the 'greatest difficulty' was to make young people want to use it. A parent and professional also warned of the risk of duplication of existing sites. Professionals compared the package to resources such as MindEd, although they acknowledged the latter was targeted mainly at professionals. Parents stated there it might not address the lack of services, particularly urgent help, out of hours.

*'It's pretty, shiny, interesting - but practically how helpful it's going to be for people in a desperate state?' (Parent FG).*

Clinical professionals also cautioned that the package itself could have side-effects, and possibly 'induce' low mood.

*'Talking about depression and thinking about it can lead to low mood' (Clinical professional FG).*

### **Method of evaluation**

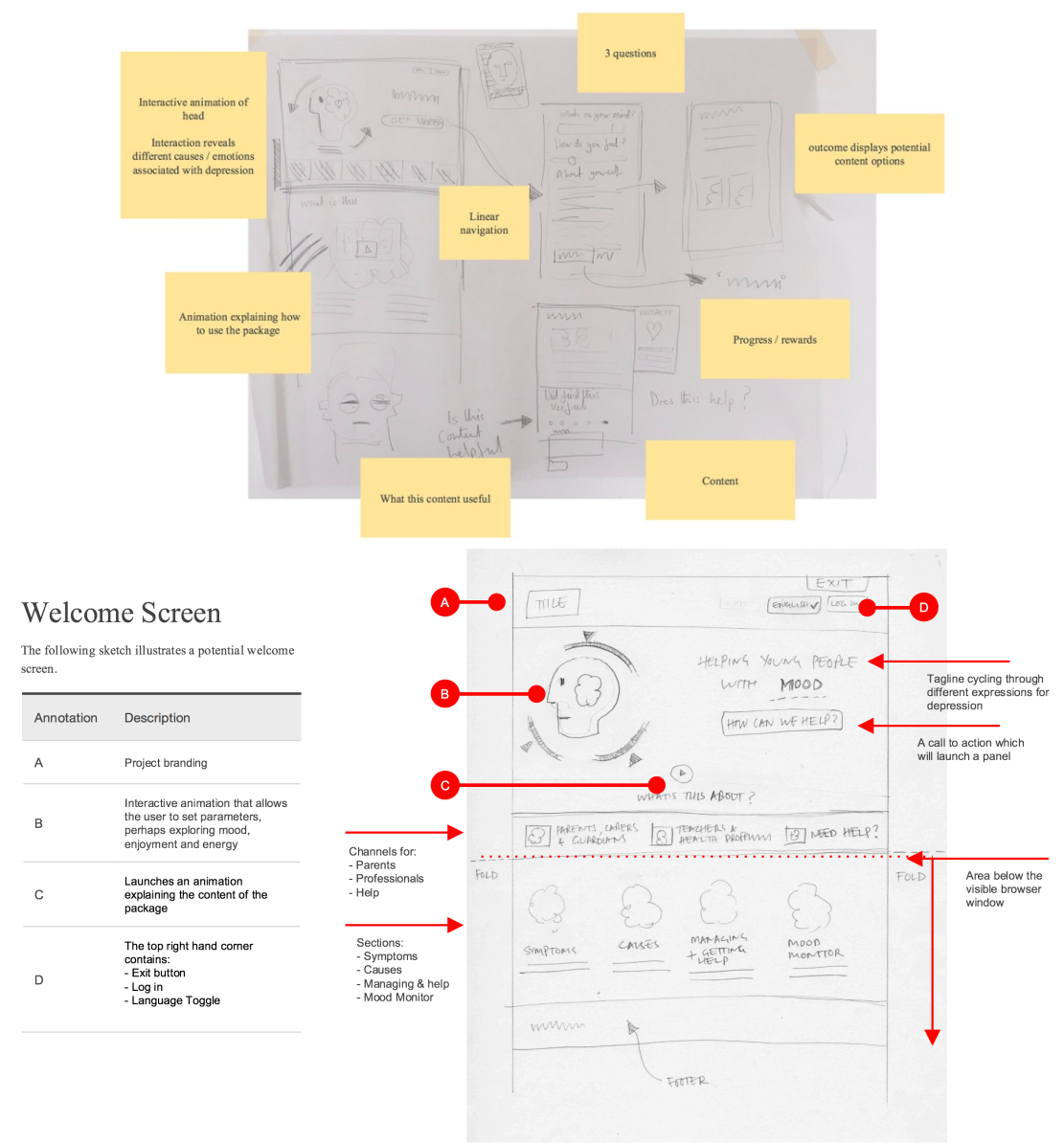
To evaluate the package, clinical professionals suggested that young people could have the option of rating aspects of the package whilst using it, for example on whether it is 'comfortable' and 'effective'. This could be out of five, as with consumer websites. However, a participant in the first young person group stated there should not be 'annoying pop-up' surveys.

Young people in group 3 suggested that young people with depression could use the package, and the outcomes could be compared with those of another group who did not have depression, but who were 'just curious'. All participants in the group stated they would be happy to be approached. Clinical professionals also suggested 'tracking' the online usage of the package.

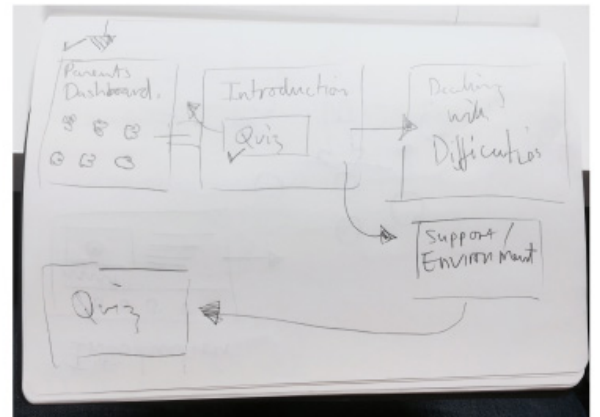
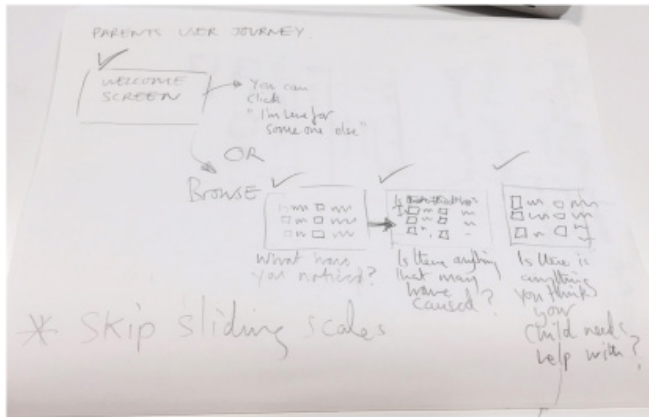


However, clinical professionals stated there was a risk that asking young people to complete scales could seem ‘condescending’. They also noted that tracking the use might require the user to register, and this made it less anonymous. Parents advised that it should be made clear to users there is no right and wrong outcome, and they are ‘not being marked out of 10 on their performance’.

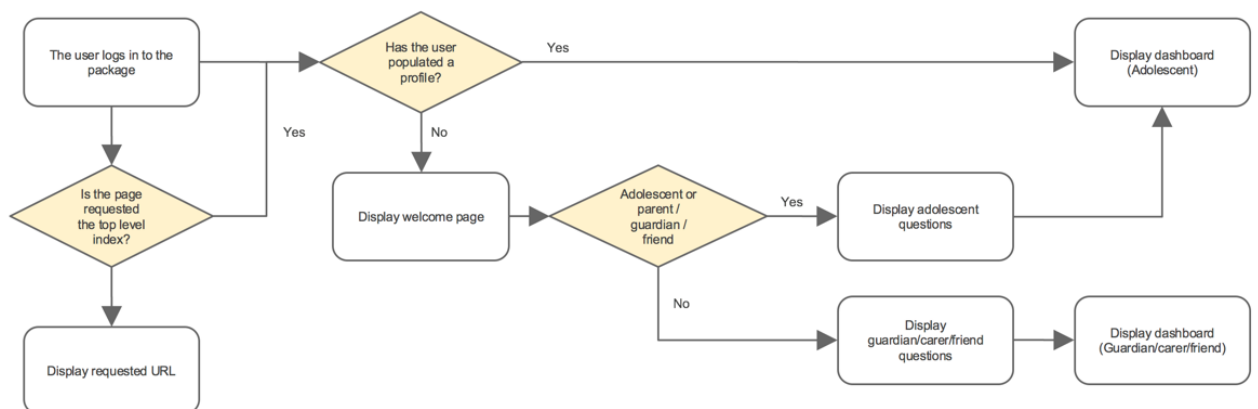
Appendix 5: Figures related to the development of the package



Early sketches for the welcome screen



Sketches for the parent/carer user journey



User flow diagram from the 'information architecture' document

## How do you feel?

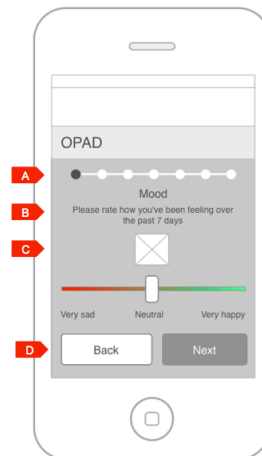
The following sketches illustrate selecting "How can we help?".



## I'm here for myself

The following wireframe illustrates the mobile "I'm here for myself" question screens.

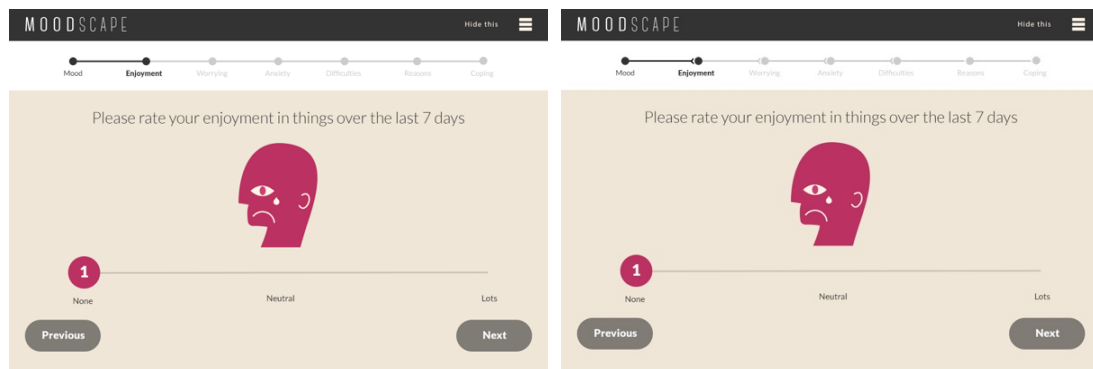
Annotation	Description
A	Indicates which question the user is currently on The number and all questions will need to be editable
B	The question is displayed here
C	An image is displayed representing the current value and when the user moves the slide the image will update The user can choose from 7 values and the slider will snap to each point
D	The user can navigate back and forth through the questions Selecting next will submit the current value



A scoring model will be adopted, the number outside of the brackets represents the slider scale and the number inside the brackets represents the weighted score. The weighting will need to be customisable per question.

Red	1(-20) 2(-10)
Yellow	3(-1) 4(0) 5(1)
Green	6(2) 7(3)

Sketches showing user options (above), and wireframes (below)

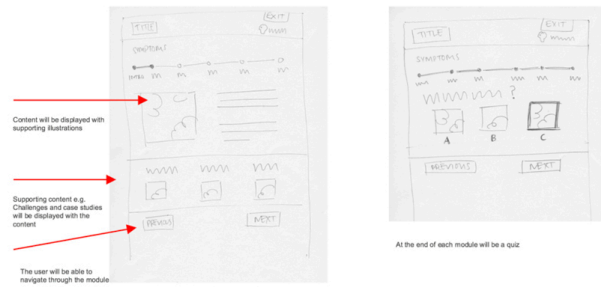


Early designs for the head icons and progress bar, to resemble a neuron (right)



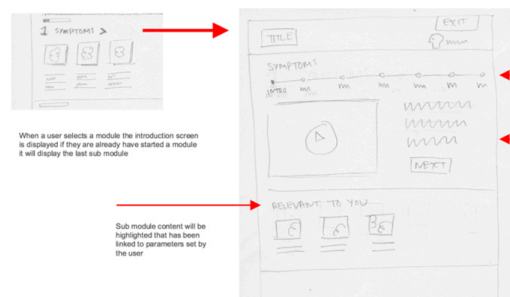
## Module Content

The following sketch illustrates the introduction to a module



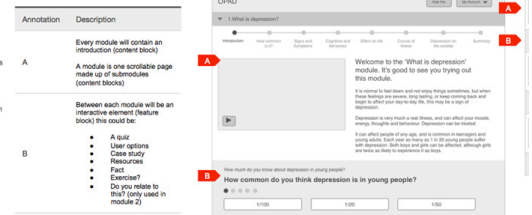
## Module Introduction

The following sketch illustrates the introduction to a module



## Module Structure

The following wireframes illustrates the module structure.

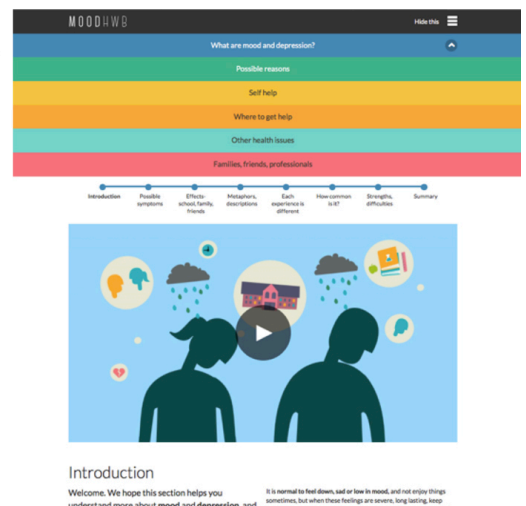
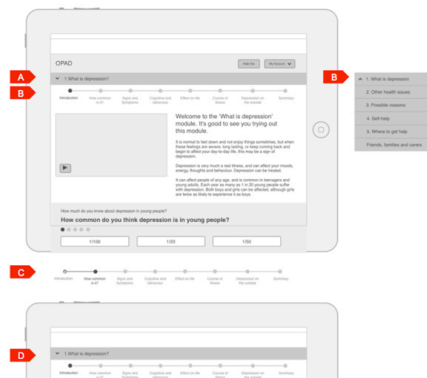


Examples of initial sketches (above, below left) and wireframes (below right) for the 'What are mood and depression?' section

## Module Navigation

The following wireframes illustrates the table/desktop module navigation.

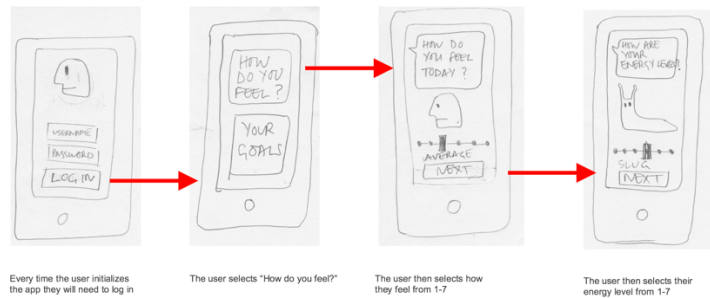
Annotation	Description
A	Module navigation The menu will display the current module Tapping the menu will allow the user to choose another module
B	Sub module navigation The menu will be displayed as a progress bar and will indicate the current module
C	When a module has been viewed a tick will be displayed
D	When the user scrolls the two menus will remain fixed to the top of the viewable area within the browser window



Navigation of the package: Wireframes (left) and colour designs (right) showing the progress bar, 'drop down' menu and introductory animation

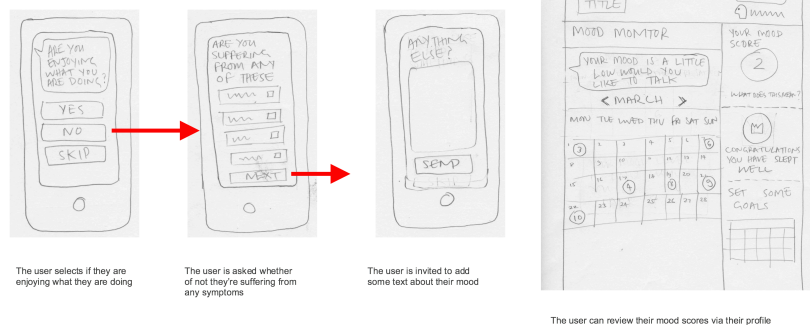
## Mood Monitor 1

The following sketch illustrates the mood monitor application



## Mood Monitor 2

The following sketch illustrates the mood monitor application



## Initial sketches for the 'Mood monitor'

### Mood monitor

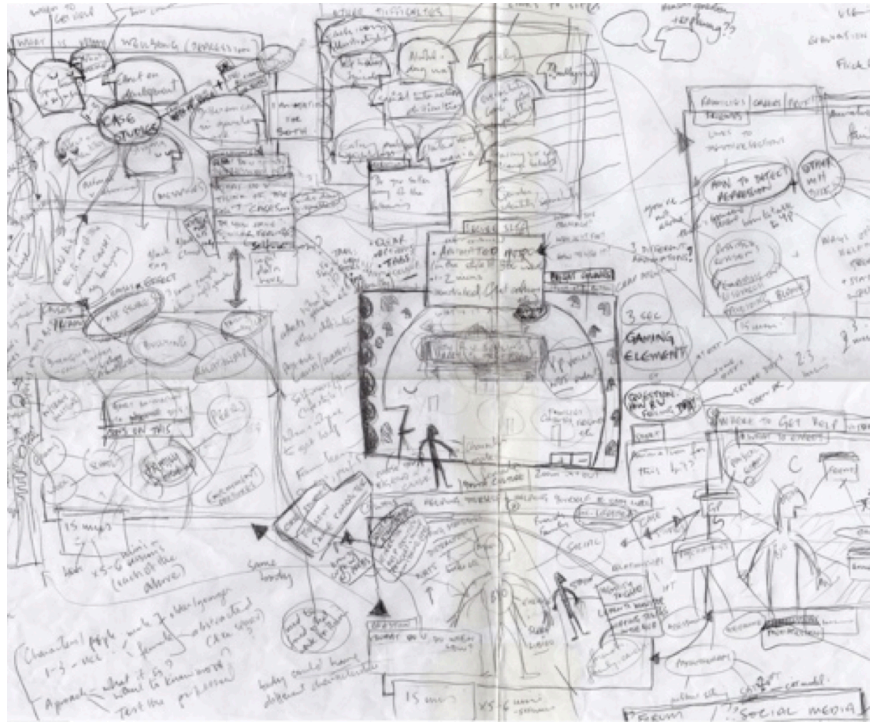
The following wireframes illustrates the mobile 'Mood monitor' screen.

Annotation	Description
A	The user can choose a month to view
B	The user can update their mood
C	The user can navigate the weeks by: <ul style="list-style-type: none"> <li>Tapping the left and right arrows</li> <li>Sliding the screens left and right</li> </ul>
D	When data is submitted a coloured dot is plotted to: <ul style="list-style-type: none"> <li>The day (5AM-12PM, 12PM-5PM, 5-12PM, 12PM-5AM)</li> <li>X axis 1 (bottom) 7 (top)</li> </ul>
E	Select a coloured dot will display a panel containing: <ul style="list-style-type: none"> <li>Score</li> <li>Date</li> <li>Timeblock e.g. 12pm - 5 pm</li> </ul>

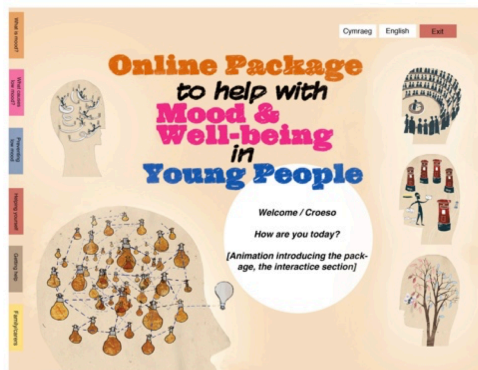


## Wireframes showing the 'Mood monitor'





Initial graphic sketches for the package and its section



Welcome/contents screen – ideas for design



Welcome screen - further ideas



Welcome/contents screen - further ideas



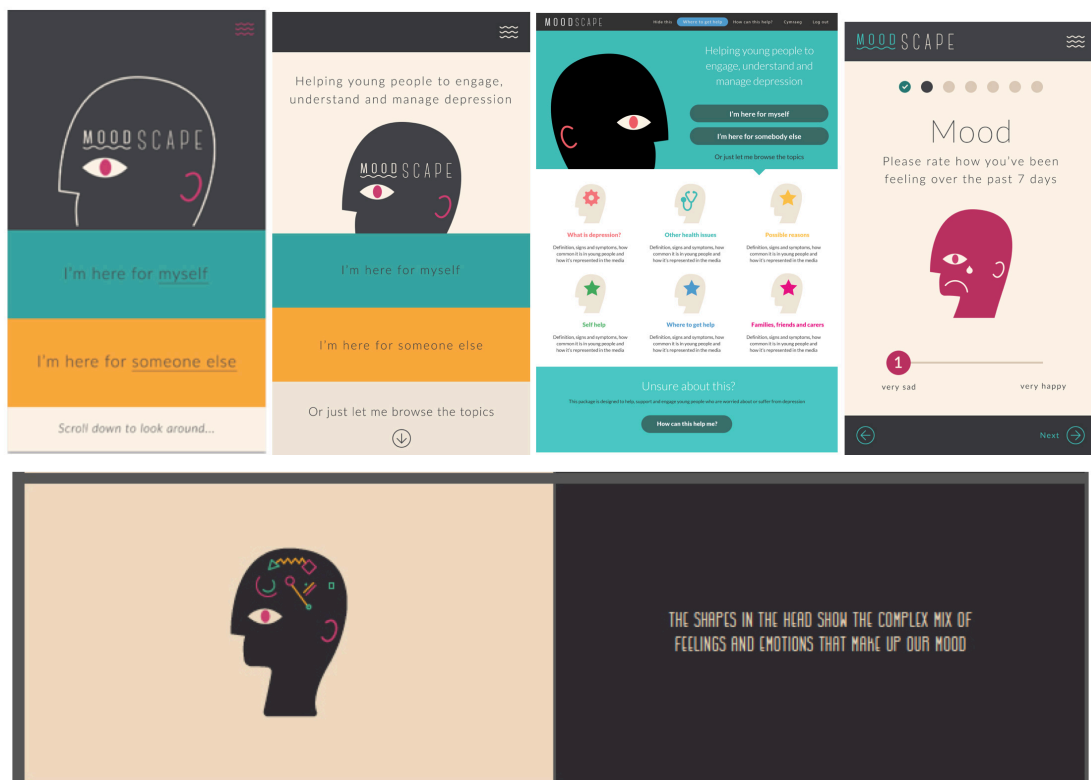
Ideas for the welcome screens and navigation using some of the images above



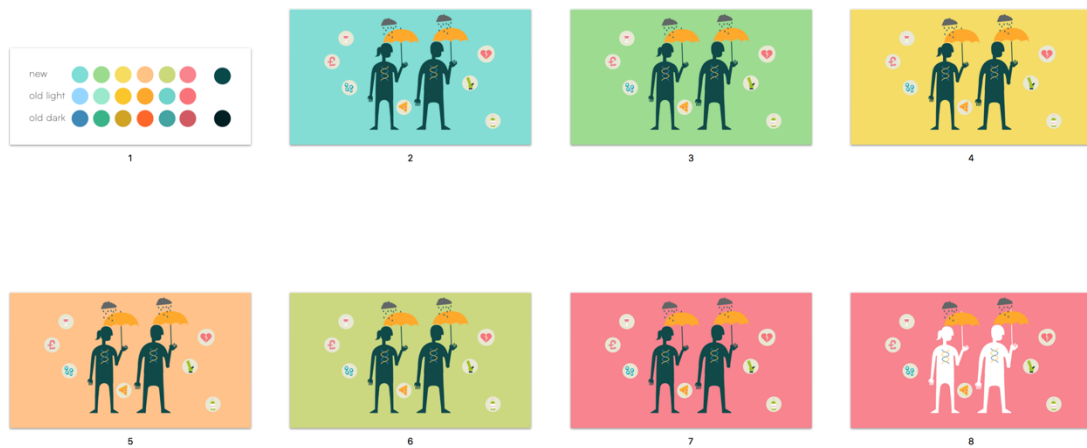
Initial ideas for the colours and general (linear) illustrative approach for the package



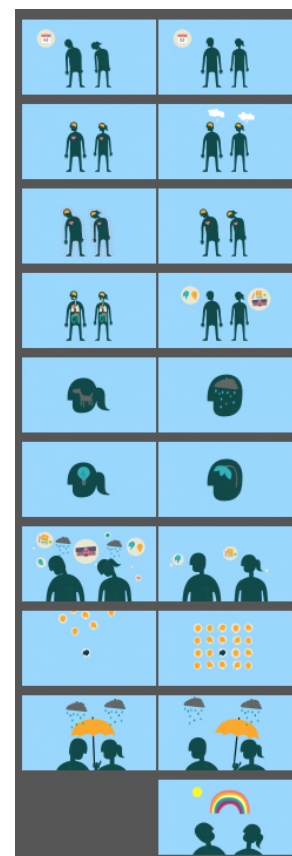
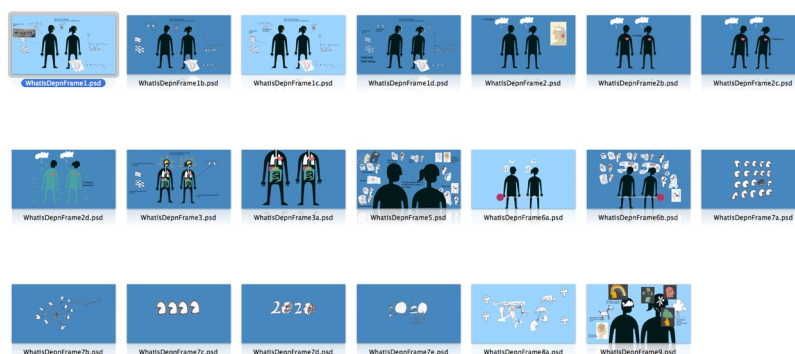
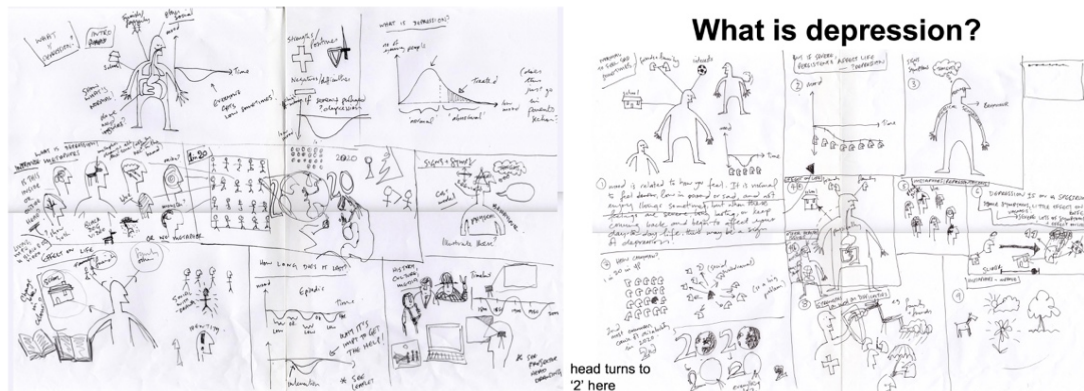




Demonstrations of the initial experimental screen and character designs



Alternative colours considered to make the package a little brighter, and softening the black characters and dark backgrounds.



Initial sketches and storyboards for the 'What are mood and depression?' animation



Voiceover artists and recording technician/editor at the recording studio