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Stepping Up
when arthritis or pain gets you down

Final Report

June 2011
Executive summary

In 2009 a team of researchers submitted an application to the beyondblue Victorian Centre of Excellence for Research into Depression and Related Disorders (bbVCoE) for a project to develop and test an internet based intervention for people with arthritis and co-morbid depression and/or anxiety. The concept for the research came from ten years of involvement with research and evaluation of self-management support programs for people with arthritis. It was clear that these programs often found people with co-morbid depression and/or anxiety too complex or that the programs were unable to meet these peoples’ needs.

Funding was awarded to develop and pilot the intervention. On the basis of an extensive consultation process a preferred model for implementing for the Stepping Up program was identified. This model was a hybrid in which an initial telephone assessment would be conducted by a health psychologist who would then allocate on-line modules to participants on the basis of their agreed needs. The health psychologist would have weekly email contact throughout the project.

The choice of this model raised the issue of the ability for the model to be rolled out and delivered through other agencies and by other service providers. For this reason, when the researchers received a second round of funding from bbVCoE, it was decided to use the money to refine the program for use by agencies and providers that have a self-management support role and to test the ability for it to be implemented and its usefulness in other settings. This decision had been made before the pilot phase of the first project and so the need to inform the second project guided some of the evaluation design for the pilot.

The main activities of the project are summarised in the following table.

<table>
<thead>
<tr>
<th>Dates</th>
<th>Main activities</th>
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<tbody>
<tr>
<td>Nov 09 – Feb 10</td>
<td>Establishment phase: Met with investigators, employed staff, established external reference group (ERG), obtained ethics approval for consultation phase</td>
</tr>
<tr>
<td>March 10 – May 10</td>
<td>Conceptual development phase: Concept mapping, literature review, review of other web-based interventions, consultation with experts and the ERG, develop and obtain feedback on discussion papers</td>
</tr>
<tr>
<td>June 10 – December 10</td>
<td>Website and material development phase: Developed web infrastructure to allow delivery of a customised set of modules to each participant. Development, consultation and revision of all program materials</td>
</tr>
<tr>
<td>December 10 – April 11</td>
<td>Pilot project phase: 43 people were recruited and 40 commenced the program. 34 people completed the program in the time frame available. Three decided the program was not for them and three could not complete in time due to other events in their lives.</td>
</tr>
<tr>
<td>May 11 – June 11</td>
<td>Evaluation and reporting phase: Data analysis and report writing.</td>
</tr>
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</table>

The Stepping Up program

A priority for the project, from the time of its initial conceptualisation, was to develop a program that was useful to people who would be likely to miss out on other programs because of the complexity, or perceived complexity, of their problems: in particular the interaction between physical and mental health problems. This raised two requirements for the researchers in developing the program: a) conceptualising complexity and b) understanding the ways in which physical and mental health problems interact. In relation to the first issue it was decided that to understand complexity it is necessary to consider:

- The number, type and severity of people’s medical conditions
- Additional social and life factors such as peoples living arrangements, relationship situation, employment situation and finances
- The trajectory of their current situation – whether they have experienced long-term spirals of decline and erosion of confidence or whether they are dealing with relatively new and acute issues
- A subjective sense of complexity where people feel that there is large amount going on in their life and that they have too many things to deal with.

In relation to the question of the interaction between people’s physical and mental health problems, there was a strong emphasis in the consultations, on the ways in which this interaction is played out in relation to current functional demands or fears about the person’s ability to function in the future.

People often consider that their depression and anxiety is understandable given the concerns that they face. They may, however, also recognise that their depression and/or anxiety has become intense enough that it is a problem in its own right.

In response to the consultations the researchers developed a model that included three main phases, the details of which can be seen in the following figure.

- A telephone assessment, in which the consumer selects one issue to address during the program

• A series of interactive self management modules, tailored to address the consumer’s selected issue and personal circumstances. Weekly email support is also available through this phase, in addition to access to website features that support client learning and change
  o The first two sessions aimed to assist people reflect on and understand their health situation better and identify their main health concern.
  o The third session was a module focusing on their identified main problem.
  o Most of the remaining sessions covered different approaches and/or techniques to help with the selected main problem.
  o The final session was a wrap up session.
• A telephone review, in which the consumer’s progress is reviewed and their need for further support assessed.

Outcomes from the pilot program

Data on outcomes and feedback on the program was obtained using a number of methods:
• Pre and post questionnaires (AQoI, heiQ, DASS, K-10)
• Demographic and diagnostic data (intake interview)
• Module rating scales, main perceived benefits and comments
• Exit interviews and summary assessments by health psychologist
• Follow-up evaluation interviews
• Usability study
• Website statistics.

The results were very positive indeed and ranked among the most positive outcomes that the researchers have seen in programs that have used the same instruments.

Some of the highlights in the outcomes data are:

- Very large changes in the negative emotions, skills and social support scales of the heiQ
  compared to all Australian programs (in some scales the changes appear to be the largest
  seen in Australia);
- Average improvement in the AQoL of 0.11, that is approximately three times the minimum
  meaningful change (in utility terms it means 11% of the difference between death and
  perfect health);
- Very high proportion of extremely positive comments at follow-up interviews (above 50%
  whereas around 20% is common)
- Very high proportion of people listed specific changes in behaviour that they have made and
  which they directly attribute to the program (> 90% whereas <50% is common for self-
  management support programs).

While a number of elements and modules were highlighted as particularly helpful by participants the
most frequent response to questioning about what aspect of the program was most helpful was that
it was the program as a whole and the way it all fitted together.

The most frequent negative comments related to timing issues: either that the program was too
short and the participants felt rushed at the end; or that they did not like being locked out of
commencing a new module for three days.

Implications for the future

There were a number of aspects of the program that the researchers and the health psychologist
believe will be difficult for non-psychologists to implement without very specific training and without
access to suitable secondary consultation support. For this reason the researchers are looking to re-

design the initial case formulation phase to make it easier for both the clinician and the participant.
The researchers have also determined that they will need to take an organisational development

approach to implementing the program in other agencies. This will be necessary to ensure that the
appropriate supports are available and that the program is implemented in a way that fits in with
the organisations priorities and work practices.
Contents

Contents ............................................................................................................................ i
Table of Tables ................................................................................................................ ii
Table of Figures ............................................................................................................... iii
Abbreviations ................................................................................................................ iv
Acknowledgements ........................................................................................................ iv

1 Background and focus for this report .................................................................... 1
  1.1 Over view of the project activities and timelines .............................................. 2

2 The Stepping Up model and program ................................................................. 3
  2.1 Conceptual starting point ................................................................................. 3
    2.1.1 The projects concept of self-management and self-management support ... 3
    2.1.2 The concept of ‘complexity’ ................................................................... 4
  2.2 Development of the model ............................................................................. 4
    2.2.1 Outcomes from concept mapping and other consultation processes ....... 5
    2.2.2 A guiding model for program development ......................................... 6
  2.3 The broadening focus – arthritis to musculoskeletal, depression and anxiety to psychological distress ......................................................... 8
    2.3.1 Target users ............................................................................................... 9
  2.4 The Stepping Up program – clinical and self-management support .......... 10
    2.4.1 Initial interview and case formulation ..................................................... 10
    2.4.2 The modules ........................................................................................... 12
  2.5 The Stepping Up program – software and website .................................... 14

3 Data collection methods ...................................................................................... 15

4 Who were the participants of the Stepping Up pilot program? ......................... 17
  4.1 Demographics ............................................................................................... 17
  4.2 Health conditions .......................................................................................... 18

5 What is the Stepping Up program? ................................................................... 20

6 Program input and completion by participants ................................................. 22

7 Program input by health psychologist ................................................................. 26

8 Program outcomes ............................................................................................. 27
  8.1 Overview of outcomes ................................................................................... 27
  8.2 Health psychologist exit interviews .............................................................. 28
    8.2.1 Improvement in main concerns .............................................................. 28
    8.2.2 Additional outcomes identified at the exit interview ......................... 32
8.3 Quantitative outcomes data .................................................................................. 33
  8.3.1 The Health Education Impact Questionnaire (HEIQ) ........................................... 33
  8.3.2 Health-related Quality of Life ............................................................................. 35
  8.3.3 Depression Anxiety Stress Scales (DASS-21) and K-10 ........................................ 37
8.4 Immediate outcomes related to each module ......................................................... 42
8.5 Follow-up interviews ............................................................................................. 43
  8.5.1 Interview data related to outcomes ..................................................................... 43
  8.5.2 Interview data related to program features and characteristics ......................... 45
  8.5.3 Overall opinions of the program ....................................................................... 46
9 USABILITY ISSUES and FEEDBACK ........................................................................ 47
10 Summary and implications for the second Stepping Up project .............................. 50
Attachments .................................................................................................................. 1
  Attachment A: Concept mapping results ................................................................. 2
  Attachment B: Discussion paper presented to External Reference Group ................... 6
  Attachment C: Project brochure ............................................................................... 18
  Attachment D: Usability interview schedule ............................................................ 19
  Attachment E: Follow-up interview schedules ......................................................... 21
  Attachment F: Main things gained from session and additional comments for each module ................................................................. 26
  Attachment G: Outcome related comments from follow-up interviews .................. 41

Table of Tables

Table 1: Main phases and activities of the project ........................................................ 2
Table 2: Description of model development activities .................................................. 4
Table 3: Summary of modules ...................................................................................... 12
Table 4: Three interface components of the website .................................................... 14
Table 5: Data collection methods for pilot phase .......................................................... 15
Table 6: Gender of pilot participants .......................................................................... 17
Table 7: Gender-age breakdown of pilot participants ................................................... 17
Table 8: Gender and rural-urban breakdown of pilot participants ............................... 18
Table 9: Referral sources for pilot participants ............................................................. 18
Table 10: Primary musculoskeletal condition and self-reported history of diagnosed depression or anxiety ........................................................................................................... 19
Table 11: Main area of concern by primary musculoskeletal diagnosis ......................... 20
Table 12: Reasons for not completing the program ....................................................... 22
Table 13: Emails sent by health psychologist - summary statistics ............................... 26
Table 14: Relationship between self-rated intensity of support by health psychologist and degree of client benefit ............................................................................................................ 26
Table 15: Health psychologist assessment of improvements in mood ......................... 28
Table 16: Health psychologist assessment of improvements in anxiety ....................... 28

Table 17: Health psychologist assessment of improvements in pain.........................................................29
Table 18: Health psychologist assessment of improvements in sleep ...................................................29
Table 19: Health psychologist assessment of improvements in fatigue ..............................................30
Table 20: Health psychologist assessment of improvements in relationship issues .............................30
Table 21: Health psychologist assessment of improvements in stress ..................................................31
Table 22: Health psychologist assessment of improvements in health-related behaviour ......................31
Table 23: Numbers identifying that they had learned new skills (at the exit interview) .........................32
Table 24: Numbers who were able to identify the next steps that they would take (at the exit interview) ........................................................................................................................................32
Table 25: Numbers reporting areas of improved confidence (at the exit interview) .............................32
Table 26: Hegel psychologist judgements of changes in positive and negative affect based on exit interviews........................................................................................................................................32
Table 27: Group Effect Sizes for Eight heIQ scales; Stepping Up participants versus a leading group program and the Australian Comparison Group ........................................................................33
Table 28: Estimates of Individual Reliable Change for eight heIQ scales; Stepping Up attendees compared with the Australian Comparison Group ........................................................................34
Table 29: DAS scores at baseline and follow-up ....................................................................................38
Table 30: K-10 scores ordered by size of average change (large to small) ............................................39
Table 31: Average module ratings from website ....................................................................................42

Table of Figures

Figure 1: Outcomes of concept mapping - chronic conditions and psychological distress interact in the functional demands of life ............................................................................................................7
Figure 2: Conceptualising the interaction between a chronic condition and psychological distress .....8
Figure 3: Outline of modules and expected flow through the program ..................................................11
Figure 4: Age decades of pilot participants - frequency chart ..............................................................17
Figure 5: Frequency chart showing numbers of people receiving different numbers of modules ....21
Figure 6: Number of modules completed by participants ......................................................................23
Figure 7: Number of days participants spent on the program .............................................................23
Figure 8: Longest gap between sessions for program participants .....................................................24
Figure 9: Amount of log-ins for program participants ..........................................................................24
Figure 10: Mean change (95% CIs) in heIQ and AQL scores .................................................................35
Figure 11: Individual change plot for AQL questionnaire ....................................................................36
Figure 12: Distribution of change in health-related quality of life scores as measured by the AQLLoL ................................................................................................................................................37
Figure 13: Change in K10 Psychological Distress for all participants ..................................................39
Figure 14: Histogram of change scores with DASS Anxiety scale showing a substantial number of participants reporting decline in depression symptoms (left side of dotted (red) line) ...........................................................................40
Figure 15: Histogram of change scores with DASS Depression ..........................................................41
Figure 16: Change in DASS Anxiety, Stress and Depression and change in K10 Psychological distress ................................................................................................................................................41
Figure 17: First health professionals' concept mapping group .............................................................2
Figure 18: Second health professionals' concept mapping group .........................................................3
Figure 19: First consumers' concept mapping group ..........................................................................4
Figure 20: Second consumers' concept mapping group .....................................................................5

Abbreviations

AQoL  Australia Quality of Life questionnaire
bbVCoE  beyondblue Victorian Centre of Excellence
CBT  Cognitive-behavioural therapy
DASS 21  Depression Anxiety Stress Scale – 21 Item version
heiQ  Health Education Impact Questionnaire
PHI  Public Health Innovation Deakin
RCT  Randomised control trial
SM  Self-management
SMS  Self-management support

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We offer very great thanks to the members of the external reference group who not only provided valuable advice at meetings but who also generously provided feedback on repeated drafts of the program modules.

Thank you to the software developers, Lovestock & Leaf, for working closely with us to develop a complex and versatile system that provided the customised content that we wished for to participants.

Chief investigators: Prof Richard Osborne; Prof Marita McCabe; Prof Rachelle Buchbinder; Stuart Cavill; Dr Sharon Haynes; Dr John Furler; Roy Betterham; Jenni Livingston

Members of the external reference group: Geraldine McDonald; Peter Price; Dr Andrea Bendrups; David Menzies; Dr Leonard Rose; Jennifer Lachai; Prof Grant Russell; Dr Denise Ruth; Dr David Clark; Dr Christine Migliorini; Jennifer Thatcher; Naomi Creek; Dr Ciaran Pier;

Project team: Dr Sarity Dodson; Yvonne Ginifer; Leanne Trinder
1 Background and focus for this report

In 2009, a team of researchers submitted an application to the beyondblue Victorian Centre of Excellence for Research into Depression and Related Disorders (bbVCoE) for a project to develop and test an internet based intervention for people with arthritis and co-morbid depression and/or anxiety. The concept for the research came from ten years of involvement with research and evaluation of self-management support programs for people with arthritis. It was clear that these programs often found people with co-morbid depression and/or anxiety too complex or that the programs were unable to meet these peoples’ needs.

The application was for a three year project including one year for development and two years for a randomised control trial (RCT). The application was partially successful and funds were awarded to conduct a one year project to develop a web-based intervention and conduct a pilot study.

In 2010, the research team submitted another application to the bbVCoE, once again seeking to conduct a RCT. Once again the application was partially successful and the research team was awarded just over one third of the funds requested and asked to submit a proposal for a modified project. By this time the preferred model for implementing the Stepping Up program had been identified. As discussed in section 2 (p. 3) this model was a hybrid in which an initial assessment would be conducted by a health psychologist who would then allocate modules to participants on the basis of their agreed needs. The health psychologist would also have weekly email contact throughout the project. The choice of this model raised the issue of the ability for the model to be rolled out and delivered through other agencies and by other service providers. For this reason the proposed second project was modified to an implementation trial in three different sites that have a role in providing self-management support services.

The anticipated requirements of the second project have determined many of the emphases of the evaluation of the first project. Also the software development process was progressed as far as possible, with the funds that were available, towards the requirements of the second project.

When reading this report, it is important to bear in mind that the researchers were not only interested in assessing the effectiveness of the program but also in developing key questions to inform the second project. These include:

- To what extent are any successes achieved due to the program rather than the particular skills of the health psychologist?
- What are the principal skills required to implement the program? What training is likely to be required?
- What features of the program are most useful and should be included or further developed in the second project?
- Which modules were most and least useful? Which need further development and in what way?
- In what ways does the web-based software need to be further developed and/or improved?

The focus of this report is not solely on requirements for the second project, however. Considerable effort was put into assessing the outcomes of the pilot in as comprehensive a manner as possible using a broad range of data sources and approaches.
1.1 Overview of the project activities and timelines

Broadly speaking there were five main phases for this project. These are briefly summarised in Table 1. The longest phase was the third phase, which involved development of the materials and the website software. As often occurs with such projects, the timelines for this phase were longer than we had hoped and we made the decision to postpone the pilot project phase until the start of 2011 so that participants’ experiences would not be interrupted by the Christmas break. bbVCoE kindly agreed to extend the project to allow this to happen.

Table 1: Main phases and activities of the project

<table>
<thead>
<tr>
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</tr>
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<td>Conceptual development phase: Concept mapping, literature review, review of other web-based interventions, consultation with experts and the ERG, develop and obtain feedback on discussion papers, Appointed health psychologist</td>
</tr>
<tr>
<td>June 10 – December 10</td>
<td>Website and material development phase: Appointed web developer, Web developer produced a set of wireframes including draft versions of most features and navigation mechanisms, these were tested with a number of consumer volunteers, Web developer developed the three required user interfaces (Section 2.5, p. 14), Obtained ethics approval for pilot phase, Developed graphical appearance of website, Developed draft materials and received feedback from ERG members and relevant experts, Finalised materials and uploaded to website (the uploading continued into January 2011)</td>
</tr>
<tr>
<td>December 10 – April 11</td>
<td>Pilot project phase: During the previous phase a number of potential recruitment sites were identified and briefed. (See Table 9, p. 18 for a list of the final referral sources), In December 2010 participant recruitment was commenced. Participants were sent pre-test questionnaires, Assessment interviews with participants occurred from 6 January till the second week in February. Participants commenced on the program as soon as their assessment interview was complete, Project implementation, Follow-up questionnaires and interviews.</td>
</tr>
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</table>

2 The Stepping Up model and program

2.1 Conceptual starting point

As stated in the first section of this report, a major reason for commencing this project was the researchers' belief—based on more than ten years of experience with self-management support programs for arthritis and other conditions—that the great majority of self-management programs available all serve a relatively narrow range of people (those defined as having high 'readiness to change' or 'potential to benefit'). The researchers also believed that these were often not the people with the greatest need and that many people who had complex needs were considered unsuitable for the majority of programs. In particular, many programs exclude people with significant psychosocial issues or active mental health problems.

It was a primary aim for the project to develop a program that would address the needs of people for whom physical health conditions and mental health conditions interact in varied and complex ways. In pursuit of this aim the researchers sought to develop a program guided by the following principles:

- Minimally restrictive selection criteria to ensure that the program was accessible to people who would be deemed unsuitable for many other self-management support programs.
- Flexibility and customisability of approach to increase the capacity of the program to meet the broadest possible range of needs for the broadest possible range of participants.
- Effective clinical risk-management processes to allow people with serious mental health conditions to participate.

While many programs take the approach that active mental health problems need to be addressed to some extent before people can focus on self-management issues, it was the view of the researchers that people's mental health issues, their physical health problems and their ability to participate in looking after their own health interact in many ways. On this basis, it was postulated that for many people these issues need to be addressed synchronously and that addressing peoples' ability to take some control of their health situation may improve their mental health status and vice versa.

2.1.1 The project’s concept of self-management and self-management support

Historically 'self-management' has been understood in terms of a specific set of behaviours and capacities including certain healthy lifestyle behaviours, actively managing one’s own relationship with health care providers, self-monitoring and initiation of contact with health service providers when necessary. People who were doing these things were considered to be ‘self-managing’ and people with the capacity to do all these things were considered to have the ‘capacity to self-manage’. People were often selected into self-management programs based on an assessment of this capacity.

An alternative view is that everyone who is conscious manages their own health conditions for at least some of the time and that this management may be helpful or destructive. According to this view everyone has the potential to improve their self-management and to increase their level of participation in health decisions and health-related actions, as well as their sense of confidence and control regarding their health conditions. In this view, self-management is seen as much as a modifiable 'state' as an intrinsic 'trait' or 'capacity'. It is considered that people’s self-management level will vary depending on the complexity of the issues confronting them and depending on whether they have entered into destructive cycles that erode their confidence and lead to negative habits, or positive cycles that build confidence and lead to positive habits.
From the start of the project the researchers wanted to build a program based on the second view of self-management. This would be manifest in terms of deliberately targeting people with ‘complex’ needs (see next section) and in terms of a focus on the person’s trajectory of self-management (i.e. the possibility of turning around negative cycles and initiating positive cycles).

2.1.2 The concept of ‘complexity’

Given that a primary focus of the program was to meet the needs of people with complex, interacting needs it was necessary for the researchers to consider their concept of complexity. Health service providers often talk of complexity in terms of the number of conditions that a person has. The researchers felt that this concept was inadequate and conceptualised complexity in terms of four interacting considerations:

- The number, type and severity of people’s medical conditions
- Additional social and life factors such as people’s living arrangements, relationship situation, employment situation and finances
- The trajectory of their current situation – whether they have experienced long term spirals of decline and erosion of confidence or whether they are dealing with relatively new and acute issues
- A subjective sense of complexity where people feel that there is large amount going on in their life and that they have too many things to deal with.

2.2 Development of the model

While the researchers had a broad concept of what they wanted to achieve and the nature of the program they wished to develop (see preceding discussion), it was necessary to undertake an extensive process of consultation and review of available models in order to develop a program model that would have the potential to allow this concept to be realised.

The consultation and review process involved a number of activities that are described in Table 2.

<table>
<thead>
<tr>
<th>Model development activity</th>
<th>Description</th>
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<tbody>
<tr>
<td>Concept mapping</td>
<td>Concept mapping is a highly structured, computer-assisted group process. It commences with a structured brainstorming process called the nominal group technique which is followed by tasks that use a computer to organise the brainstormed statements and produce a map. Four groups were conducted: two with health providers and researchers, and two with consumers. The resultant maps are presented as Attachment A.</td>
</tr>
<tr>
<td>Literature review (focused on evidence re online intervention features)</td>
<td>The research team had previously completed numerous related literature reviews on topics such as the effectiveness of self-management support activities and resilience. The focus of the literature review for this project was on the evidence related to particular features of online interventions such as guided access vs open access, discussion groups and session time.</td>
</tr>
<tr>
<td>Examination of other web-based interventions</td>
<td>The research team examined every web-based intervention that could be found that related to mental health interventions. They also reviewed a number of other chronic disease web based interventions.</td>
</tr>
<tr>
<td>Meetings with developers/operators of some other interventions</td>
<td>The researchers had meetings or phone conversations with the developers of a number of Australian, web-based interventions.</td>
</tr>
<tr>
<td>Health psychologist input</td>
<td>The Health Psychologist for the program was appointed in March 2010 and provided considerable input into the design of the program. One area in which her input was particularly important was in considering how to build upon the...</td>
</tr>
</tbody>
</table>
2.2.1 Outcomes from concept mapping and other consultation processes

The four concept mapping groups responded to a seeding statement which was:

Thinking as broadly as possible, generate statements about...

What do people with depression/ anxiety and a musculoskeletal problem need to know and be able to do to help them live well?

The first health professional group had a number of pain management experts and the results of the group (Figure 17 in Attachment A) reflected contemporary understandings of the interaction between cognitive and emotional conditions and pain. The group provided a lot of information about the dynamics of pain and cognitive and behavioural approaches to pain management. The group did not consider other functional issues as much and they realised this at the end. When they were asked to reconsider the seeding statement and look at their map to identify what might be missing, they came up with quite a long list of other functional concerns.

The second health professional group was small (five people) but diverse and included people from rheumatology, community health, self-management support and health promotion backgrounds. The results (Figure 18 in Attachment A) covered a broader range of issues than the first group and placed considerable emphasis on social and service delivery factors. The group identified a set of ‘self-management ‘how tos’. These were located at the centre of the map and viewed as being dependant on each of the major domains at the edge of the map (‘knowledge and beliefs’, ‘social inclusion’, ‘empowerment and motivation’). This group was satisfied that their map included all of the important concepts in responding to the seeding statement.

Both of the consumer groups included some people who were experiencing high levels of distress (K-10 scores >35) that they associated with their pain or their physical health problems. All of these people expressed the view that they enjoyed the concept mapping process and found the opportunity to talk about their issues helpful.

The first consumer group (Figure 19 in Attachment A) included a number of people who had experienced quite rapid functional decline and had high levels of anxiety about how much further this would progress and whether or not they would be able to cope with the demands of their life. Anxiety about the future featured strongly in the statements produced by this group. The group emphasised the need for reassurance including exposure to reassuring role models of people who were coping with their condition. The group recognised that sometimes anxiety can take on a life of its own and become a problem that is not related to realistic expectations of the future but several people in the group were at a point in the progression of their condition where they did not know what their realistic expectations were and had no way to assess or calibrate what was a reasonable level of anxiety. Both of the consumer groups highlighted the fact that the interaction between a person’s physical and mental health problems often plays out in the...
functional domain; that is, in relation to difficulties meeting the current functional demands of life or concern about their future ability to meet these demands. As discussed below (Section 2.2.2, p. 6), this concept became one of the guiding principles for development of the Stepping Up program.

The second consumer concept mapping group (Figure 20 in Attachment A) placed much greater emphasis on relationships within a person’s daily life and also with other service providers. Anxiety about the future featured much less strongly than in the first group, probably because the participants in this group had lived with their condition for a long time and were not in a stage of rapid decline. They still had an emphasis, however, of functional concerns but they expressed these more in terms of their ability to fulfill social roles. They also put a lot more emphasis on what they needed from service providers and the central group of concepts were primarily about knowing how and where to get your needs met.

2.2.2 A guiding model for program development

One of the main outcomes of the concept mapping groups was to focus the researchers’ attention on the question of the nature of the interaction between a person’s physical and mental health conditions. Each of the groups provided a particular emphasis and set of insights in relation to this question:

- The first health professional group emphasised current knowledge about the cognitive and behavioural factors involved in this interaction, particularly in relation to chronic pain.
- The second health professional group emphasised the importance of a core set of skills and of social and professional supports in enabling people to manage this interaction.
- The first consumer group emphasised the importance of the functional domain as the field in which this interaction often plays out. They also emphasised the need to consider people’s very real concerns about the future and help them manage these concerns at a practical, cognitive and emotional level.
- The second consumer group emphasised that people need the knowledge and know-how, as well as access to appropriate services, to enable them to manage the demands of their life.

This focus on the interaction between a person’s physical and mental health conditions became a guiding principle for the development of the Stepping Up program, particularly the ways in which this interaction is played out in current functional demands or fears about the person’s ability to function in the future (Figure 1).
Participants in the concept mapping groups mentioned a number of common, functional scenarios or situations that are often associated with significant interactions between the person’s physical and mental health conditions:

- dealing with a new diagnosis (grief, loss of expectations, fear for social roles (e.g. parenting), fear of disease progression, handing power to medical professions fear of genetic or other transfer, guilt and shame)
- long-standing disease associated with a long-term erosion of confidence, function and perceived well-being
- facing decisions about parenthood and child-raising
- circumstances where a person’s condition(s) have materially affected their employment or primary occupation (including roles as carer or parent)
- chronic pain syndromes
- people experiencing acute changes in their condition
- dealing with the stress of intensive involvement with health services (e.g. hospitalisation, surgical waiting lists).

The prevalence of specific functional concerns varies from chronic disease to chronic disease but several of these concerns will be found among people with all chronic illnesses.

Addressing the thinking, practicalities and experiences in relation to these functional experiences and concerns often breaks the cycle of negative interaction and decline. Therefore addressing the needs of people with co-morbid chronic illness and depression or anxiety, needs to involve all three components: their physical disease, their mental health conditions, and the functional concerns through which these interact.

Figure 2 attempts to analyse the interaction between a person’s physical and mental health conditions a bit further. It is important to recognise that many people with a chronic musculoskeletal condition have legitimate reasons for sadness and worry and have legitimate functional concerns related to their current and future life.

2.3 The broadening focus – arthritis to musculoskeletal, depression and anxiety to psychological distress

The decision was made to extend the scope of the program to include not only people with arthritis but people with all musculoskeletal conditions and also chronic pain syndromes. It was also decided to include not only people with a current diagnosis of depression and/or anxiety but also people with past diagnoses as well as people who were experiencing psychological distress that may indicate undiagnosed depression and/or anxiety or that may interact with their other health problems in a way that could lead to depression or anxiety. This decision was partly based on our conceptualisation of the interaction between a person’s physical health and mental health as a dynamic process that can have different trajectories and enter different phases and cycles at different points in a person’s life.
2.3.1 Target users

As a consequence of these decisions the target group for the program was:

- People with a diagnosed musculoskeletal condition or with chronic pain WHO ALSO...
- ...are experiencing current or recent psychological distress or have a diagnosis of depression (mild to moderate), panic disorder, GAD, social phobia, specific phobia, and/or stress.

The program also looked to recruit people who:

- have difficulty accessing other existing care options;
- are reluctant to engage with more traditional modes of support; or
- have found other forms of support ineffective because the content was not relevant to their situation, or the expectations relating to amount, type, or speed of change were too great.
2.4 The Stepping Up program – clinical and self-management support

As a consequence of the processes and considerations presented in the previous section, the researchers developed a service delivery model that included the following features (see Figure 3, p. 11):

- A screening and recruitment interview undertaken by a member of the research team.
- An assessment interview with the health psychologist.
- A case formulation based on the assessment interview. This resulted in establishing each participant’s main goal for the program, and the development of the tailored program to support working on contributing issues identified during the assessment. For each participant, the program included:
  - A module discussing the experience of living with, and managing a musculoskeletal condition
  - A taking-stock session
  - A module focusing on their main problem
  - Up to six modules with activities and techniques to help them address their main problem
  - A final review module to assist with the development of a relapse prevention plan
- The ‘Me map’ – a pictorial summary of how people reached their current situation. This was produced and uploaded by the health psychologist based on the whole-case formulation process, in addition to input by each consumer during reflective exercises in the early sessions.
- Key features of the program also included a number of lists that were developed by the consumer after reflection. These lists could be added to or changed, and were available for reference during the course of the program:
  - Important things – things that are important in the participant’s life.
  - Helpful activities – activities that they have found helpful to them in the past.
  - Good stuff – things that are significant positives in their life.
  - Unhelpful activities – things that they do or that happen that they feel are unhelpful to them.
- Each participant was introduced to the concept of problem solving, and then supported to develop skills that enabled each participant to:
  - Identify key issues that they consider to be problems that they would like to work on, including the things that impact on their main problem.
  - Develop and implement steps – explore things they could do to address their main problem using small and achievable steps.
- Clients were free to email the health psychologist as much as they wish but only received an email in return once per week.

For most people, the full program involved working on 7 to 10 modules. (See Figure 6, p. 23)

2.4.1 Initial interview and case formulation

The case formulation stage was a labour intensive activity for both the health psychologist and the participant. Case formulation is both a process and an output:

- As a process, the case formulation:
  - Initially takes place after initial assessment and prior to the planning of care (although it is an ongoing activity);
  - Involves the client and health provider developing working hypotheses relating to how and why particular issues have arisen for the client;
- Assists with the planning of care, but is also a therapeutic process in itself by building client insight into the nature and development of their problems and patterns of thinking and behaving.
- As an output the formulation of the client’s presenting problems becomes the ‘road map’ to ensure that the intervention has a structure, focus, and intensity that is appropriate for each individual.
- It includes working hypotheses developed collaboratively with clients relating to:
  - Vulnerability / predisposing factors (such as early experiences, unhelpful beliefs, personality styles)
  - Critical events / precipitating factors that activated current presenting problems
  - Maintaining / perpetuating factors
  - Protective factors.

The evaluation of the pilot investigated the value of this activity in detail (8.5.2, p. 45).

Figure 3: Outline of modules and expected flow through the program
2.4.2 The modules

Table 3 presents a brief summary of each of the modules in the program. Participants were ‘locked out’ from commencing the next assigned module for three days after they completed each module. The reason for this was to ensure that people did not rush through the content and that they had time to reflect and try and act upon the content of each module. The health psychologist was able to override this at her discretion.

A number of participants were frustrated by the lock-out and indicated that this was the ‘least liked’ feature of the program (See section 8.5.2, particularly ‘Timing issues’ in p. 45). In some cases, this was because they knew that they only had access to the program for a limited time and wanted to see as much of the content as possible.

Table 3: Summary of modules

<table>
<thead>
<tr>
<th>Module</th>
<th>Overview</th>
<th>Structure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Let me show you around</td>
<td>Introduces the program, activities, features, and how to navigate the website.</td>
<td></td>
</tr>
<tr>
<td>Managing your health</td>
<td>In this session, we talk about the experience of living with and managing a musculoskeletal condition, and how the program will help to find a balance. Introduced to the three cases studies.</td>
<td>Learn about musculoskeletal conditions</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Reflection and writing your story</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Creating lists of important things, helpful activities, what can change, what can not</td>
</tr>
<tr>
<td>Taking Stock</td>
<td>In this session, we will spend time reflecting on your situation and decide the best place to start to achieve your goals.</td>
<td>Reflection, and list the good stuff, things you are grateful for in your life, how your problems developed, and how they are affecting your life, what makes them worse, and your strengths</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Revisit goals set in the assessment interview, and problems identified</td>
</tr>
<tr>
<td>Feeling down?</td>
<td>In this session, we begin the journey to better manage your mood.</td>
<td>Learn about mood, cycle of depression, and reversing this cycle</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Reflect on your symptoms, losses, causes of low mood, things you have stopped doing because of low mood</td>
</tr>
<tr>
<td>Getting Back To It</td>
<td>In this session, you will make some plans to help you get back to living an enjoyable and rewarding life.</td>
<td>Reflection, on being less active, the consequences, strategies to overcome</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Create lists for enjoyable activities, chores and responsibilities</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Identify exercise to get back into, monitor your activity, and plan activities over coming weeks</td>
</tr>
<tr>
<td>In Pain?</td>
<td>In this session, we begin the journey to better manage your pain.</td>
<td>Learn about acute and chronic pain</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Reflect on your current pain, and the relationship between pain and stress, how do you manage your pain</td>
</tr>
<tr>
<td>Pain Reduction Tips</td>
<td>In this session, we discuss some pain reduction approaches you might like to discuss with your health care team to see if they are suitable for you.</td>
<td>Learn about different pain therapies, pain and exercise</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Reflect on your experience</td>
</tr>
<tr>
<td>Improve your sleep!</td>
<td>In this session, we begin the journey to better manage your sleep.</td>
<td>Learn more about sleep</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Reflection on problems, getting to sleep, your sleep habits, triggers to your sleep problems</td>
</tr>
<tr>
<td>I Think... Therefore I</td>
<td>In this session, we discuss the connection between what you think and how you</td>
<td>Learn about thoughts and feelings, and actions,</td>
</tr>
<tr>
<td>Module</td>
<td>Overview</td>
<td>Structure</td>
</tr>
<tr>
<td>---------------------</td>
<td>--------------------------------------------------------------------------</td>
<td>---------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Feel...</td>
<td>feel, and you will pinpoint the thoughts that are causing problems for you. Create a thought diary.</td>
<td>Unhelpful thoughts and how they are linked.</td>
</tr>
<tr>
<td>Loosen Up!</td>
<td>In this session, we will discuss strategies to help you relieve your muscle tension.</td>
<td>Learn about stress, anxiety and muscle tension, and strategies for relieving muscle tension. Experience the relaxation audio</td>
</tr>
<tr>
<td>Breathe!</td>
<td>In this session, I introduce two breathing strategies for you to try.</td>
<td>Learn about stress, anxiety breathing, and breathing techniques. Experience the breathing audio</td>
</tr>
<tr>
<td>Exhausted?</td>
<td>In this session, we begin the journey to better manage your fatigue.</td>
<td>Learn about fatigue and the fatigue cycle. Reflection, what are your symptoms, triggers, consequences</td>
</tr>
<tr>
<td>Worried?</td>
<td>In this session, we begin the journey to better manage your worry.</td>
<td>Learn about worry, and the worry cycle. Reflect on what you worry about, and what contributes to this worry</td>
</tr>
<tr>
<td>Stressed?</td>
<td>In this session, we begin the journey to better manage your stress.</td>
<td>Learn about worry. Reflect on how stress affects you, symptoms, and what causes this stress</td>
</tr>
<tr>
<td>Make a change!</td>
<td>In this session, we begin the journey to make a lasting, positive lifestyle change.</td>
<td>Learn about making change. Reflect on the habit you want to change. Create a habit record</td>
</tr>
<tr>
<td>Let's Make a Plan</td>
<td>In this session, you will start to plan how you will create your healthy habit.</td>
<td>Learn about motivation, smart goals. Reflect on the habit you want to change. Create a keeping track record</td>
</tr>
<tr>
<td>Daytime Habits and Sleep Space</td>
<td>In this session, you will plan some changes to your daytime habits and sleep space, as a way to improve your sleep.</td>
<td>Learn to postpone worries, create a worry time, problem solve. Reflect on habits, changes to make. Create worry-time worksheet</td>
</tr>
<tr>
<td>I Believe... Therefore I Think...</td>
<td>In this session, we introduce the role of beliefs in influencing how you feel and act, and help you identify the beliefs causing problems for you.</td>
<td>Learn about beliefs, rules, assumptions. Reflect on your beliefs, actions and consequences. Create if-then worksheet</td>
</tr>
<tr>
<td>Worry Management Tips</td>
<td>In this session, we discuss a few more worry management strategies for you to try.</td>
<td>Learn about postponing worry, worry time and problem solving. Reflect on your worries. Continue worry time worksheet</td>
</tr>
<tr>
<td>Balancing activity &amp; rest</td>
<td>In this session, we discuss how to build this skill and assist you to take steps to balance your activity levels.</td>
<td>Learn about boom/bust cycles, pushing, pacing. Reflect on your own boom/bust cycle, setting base line. Create watching your results worksheet.</td>
</tr>
<tr>
<td>Habit Change Tips</td>
<td>In this session, we discuss some things you can do to make creating your healthy habit that a little bit easier.</td>
<td>Learn about strategies for change including rewards and supports.</td>
</tr>
<tr>
<td>Improve your Relationships</td>
<td>In this session, we begin the journey to make a lasting positive change in your relationships.</td>
<td>Learn about common relationship problems including communication, anger, frustration, quality-time.</td>
</tr>
<tr>
<td>Panicked?</td>
<td>In this session, we begin the journey to better manage your anxiety.</td>
<td>Learn about anxiety and panic, symptoms, panic attacks and the cycle of anxiety. Reflect on your symptoms, what you get anxious about, what contributes, and avoidance.</td>
</tr>
<tr>
<td>Take Action!</td>
<td>In this session, we examine the problem.</td>
<td>Learn about avoidance.</td>
</tr>
</tbody>
</table>
## 2.5 The Stepping Up program – software and website

Table 4 describes the three main components of the website and underlying software. Overall the software is a very sophisticated system that allows a high level of interactivity and allows modules to be developed and delivered in a way that is highly customisable to the needs of individuals and potentially to different groups of people. The researchers believe that the software has potential applications that far exceed this particular program and this particular target group.

### Table 4: Three interface components of the website

<table>
<thead>
<tr>
<th>Website interface</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Client interface</td>
<td>This is the interface seen by participants. They are initially presented with an introductory page from which they can access the next scheduled module, previous modules and the various products of the case formulation (see list in 2.4.1, p. 10). They also have access to a private online diary and an interface for messaging the health psychologist. All components are printable with the exception that participants could not easily print out an entire module in the follow-up interviews this was cited by some participants as a disappointment. Some of the modules had downloadable recordings to assist with activities such as relaxation. There were some additional information sheets and links provided.</td>
</tr>
<tr>
<td>Clinician interface</td>
<td>This interface enables the health psychologist or managing clinician to see aspects of the clients work related to case formulation; to receive and send messages; to assign modules and to monitor when the client logs on and when they complete a module.</td>
</tr>
<tr>
<td>Management interface</td>
<td>This is the least developed interface and the researchers hope to obtain funds in the future to develop this interface further. This interface allows new modules to be developed and uploaded and allows reporting on data collected within the system.</td>
</tr>
</tbody>
</table>
Section 2: Implementation and evaluation of the pilot

3 Data collection methods

The Stepping Up program recruitment, implementation and evaluation consisted of different data collection methods and tools, and a recruitment interview, which included the collection of demographic, computer-use and health information.

During implementation of the program, the health psychologist collected information relating to assessment, progress and outcomes from a clinical perspective. This included an exit interview with all but two of the total participants (95%). Additionally, participants completed self-assessment features built into the program.

An evaluation interview was conducted with 84% of total participants and included open-ended questions regarding their experience with the program, and questions relating to usability of the website (See interview schedules in Attachment E).

Pre and post questionnaires were received from 84% of participants (a different mix to those who participated in the evaluation interview).

Usability interviews were also conducted with six participants during the program implementation. Website data was extracted once the program was completed. A log of technical issues was kept by the project team in response to participant requests for advice and assistance.

Table 5: Data collection methods for pilot phase

<table>
<thead>
<tr>
<th>Data collection activity</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre and post questionnaires</td>
<td>Four standardised questionnaires were administered at the time of the initial intake interview and two weeks after completion of the program. These were a measurement of self-management related status (Health Education Impact Questionnaire, the heIQ); a measure of depression, anxiety and stress (Depression, Anxiety and Stress Scale, the DASS 21); and a measure of psychological distress (the K10). The K10 was administered orally during the intake and exit interviews, while the other questionnaires were paper-based and mailed out to each participant.</td>
</tr>
<tr>
<td>Demographic and diagnostic data</td>
<td>These included age and sex, postcode, musculoskeletal diagnoses and mental health diagnoses.</td>
</tr>
<tr>
<td>Module rating scales, main perceived benefits and comments</td>
<td>Participants were able to rate each module using a set of sliding scales at the end of the module. Modules were rated on understandability, confidence that they could be implemented and overall value. Participants were also given space to record the main benefits they believe they got from the module and to provide any additional comments that they wished.</td>
</tr>
<tr>
<td>Exit interviews and summary assessments by health</td>
<td>The health psychologist conducted an exit interview with each participant and made judgements about improvements in relation to a number of symptoms,</td>
</tr>
<tr>
<td>Psychologist</td>
<td>Whether or not these symptoms represented the person's main problem.</td>
</tr>
<tr>
<td>-------------</td>
<td>---------------------------------------------------------------------</td>
</tr>
<tr>
<td>Follow-up interviews</td>
<td>Follow-up interviews were conducted approximately two weeks after completion of the course. People who did not start or did not finish the course were also interviewed. 36 interviews were conducted.</td>
</tr>
<tr>
<td>Usability study</td>
<td>One of the researchers did a set of interviews with six people midway through implementation of the program in which issues related to the function and usability of the website were discussed in detail.</td>
</tr>
<tr>
<td>Website statistics</td>
<td>The software developers provided detailed statistics on log-ins to each module.</td>
</tr>
</tbody>
</table>
4 Who were the participants of the Stepping Up pilot program?

4.1 Demographics

The Stepping Up program recruited 43 people to the program. The majority of participants were women (77%), the average age was 48, with the age range between 22 to 85.

<table>
<thead>
<tr>
<th>Gender</th>
<th>Freq.</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>33</td>
<td>76.74</td>
</tr>
<tr>
<td>Male</td>
<td>10</td>
<td>23.26</td>
</tr>
<tr>
<td>Total</td>
<td>43</td>
<td>100.00</td>
</tr>
</tbody>
</table>

Table 6: Gender of pilot participants

Figure 4: Age decades of pilot participants - frequency chart

<table>
<thead>
<tr>
<th>Decade (age)</th>
<th>20s</th>
<th>30s</th>
<th>40s</th>
<th>50s</th>
<th>60s</th>
<th>70s</th>
<th>80s</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>3</td>
<td>12</td>
<td>8</td>
<td>6</td>
<td>3</td>
<td>1</td>
<td>0</td>
<td>33</td>
</tr>
<tr>
<td>Male</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>10</td>
</tr>
<tr>
<td>Total</td>
<td>3</td>
<td>13</td>
<td>9</td>
<td>8</td>
<td>5</td>
<td>3</td>
<td>2</td>
<td>43</td>
</tr>
</tbody>
</table>

Table 7: Gender-age breakdown of pilot participants

Men were more likely to be older, with 80% of men aged in their 50s or older, and the women more likely to be younger, with 88% of women aged in the 50s or younger. (70% in 40s or younger)
Participants represented a broad range of the population with 37% living in rural areas, and with a range of employment status including retired, full time, part time and casual workers, students and unemployed. Data on type of employment was not collected but several participants volunteered their profession, which confirmed the broad range of participants across socio-economic groups. Some (26%) had carer responsibilities for member/s of their families.

<table>
<thead>
<tr>
<th>Rural or urban</th>
<th>Rural</th>
<th>Urban</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>12</td>
<td>21</td>
<td>33</td>
</tr>
<tr>
<td>Male</td>
<td>4</td>
<td>6</td>
<td>10</td>
</tr>
<tr>
<td>Total</td>
<td>16</td>
<td>27</td>
<td>43</td>
</tr>
</tbody>
</table>

Arthritis Victoria was the main referral source. 60% of total referrals came through the Arthritis Victoria website or through the email to the Young Women’s Arthritis Support Group. All referrals from both these sources were women. Five of the ten men were referred by CI/ERG members who had placed deliberate emphasis on recruiting men.

It must be noted that the recruitment strategy included active recruitment by members of the Expert Reference Group (ERG) and project Chief Investigators (CIs), however self-referral was the most common method, and accounts for more than 70% of participants.

<table>
<thead>
<tr>
<th>Referral source</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Arthritis Victoria</td>
<td>26</td>
<td>60.47</td>
</tr>
<tr>
<td>CI/ERG member</td>
<td>7</td>
<td>16.28</td>
</tr>
<tr>
<td>General Practitioner</td>
<td>2</td>
<td>4.65</td>
</tr>
<tr>
<td>Other</td>
<td>5</td>
<td>11.63</td>
</tr>
<tr>
<td>Southern Health</td>
<td>3</td>
<td>6.98</td>
</tr>
<tr>
<td>Total</td>
<td>43</td>
<td>100.00</td>
</tr>
</tbody>
</table>

**4.2 Health conditions**

Participants reported a broad range of primary musculoskeletal (MSC) conditions including rheumatoid arthritis (33%), osteoarthritis (30%), fibromyalgia (7%), and other forms of arthritis, back pain and chronic pain conditions.
A significant number of participants reported a current mental health diagnosis of anxiety or depression (33%), However, the majority reported past history of anxiety (70%) or depression (80%), and of those participants with a history of depression or anxiety (n=37), 73% reported having experienced both.

<table>
<thead>
<tr>
<th>Primary MSC</th>
<th>Self reported history of anxiety or depression</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Back pain</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Chronic pain</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Fibromyalgia</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Idiopathic arthritis</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Non-specific arthritis</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Osteoarthritis</td>
<td>0</td>
<td>13</td>
</tr>
<tr>
<td>Osteoporosis</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Psoriatic arthritis</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Rheumatoid arthritis</td>
<td>3</td>
<td>11</td>
</tr>
<tr>
<td>Sacroiliac arthritis</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>6</td>
<td>37</td>
</tr>
</tbody>
</table>

In addition to the complex history of musculoskeletal condition and co-morbid anxiety or depression, 49% of participants also reported between 1 and 3 additional chronic health conditions, including diabetes, respiratory conditions and additional musculoskeletal conditions.
5 What is the Stepping Up program?

The Stepping Up program supported each participant to focus on one key area of concern that was determined through an assessment interview conducted by the health psychologist with each participant. There were eight key areas of concern that a participant may be allocated to, including fatigue, mood, pain, physical activity, sleep, stress, worry and panic. Comparing the nomination of the main area of concern with the primary MSC condition for each participant, all areas were reasonably covered except for panic (1 participant). Pain received the greatest focus (11 participants) and drew participants from across most of the MSC conditions (7 of 9).

<table>
<thead>
<tr>
<th>Table 11: Main area of concern by primary musculoskeletal diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Main area of concern</strong></td>
</tr>
<tr>
<td>---------------------------</td>
</tr>
<tr>
<td>Back pain</td>
</tr>
<tr>
<td>Chronic pain</td>
</tr>
<tr>
<td>Fibromyalgia</td>
</tr>
<tr>
<td>Idiopathic arthritis</td>
</tr>
<tr>
<td>Non-specific arthritis</td>
</tr>
<tr>
<td>Osteoarthritis</td>
</tr>
<tr>
<td>Osteoporosis</td>
</tr>
<tr>
<td>Psoriatic arthritis</td>
</tr>
<tr>
<td>Rheumatoid arthritis</td>
</tr>
<tr>
<td>Spondylitis arthritis</td>
</tr>
<tr>
<td><strong>Total</strong></td>
</tr>
</tbody>
</table>

During the assessment interview, and in relation to their main area of concern, participants talked about wanting to try new ideas; learn more; to understand better; to learn new strategies and skills to better manage their concerns. For others, it was more specific: wanting to be more active; wanting to improve their quality of their sleep. Others voiced their need to pace themselves better; feel better; panic or worry less; to make changes to what they do, or how they think.

These broad areas of concern were supported by a range of modules (29) of which between 7 and 14 (mean 10.3) modules were allocated to each participant. These modules included topics such as: managing your health; overcoming obstacles; change your mind; feeling down. (For a description of all modules, see Table 3, p 12). The choice of module allocation was based on the one hour telephone assessment conducted with each participant. A program was tailored program to each participant which considered the main area of concern, specific content (specific modules) and varying degrees of intensity (more or less modules allocated).
It must be noted that the final number of modules assigned to a small number of participants varies slightly from the original allocation. There was slower than expected progress by a number of participants, and so the number of modules allocated was reduced by one or two for some participants to ensure that each person could complete their program in the time that was available. This adjustment was made by the health psychologist in consideration of the assessment, progress, and core needs of the participant.

The program was designed to run for 42 – 70 days. The participants averaged 47 days work on the program (range 0 – 74 days) for all 43 participants.
6 Program input and completion by participants

Of the 43 participants enrolled in the Stepping Up program, three participants did not start the program. Only one of these is of concern, as the participant logged in 21 times over a period of eight days, but was unable to actually start the program. Technical support from the project team was offered, but was probably not timely enough to overcome the frustration and loss of motivation to engage. The other two participants who did not commence the program cited competing life priorities and only one of them actually logged on to the Stepping Up website.

Of the 43 participants recruited to the program, 34 (79%) completed the program to the satisfaction of the health psychologist. This figure includes two participants who did not quite finish, but were satisfied with what they had done. Six participants (14%) discontinued for different reasons, which are explained in the following section. The analysis of the program input and outcome data in the remainder of this report will include all data relating to those participants who started the program (n=40), and will exclude those who did not start the program (n=3).

The recruitment process took considerably more time than anticipated to get near to the desired participant numbers, which consequently reduced the time available for those starting the program during the later stages of recruitment. However, this does not appear to be a significant factor in terms of participants being unable to complete the program. Some participants who did complete the program felt rushed towards the end of the program when they were required to complete a small number of modules before the program was closed down. However for the majority, participants were able to finish in their own time. The two participants who were willing but unable to complete the program spent a total of 62 and 74 days enrolled in the program, however both participants had at least one significant break between logins (19 and 23 days).

Six participants discontinued the program including three participants who were dissatisfied in terms of the tone of the program and its content. One participant struggled with the technical aspects of the program interface, and another had too many competing priorities.

<table>
<thead>
<tr>
<th>Reason for not completing program</th>
<th>Did not start program</th>
<th>Discontinued program</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dissatisfied with the program - tone, content</td>
<td></td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Technical difficulties</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Competing priorities</td>
<td>2</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Incapacitated</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>3</td>
<td>6</td>
<td>9</td>
</tr>
</tbody>
</table>

For those participants who discontinued the program due to dissatisfaction (n=3), they logged in between 2 and 6 times, and completed between 2 and 4 modules. Based on this experience with...
the program, one described the program as “patronising” and “frustrating” while the other two also noted frustrations and indicated disagreement with some of the messages in the program (such as the idea that it is possible to do something about your own pain). Participants described losing patience and skipping sections.

In addition to questionnaires and interview data, a range of data was extracted from the website and will support the description of login and work patterns and input by participants.

The number of days enrolled in the program was determined from the first to last login by each participant. The average number of days enrolled in the program was 50 (range 2 – 74), and the average number of logins by each participant was 17.7 (range 2 – 43). The average gap between sessions was 14.3 days (range 0 – 32 days). This data demonstrates the significant variation in the way and extent to which people engaged in the Stepping Up program.
For most of the program period, once participants completed a module they were locked out of the program for three days before getting access to the next module. Towards the end of the pilot program, the lockout feature was removed to allow the participants who were lagging behind to complete their final modules as quickly as possible.

Figure 8: Longest gap between sessions for program participants

There is great variation in the number of logins by each participant. The six participants who discontinued the program logged in six times or less. Some people discussed reviewing their previous modules and making changes, however others stated they did not go back over their previous work. In addition, the majority of people stated they spent approximately 20 – 30 minutes on each module. A few people reported at interview that they spent some hours working on each module. We do not have website data available for this report to demonstrate the time spent by each participant logged into the program.

Figure 9: Number of log-ins for program participants

During the program, each participant had the opportunity to email the health psychologist with questions and concerns, in the knowledge that they would receive a weekly email that would
include feedback, answers to queries, and encouragement or support. An average of 4.8 emails was sent by each client (range 0 – 17). However, this figure probably does not provide insight into the level of engagement with the program by each participant because some clients who didn’t email, did engage with the program and did not require this nature of support from the health psychologist at all.
7 Program input by health psychologist

Support from the health psychologist varied greatly across the participants. The number of emails sent to each client averaged 13, with a range of 5 to 19 emails. A few clients also received phone calls to address serious or complicated concerns. The number of emails was responsive to clinical need, which was recognised through participant-input into their workbooks, and email correspondence and requests from each participant.

<table>
<thead>
<tr>
<th>Number of messages sent by health psychologist to participants</th>
<th>Number of participants</th>
<th>Mean</th>
<th>Min</th>
<th>Max</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>39</td>
<td>13.0</td>
<td>5</td>
<td>19</td>
</tr>
</tbody>
</table>

At the completion of the program, the health psychologist made an assessment of each participant in terms of the level of clinical support that had been provided during the program, and the level of benefit derived from this support. There appears to be a direct relationship between the level of support provided and the level of benefit achieved, with those participants receiving more clinical support having the greater degree of benefit.

<table>
<thead>
<tr>
<th>Intensity of program support</th>
<th>Degree of benefit client derived from support provided</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>None</td>
</tr>
<tr>
<td>None</td>
<td>2</td>
</tr>
<tr>
<td>Low</td>
<td>8</td>
</tr>
<tr>
<td>Some</td>
<td>0</td>
</tr>
<tr>
<td>Moderate</td>
<td>0</td>
</tr>
<tr>
<td>Significant</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>10</td>
</tr>
</tbody>
</table>

The nature and range of support varied considerably across participants, and was based on identified need, and also how engaged each participant was with the health psychologist. The main support strategies focused on participant engagement and reinforcement, along with encouragement, validation and guidance. More specific support included challenging previous cognitive and behavioural patterns, building insight, problem solving and further education.
8 Program outcomes

Several variables were measured to determine program outcomes for each client who participated in the program. This analysis includes all participants who commenced the program and who participated in an exit interview with the health psychologist (n=38). The health psychologist has made a clinical judgment for outcomes based on the assessment and exit interviews, and workbook entries and self assessment by each participant. Outcomes include:

- Improvements on the standardised questionnaires administered before and after the pilot
- Improvement in main concern (mood, anxiety, pain, sleep, fatigue, relationship, stress) – self reported, health psychologist judgement
- Behaviour change – self reported
- Other perceived benefits.

8.1 Overview of outcomes

Overall the outcomes from the pilot were extraordinary. Although there was no direct comparator group, there are substantial comparative data sets available for some of the instruments that were used. The researchers also have considerable experience in evaluating self-management and similar programs and have an understanding of what is usually achieved in terms of outcomes such as changes in health related behaviours and the proportion of people who make extremely positive (effusive) comments at interview. Some of the highlights in the outcomes data presented in this section are:

- Very large positive changes in the negative emotions, skills and social support scales of the heIQ compared to all Australian programs (in some scales the changes appear to be the largest seen in Australia);
- Average improvement in the Aqol of 0.11, that is approximately three times the minimum meaningful change (in utility terms it means 11% of the difference between death and perfect health);
- Very high proportion of extremely positive comments at follow-up interviews (above 50% whereas around 20% is common)
- Very high proportion of people listed specific changes in behaviour that they have made and which they directly attribute to the program (> 90 % whereas <50% is common for self-management support programs).

One surprising aspect of the outcomes was the very large change in the social support scale of the heIQ, given that this was an internet-based intervention. This is discussed in detail later in this section.

One factor that may have contributed to the size of the changes observed is that the program deliberately sought to recruit people with relatively severe problems. These people may often be excluded from other self-management support and clinical programs, therefore it is possible that participants in the Stepping Up program simply had more room to improve [see comments related to the Aqol, Section 8.3.2, p. 35]
8.2 Health psychologist exit interviews

8.2.1 Improvement in main concerns

Mood

<table>
<thead>
<tr>
<th>Mood a concern at assessment</th>
<th>Improvement in mood reported</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No</td>
</tr>
<tr>
<td>No</td>
<td>11</td>
</tr>
<tr>
<td>Yes</td>
<td>4</td>
</tr>
<tr>
<td>Total</td>
<td>15</td>
</tr>
</tbody>
</table>

The majority of people (82%) who indicated that mood was a concern at assessment, reported an improvement in mood when the Stepping Up program was completed. Four people (18%) did not. These four participants cited serious health concerns as the main reason for not having improved their mood. For those whose mood improved, responses were many and varied and included feeling proud, motivated, hopeful and positive; being more optimistic about the future; and having more realistic expectations. Others stated they were less reactive, less irritable, and not so angry, frustrated or feeling guilty as before.

Other participants cited external factors in addition to the Stepping Up program that have impacted positively on their mood. These included better health, less pain, new medications, and more sleep and exercise.

It is also worth noting that five of the eleven people who did not express mood as a concern at assessment, did indicate they had improvement in mood at the end of the program.

Anxiety

<table>
<thead>
<tr>
<th>Anxiety a concern at assessment</th>
<th>Improvement in anxiety reported</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No</td>
</tr>
<tr>
<td>No</td>
<td>9</td>
</tr>
<tr>
<td>Yes</td>
<td>7</td>
</tr>
<tr>
<td>Total</td>
<td>16</td>
</tr>
</tbody>
</table>

74% of participants, who expressed anxiety as a concern at the beginning of the Stepping Up program, experienced an improvement in anxiety. These participants described their improvements as feeling more in control, worrying less about symptoms, overcoming guilt, being more aware of worry, and feeling positive. They have achieved this through dealing with issues as they arise, letting go of things out of their control, using self-talk, challenging avoidance.
behaviours, using walking, relaxation and mindfulness strategies, and not getting caught up in negative thoughts.

26% of participants, who expressed anxiety as a concern at assessment, did not experience any improvement. Concern for the future, family issues and other life factors including work and health weighed heavily.

**Pain**

<table>
<thead>
<tr>
<th>Pain a concern at assessment</th>
<th>Improvement in pain reported</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>Yes</td>
<td>16</td>
</tr>
<tr>
<td>Total</td>
<td>20</td>
</tr>
</tbody>
</table>

Pain was cited by 89% of all participants as a key concern at assessment. Of these, 53% reported an improvement in pain.

For those who experienced an improvement in pain, the improvement related to levels of pain, acceptance of pain, coping skills and managing flares. Changes in exercise levels, attitude, and medications, and prioritising pain management and learning new strategies were listed as reasons for their improvement. Participants talked of coping better, handling pain better, and being more accepting of their condition.

Many people (47%) did not experience an improvement in their pain. Cold weather, medication changes, current flare and other health conditions impacted on participant’s pain. Others talked about not being worried about it now, that they understood pain better, even if their pain was still the same as before.

**Sleep**

<table>
<thead>
<tr>
<th>Sleep a concern at assessment</th>
<th>Improvement in sleep reported</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>10</td>
<td>1</td>
</tr>
<tr>
<td>Yes</td>
<td>10</td>
</tr>
<tr>
<td>Total</td>
<td>20</td>
</tr>
</tbody>
</table>

Sleep was a concern for 27 participants at assessment. Of these, 17 (63%) reported an improvement, many of them describing the improvement as significant. Participants described feeling more rested due to not waking up as much during the night, finding it easier to get to sleep, getting back to sleep more easily, and needing to sleep less during the day. Successful
strategies for improving sleep included getting up at the same time every morning, not taking day
naps, not reading in bed, and practicing relaxation and breathing strategies.

37% of participants for whom sleep was a concern, did not report any improvement that they are
still sleeping poorly, waking during the night, being unable to get back to sleep, and needing to
nap regularly during the day.

**Fatigue**

Table 19: Health psychologist assessment of improvements in fatigue

<table>
<thead>
<tr>
<th>Fatigue a concern at assessment</th>
<th>No</th>
<th>Yes</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>6</td>
<td>3</td>
<td>9</td>
</tr>
<tr>
<td>Yes</td>
<td>6</td>
<td>23</td>
<td>29</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>12</strong></td>
<td><strong>26</strong></td>
<td><strong>38</strong></td>
</tr>
</tbody>
</table>

29 participants were concerned about fatigue at the beginning of the Stepping Up program. Of
these, 23 (79%) reported an improvement at the end of the program, many of them describing a
significant improvement, stating they felt more energetic, less exhausted, and able to do more.
They discussed strategies including exercise and changed sleep patterns as reasons for this
improvement.

For those who didn’t improve (21%), participants talked about busy lives, family stresses, and high
workloads. Sleep was also an ongoing issue.

**Relationship**

Table 20: Health psychologist assessment of improvements in relationship issues

<table>
<thead>
<tr>
<th>Relationship a concern at assessment</th>
<th>No</th>
<th>Yes</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>31</td>
<td>1</td>
<td>32</td>
</tr>
<tr>
<td>Yes</td>
<td>2</td>
<td>4</td>
<td>6</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>33</strong></td>
<td><strong>5</strong></td>
<td><strong>38</strong></td>
</tr>
</tbody>
</table>

Only six participants raised relationships as a key concern at the beginning of the Stepping Up
program. Of these, four participants reported an improvement. For those who improved, they
discussed getting along with people better, joining social groups, and going out on social occasions
more often. Two people did not have any improvement.
Stress

Table 21: Health psychologist assessment of improvements in stress

<table>
<thead>
<tr>
<th>Stress a concern at assessment</th>
<th>No</th>
<th>Yes</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>10</td>
<td>0</td>
<td>10</td>
</tr>
<tr>
<td>Yes</td>
<td>4</td>
<td>24</td>
<td>28</td>
</tr>
<tr>
<td>Total</td>
<td>14</td>
<td>24</td>
<td>38</td>
</tr>
</tbody>
</table>

Stress was a key concern for 74% of total participants. Of these, 86% reported an improvement at the end of the program. Participants talked about being more proactive, attending to responsibilities, and keeping on top of things better. They felt less irritable, more relaxed, and less worried, more calm, describing less muscle tension. They felt they were coping better, and were taking more time for themselves. Some participants stated this was despite ongoing serious life issues that were occurring during the time they were on the program. Several had made key decisions, and had learnt to say no. Relaxation and exercise were cited as helpful strategies.

Most of those who didn’t improve talked about concurrent serious life issues.

Health related behaviour

Table 22: Health psychologist assessment of improvements in health related behaviour

<table>
<thead>
<tr>
<th>Behaviour change reported</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>3</td>
<td>7.89</td>
</tr>
<tr>
<td>Yes</td>
<td>35</td>
<td>92.11</td>
</tr>
<tr>
<td>Total</td>
<td>38</td>
<td>100.00</td>
</tr>
</tbody>
</table>

Most participants who participated in the program (92%) reported at least one change in behaviour, with many participants reporting more than one. By far the most popular was being more active, with more than half the participants having made a change in this area. Six (14%) participants chose physical activity as their main area of concern, however, an improvement in physical activity was reported by more than 50%. Participants talked about swimming, riding, stretching, walking more often, and walking longer distances.

Changed sleeping behaviours, increased social activities, pacing themselves better, and making diet changes were also common. Several people found new health practitioners to support them in their healthcare and management, while others practised relaxation, breathing and increased their self care.

Three participants stated they had too much stress going on in their lives right now to be able to change anything.
8.2.2 Additional outcomes identified at the exit interview

In the exit interviews, the health psychologist assessed a number of additional outcomes including the participant's ability to identify new skills they had learned; their ability to identify future steps they would take to continue to improve their well-being; self-reported improvements in confidence and a global assessment of changes in both negative and positive affect.

<table>
<thead>
<tr>
<th>Additional skills developed</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>8</td>
<td>21.05</td>
</tr>
<tr>
<td>Yes</td>
<td>30</td>
<td>78.95</td>
</tr>
<tr>
<td>Total</td>
<td>38</td>
<td>100.00</td>
</tr>
</tbody>
</table>

Many participants reported learning new skills from the Stepping Up program that will support them into the future. Problem solving and planning, relaxation, mindfulness, worry management and pacing were the main skills reported. Additionally, self-talk, assertiveness, and challenging negative thinking were also reported.

<table>
<thead>
<tr>
<th>Able to identify next steps?</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>9</td>
<td>23.68</td>
</tr>
<tr>
<td>Yes</td>
<td>29</td>
<td>76.32</td>
</tr>
<tr>
<td>Total</td>
<td>38</td>
<td>100.00</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Improved confidence to make changes/manage symptoms?</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>6</td>
<td>15.79</td>
</tr>
<tr>
<td>Yes</td>
<td>32</td>
<td>84.21</td>
</tr>
<tr>
<td>Total</td>
<td>38</td>
<td>100.00</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Increased positive affect</th>
<th>Decreased negative affect</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>Yes</td>
<td>3</td>
</tr>
</tbody>
</table>

8.3 Quantitative outcomes data

Four standardised questionnaires were used as pre-post tests as described in Table 5, p 15. The heiQ, AQoL and DASS were administered as mail questionnaires while the K-10 was administered orally during the intake and exit interviews. Full pre-post data was obtained from 29 of the 32 people who completed the program (91%), 6 of the 8 people who did not complete the program (75%) and one of the three people who did not start the program.

8.3.1 The Health Education Impact Questionnaire (heiQ)

The heiQ is a tool developed to measure the outcomes of health education and self-management support programs. It has been used for hundreds of programs across Australia, has been translated into 17 languages and is used in more than 20 countries.

Table 27 shows the average change in scores on the heiQ for the Stepping Up program, for one of the most successfully measured group program in Australia to date\(^1\), and the overall average for all self-management programs that have used the heiQ in Australia. The Stepping Up program results exceeded the Australian averages on every domain and the effect was nearly triple the average effect for the emotional distress scale. The Stepping Up pilot also exceeded the results of the leading known group program in relation to ‘Skill and technique acquisition’, ‘Social integration and support’ and ‘Emotional distress’.

<table>
<thead>
<tr>
<th></th>
<th>Stepping Up</th>
<th>Leading group-based program</th>
<th>Australian Comparison group</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health Directed Activities</td>
<td>0.44</td>
<td>0.50</td>
<td>0.38</td>
</tr>
<tr>
<td>Positive and Active Engagement in Life</td>
<td>0.42</td>
<td>0.65</td>
<td>0.32</td>
</tr>
<tr>
<td>Self Monitoring and Insight</td>
<td>0.43</td>
<td>0.51</td>
<td>0.35</td>
</tr>
<tr>
<td>Constructive Attitudes and Approaches</td>
<td>0.29</td>
<td>0.36</td>
<td>0.19</td>
</tr>
<tr>
<td>Skill and Technique Acquisition</td>
<td>0.77</td>
<td>0.63</td>
<td>0.45</td>
</tr>
<tr>
<td>Social Integration and Support</td>
<td>0.43</td>
<td>0.37</td>
<td>0.15</td>
</tr>
<tr>
<td>Health Services Navigation</td>
<td>0.29</td>
<td>0.32</td>
<td>0.17</td>
</tr>
<tr>
<td>Emotional Distress</td>
<td>-0.55</td>
<td>-0.35</td>
<td>-0.18</td>
</tr>
</tbody>
</table>

Table 28 presents a more rigorous way of looking at the results of the heiQ. It considers the possibility that changes in scores may happen by chance, as well as the baseline scores of participants, and then estimates the proportion of people whose improvements were more than an amount that could be reasonably attributable to chance. This is called a ‘positive reliable change’ and the table compares the proportions of people demonstrating a positive reliable change within the Stepping Up program and for the overall pool of Australian data. In this case the Stepping Up program greatly exceeded the Australian figures (by more than

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\(^1\) This only considers studies that are registered, as required, to use the heiQ tool and for which the research team therefore has data.

10% of participants) for ‘Constructive attitudes and approaches’, ‘Social integration and support’ and ‘Emotional Distress’.

Table 28: Estimates of Individual Reliable Change for eight heIQ scales: Stepping Up attendees compared with the Australian Comparison Group

<table>
<thead>
<tr>
<th>heIQ Domain</th>
<th>Program</th>
<th>Estimated percent of participants showing a Positive Reliable Change at follow up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health-Directed Activities</td>
<td>All Australian</td>
<td>26.1</td>
</tr>
<tr>
<td></td>
<td>Stepping Up</td>
<td>17.7</td>
</tr>
<tr>
<td>Positive and Active Engagement in Life</td>
<td>All Australian</td>
<td>22.1</td>
</tr>
<tr>
<td></td>
<td>Stepping Up</td>
<td>25.8</td>
</tr>
<tr>
<td>Self-Monitoring and Insight</td>
<td>All Australian</td>
<td>15.3</td>
</tr>
<tr>
<td></td>
<td>Stepping Up</td>
<td>14.3</td>
</tr>
<tr>
<td>Constructive Attitudes and Approaches</td>
<td>All Australian</td>
<td>20.3</td>
</tr>
<tr>
<td></td>
<td>Stepping Up</td>
<td>30.6</td>
</tr>
<tr>
<td>Skill and Technique Acquisition</td>
<td>All Australian</td>
<td>27.8</td>
</tr>
<tr>
<td></td>
<td>Stepping Up</td>
<td>33.3</td>
</tr>
<tr>
<td>Social Integration and Support</td>
<td>All Australian</td>
<td>17.1</td>
</tr>
<tr>
<td></td>
<td>Stepping Up</td>
<td>27.8</td>
</tr>
<tr>
<td>Health Service Navigation</td>
<td>All Australian</td>
<td>17.0</td>
</tr>
<tr>
<td></td>
<td>Stepping Up</td>
<td>22.2</td>
</tr>
<tr>
<td>Emotional Distress</td>
<td>All Australian</td>
<td>17.5</td>
</tr>
<tr>
<td></td>
<td>Stepping Up</td>
<td>36.1</td>
</tr>
</tbody>
</table>

Impact on “social integration and support”

At first glance it appears surprising that the program appears to have led to such a large improvement in the ‘Social integration and support’ scale given that it is an internet-based activity that did not involve any significant group component. Indeed the effects on this scale were substantially greater than for the Australian average, most of which DOES relate to group programs. The data from the interviews with participants casts some light on why this may be the case.

First it is important to note that the ‘Social integration and support’ scale does not measure social interaction in general but the extent to which people feel supported in dealing with their health problems. In this regard, many of the participants noted that, as suggested in the modules or by the health psychologist, they had taken actions that may have directly led to them feeling more supported. These actions included:

• Discussing particular issues with family members
• Discussing particular issues with a GP or other health provider
• Re-joining previous social activities
• Joining new group activities (e.g., Pilates).

In addition, several participants felt that the program itself and the contact with the health psychologist was a real support to them. Some even expressed the view that the characters in the case studies that were used throughout the modules made them feel a bit more normal and less alone.

8.3.2 Health-related Quality of Life

Health-related quality of life was measured using the Assessment of Quality of Life instrument which measures over all HRQoL on a utility scale between 0.0 (death) and 1.0 (perfect health). The mean utility at baseline was 0.58 units, which is quite low compared with the general population (about 0.8 units). At follow-up, the average AQoL score was 0.70, a substantial improvement. The average improvement across individuals was 0.11 units as shown in Figure 12 below. A minimally important difference for the AQoL has been described as 0.06 units providing evidence that the effect we have observed is large. Note that many individuals reported a very large improvement, >0.2 units.

Figure 10: Mean change (95% CIs) in heIQL and AQoL scores.

Note that the centre point of each line is mean change and lines to the top and bottom of the centre point are 95% CIs.

When the lines do not cross “0” it is implied that the change is approximately statistically significant.
Figure 11 shows the individual change plots for the AQoL questionnaire. Each vertical line represents baseline score at the top and follow-up score at the bottom. To the left of the left (red) dotted line are individuals who had a negative change (decline) in AQoL scores. Individuals between the two dotted lines did not change between assessments. The individuals to the right of the right dotted line (blue) started lower at baseline and improved. The individuals to the far right had the largest improvements. It can be seen that a large proportion of participants had large improvements.

It can be seen in this figure that those who reported a decline tended to start with reasonably high HRQoL at baseline. Many people who reported improvements seemed to do so mostly if they entered the intervention with low scores, which is expected.

In order to help get a sense of the significance of the .11 average improvement in the AQoL, it is worth noting that on the AQoL, a score of zero is equal to death or health states that are considered as bad as death while a score of 1.0 equates to perfect health. A change in score of .11 therefore equates to approximately 11% of the difference between death and perfect health. In comparison to other interventions for which AQoL data is available, this is a very large improvement for an intervention of the duration and intensity of the Stepping Up program.
8.3.3 Depression Anxiety Stress Scales (DASS-21) and K-10

As shown in Table 29 the median stress level at entry to the intervention was at the high end of normal, indicating that almost half of the participants had at least mild stress or worse. This was the same finding for anxiety. For depression, at least half the participants had mild symptoms. The Anxiety and Depression scales are shown in more detail in Figure 15 and Figure 16 where the size of the change is shown in individuals. Figure 10 summarises the average change in DAS Anxiety, Stress and Depression and the K10 Psychological distress. This figure shows that the biggest average improvement was in depression and the change in DAS depression was statistically significant. Note that these analyses indicate that the ‘true’ average improvement lies somewhere between -6 to 0 units, suggesting that the ‘true’ effects size of the intervention may be quite large. An improvement of 6 units for the Depression scale moves a person one whole category change, i.e., from severe to moderate, or moderate to mild, etc.
Table 29: DAS scores at baseline and follow-up.

<table>
<thead>
<tr>
<th></th>
<th>Baseline</th>
<th></th>
<th></th>
<th>Follow-up</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Stress</td>
<td>Anxiety</td>
<td>Depression</td>
<td>Stress</td>
<td>Anxiety</td>
<td>Depression</td>
</tr>
<tr>
<td>N Valid</td>
<td>43</td>
<td>43</td>
<td>43</td>
<td>36</td>
<td>36</td>
<td>36</td>
</tr>
<tr>
<td>Missing</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>7</td>
<td>7</td>
<td>7</td>
</tr>
<tr>
<td>Mean</td>
<td>14.1</td>
<td>7.1</td>
<td>12.1</td>
<td>11.5</td>
<td>5.2</td>
<td>8.7</td>
</tr>
<tr>
<td>Median</td>
<td>14.0</td>
<td>6.0</td>
<td>10.0</td>
<td>10.0</td>
<td>2.0</td>
<td>6.0</td>
</tr>
<tr>
<td>Std. Deviation</td>
<td>9.5</td>
<td>7.7</td>
<td>11.0</td>
<td>8.2</td>
<td>6.4</td>
<td>9.8</td>
</tr>
<tr>
<td>Minimum</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Maximum</td>
<td>38</td>
<td>28</td>
<td>38</td>
<td>36</td>
<td>24</td>
<td>40</td>
</tr>
<tr>
<td>Number of people</td>
<td>11</td>
<td>13</td>
<td>14</td>
<td>6(^1)</td>
<td>8(^2)</td>
<td>8(^3)</td>
</tr>
<tr>
<td>moderate or more</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>severe (see grid below for classification)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Classification of the DAS scores:

<table>
<thead>
<tr>
<th></th>
<th>Depression</th>
<th>Anxiety</th>
<th>Stress</th>
</tr>
</thead>
<tbody>
<tr>
<td>Normal</td>
<td>0-9</td>
<td>0-7</td>
<td>0-14</td>
</tr>
<tr>
<td>Mild</td>
<td>10-13</td>
<td>8-9</td>
<td>15-18</td>
</tr>
<tr>
<td>Moderate</td>
<td>14-20</td>
<td>10-14</td>
<td>19-25</td>
</tr>
<tr>
<td>Severe</td>
<td>21-27</td>
<td>15-19</td>
<td>26-33</td>
</tr>
<tr>
<td>Extremely severe</td>
<td>28+</td>
<td>20+</td>
<td>34</td>
</tr>
</tbody>
</table>

\(^1\) 7 cases provide no data at follow-up, 2 of these cases had high scores at baseline
\(^2\) 8 cases provide no data at follow-up, 3 of these cases had high scores at baseline
\(^3\) 8 cases provide no data at follow-up, 2 of these cases had high scores at baseline

Scale on the Y axis is scale score and X is each participant (case number) ordered from those who had largest decline to those who have largest improvements. Note that the majority of participants had small to quite large improvements.

(NB Case 1, who showed the largest deterioration, did not complete the program.)

Table 30 lists the individual items of the K-10 in order of the size of the change in that item. It is notable that the largest changes were seen for some of the most extreme items such as 'so sad that nothing could cheer you up'. This suggests that the program did include a number of people with severe psychological distress and that these people did improve during the period of participation. While it is impossible to prove that the program caused this improvement, several of these people did attribute their improved status to the program and were able to identify specific aspects of the program that were of benefit to them (see qualitative outcome data, Section 8.5.1, p. 43).

Table 30: K-10 scores ordered by size of average change (large to small)

<table>
<thead>
<tr>
<th>It</th>
<th>In the last four week show often did you feel...</th>
<th>Pre-mean</th>
<th>Post-mean</th>
<th>change</th>
</tr>
</thead>
<tbody>
<tr>
<td>9</td>
<td>so sad that nothing could cheer you up</td>
<td>1.81</td>
<td>1.41</td>
<td>-0.40</td>
</tr>
<tr>
<td>1</td>
<td>tired out for no good reason</td>
<td>2.98</td>
<td>2.61</td>
<td>-0.37</td>
</tr>
<tr>
<td>6</td>
<td>so restless you could not sit still</td>
<td>1.70</td>
<td>1.39</td>
<td>-0.31</td>
</tr>
<tr>
<td>8</td>
<td>that everything was an effort</td>
<td>2.52</td>
<td>2.22</td>
<td>-0.30</td>
</tr>
<tr>
<td>2</td>
<td>nervous</td>
<td>2.38</td>
<td>2.12</td>
<td>-0.26</td>
</tr>
<tr>
<td>5</td>
<td>restless or fidgety</td>
<td>2.47</td>
<td>2.22</td>
<td>-0.25</td>
</tr>
<tr>
<td>3</td>
<td>so nervous that nothing could calm you down</td>
<td>1.50</td>
<td>1.34</td>
<td>-0.16</td>
</tr>
<tr>
<td>4</td>
<td>hopeless</td>
<td>1.76</td>
<td>1.61</td>
<td>-0.15</td>
</tr>
<tr>
<td>10</td>
<td>worthless</td>
<td>1.58</td>
<td>1.54</td>
<td>-0.04</td>
</tr>
<tr>
<td>7</td>
<td>depressed</td>
<td>1.98</td>
<td>1.98</td>
<td>0.00</td>
</tr>
</tbody>
</table>

Figure 14: Histogram of change scores with DASS Anxiety scale showing a substantial number of participants reporting decline in depression symptoms (left side of dotted red line)

Histogram

Mean = -1.38
Std. Dev. = 7.068
N = 30

Decline in anxiety symptoms (left side of dotted red line)
Decline in depression symptoms (left side of dotted (red) line)

Figure 16: Change in DASS Anxiety, Stress and Depression and change in K10 Psychological distress.

Note that when the 95% CI does not cross zero (dotted red line) the change is approximately statistically significant.
8.4 Immediate outcomes related to each module

At the end of each module participants were presented with a screen with a sliding scale that they could use to rate the module in terms of:

- Their ability to understand the information in the module
- Whether they completed homework tasks in relation to the module
- Their confidence in their ability to implement some changes based on the module
- Their perception of the overall usefulness of the module.

They were also invited to state ‘the main things they got from the session’ and provide any additional comments. These responses are listed in full as Attachment F.

Table 31 lists the responses to the ratings questions with the responses listed in descending order of value. It is important to note that the number of responses available for the modules varies greatly so it is difficult to make direct comparisons. Another limitation to these data is the fact that people rated the modules immediately upon completion of the session at which time they may not have realised the ultimate value of what they had learnt. An example of this is the two sleep-related modules. They received a relatively low value rating and yet sleep was frequently cited as one of the main areas where people made improvements.

<table>
<thead>
<tr>
<th>Table 31: Average module ratings from website</th>
<th>Confidence</th>
<th>Homework Done</th>
<th>Understand Info</th>
<th>Useful</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stressed</td>
<td>8.00</td>
<td>10.00</td>
<td>9.50</td>
<td>9.50</td>
</tr>
<tr>
<td>Worry management tips</td>
<td>8.20</td>
<td>4.56</td>
<td>9.10</td>
<td>8.20</td>
</tr>
<tr>
<td>Breathe</td>
<td>8.45</td>
<td>7.82</td>
<td>9.09</td>
<td>8.18</td>
</tr>
<tr>
<td>Wrapping things up</td>
<td>8.29</td>
<td>6.20</td>
<td>8.71</td>
<td>8.10</td>
</tr>
<tr>
<td>Be mindful</td>
<td>8.37</td>
<td></td>
<td>9.00</td>
<td>8.00</td>
</tr>
<tr>
<td>Habit change tips</td>
<td>8.50</td>
<td></td>
<td>8.75</td>
<td>8.00</td>
</tr>
<tr>
<td>Worried</td>
<td>8.40</td>
<td>4.75</td>
<td>10.00</td>
<td>8.00</td>
</tr>
<tr>
<td>I think</td>
<td>8.00</td>
<td>6.82</td>
<td>8.64</td>
<td>7.77</td>
</tr>
<tr>
<td>Balancing activity and rest</td>
<td>7.00</td>
<td>6.36</td>
<td>7.85</td>
<td>7.77</td>
</tr>
<tr>
<td>Change your mind</td>
<td>7.63</td>
<td>6.89</td>
<td>8.74</td>
<td>7.74</td>
</tr>
<tr>
<td>Getting back to it</td>
<td>7.33</td>
<td>6.75</td>
<td>8.75</td>
<td>7.67</td>
</tr>
<tr>
<td>Let’s make a plan</td>
<td>9.33</td>
<td>6.00</td>
<td>9.00</td>
<td>7.67</td>
</tr>
<tr>
<td>Loose up</td>
<td>9.00</td>
<td>6.60</td>
<td>9.45</td>
<td>7.60</td>
</tr>
<tr>
<td>Overcoming obstacles</td>
<td>7.60</td>
<td>7.00</td>
<td>8.40</td>
<td>7.60</td>
</tr>
<tr>
<td>Feeling down</td>
<td>7.29</td>
<td>4.83</td>
<td>9.29</td>
<td>7.57</td>
</tr>
<tr>
<td>Managing your health</td>
<td>7.18</td>
<td></td>
<td>9.14</td>
<td>7.46</td>
</tr>
<tr>
<td>Exhausted</td>
<td>7.71</td>
<td>7.00</td>
<td>8.86</td>
<td>7.43</td>
</tr>
</tbody>
</table>
8.5 Follow-up interviews

Everyone who was recruited to participate in the program was approached to participate in a follow-up interview, including those who did not start the program and those who did not complete it. The interview schedules for the three groups are provided as Attachment E.

There were two main purposes of the interviews:

a) To provide supplementary outcomes information including information that may help interpret other outcomes data as well as the participants’ own perceptions of their outcomes and the benefits of participation.

b) To collect information that can be used to improve the program for future users including those who will participate in the second Stepping Up project.

8.5.1 Interview data related to outcomes

While comments that related to outcomes could be found in responses to nearly all of the questions, the questions that most directly related to outcomes were:

• Which were the most useful activities that you learnt or used in the program which helped you make progress on your goal or main problem you chose to work on?

• What was the most important or useful thing that you got out of the program?

• Were there other things that you have achieved? And the pair of questions...

• Can you tell me what you wanted to achieve? and, Have you been able to achieve what you wanted for this program?

The responses to these questions are provided as Attachment G (with all potentially identifying comments deleted or edited).

Qualitative information on outcomes supplements the quantitative data in two main ways. First it provides detail related to the changes that are measured, but not really described, in the quantitative data. Second, the qualitative data can also provide information that supports our ability to say that the program was the cause of the measured changes or not. For example if someone says “the program was great but I also had an operation that took away most of my pain” we would conclude that the program was possibly NOT the main cause of any measured changes. On the other hand there are certain types of qualitative information that support a conclusion that a program WAS the primary cause of observed changes. These include:

• Comments that show that the changes occurred very rapidly relative to the time that a problem has existed (e.g. (hypothetical examples) ‘I couldn’t move my neck all day and the moment the physio manipulated it, I could move it fine’ or ‘This is the first time in 10 years that I have been able to walk past my letter box and now I can walk to the shops’).

• Comments that identify a perceived mechanism of benefit (e.g. (hypothetical) ‘It gave me the confidence to go to the gym and not care what anyone thought’)

• Comments in which the participant clearly attributes the change to the program (subjective perception that the program caused the benefit).

Summary of described outcomes
Attachment 1 lists all of the responses to the questions that most commonly elicited responses about outcomes. Some of the notable features in this data are:

• All but one person noted some specific behavioural changes. In the researchers’ experience this rarely exceeds 50% in self-management programs.

• There were very few comments describing the outcomes of the program as ‘reinforcing what I already knew’ or ‘providing reassurance that I am on the right track’. In the researchers’ experience, it is common in self-management programs that at least 50% of participants identify the main benefit as reinforcement or reassurance. No-one identified these as the main benefits of the Stepping Up program.

• The identified main benefits (in order of frequency of mentions) were: insights that altered the participant’s mental approach to their problems; specific actions they had taken or techniques that they had applied; increased well-being (psychological and/or physical). (See Attachment G, question 4).

• For most of the identified ‘main problems’ (Attachment G, question 10), participants stated that they had improved but that the improvement was not complete. Most considered it a work in progress. Approximately one third made comments that indicated that they believed that they would be able to make further progress.

Comments relating to the causal efficacy of the program
There were numerous comments in which participants noted changes in their mental approach, their ability to cope with a particular problem, their symptoms and/or their emotional state, and in which they directly linked this to new insights or the application of techniques gained through the program. (Many of these are listed in Attachment G, especially question 5).

There were three people who mentioned other concurrent events that also contributed to their outcomes (medical or surgical interventions, holidays). There was one who mentioned a rapid decline in health status as the main reason why they did not benefit in terms of symptoms.

For most participants there was insufficient data to say with certainty that the reported benefits were a major change from very long-term problems and in future evaluations related to this program the researchers will seek more information about the duration of problems for which a substantial improvement is noted.
8.5.2 Interview data related to program features and characteristics

The role of the health psychologist and the initial assessment and case formulation interview

The responses in relation to the initial assessment and case formulation process indicated that for many people this was a difficult process that they did not fully understand at the time. Some felt that it repeated things that they had done before. Having made these comments, however, many people indicated in later comments that the initial work laid a foundation for things that they achieved later. Several people made specific comments that indicated that the value of the case formulation stage only became clear to them later in the program and several more mentioned specific products of the case formulation process as important contributors to their outcomes. There were also several comments in which people recognised that the process was an assessment process that led to the establishment of their program.

The role of the health psychologist is discussed in detail in Section 10, p 50. As noted in that section most mentions of the health psychologist’s role related to either specific suggestions or advice about a general approach to follow in working through the modules. People appreciated the weekly emails but there was no indication that the interaction with the health psychologist was the primary therapeutic process for any of the participants. All comments related to the health psychologist’s role were very positive.

The modules and their content

Nearly all of the modules were cited by at least one person as being the main thing they got from the program, (or had content that related to things that at least one person said was the main thing that they got from the program) (Attachments F and G). At the same time most of the modules received at least one comment that the module really wasn’t for that participant.

The modules that had the most extreme responses were:

- The two modules related to sleep
- ‘Exhausted’
- Mindfulness
- ‘I think’ and ‘Changing your mind’.

With the modules related sleep, exhausted and to some extent the pain modules, the majority of comments were positive and people appreciated the practical focus and ideas. The changes related to these modules were usually considered partial successes or a work in progress. Several people listed sleep improvements as the main benefit they received from the program. For each of these modules, one or two people expressed frustration, indicated that the suggestions were simplistic, that they had already done all those things, and whose tone seemed to express that they felt they were being talked down to.

The other group of modules that drew some extreme responses were the modules with a cognitive focus such as ‘mindfulness’, ‘I think’ and ‘changing your mind’. Many people found these somewhat challenging both intellectually and emotionally but most people found them worthwhile. Specific changes in thinking and attitude related to the content of these modules, were the most frequently listed main benefits. Once again, there were two people who found some of this content objectionable and who stated that they felt like they were being “invalidated” or “brainwashed”.

Timing issues

The most frequent negative comments about the program were related to timing issues. In particular, that people felt rushed towards the end of the pilot and/or that they were disappointed that they would not get
the chance to do more of the content. In some ways it is a positive reflection on the program that for most people the worst thing about the program was that it ended.

A related issue was the three day lock-out between modules. This was built into the program to ensure that people did not just surf quickly through the content, and also to apply best-practice principles in behaviour change interventions, including presenting information in small chunks and allowing people time to absorb and attempt to apply new learning. There were a number of people who disliked this feature. For several of these people the reason was that they knew their time on the program was limited and they just wanted to see more of the content. For three people, however, the three day lockout was a frustration in and of itself. For at least one of these people, this was related to scheduling issues: their available time tended to come in blocks followed by a number of days when they could not access the program so they would prefer to do more than one module at those times when they could access the program.

Other features and characteristics of the program

Participant feedback about other features of the program is considered in the following section on usability (Section 9, p. 47). These include feedback on:

• The case studies
• The desirability of a space for interacting with other participants
• Website functioning and usability.

8.5.3 Overall opinions of the program

The majority of overall comments about the program were positive and most people were very disappointed that it ended. Effusive comments are comments that include words like ‘great’, ‘wonderful’, ‘fantastic’ or comments like ‘one of the most useful things I’ve done’ or ‘has made a real difference in my life’. 19 of the people interviewed (50%) made effusive comments of this type at some point in the interview. This is very high given that about 20% is most common in the programs previously evaluated by the researchers.

On the other hand, there was one person who never got used to ‘talking to a computer’ and who dropped out because the computer-based intervention did not suit them at all and they wanted to talk to a person. (“This is not for me - totally alien and annoying to work on the computer like this - it is simplistic and nothing to do with me”).

When asked about the most useful aspects of the program the most frequent response was that it was the program as a whole, they way that it fitted together. Even in comments about specific modules there were times when people indicated that a module was difficult and not really their favourite but that they could see its importance in the overall program.
9 USABILITY ISSUES and FEEDBACK

Several issues have been reported in the previous sections of the report. However, a summary of the issues is presented here. Please note that the strengths of the program design and website interface are not summarised here.

The issues discussed in this section were identified through the follow-up interviews, call logs, web statistics, the usability study and emails to the health psychologist.

Technical issues were experienced by a few participants, which impacted on their engagement. Previously noted is the one participant who logged on 21 times but never commenced the program. A second participant discontinued the program due to difficulties with navigating the program and being able to follow instructions. Only a small number of people (5) requested technical support from the project team, and this was generally due to confusion about navigating between sessions and within modules, and due to lost or changed password issues. The ‘next’, ‘continue’, and ‘start’ buttons appear to have created this confusion, which resulted in two participants thinking they had finished their program, and another not knowing they had completed modules. Several other participants received support from family members to learn and become familiar with the program. Two people also felt overwhelmed with the number and variety of features that were available.

Some people experienced browser issues, but generally this was overcome with updates and change of browser.

There are a number of bugs in the system that have been identified and which the team plans to rectify during phase 2 of the program.

- Sending of “session now ready” emails when the session was not ready
- Moving backwards instead of forward in the program does not save work that has been entered
- Issue with emails being cut off after a line or two
- Completed button not working properly in “about me”

There are also design issues that can be improved based on feedback from participants. Suggestions have been made in terms of changes and improvements based on participant experience.

- Having goals and homework activities presented from week to week so that participants do not have to search back through previous modules
- Being able to delete or file emails
- Having a map of the whole program for each participant
- Being able to maximize emails to reduce key strokes.

The website itself experienced some issues including freezing and slow to load, which required an upgrade during the implementation phase.
One serious event occurred with one participant finding text that had been imported into his program that had probably come from one of the test programs. The team is confident that there was no breach of confidentiality for any of the participants, as this data was concerned with a health issue (smoking) that was not experienced by any of the enrolled participants.

The question was asked of all participants whether they would have preferred a "chat room" option. Eight people said no, five people were not sure, and twelve people indicated this would be a good idea. Suggestions included a blog, a message board, having it as an option, and if it was included near the end of the program.

There was overwhelming satisfaction with the three cases presented within the program except for two participants, of which one was dissatisfied with the program overall, and the other didn’t really like the look of one of the cases.

The reminder emails were greatly appreciated, with 17 people indicating they found them very helpful, to remind them to get back on their program, and to motivate them. Only one person did not like the reminder emails.

A number of features were incorporated into the program to enhance interaction, and to promote engagement. Additional workbook entries were counted, however this data demonstrates that although nearly everybody entered one extra entry, for the most part, this feature was not taken up to any great degree.

![Graph showing frequency of additional workbook entries](image)

An additional program feature was “my week” a tool to support planning activities. The majority of participants did not utilise this feature much, however, there were 12 participants who made at least 20 entries into their “my week” facility. The number of entries could have been made over the whole program, or only over one or two weeks. This data is better explained in combination with the evaluation interviews, which included usability questions. A number of participants explained that they already had calendars or diaries that were sufficient for all their planning needs. Only two participants reported they found it useful, whereas twelve participants described it as unhelpful or that they didn’t like it.
10 Summary and implications for the second Stepping Up project

At the start of this report we stated that, in addition to assessing the outcomes and value of the pilot Stepping Up program, we wished to answer questions to inform the roll-out of the program to other agencies in the second Stepping Up project. These questions were:

- To what extent are any successes achieved due to the program rather than the particular skills of the health psychologist?
- What are the principal skills required to implement the program? What training is likely to be required?
- What features of the program are most useful and should be included or further developed in the second project?
- Which modules were most and least useful? Which need further development and in what way?
- In what ways does the web-based software need to be further developed and/or improved?

In this section we present a brief summary of our conclusions in relation to each of these questions.

To what extent are any successes achieved due to the program rather than the particular skills of the health psychologist?

There were two main aspects of the health psychologist’s role that were possible contributors to the improvements reported by participants. The first was the direct contact with the client during the case formulation phase and weekly emails. The second was her role in structuring the program for each individual.

While there were no participants who directly stated that the interaction with the health psychologist was the most important aspect of the program, there were several who referred to particular interventions or suggestions from the health psychologist that were critical in determining how they approached the program. These shaping interventions and suggestions included:

- Permissions – statements that made the participant feel that it was alright to do something for themselves (e.g. permission to relax with the materials rather than treating them like work; permission to have some unstructured time; permission to focus on themselves)
- Suggested general approaches to using the materials (e.g. how some people could approach them in a way that helped them achieve more structure in their life and how others could approach them in a way that allowed them to relax from trying to structure every aspect of their lives).

Overall, there were no participants for whom the consultation with the health psychologist was more important than the content of the program.

What are the principal skills required to implement the program? What training is likely to be required?

According to the health psychologist, the assessment and case formulation process took a considerable amount of time with many patients and involved the use of a range of skills that need to be developed with practice. Also there were people who had quite severe psychological symptoms and for whom considerations of risk assessment arose. Based on these considerations the research team have reconsidered the issue of training and now believe that more will be required to implement the program in other settings than simply training individual practitioners. Rather, the researchers believe it will be necessary to work with the agencies that provide the service to develop a system for implementation that includes training, secondary consultation support, clinical risk management and evaluation and quality control.
What features of the program are most useful and should be included or further developed in the second project?

In addition to the refinements already suggested in this section, there were other features of the program that were valued by many participants and which will be further developed in phase 2.

One feature that was appreciated by many participants was where downloadable recordings were provided to assist relaxation and mindfulness. The researchers will be looking to increase the number of downloadable tools for phase 2. The program will also include video content demonstrating some of the skills discussed in the modules.

Another feature that was appreciated was the case studies and the researchers will be looking to increase the variety of case studies and add some video case study material in phase 2.

Which modules were most and least useful? Which need further development and in what way?

As noted previously, nearly all of the modules were cited by at least one person as being the most useful thing in the program. The materials that were most frequently mentioned as being useful were those that included specific practical techniques and/or provided recordings to assist relaxation and mindfulness.

As noted in Section 8.5.3 (p.46), most people had a sense that the program was more than just a set of modules and that the most valuable aspect of the program was the overall design and the way in which everything combined.

Overall, the modules that need to be improved most are those that could benefit from some more multidisciplinary input, including the modules on pain management and fatigue.

In what ways does the web-based software need to be further developed and/or improved?

Several bugs were identified during the implementation of the project that need to be rectified for the second project. Additionally, design issues and suggestions for improvement were made by participants during the usability and follow-up interviews. These will all be considered within budget constraints for the second project.

As previously stated, the three interfaces all require some work, with the most work required on the management interface. This will require significant budgetary support which has not been sourced at the time of writing this report.
| Attachment A: | Concept mapping results |
| Attachment B: | Discussion paper presented to External Reference Group |
| Attachment C: | Project brochure |
| Attachment D: | Usability interview schedule |
| Attachment E: | Follow-up interview schedules |
| Attachment F: | Main things gained from session and additional comments for each module |
| Attachment G: | Outcome related comments from follow-up interviews |
Attachment A: Concept mapping results

Figure 17: First health professionals' concept mapping group

MISSING:
- More on treatment options
- Irritability and anger
- Detailed relationship problems
- What to do when things get worse
- Communication
- Dealing with stigma
- Graded return to meaningful occupation
- Moving from a patient to a person
- Mechanics and pacing
- Specialist physios and OTs
- Financial

Figure 18: Second health professionals' concept mapping group

MISSING:
- Knowledge of condition
- Knowledge and beliefs about disease impact and processes
- Role of physical activity
Our thinking and some key questions

The purpose of this letter is to update you on the progress of the project, ‘An innovative e-self-management support system for people with depression and anxiety and co-morbidities’, particularly our thinking around a number of key issues. We are also seeking your advice in relation to some key questions related to these issues. In summary the issues are:

1. The likely user population
2. The need for a personal contact component
3. Expected outcomes
4. The group component of the model
5. Some initial thoughts on modules
6. Potential contribution to existing knowledge from this project
7. Future timelines and locations of ERG meetings.

Before discussing these issues however, we would like to present a brief overview of progress to-date and of the overall program model as far as our thinking has progressed.

Progress to-date

Key achievements to date include:

- Appointment of all staff including a health psychologist
- Establishment and first meeting of the Expert Reference Group
- Discussions with providers of online interventions re design and delivery issues
- Conducted first 3 concept mapping groups (2 with health professionals and 1 with consumers) and set up second consumer group
- Commenced a literature review focusing on online interventions for people with musculoskeletal conditions OR depression or anxiety and also on evidence based interventions for people with both groups of conditions
- Commenced developing a design brief for the website and have made contact with several web developers/ development companies.

This last point is a critical issue for the ability of the program to meet its timelines and is in turn dependent on a number of decisions about the service delivery model. This is the rationale for a number of the questions we pose later in this document.

Overview of the model

The following page contains a diagram showing our current thinking about the service delivery model. The diagram shows our view of the likely flow of user experience with the program.

The key questions arising relate to the role of the health psychologist and in particular the extent (or not) of a direct contact role, the nature of the group interaction component and the content of the modules. These are discussed in the following section. The model reflects four main components of the intervention

1. Psychologist support
• Focused on and initial discussion to assist participants to clarify personal priorities and health impact
• Respond to questions and moderate group discussion
• Referral

2. Modules
• Self-assessment, educational and therapeutic modules
• Mix of core and optional modules

3. Discussion forum
• Thematic group discussions conducted over a one week period
• Key points wrapped up into FAQ weekly

4. Additional resources
• Supplementary resources and links that may be referred to within certain modules or the group discussion
• Open access
Specific issues for input

We realise that not everyone on the ERG has experience relevant to all of the issues listed below. Please don’t feel that you have to respond to every question.

1. The likely user population

Based on some of the discussion at the first ERG meeting we consider that there are likely to be two main groups of users for the program. We have called these consumer archetypes and describe them as:

- The Long-term Affected with Multiple Morbidities:
  We expect that the first and largest group is likely to be people who have had long-term musculoskeletal problems and have experienced some erosion of confidence and function which is related to the development of depression and/or anxiety. We see the trajectory of the life journey as a key issue for this group (a sort of spiralling down) and see the reversal of this trajectory as a key aim. We believe that many will have developed habits of thought and action that contribute to their trajectory.

- The Newly Diagnosed:
  We expect that a second group will be people who have been diagnosed relatively recently with musculoskeletal conditions and/or who have only recently started to experience effects such as pain and/or decreasing function. In this group depression and/or anxiety may be related to grief and anger and the need to modify expectations (real or perceived). We expect that in this group access to accurate information and the need to address false beliefs will be a critical issue.

Questions

Do you agree that these are likely to be the main users of the program?

<table>
<thead>
<tr>
<th>YES</th>
</tr>
</thead>
<tbody>
<tr>
<td>I think we need to make the distinction between potential ‘program users’ and the broader population of individuals experiencing depression and/or anxiety alongside their musculoskeletal condition</td>
</tr>
<tr>
<td>- To be eligible - individuals experience anxiety/depression + musculoskeletal condition. May be due to:</td>
</tr>
<tr>
<td>□ Circumstances largely unrelated to their musculoskeletal condition (i.e. co-occurring depression and/or anxiety)</td>
</tr>
<tr>
<td>□ Difficulties adjusting to or managing their musculoskeletal condition or its treatment (i.e. musculoskeletal condition leading to depression and/or anxiety)</td>
</tr>
<tr>
<td>□ Complex interplay between emotional and physical experiences (i.e. bidirectional influence of musculoskeletal condition and anxiety/depression)</td>
</tr>
<tr>
<td>- Likely ‘Program User’</td>
</tr>
<tr>
<td>□ Willing to engage with support</td>
</tr>
</tbody>
</table>

Attachments page 8
Do you agree with these broad descriptors of likely need? If not, how would you modify or add to them?

<table>
<thead>
<tr>
<th><strong>Willing &amp; suitable for web-based intervention</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes, but I think the order of main users may be group b followed by group a, above. Consideration should be given to the age and gender of participants.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>I think these two groups will be the main target audiences although I can’t help thinking that there may be a chronic pain group with unique requirements that sits outside these two</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>I believe the above groups would most likely be the 2 main types of users. I was wondering about partners of these users? Could there be an avenue for them to participate, as they do suffer as well. Perhaps there could be a module for them or an area where they can have input into their loved one’s goals.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>On the whole yes.</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>I would expect a 3rd group that has elements of both the previous groups will be evident, i.e., those with longer term musculoskeletal problems who have had a recent significant deterioration that will feel like another new injury.</td>
</tr>
</tbody>
</table>

Yes, if these are to be used for the researchers purposes. If the descriptors are to be used for other purposes they may need revision. E.g. if they are to be used during recruitment they will need to be much more specific and targeted to a lay audience.

Again, need might be defined in relation to their need for support (for anxiety/depression) broadly, and their need for web-based mode of support (i.e. issues associated with access to other forms of support or preference for web-based support).

Uncomfortable with “false beliefs”; in whose opinion are the beliefs false. Can this be worded differently?

What about a situation where you have a friend/relational who is described in group A, but they don’t want to take the step to join the program. They don’t want any help but you want to do something to help them. Could this concerned person join the program on a different level to get information and learn techniques that might be able to help their friend?

Can participants who enrol via ‘open access’ be explained a little more? Are these just the general public who find the site? In the randomised trial you mention later on, does this include the general public or just people recommended through the project? When the system is functioning and up and running, where are the participants coming from? I assume anyone will be able to access it and register? Are there plans in place for promoting the site? How will people find out about it? This may be too early to worry about at this stage, but something to consider as this may affect design elements. Without sounding cheeky - an awesome website is only good if people know it is there!

In my experience in conversation regarding treatments (medical, pharmaceutical, etc...)

Attachments page 9
2. The need for a personal contact component

We believe that the users of this program (particularly group a, above) are likely to be among the more complex groups who use self-management programs/services and that many will have experienced significant erosion of confidence and mastery. We expect that most will require considerable assistance in reflecting on the role of their health problems in their life, developing confidence that some change is possible and developing goals (aspirations) that are achievable in the short-term and which are perceived as meaningful to them. We also consider that it is likely that many will have experienced numerous obstacles and set backs in their previous attempts to make changes in their life and may need assistance to ensure that they achieve some experiences of success through their involvement with the program.

Even in programs that provide face-to-face services, working through these issues with people in this group is a complex and highly skilled task. At this stage we do not believe that any of the personal reflection and goal-setting type modules that we have seen are up to the task on their own. For this reason we propose that the 60 people who participate in the trial will be offered 1 to 2 phone consultations with the health psychologist and some additional personalised support. In addition people who require more extensive personal support will be appropriately referred.

Questions

Do you agree that an element of personal support, particularly an initial clinical discussion that helps participants explore their health issues and aspirations and to set short-term goals is likely to be necessary for this population group?

| Yes. Based on my experience with online therapy for mental illnesses, programs with support from a psychologist (usually this has been email-based counselling) were more successful | Would provide opportunity to build rapport and enhance engagement with the program |
| | - Allow assessment and care planning – which would be difficult to do justice to using an automated program |

Yes, particularly important for older persons

| Yes I think this is crucially important. This initial discussion may need to stretch over a few sessions before individuals are ready to begin the goal setting process. Moving into the goal setting process to quickly can impact on individual ownership and willingness to action these goals. | Some may not want the personal support, particularly the phone calls, as one reason they have decided to use the online system is to do things their own way, without wanting to talk to anyone. I guess it depends on the extent of their condition. There would be some that might need close guidance, but I would think a large majority would see it as a sense |
**3. Expected outcomes**

In considering the expected outcomes of the program for participants it is necessary to consider a) the likely profile of needs as discussed above, and b) dosage issues. Specific dosage considerations are:

- **Duration:** For most people the period of participation will be 6 to 10 weeks
- **Intensity:** The amount of involvement is largely controlled by the participant

---

**Personal contact will be important. It need not take up a huge amount of time. What will be important to think of is the form it takes since aside from the 60 in the trial, you will have no control over where in the world they come from**

---

**Are there any specific emphasis this personal support should have or additional areas where personal support is likely to be required?**

This is likely to be dependent on individual participant’s needs. If there is scope to adapt the support to individuals needs this would be ideal however, if the research requires that support be standardised then I would suggest more than 2 phone calls or otherwise email based support that is regular.

- Socialisation to the treatment approach (introduction, explanations, registration, opportunity to ask questions)
- Assessment
- Care planning
- Referral

Just the obvious like expert help that would be required to assist people with physical activity and dietary programs for eg

Better answered after I have more detail of the program itself

---

**Are you aware of any tools that are currently available online or that could be delivered online that have the potential to enable people to work through the exploratory and goal setting phase independently?**

No

Maybe some of the Flinders and Health Coaching Australia tools

*I rather like the living life to the full website and recommend you explore it for yourselves – www.livinlifetothefull.com*
• Intensity: Most of the intervention is on-line with limited opportunity for personal interaction

• Follow-up time frame: we only have the opportunity to follow people up at most 2 weeks after completion of the program

Based on all of these considerations we consider that a prioritised list of individual outcomes could be:

1. Outcomes related to trajectory and experience of success:
   a. Have experienced success in making at least one change that is considered to be of significance by the individual
   b. Increased confidence in their ability to make changes
   c. Demonstrated capacity to identify additional beneficial changes and strategies for achieving these
   d. Have identified additional, specific planned changes
   e. Know how to overcome problems and deal with setbacks (or obtain assistance to do so)

2. Outcomes related to beliefs (maybe first priority for some people in group b)
   a. Understand that disability is not a necessary corollary of impairment nor handicap of disability (without the jargon) – In particular for people with chronic pain to overcome the association between pain and loss of function
   b. Overcome false beliefs related to pain, physical activity and potential harm

3. Personal outlook outcomes: These are likely to be based on 1 and 2 and include:
   a. Confidence in the ability to manage their health issues (health related self-efficacy)
   b. Confidence in their ability to live well
   c. Increased positive affect (e.g. the heIQ ‘positive and active engagement in life changes’)
   d. Decreased negative affect (depression and anxiety)

4. Additional general self-management outcomes:
   a. Obtained specific coping techniques
   b. Specific health related behaviours

Questions

Do you agree with this list of outcomes? How would you modify or add to them?

| Yes, although it is of course important to use valid/reliable measures for some of these outcomes (e.g. negative affect). |
|---|---|
| 1. Goal attainment and factors associated with attainment of these goals (i.e. keep focus of changes in confidence, motivation, beliefs etc specific to the area that the client has nominated to improve). |
| 2. Skill development - skills that can be applied across domains (i.e. goal setting, problem solving, etc) |
| 3. Self-perceived self-efficacy & motivation to manage health issues (a more global – less behaviour specific concept) |
| 4. Experience of symptoms (mood, anxiety, stress, pain) |

Attachments page 12
Increased sense of control and autonomy.
Decreased anxiety and depression.

Possibly some specific content and recognition of the four environments of health and how to problem solve around what seem to be insurmountable barriers for some people.

These outcomes seem very comprehensive. The only one I might add under Personal outlook is: ‘Increased self-esteem and social activity’?

Do you agree with the priority of these outcomes? How would you modify it?

- No. Better would be points under 3, then 4, 2, 1. I think personal outlook most important, followed by group support.
- Loss of control added to 2a

Are there any specific tools or assessment strategies that you would recommend for any of these outcomes?

- DASS, Beck Depression and Anxiety Inventories, SF-12 or similar may be useful for 3d particularly. I have a health related self-efficacy scale which can be adapted for use for particular populations however, the psychometrics have not be thoroughly tested
- For 1 – this could be built into the program and perform a clinical as well as evaluation function
- For 2 to 4 – form part of assessment and review

4. **The group component of the model**

We believe that it is important to provide an opportunity for group members to interact with each other and to share experiences and ideas. We recognise, however, that live interaction may mean that some people can’t participate because of time issues or because their typing skills are not sufficient. We do, however, wish to maintain some focus to the discussion. We are currently considering a model where an asynchronous discussion is kept open for a week. The discussion would be opened with a focus on particular issues but there would be some freedom for it to develop to include other issues within the week. The discussion would be moderated by the health psychologist and at the end of the week she would produce a permanent record of key issues in a sort of FAQ page.

**Questions**

- Do you consider that opportunities for group interaction are important? Does this receive sufficient emphasis in the proposed model?

  Yes, I think this is a useful aspect of the model and the flexibility of the discussions is important. Note that some participants may not actively participate in this but may still find...
5. Some initial thoughts on modules

Our thinking about content is very much a work in progress and will continue to be informed by consultations, the concept mapping groups and the literature review. None-the-less, the, work done thus far and the considerations about target groups and outcomes discussed above have led to the development of some ideas about content. The modules are not necessarily conceptualised as educational or informational but may have a self-reflective, therapeutic, modelling or experiential focus.

Possible modules include:

Core modules:

1. Reflection on personal aspirations and the impact of health issues
2. Making successful changes
3. Dealing with false beliefs (especially re symptoms, function and potential damage)
4. Understanding and managing moods
5. Constructive relationships (nurturing personal relationships; social and professional relationships including stigma)
6. Dealing with setbacks

Optional modules:

7. Understanding pain
8. Strategies for dealing with stress and anxiety
9. Work issues

Attachments page 14
10. Newly diagnosed

Questions
What modules do you think should be offered as core or optional modules?

<table>
<thead>
<tr>
<th>Module</th>
</tr>
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<tbody>
<tr>
<td>Mood – introduction</td>
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<tr>
<td>Mood management – behavioural activation</td>
</tr>
<tr>
<td>Mood management – cognitive strategies – thinking feeling connection</td>
</tr>
<tr>
<td>Mood management – cognitive strategies – disputation &amp; balanced thinking</td>
</tr>
<tr>
<td>Mood management – cognitive strategies – underlying beliefs</td>
</tr>
<tr>
<td>Mood management – prevention planning</td>
</tr>
<tr>
<td>Worry – introduction</td>
</tr>
<tr>
<td>Worry management</td>
</tr>
<tr>
<td>Panic &amp; anxiety – introduction</td>
</tr>
<tr>
<td>Panic &amp; anxiety – managing physical symptoms</td>
</tr>
<tr>
<td>Panic &amp; anxiety – cognitive strategies – thinking feeling connection</td>
</tr>
<tr>
<td>Panic &amp; anxiety - cognitive strategies – disputation &amp; balanced thinking</td>
</tr>
<tr>
<td>Panic &amp; anxiety – talking avoidance</td>
</tr>
<tr>
<td>Panic &amp; anxiety – cognitive strategies – underlying beliefs</td>
</tr>
<tr>
<td>Panic &amp; anxiety – prevention planning</td>
</tr>
<tr>
<td>Sleep management?</td>
</tr>
<tr>
<td>Pain management ….</td>
</tr>
<tr>
<td>Stress management…</td>
</tr>
<tr>
<td>Becoming more physical active</td>
</tr>
</tbody>
</table>

I think all of above should be core. The “optional” ones are highly important. Would not delineate between core and optional. Everything important should be included and everything should be optional.

Musculoskeletal health function activities of daily living maintaining independence where possible

I think 7, 8 & 10 should be part of the Core modules as well as 1-6.

SMART – goal setting?

5 areas approach (as taught in living life to the full website)
Acceptance
Relaxation
Depending on the level of depression & anxiety – if significant then this will have to be addressed first before optional modules. Also how is level of depression/anxiety going to be assessed before participating in program - not just the initial 60 but after full roll-out?

Do you have any additional suggestions on content that you think is particularly important either within the proposed models or additionally?

"Understanding and managing moods" and "Strategies for dealing with stress & anxiety" seem to be very similar content ideas. These could be combined.

Attachments page 15
6. Potential contribution to existing knowledge from this project

We recognise that this project is ambitious in that it is attempting to deliver an online service to a group of people with complex needs who present many challenges to skilled practitioners in a face-to-face setting. We are looking to extend the project to conduct a randomised trial over 2011 and 2012. This will depend on a successful application to the next beyond blue VCOE funding round (May 2010) and a key issue will be to demonstrate the potential contribution to knowledge of this program. Some of the issues that we consider to be likely contributions are:

1. Development of a program with the potential to be replicated broadly
2. Development of an intervention that has demonstrated ability to reach people who do not typically access self-management programs (e.g. rural, don’t like groups, full-time workers, men)
3. Increased understanding of the potential and limitations of online interventions and mixed online/personal interventions for people with a complex mix of physical and mental health conditions
4. Understanding the potential for delivering an intervention focused on:
   a. Mastery and experiences of success
   b. Dealing with false beliefs and non-constructive habits of thought in an online intervention.

Questions

What do you see as the most important potential contribution of this project to the development of knowledge in this area?

Contributions 1 and 2 above as these are great areas of need. Beyond Blue appear to target areas/populations in which services are limited and therefore will be attracted to a project with potential to improve service delivery. Contributions 3 and 4 are important but other researchers have made inroads in this respect, albeit with other populations.

Point 2 above

What are the core components and levels of intensity required for an online intervention for people with physical and mental health issues? What sort of reach if any will a project like this achieve in the most disadvantaged communities and what alternative technologies or
<table>
<thead>
<tr>
<th>combination of technologies best suit these groups.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have to think some more before able to provide good response</td>
</tr>
<tr>
<td>(and that is not another way of saying the project is not worthwhile)</td>
</tr>
<tr>
<td>You all seem to be doing a great job.</td>
</tr>
</tbody>
</table>
Stepping Up is a new internet-based program for people who have arthritis, back pain or a musculoskeletal condition.

For further Information please contact:
Yvonne Ginnivan
03 9244 6517
info@steppingup.org.au

www.steppingup.org.au

What is Stepping Up?
Stepping Up is a free online program for people with arthritis, back pain or other musculoskeletal conditions.
Stepping Up supports you to manage some of the life challenges commonly experienced by people with these conditions. Challenges may include chronic pain and fatigue, making lifestyle changes, sleep problems, work and anxiety, and depression and stress.

During the Stepping Up program you will have access to:

- a 45-minute telephone discussion with an experienced health professional who will help you identify your needs and set up a program tailored to your needs;
- a series of six online sessions (about 30 minutes each) that contain information, examples and activities to support and guide you as you work towards your goals;
- an experienced health professional who will support you by email.

Is Stepping Up for you?
Stepping Up is suitable for you if:
1. you have a musculoskeletal condition such as arthritis, osteoarthritis or back pain;
2. you would like some extra support to better manage your stress, mood, anxiety, worry, pain, fatigue, sleep or to make a lifestyle change;
3. you like the idea of a program that you can do from home at a place and time that suits you;
4. you have access to an internet browser.

When?
A trial of Stepping Up will be conducted from January to March 2011.

Where?
Stepping Up is accessed through the internet. You can participate from the convenience of your home.

If you would like more information, or if you are interested in participating in the research trial, please contact the Stepping Up team.

Phone:
Yvonne 03 9244 6517
Email:
info@steppingup.org.au
Website:
www.steppingup.org.au
## Usability Interview Schedule (March 2011)

1. Thinking about the first time you used Stepping Up, can you tell me what happened?
   - How long did you stay on the Stepping Up site?
   - What aspects of the program/sessions did you do?
   - Do you know if you did one or two sessions in that first go?
   - Did you explore the site? (ie. Messages? About Me? My Workbook? My Week?)
   - Did you have any thoughts from that first session?
   - So once you had a look around you felt you knew how it worked?
   - Did you read any messages?

2. Once you had a couple of goes using the Stepping Up website, how did you find it?

3. Thinking about the most recent time you used Stepping Up, can you tell me what happened?
   - So you're using the my week? And had a look at your calendar
   - Did you add any activities or edit anything?
   - Did you look at any other parts
   - When you get that did I say that feeling, what does that make you think?
   - Did it still feel true to you?
   - How long were you logged in last session?
   - And most of that time was doing the program?
   - Did you send any messages last time?

4. Was the Stepping Up website what you thought it was going to be like?
   - In what ways is it most like that?

5. Thinking about how you use the Stepping Up website now, can you tell me how using the Stepping Up website compares with using other internet sites?

Thinking about the Stepping Up, can you tell me which parts you found most useful and why?

- What session are you up to at the moment?
- Have you ever reviewed a session? (ie. re-read the information and/or your responses within the session)
- Did you print off any worksheets in the modules?
- Do you have access to a printer at home?
- Did you listen to the audio tracks in the modules?
- Did you use these features (only if they haven't mentioned a feature):
  - Messages? How did you put it to use?
  - About Me? How did you put it to use?
  - My Workbook? How did you put it to use?
    - do you ever edit anything in the My Workbook view
  - My Week? How did you put it to use?
    - So even now when you use it you might do it wrong?
  - Personal Settings? How did you put it to use?
  - Help text? How did you put it to use?

Did you receive reminder emails from Stepping Up? How did you feel about receiving these emails?

Did you receive message notifications in your email when [the health psychologist] sent you a Stepping Up message? How did you feel about receiving these emails?

Do you need any use any special tool to facilitate your use of computer?
- You don't magnify the screen or anything

Were you able to see the colours or read the text in Stepping Up?

How often do you use a computer (at home or at work)?

On average, how long would you spend in front of a computer continuously?

What do you usually use your computer for?

Have you ever used a chat feature on the internet? ie. Where you have a typing conversation to another person

---

Attachments page 19
<table>
<thead>
<tr>
<th>Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>In real time? How did you find that experience?</td>
</tr>
<tr>
<td>Regarding the website do have anything else you’d like to talk about?</td>
</tr>
<tr>
<td>Would you recommend Stepping Up to others?</td>
</tr>
</tbody>
</table>

Attachments page 20
Attachment E: Follow-up interview schedules

The following schedules are for interviews conducted two to three weeks after participants completed the course.

Evaluating Stepping Up: Interviews with consumers

Purpose of the interview:

1. To gather information to help improve the website/program operations (features, usability)
2. To find out which components of the program may have contributed to the impact of the program (modules or strategies)
3. To find out the impact of the intervention on their conditions from the perspective of the participant
4. To support future recruitment – who it works for, setting expectations
5. To build evidence for decisions to be made for phase 2 (provider, features, content, design, consumers)

There are three different basic interviews:

   (1) non starters (did/didn't log on)
   (2) non finishers (quit the program, didn't progress or couldn't finish in the timeframe allowed)
   (3) completers

Each interview will need to be tailored to the extent to which the person got through the program.

Interview

Introduce self.

Confirm with client the purpose of the phone call is to discuss their experience with the pilot Stepping Up Program so that we can improve the program for others in similar situations.

Ask for consent to record the interview

At end of interview, thank them for their time and advise them that we will send out (post or email) a summary of the project results when they are available.
Completers, include usability

**Setting the Scene:** You have recently completed the stepping up program. I would like to ask you a few questions about your experience with the program, the things that went well, and also the things that didn’t go so well, so that we can understand what is happening here and improve the program for the future.

1. Was the Stepping Up program what you thought it was going to be?

2. At the beginning of the program, you had an interview with [the health psychologist]. What do you think its purpose was? Was there anything that you found useful from this interview? Can you tell me about these things? Was there anything you found unhelpful?

**Setting the Scene:** Your Stepping up program was created specifically for you, and included a number of sessions that focused on different issues and offered different strategies and activities for you to achieve your goal or main problem that you set at the beginning of the program.

3. Which were the most useful activities that you learnt or used in the program which helped you make progress on your goal or main problem you chose to work on?

4. What was the most important or useful thing that you got out of the program?

5. Were there other things that you have achieved? Can you tell me about these things?

6. Were there aspects of the program that did not go so well for you? Can you tell me about these?

**Setting the Scene:** You have recently completed your Stepping Up program sessions and had another interview with [the health psychologist].

7. Was there anything that you found useful from this interview? Can you tell me about these things?

8. Was there anything that was unhelpful? Can you tell me about these concerns?

9. At the beginning of the program, you decided on an issue that you wanted to work on, or a goal that you wanted to achieve.

10. Can you tell me what you wanted to achieve?

11. Have you been able to achieve what you wanted for this program?

12. If yes, what were the main things that helped you do this?

13. If no, why not, what were the reasons why you didn’t achieve this?

14. Was there something else that we could have included in the program that might have been able to help you?

15. Do you have any other suggestions about the Stepping Up Program and how we can improve it for you?

16. Is there anything else about the stepping up program that you would like to tell me?

17. Reflecting on the program now, (and you have noted that it helped you or not) would you say that it was the program as a whole that helped you, or were there particular elements that helped most? What were they? Were there also other changes happening in your life (outside the program) that have helped you? What were they?

18. Was the outcome from this program worth the effort you put into it?

Attachments page 22
### Usability

**Setting the scene: first of all I would like you to think about the website, and your experience with getting started and working within the website**

1. Did you have/need someone to help you getting started on the Stepping Up program? Did you need help also during the program? Can you tell me about this?

2. How long (how many log ins) did it take before you were comfortable to move around the website. Did you have any difficulties doing this? Can you tell me about this?

3. Were you ever concerned about losing your work within the stepping up program, or that you might not be able to get back to where you were? Did you ever lose data?

4. Did you have any technical issues while using the stepping up program that you were able to work out yourself? Can you tell me about this?

5. Did you ever need to seek technical advice to use the stepping up website from the program staff? Can you tell me about these? Were there any issues that were not able to be resolved?

6. Was there a pattern to your use, or did you change each time you logged in. If there was a pattern, can you describe it?

7. How long approximately did it take you to complete each session?

8. How much time did you spend on activities between the sessions?

9. What did you like most? Least?

10. Did you review any of your sessions? To what extent did you change what you had written? What were the reasons why you may have done this? Is what you have written true to you? Did you appreciate the opportunity to review what you had written?

11. Case examples: were you able to relate to any of the case examples? Did the case examples help you with understanding and working through the sessions?

12. How did you feel about receiving reminder emails from Stepping Up? Were they useful?

13. When we designed the program, it was intentional that you wouldn’t have contact with other participants. Some people have suggested that they would have liked to interact more with the other participants. Having completed the program, what are your thoughts about this idea?

**Setting the scene: There were a number of different features available in the program that we haven’t talked about yet. I would like to ask you to respond briefly about these, and find out the ones that you may have found useful, and those that you didn’t.**

- Messages (sending receiving emails, getting support or feedback from HP or being able to ask questions)
- Writing into the text boxes
- Creating lists
- Important things
- Helpful activities
- Good stuff
- Unhelpful activities
- Problems
- Steps
- Fact sheets and information about different issues
- Worksheets (able to print off / need a printer)
- Me Map
- My workbook
- Planning activities, using the diary

Attachments page 23
1. Audio tracks
2. Setting small goals (between session activities)

14. Regarding the website, do you have anything else you would like to talk about?

15. Final question: Are you willing to be contacted in the coming months regarding video content production. This would involve either demonstrating something on camera (e.g., a relaxation exercise), talking about their personal experiences living with their musculoskeletal condition, or discussing strategies/approaches that they have used and found helpful in the management of their health.

**Non Completers, include usability**

<table>
<thead>
<tr>
<th>Question</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Setting the scene: You started the Stepping up program with an interview</td>
<td>with [the health psychologist] and completed a number of sessions <strong>before you stopped the program</strong>.</td>
</tr>
<tr>
<td>OR</td>
<td>I would like to ask you a few questions about this so that we can understand better what is happening here to improve the program for others.</td>
</tr>
<tr>
<td>1. Why did you choose not to finish the program? <strong>OR</strong> why were you unable</td>
<td>to finish the program?</td>
</tr>
<tr>
<td>2. What were your initial expectations of the program? Did these</td>
<td>expectations change? Why do you think there was a change?</td>
</tr>
<tr>
<td>3. You completed an interview with [the health psychologist]. Was there</td>
<td>anything that you found useful from this interview? Can you tell me about these things?</td>
</tr>
<tr>
<td>4. Did you have any problems with this interview? Can you tell me about</td>
<td>these things?</td>
</tr>
<tr>
<td>5. You completed (one or more) sessions of the Stepping Up program. Was</td>
<td>there anything that you found useful from these sessions? Can you tell me about these things?</td>
</tr>
<tr>
<td>6. Did you have any problems with the sessions? Can you tell me about</td>
<td>these things?</td>
</tr>
<tr>
<td>7. Have you made any changes because of your involvement in the program?</td>
<td>Can you tell me about these things? Did the program help you make these changes? Can you tell me</td>
</tr>
<tr>
<td>8. These changes made a difference to your health and/or how you are</td>
<td>how you think this happened?</td>
</tr>
<tr>
<td>9. Were there concerns that you also had with the program? Can you tell</td>
<td>me about these concerns?</td>
</tr>
<tr>
<td>10. Is there anything about the program that could be changed to make it</td>
<td>more useful for someone like you?</td>
</tr>
<tr>
<td>11. Is there anything we could have explained better when we were</td>
<td>introducing you to the program that would have helped you decide if the program was suitable or</td>
</tr>
<tr>
<td>12. Is there anything else about the stepping up program that you would</td>
<td>like to tell me about?</td>
</tr>
</tbody>
</table>

Attachments page 24
### Non Starters

Setting the scene: Although you came into the stepping up program and had an interview with [the health psychologist], you didn’t go any further. I would like to ask you a few questions about this so that we can understand better what is happening here to improve the program for others.

1. Can you tell me why you didn’t go any further?

2. What were your initial expectations of the program? Did these expectations change? Why do you think there was a change?

3. You completed an assessment interview with [the health psychologist] at the beginning of the program. What do you think was the purpose of this interview? Was there anything that you found useful from this interview? Can you tell me about these things?

4. Did you have any problems with this interview? Can you tell me about these things?

5. Is there anything that could have been explained better when you were first introduced to the program; something that would have helped you decide if the program was suitable or not for you?

6. Was there anything that we could have done or explained to you that may have made it easier/possible for you to get started on the program?

7. You completed an exit interview with [the health psychologist] just recently. What do you think was the purpose of this interview? Was there anything that you found useful from this interview? Can you tell me about these things?

8. Have you made any changes because of your involvement in the program? Can you tell me about these things? Did the program help you make these changes? Can you tell me how you think this happened?

9. Have these changes made a difference to your health and/or how you are feeling? Why do you think they’ve made a difference?

10. Is there anything else about the stepping up program and your experience that you would like to tell me about?

### For those who logged on but didn’t do any sessions:

11. You logged in to the Stepping Up website, but did not commence any sessions that were set out for you. Can you tell me why you didn’t go any further?
Attachment F: Main things gained from session and additional comments for each module

The following table presents data from the evaluation screen that came up at the end of each module. Participants were asked to list the main things that they got from the sessions and any additional comments that they wished to offer.

<table>
<thead>
<tr>
<th>Balancing activity and rest</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Main things you got from the session...</td>
<td></td>
</tr>
<tr>
<td>That moderating your activity can help in managing fatigue. That the over-sensitising of the pain parts of our brain can be altered by changing the 'boom-bust' cycle.</td>
<td></td>
</tr>
<tr>
<td>The need to pace myself and have periods of rest or different activity between main activity at time. loving the break down of pacing and having breaks</td>
<td></td>
</tr>
<tr>
<td>I really liked the idea of spending 10 mins at the end of the day to reflect and plan for the next day.</td>
<td></td>
</tr>
<tr>
<td>doing things in moderation</td>
<td></td>
</tr>
<tr>
<td>i need to pace myself and not over do it</td>
<td></td>
</tr>
<tr>
<td>Frustration - not at all clear how the prescription fits</td>
<td></td>
</tr>
<tr>
<td>Ways to build up your activity levels</td>
<td></td>
</tr>
<tr>
<td>That pacing &amp; rest is important</td>
<td></td>
</tr>
<tr>
<td>Making sure that I pace myself instead of setting my goals too high and not getting things done</td>
<td></td>
</tr>
<tr>
<td>planning out the steps i need to take to increase my ability to perform tasks even if that task is only sitting or standing.</td>
<td></td>
</tr>
<tr>
<td>the idea of scheduling in rest breaks</td>
<td></td>
</tr>
<tr>
<td>Other comments...</td>
<td></td>
</tr>
<tr>
<td>The practical resources, such as the 'Watching the results' forms are fantastic!</td>
<td></td>
</tr>
<tr>
<td>Not to expect too much too soon in activity levels, be careful to not do so much as to bring on extra pain.</td>
<td></td>
</tr>
<tr>
<td>At the beginning at the session I wonder if it is relevant to me but then at the end of each session it all comes together and seems to make a lot of sense.</td>
<td></td>
</tr>
<tr>
<td>I wish there were more helpful pages to print and fill in during the week to see progress</td>
<td></td>
</tr>
<tr>
<td>I think this will be hard for me to do, as often I just have to push on with things regardless of how I am feeling. E.g., I can’t rest, even if I want to, if I need to make the kids lunch, or pick up my daughter from kinder, go to work, etc</td>
<td></td>
</tr>
<tr>
<td>The percentage part was not very clear.</td>
<td></td>
</tr>
<tr>
<td>the watching the results chart looks like a good idea</td>
<td></td>
</tr>
</tbody>
</table>

| Be mindful |          |
| Main things you got from the session... |          |
| How I can get swept away by my thoughts and feelings, which are just that - not reality. |          |
| mindfulness in not relaxation |          |
| I have to pay more attention what goes on around me. |          |
I think mindfulness is going to take time for me to achieve.....definitely something I will need to work on.

I don’t really understand what mindfulness is or why I should do it to be in the moment and just be!

The meditation tracks were excellent and food for much thought.

That there is a tool out there which can help make me less anxious and which does not involve adding tasks to my

Clear strategies to try, which may help me manage my feelings of pain and discomfort

Our interpretation what is happening to/around us affects how we feel

I need to be aware of what I am doing and thinking and not just let things go by

meditation

the idea of mindfulness. I didn’t know about this before

I realized that I am not very “mindful” of what I do every day...

mindfulness sessions to practice

Other comments...

It’s great you’ve included the audio files of mindfulness exercises to download.

I have looked at this topic heaps in the past couple of years and I know it pretty well, good to re-cap it.

Of all the sessions so far I think this one is the most challenging for me.

Are you aware that the third mindfulness recording only goes for 5 min not 12 minutes, and the fourth mindfulness recording is cut short - it finishes before the end.

I need to try mindfulness out a bit more but I think this will turn out to be the most useful session I’ve done so far.

Breathe

**Main things you got from the session...**

The calming breathing exercise.

I know the strategies will help and I just want to get into a habit of using them.

that there are effective tools/strategies I can use to help me with relaxation and pain relief

I didn’t know that the breathing has a feedback effect to the body. I will make more of an effort to be aware of my breathing so I can trick my body into being more relaxed!

Breathing technique

that I need to be aware of my breathing to be able to know if I am getting stressed and if I am how to help relieve it

That breathing fast puts your body in an adrenalin state, where you have to fight/flight... and that’s why you can relax, so controlling your breathing will help you and your body move out of this state.

To be aware of my breathing...

2 techniques ‘chosen’ for me which I can trial

Other comments...

Being able to listen to & download the meditation exercise is a fantastic addition to the program.
There wasn’t much mention of how it relates to pain management.

I think I will need to review this a few times to make it an auto response.

I had real trouble doing the first breathing technique, I feel like I was too wound up, I also had to stop the session because I wasn’t relaxed enough at that moment to answer the questions.

### Changing your sleep pattern

#### Main things you got from the session...

- reading about sleeping
- sleep can be controlled more.
- The information about the waves of sleepiness in the evening.
- Devising a clear plan for improving my sleep pattern
- how to change wake up times and the benefit of regular waking times, sleep in not good
- being away of your sleeping habits is important to know how to make changes to correct sleeping problems not having your habits set in cement be willing to make adjustments

#### Other comments...

- The going to sleep later and getting up earlier, I think will make me more tired really.
- Don’t think the sleep compression applies to my problems with disruptive sleep due to pain, I will not try this.
- It is very hard to set a particular time for sleep as I work split shift and usually only get about 6 hours of sleep

### Change your mind

#### Main things you got from the session...

- Don’t believe your thoughts, no matter how real they feel!
- Changing the way I think about things does not have to be negative.
- Changing and slowing down to look at my thoughts is simple and easy and helpful
- that the feeling dependant a lot on how other people react to me
- Revising this topic. Will be good to keep putting in practice and be more mindful and reactive of these thoughts.
- That mental health is so very important in our overall well being and that negative thoughts CAN be changed.
- Concentrate on the positive-get rid of the negative tapes in my head
- you can change the way you think and when you think about it its not that hard to do!!
- changing the way that I perceive myself
- conscious of unhelpful thoughts and how to change them
- Positive thinking is not always feasible
- I’ve already said & I’m annoyed that my comments have gone. Too late? Stuffing up again with technology? Now the comments are here!
- That it is possible to change modes of thinking which lead to negative emotions but that time and effort is required to do this.

Attachments page 28
Clear strategies for dealing with negative thoughts

Realizing that things are probably not as bad as I think they are
I liked the process and will be able to use it in future

Other comments...

The worksheets & online reflections are really helpful.

I have tried and succeeded in changing my thoughts and therefore behaviour with regard to the children at the school over the road.

trying hard!!

This was an excellent session. Identifying my negative thought and then supplying an opposite viewpoint really made me aware that I could “change” things.

Grateful for the opportunity. But I view this session as a brainwashing exercise. I’m feeling invalidated & angry.

This seems harder to apply than mindfulness as it takes quite a bit of time and effort to deconstruct each negative thought and re-construct a new thought in its place.

I’m not sure I will have enough time to properly complete the written exercises

Daytime habits and sleep space

Main things you got from the session...

the sessions are very good

frustration - I have a very clean room, I do not let light in, all my technologies are turned off or away and I have a very comfortable bed and pillow

Similar to the last session, I feel good that I have got quite a few supportive things that I already do during the day to help me sleep well. It’s also good that the bedroom environment is recognised as influential on our sleep.

Producing a clear written plan of how I will try to change my daily routine.

how to make bedroom more friendly

that sleeping has a lot of things that can effect it the environment eating or drinking habits exercise and sunlight

I will or need to push the worry out of my mind and set aside time to worry.

Other comments...

I hope that I could get more out of this session as I do have issues sleeping, and yet not much came out it at all.

Exhausted

Main things you got from the session...

The information about fatigue i.e. I learnt that there are actual physical effects/results of fatigue (which validates my experience!), that fatigue due to chronic illness is a false alarm & that too much rest can increase fatigue.

What fatigue is and what I do that creates a circle for me
the cycle is exactly what I am doing. I would like a print out of the cycle that I could pin up
somewhere to remind me not to over do it

That we need to change what we do to stop fatigue being a cycle
that fatigue is a vicious cycle

**Other comments...**
A REALLY useful module. Thank you. (And I'm really enjoying the program so far!).
This session made me feel down after I had finished and was left without a sense of what I can do in terms of my fatigue levels. I hope the next session helps me to do just that.

**Feeling down**

**Main things you got from the session...**
the session is very good
I am starting to understand my feelings better
understanding, validation
you are pushing me in the right direction
It was good to think about my depression, even if it was of a different kind from that described.
The concept of the vicious cycle of depression
to be stronger

**Other comments...**
I nearly went past this session
The session was helpful for the doors it opened to reflection.
I have been trying what this session has suggested but I have failed, I don't feel supported. Maybe I need to speak to someone with my husband present.

**Getting back to it**

**Main things you got from the session...**
its help me
Doing something is important no matter how I feel or the pain I have. Be careful and make sure the activity/exercise is appropriate
I feel I am starting to build up my confidence more.
setting a definite target and getting some ideas of how to spend my time
A lot of it is common sense - I just hope I can do it.
Despite my inertia I have committed to some things
It was helpful to think in terms of specific tasks and undertakings
I have learnt a lot about my pain
Affirmation that it is neither a waste of time nor an unnecessary indulgence to do something that I enjoy as well as something that gives me a sense of relief and achievement; and peace of mind.
to do something that I have always enjoyed and keep at it and then see how I feel
Planning gets things into action and doing things stops you from getting stuck in your problems

**Other comments...**
I believe

In pain

Habit change tips

Main things you got from the session...

I like being able to print off sheets and fill them in. I wish there were more of them throughout the course.

I don’t trust myself.

The ideas list was a good thing.

There was some element of repetition from the last session, but that perhaps serves to make each step clear.

My heart and brain are very grateful; but my back isn’t. I wish that I could have had more time so that I could finish this program. I’m very busy trying to survive. I don’t want to make too much forward commitment. I’ve completed my commitments from previous session

Main things you got from the session...

I have been pushing myself too hard. It’s OK to occasionally not succeed.

I do not think I have many habits I have to break, so it was difficult for me to find motivation in this session.

To use a supportive person as an aid in maintaining my goals.

Other comments...

this session was very motivating.

Thanks for your support.

It would be helpful if I could click a tag to About Me when asked to fill out rewards rather than have to exit the worksheet and go back to another window.

I believe

Main things you got from the session...

That there are a lot of things beyond our control and that is part of life and we just have to make the best of it.

my thoughts affect my beliefs and sometimes they are not really reasonable.

I need to practice the new statements to have more positive thoughts.

Other comments...

I believe that a plan for each day is helpful but could also make you more inflexible.

In pain

Main things you got from the session...

I’m not sure I agree that you can make yourself feel less pain or less pain messages are sent, what helps to reduce pain, what might set off the pain.

Learning about how your body can become more sensitive to pain when you have been in pain along time.

Understanding a bit more.
I am feeling more motivated to try and do activities to alleviate my pain and boredom.
understanding of how the pain is processed in my body.
the thought that it may never go away, maybe I'm going to have to come to terms with that thought
Other comments...
I'm looking forward to learning about the boom/bust concept

I think

Main things you got from the session...
that you can change thoughts to be a benefit
That I am not at the mercy of my emotions and I have a lot of control over how I feel if I become
more aware of the unhelpful thinking patterns I am getting into.
We can change the way we think and therefore act.
I was happy that I could identify my thoughts and the way they went - that was very interesting
I found that at this time I feel less tension or stress.
I have done this concept before so it was just re-emphasising it.
How my thinking impacts on my mood and how destructive negative thoughts can be.
That others must have the same thoughts as me
remembering that I need to look at the way I process my thoughts
To change my thoughts, & liked the thoughts dairy.
I found it frustrating. My life is not a series of isolated events that turn up and have to be evaluated -
it streams and doesn't generate specific responses either + or -.
disappointment that I can't really identify my unhelpful thoughts; fatigue. Many days later I've
thought about it and decided that I can identify some of those 'unhelpful' thoughts.
That I have particular thought patterns which trigger some of my negative feelings and if I could
somehow change these thought patterns I might be able to get rid of many negative feelings
It helped me to reflect on my possibly unhelpful thought processes and consequent behaviours
Seeing that I have negative thoughts and need to deal with them
seeing this on paper, even though I know this it will give me the confidence to think positively like I
use to
Looking at the different thought filters and seeing which ones applied to me
That how I think has an impact on how I feel.

Other comments...
a hard session, I think I need to do more work here. I have spent more time on this session
I liked this program a lot "I think therefore I feel"
because I'm not doing anything only reading relaxing my pain level is not as bad.
Practice makes perfect.
This was a really valuable session. It will be a
hope I can change it.
I seem to be losing touch. The stuff distinguishing between feelings and emotion is difficult.
I’m feeling a bit frustrated with all that I have to do and the fact that I’m feeling used by some people in the family. Thank you. Many days of reflection & thought diary later, I feel that I’m ready to have another go at this. Thank you very much, I hope

It feels like the session ended halfway through a topic. I’m not sure there’s anything practical I can do with this knowledge yet.

This session I found to be quite difficult to complete, in terms of providing examples of my own thoughts and behaviours

### Improve your sleep

**Main things you got from the session...**

- Helps me
- What really affects sleeping
- An appreciation that my sleep problem is not as bad as some people experience.
- It helped me identify some likely causes of my sleep problems
- Bad sleeping habits that continue for over a month usually become ongoing problems
- That the bedroom needs to be reserved for sleeping not watching TV or reading
- My sleeping pattern can be fixed

**Other comments...**

- What other strategies can I do to improve my sleep?
- It was useful to put my thoughts in writing in a systematic way

### Let’s make a plan

**Main things you got from the session...**

- Making a plan and writing it down
- Planning is vital and wanting to change for myself - no-one or anything else
- A plan to achieve my goals

**Other comments...**

- Looking forward to the week’s work and next session

### Loosen up

**Main things you got from the session...**

- A reminder of techniques I can use for relieving pain & tension such as heat.
- A list of what I can do to help my tension. I like seeing all my options
- Be aware of tension and act on it ASAP.
- How tense a person is without actually realising it.
- Heat therapy is a form of relaxation
- That there are simple exercises I can use to help me relax/de-stress in my own home

I think I am already utilising muscle relaxation in my daily life and the session helped me feel good about what I am doing in this area.
That muscle tension can make chronic pain even worse

Re-enforced what I am doing is right and great to now have an audio guide for muscle relaxation

I was inspired to try the muscle relaxation therapy, and thought about getting a massage

the progressive muscle relaxation

it re-enforces a lot of things I already find useful also the new muscle relaxation technique should be worth perfecting

muscle relaxation

Progressive muscle relaxation—loved it as I feel very relaxed...

ideas for helping reduce muscle tension

that I need to relax my muscles

Other comments...

I have been introduced to all of these techniques before. I liked the progressive muscle technique. I would like to be able to download that as a track to use elsewhere, and to have it on my iPod too. I find relaxation makes me really tired. So if I do it

I really enjoyed this session...it worked for me!

I already knew and practice all that was presented in this session

next time I will apply to other areas where I feel tension

Make a change

Main things you got from the session...

Habit forming. List of things that get in the way

I have started thinking about habits and the impact they may have on my wellbeing

nothing!

Pointing out the reasons my habits don’t change

An interesting session. Learned good things.

Other comments...

When you ask me to connect to my workbook to reflect on past factors that have helped me to make changes and to enter them in the workbook, I wasn’t sure of how to get there (other than by quitting) or whether I was in the workbook already. It might be

This is not for me - totally alien and annoying to work on the computer like this - it is simplistic and nothing to do with me.

Managing your health

Main things you got from the session...

A good description of healthcare providers available to help.

The chance to reflect on my health issues, rather than just be given strategies

I am not alone

That I have to make the effort to make my life more balanced, and be able to accept that while this condition will probably be long-term, I will be able to live a fulfilling life that I want to live.

that I can do more to help myself
Write things down. It helps to voice when there is no one to turn to. I am not alone, there are other stories similar to mine.

It was good to really identify things whether it was feelings, ideas or plans.

There are things you can do to improve your health when you have chronic pain

That we all seem to struggle with the same issues

It brought home to me the extent and reality of my condition

to utilise my specialist and go to help link me into to other health professionals and it will take time to make effective changes

thinking about what I could change and what I could not

there is help out there & I should be able to afford & access it.

I will have to do something for myself

It helped me think more actively about issues which I might otherwise merely endure.

Yet more time wasted on computers.

Things I didn't know before, I understand now.

feeling that might have a bit of control; that I'm not alone; that it's OK to ask my GP

That I need to start taking action

I was surprised that when I identified my fear of losing my husband in the future, I cried. This helped me realise this is quite a big thing for me and I need to recognise that fear and work out how to deal with it.

To reflect on what is currently working to improve my health

Thinking about other ways that I can improve my health

I haven't really thought about the things that are important to me and what "I would like to be" as a person.

Awareness that I need to get motivated to get myself active

The feeling of understanding from what was said and asked. To know that even though I am the only person that is in my group of people around me that has constant pain I am not the only person in the world with it.

that I am not alone a lot of people have the same struggles

helpful to write some of this stuff down

Made me start to think more about management and what I can do to prevent flare ups

Thinking about who else can help

Focus on what is important

That there are options that I haven't explored yet that might help me to cope better with my health problems.

seeing what other people are dealing with made me reflect on my condition and how I can try and manage it more

Time to reflect and focus.

Other comments...

So far the course is very positive and empowering. I really like the focus on what you can change. The graphics are great as well!
Overcoming obstacles

Main things you got from the session...
- Though I did not learn anything new I found I was not alone
- I have been doing this for at least 11/2 hrs
- Not at the moment.
- clicking on that green button was tricky. I kept trying to drag it but it wouldn’t move.
- I still feel isolated!
- It was painful to write out my story and needed a few days off
- easy to follow
- I suspect that the course will be as good as the energy that I put into it.
- not impressed with this computer based thing - I sit in front of one all day don’t need it at weekend or after hours - Not helpful and frustrating.
- I suspect this session would have been more useful to me about six months ago and would also have stopped me being so miserable back then. A lot of the stuff (like the list of useful health professions, for example) I have already had to figure out for m
- I would like to know if I should go to my GP to get help for some of my pain as I tend to just use the rheumatologist as they are specialised. When my knees where the problem I started a pain journal because I was taking all the pain our on my husband, I
- happy, thanks
- Just to say that just sitting and having “quiet, me time” has been enjoyable and not a chore at all.

Other comments...
- I feel I am going well with the program

Pain reduction tips

Main things you got from the session...
- I already knew about the information presented in this session.
- There are some simple strategies that I can use to reduce my pain
- realising that I am doing a lot to assist in my pain reduction understanding
- I need to think about what medications I need to better manage my pain
- reminding what really works to reduce my pain and to keep track of anything that I have tried.
- manage it before it manages me
Stressed

Main things you got from the session...
That I'm not alone in feeling very stressed at times.

Other comments...
So far so good!

Taking stock

Main things you got from the session...
Thinking and writing.

How your personality & other wider issues can affect your health.
Take things slowly and concentrate on one issue at a time until it is resolved
That I really need to start looking at my situation and actively change it to see if that helps
Offloading my feelings
that now I have a new problem which has taken over until the pain is gone
Clarity
I felt that "things" were clearer.....small steps being the "key."
It took a long time (2 hours!) but I have decided my main problem is pain. Fatigue is secondary.
that other people feel like me
to remember to look at the positive aspects of my life - to remind myself how I cope with stressors in the past and to focus on one thing at a time
thinking about what go me to this point
Good feeling for helping myself with my life.
You are trying to get me to set goals and I'm not sure where to begin.
Starting a process of confronting some reasonably uncomfortable things about myself
Understanding a little bit more
Anger and frustration at losing my responses, and with my issues documented
Unexpectedly, I gained insight into another problem besides the sleep problem
I have the tools to turn my situation around.
It was helpful to think and write about the questions that were posed
Identifying things that are linked to my problems
thinking about things that I wouldn't usually
I need to focus on what I need to do to manage my pain
reminding me to think of the good things in my life. Making me think whether it really is a good idea to not talk about how I am feeling and ignoring the problems
good to see how problems and issues are all connected in making things worse
made me think about triggers more
focus on what’s working well for me
That there is not just one thing that is impacting on my life...many things play a part.
just to be happy and grateful for what I have in my life

Attachments page 37
**Worry management tips**

**Main things you got from the session...**
- remember about "worry-time"
- Making a time to worry and being conscious of it.
- That change is possible but not easy,...takes a lot of effort to restructure negative practises.
- types of worries and how to deal with them
- that we can control our worries take charge of them and therefore we are in control not them
- Be aware of my worrying ...
- information about worry. demystifying worry myths. a good tool.

**Other comments...**
- Very useful...need to practice it though
- I have found the last couple of sessions to be more challenging .....needing more effort to facilitate change.

**Worried**

**Main things you got from the session...**
- A step to managing unhelpful worry.
- to stop worrying about things that are outside my control.
- Realised I don’t really have a problem with worry at the moment
- the cyclic nature of worry and anxiety and how it feeds on your fears and becomes bigger, and how
you actually have to re enter life to get through it, and because you back out of life things/situations might not be as bad as thought.

- learning more about worry, writing my worry list, having a defined goal of being 'present' to thoughts

Other comments...

I must look to the future with optimism & confidence.

Ready for some tools to handle worry if I have a rough patch with my arthritis again down the track. Perhaps they'll come in a later session?

Wrapping things up

Main things you got from the session...

strategies and plans help in achieving a goal and being aware when a problem arises

Reviewing what I’d learnt over the program & a reminder about what helps me.

the sessions have been very helpful

We all slip up at time so therefore none of us is perfect

review - love a review of everything I have done!

That I am confident I can change my moods with a little though.

Looking back at what I have learnt and what I need to do to keep going and keep moving forwards.

That I have changed for the better.

slip-ups happen but where do you get help?

stay positive - you know what to do

small steps achieve just as much as big steps, when you slip up you go back, take a breath and move forward

thinking about when to get extra help

that it is in my control to manage my health & well being

I am still uncertain about your goals

understanding of my pain

the opportunity to reflect on how successful the programme was, and how successful I have been.

A feeling of confidence that I am taking positive steps to improve my situation

That it’s important to recognise when you start to go ‘downhill’

It was good to think about information from earlier sessions as I have forgotten some of it.

I now realise that I can use the things that I have learnt on an ongoing basis and I now have something to fall back on when I feel I am slipping back

knowing what to look for to recognise mood swings and how to help them

great to finish and reflect

knowing what tools to use when fatigue and pain are coming on

To remember what I have learned from the program

Raised awareness.

Other comments...
achievement in gradual steps is a great motivator to keep going

the important thing is to recognise when I am starting to slip up and work to bring myself back on track.

enjoyed!

I dint think that I would get much out of the course because I have been dealing with my problems for the last thirty years and I did not think there were so many other ways of dealing with them.

Thanks heaps, this has been awesome.

For change to occur there needs to be a multi faceted approach.....stepping up achieves this!

I'm sad this is the last session

thanks to those who went to the trouble to design this program

The last 2 sessions were disappointing

There was a serious event in an early room where someone else's materials got introduced into my room. This could obviously have embarrassing consequences.

This has been my worst session. I'm very grateful not to have done the program but I'm not doing so well this session. I think I still need more time. Thank you for the extensions that you've allowed me.

The

It was a bit rushed at the end cos I didn't have enough time to complete the sessions timely

Thank you for the opportunity. I wish I had the time to spread it over a longer time frame, but I'm still happy I have attempted it.
### Attachment G: Outcome related comments from follow-up interviews

<table>
<thead>
<tr>
<th>3. Which were the most useful activities that you learnt or used in the program which helped you make progress on your goal or main problem you chose to work on?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breathing technique helps me when I feel anxious or when I am going to bed. I have printed stuff out to read through in the future for reference, especially about the breathing techniques. Putting the clock where I can’t see it at night time, so I can’t focus on it (in the bedroom). I am still doing this, definitely. I have also got my husband to do the breathing and clock thing too. He had surgery and had pain and wasn’t sleeping well after his surgery.</td>
</tr>
<tr>
<td>[she got her notes to answer this] Thinking patterns, managing health (related to the 3 case studies), taking stock, balancing activity and rest, improving sleep, daytime habits and sleep space. Setting appropriate goals and not trying to do too much too quickly, I am hampered because of my back and the need to lose weight. We decided that walking would be good. It started with 1000 steps but I couldn’t cope, so I walked until the pain was too bad, and then did 80% of that. This was 560 steps. It was increased by 10 steps each time. I only got up to 580 steps but my back became unbearable, so for the last two weeks I have been seeing my physio (who had heard of the program. The evaluator suggested the participant’s physio contact the Stepping Up program health psychologist to discuss using some of the materials the participant showed the physio.)</td>
</tr>
<tr>
<td>I have done the journal before, and already knew about being mindful and meditation, but I didn’t (and still don’t) do this very well. Forget now. Everything helped me most. I’m without help at home around here. A neighbour looked after things when I was in hospital. Techniques for sleep, to de-clutter my room, not read in bed, get dark and no tv; also getting up at a regular time. I never used to do that, and I have made these changes now. Also, I have learnt about breathing, how to slow down my heart rate. I haven’t done the relaxation yet, but will. Have downloaded this. The habit-forming activity. She found it is reasonably easy to break a habit. Giving yourself a reward. Pairing an activity. I learnt inactivity makes you worse, so now I try to walk almost every day, I achieve this a little of the time. I also try and stay out of bed more, and I achieve this some of the time.</td>
</tr>
<tr>
<td>His main goal was to improve sleep. The most useful activities were setting up a bedtime, rigorising a consistent sleep cycle, to come up with a plan and write it down. Other things that were useful were strategies to do with worry. The program encourages you to write things down. Once you have a plan, you can work toward achieving the goals. She was very interested in a lot of it and really enjoyed the mindfulness component. The audio tracks on meditation were fantastic, as were the exercises on worried thoughts and setting aside worry time. When, towards the end, I decided on some of the things (6-7), like taking a holiday, doing something different... it was very useful, because usually when I get a bit depressed I go to bed. This (set of alternatives) makes it a lot better. In the beginning, the program was prodding me to get off my backside to do things. It was going ok; I was carried along with it. But I lost that as the program progressed. It got a bit strange. Session 9 &amp; 10 lost me, I was puzzled with this. I don’t get high and low mood, it doesn’t go up and down. They were lacking a clear statement of our objectives. It was a challenge to think positively and energetically about how you manage your life and push boundaries. It challenged assumptions, and reaction to depression, made you interrogate your habits, and consider entrenched new ones. The techniques for management of worry, how to go to bed and sleep, relaxation, questioning thoughts. The case examples makes her feel she is not the only one.</td>
</tr>
</tbody>
</table>

Me map
3. Which were the most useful activities that you learnt or used in the program which helped you make progress on your goal or main problem you chose to work on?

Breathing exercise
Relaxation
Strategies on pain management (hot packs, showers)

The activities on pacing, getting other help, and using the relaxation.

1. “What was outstanding was building a plan to pace better and to be able to use pacing proactively rather than reactively as I’d been doing”.
2. “Having homework to do.”
3. “Knowing the structure of my thinking patterns and having tools to fill in to make the steps to do this. They were like stepping stones”

**The caveat was that I would have liked to have better used the desensitisation steps, as the session went too quickly to do exercise for doing it effectively. The participant also thought it was “something in me” that made this not work for her, although she really wanted it to.

Working through sessions, setting goals and reporting back were most useful. I didn’t meet all my weekly goals, I fell down a bit. I had a very big stress going on which I hadn’t identified. One session was about identifying the things that helped, the things that didn’t help. It brought about the new issues, and how to tackle it, I wasn’t aware. I worked on this issue more than the sleep issue which was my main goal.

Walking. Couldn’t think of any others.

I think it was excellent that there was a lot of space for reflection. There was a lot of information but there was also time to reflect and worksheets to use to help with this. One that was really useful for me was printing out the one called “watching the results” – at different times in the day you show the link between mood and activity and fatigue. The workbook record was good for me as it was all in the one place for reflection.

Yes, suggestions were good.
The examples of people were very good, highlighting everything that was identified, it was good to validate.

I was encouraged to do something for my body, affirmation, encouraged to do things to lift my spirit. This was very good (affirmation). It was pleasurable, not illegal, not harmful.

She liked knowing about how a stress/anxiety/panic response was the body’s normal physiological functioning. Some of the strategies were hard to do because she didn’t have a lot of time. She would prefer not to have to wait for three days. She feels it would be good to be able to pace herself and work out how long between sessions works for an individual. When the email came through it said her next session was ready but the session wasn’t actually ready until the following day.

Letting go of worry was a really practical thing to learn. She didn’t like the breathing exercises.

The main one was the mindfulness stuff. Some of the earlier stuff (in the program) would have been better about 6 months earlier - when I was getting my head around diagnosis of rheumatoid arthritis. (Comments about how doctors seem to delay diagnosis of RA) So I’d recommend the program for people at diagnosis, or even pre-diagnosis in some people, in the suffering process.

[You chose not to complete the last 2 sessions. Can you tell me about this?]

Sure. When I started Stepping Up, it coincided with going back to work and getting my symptoms under control. I was much shorter on time because I’d returned to work; I didn’t need so much around symptoms and I’d also got my head around having RA. So there were other things that were higher up my list of priorities than the program, and I didn’t feel like doing more until I got to the mindfulness bit because of my time constraints.

“Planning what I was going to do instead of just drifting along.” Having activities and planning the exercises (physical and mental). Giving her ideas on how to manage her pain.

Helping me manage my pain
Meditation was really useful for me

Goal setting, so simple but so important to see you move to a better place, helped me on a path, and out of a hole I was in.
4. What was the most important or useful thing that you got out of the program?

Reviewing what is happening, reflecting, setting goals, making changes. These can be small. Setting steps, making a little tweak in what I am doing can make a big difference.

Improved sleep. The program offered ideas and a new strategy.

Two things were equally important. 1. Take small steps and not listen to the people around me, and 2. that I’m allowed to have bad days when I can’t walk. 400 steps is better than nothing.

I have brought new skills, thoughts and tools for me to manage better. I have learnt that a thought is not necessarily correct. And I can take comfort from this. I am better able to deal with my interpersonal relationships.

Just to get me better. I feel healthy now, I feel as if I’m always laughing. I don’t lose sleep now. If I wake at 4am, I just turn on the radio and go back to sleep and when I wake again at 6.30 at the proper time I get up and start the day properly.

Just taking a small step at a time rather than trying to do everything at once.

I learnt inactivity makes you worse, so now I try to walk almost every day, I achieve this a little of the time. I also try and stay out of bed more, and I achieve this some of the time.

Improved quality of sleep. He hasn’t reached his final aim but he can see he has made progress. He used tips such as closing the curtains, no coffee or alcohol at night before bed. The management of worries strategies such as deferring the worry to a time the next day didn’t work so well for him because he didn’t have specific worries. He was just reflecting on what he did during the day. It felt contrived to delay it until the next day. He felt it was not always practical to carry the worry management sheet around with him. The things that worked best for him were the changing habits strategies and working to a plan.

A few moments when she was reading through the program and was reminded of things about managing stress. The mindfulness section.

I haven’t been depressed for the last 4, 5 or 6 weeks and don’t even feel like I’m getting depressed any more. If I feel it coming on, I look at it differently.

Prompt a degree of reflection and response.

Helps to try and remain enterprise and optimistic.

I found the link to the mindfulness website and anxiety/meditation audio really good.

Relaxation, stepping away from the worry was helpful to manage it. To look at her thoughts and think “Is it really worth the worry?”

Pain management, and the different strategies.

That it is important to look at things from another perspective. To make sure you do things that are positive ie the physio, go out with friends.

“Using the tools to build a more satisfying life.” “I took things from several sessions – proactive planning, building in pacing, and pacing gives me the confidence to do something physically challenging in the morning and different in the afternoon. It is most empowering thinking about doing something with your life. And “not feeling guilty about resting”.

Mental aspirations

How they interviewed other people and how those people overcame their problems, because everybody is different. He liked that they found their own way to be comfortable with what they were doing. He liked that he could find his own way of dealing with his pain.

Probably the information regarding fatigue and managing fatigue and trying to balance lifestyle to have less fatigue. The information was really good and having the explorations to consolidate the information.

It forced me to do things instead of just talking about it. There were deadlines, and I had to keep going back, it kept me honest, and made me be more proactive. It was like going to weight watchers, having to front up, and write everything down.

Affirmations. Some thoughts are good. Depression is a vicious cycle, it feeds itself. I think I finally got this in the program, what the problem was.

Most useful – “The most useful thing I got out of the program was probably the Me Map and seeing the picture of what the negatives and positives were in my life and how the negatives all bound together and made things more
4. What was the most important or useful thing that you got out of the program?

Negative but that the positives also had the power to do that as well."

I think the mindfulness skills. [Why?] Because I have a tendency to over-analyse, and I love being in control. When you have arthritis, you have no idea for the next day whether you will be firing on all cylinders or consumed with pain. So it's about dealing with that uncertainty. In my profession it's all about anticipating and planning about what is going to happen.

With mindfulness, I have a skill to explore in the future and use again when it's needed.

She got good motivation to try things (like the breathing exercises) and seek help from other people.

That it was holistic.
That I am not alone (to know this).
That how I feel is normal and it is okay.
More about centring me back, not feeling wrong, or my fault, that I do have control on what I do.

5. Were there other things that you have achieved? Can you tell me about these things?

Re the balancing rest and activity – she questioned why she was going to the gym and doing other things and realised she was doing them out of guilt, not because she was enjoying it. It helped her to change her habits. Changing the way she thinks – ie instead of saying she is a worrier, she says she thinks about things more than others – putting a positive spin on the words she uses.

Only trying to do one thing at a time. In the past, I've been trying to do too much. So just walking and then strength training when I'm feeling very comfortable with that.

Don't know. I've achieved a hell of a lot – feel better now, feel happier, go out more, go to church every Sunday, go to the men's shed, ring my stepson and he tells me I'm a good stepdad.

(What did you do these things before the Program?)

No

I think that I worry less, even though I don't really worry, I haven't been worrying a lot lately.

To think about things a bit more. E.g. The ones where you have to think through things and make a plan, record the results. It is good way to make you stick to a plan.

With regard to worry management, the relaxation was useful. He downloaded the audio to his MP3 player and used it to help him get to sleep. The relaxation exercise of tensing and relaxing the muscles worked amazingly well. The mindfulness approach focusing on breathing was a good way of emptying your head of thoughts and just focusing on relaxing and going to sleep. It was good to reflect on problems (pros and cons) and thinking about your strengths as well as problems. He found it quite an effort to write these things down into the program but it was worth doing. It is something he would not have done without prompting. The program asked you to analyse events in your own life and the process of doing that online enforced discipline. He is not sure how much he will continue this after the program.

Not sure if it was specifically and only the Stepping Up program because she started a few other things at the same time, but she continues to be aware of her "various cognitions", ie, to do with the mindfulness sections.

It's brought a lot of confidence back. I'd lost a bit of confidence.

It was all interrelated. Managing worry helped sleep and stress levels. Really enjoyed the relaxation audio. Very helpful. She tends to keep going and not stop so it was good to stop.

Ways to keep motivated, keep on task. It made me go back to my rheumatologist regarding a trial I was supposed to go on, and now I hound him especially about pain medication. I was using a medication which wasn't working, asked actively about this. I also got feedback on an RCT pain trial. Now I know about the process and time line, and have other pain relief I can use in the meantime, and plan to get into the trial.

Ways to deal with pain and fatigue. She was given more information about this in the interview with the health psychologist.

"Structure was good. I deeply wish I'd had this when going through the ramp up of my arthritis."

Bull's "optimism when losing parts of your life".

Valued the examples of others, related particularly to Robert (one of the SU case examples); she understood the things he was saying.

The homework pattern set up is very good.

The sleep issue was a reachable goal that I set myself. It (the program, goal setting) was not "pushy", it was realistic.
5. Were there other things that you have achieved? Can you tell me about these things?

I liked the email reminders and questions and comments, knowing that someone else was interested and cheering me on, even though I have a supportive family. Journaling and being able to look back, I wrote 9 pages, and saved it and keep it on my computer. Having it on paper really helped me prioritise and recognise things that I have changed. I am still using it. I am keeping up with some habits I developed from the program. I learnt that sleepiness comes in waves. I am now more aware to catch it.

I set a goal to get into bed at a certain time, I keep doing this. Before it was vague, and didn’t put enough effort into it. The stretching and exercising are still sporadic.

I’m too much of a one-way ticket because I know someday this will all be fixed [he is talking about having surgery]. He mostly concentrates on walking.

Well, one goal was to start Tai Chi and I’ve completed an eight week course alongside the program. I had been thinking of doing it for a while, and it was good to do it at the same time and look at how it was affecting me physically. Psychologically, I’m less reactive to symptoms. The mindfulness and cognitive therapy sessions have helped to show that how you are thinking about something can affect the person and fatigue. They helped well.

It meant that I went out, and followed up on things. For ex I went to YWASG, for the first time. I said I would go for a year, and finally I went, and came back raving! I have borrowed books, read cases, met other girls, kids, can relate to them. This was huge, dealing with this thing on my own, for 20 years, and there has never been anyone to talk to, who understands, there was no one. I also decided to do volunteer work, and I start next week. I have been saying I would do this for a long time, and now I am. YES, it is because of the program, yes I would say it was.

More a thought process. I have become more motivated, in getting things done. I tend to procrastinate! I got jobs done, but I can’t remember what they were. It was good, my mood lifted a bit. My motivation is still there now, I suspect it will go but I suspect it will go. [Interviewer asks why?] It is a way of thinking. I think of the program in a very positive way. My thoughts, I learnt about this, and so have increased my motivation.

To work on a big issue that is ingrained in life as a negative pattern in 6-8 weeks and make a change is hard, but she is at a point now where she is working on strategies, she can see the whole picture now, can see what she needs to work on and that she needs to use the strategies. She feels she is on the way to achieving her goal but she doesn’t feel she is there yet.

Well, other things were, in a way, useful. I’m used to listing things to make life easier. It alleviated worry to put things on a list, controlling things that could be controlled, and I do this really well in my life. I have a nanny for the children and I’m back at work. But it was only through the human intervention of the health psychologist in the program that the idea of not relying on having control of my life because of a chronic disease arose. And that I should expose myself to less planning. This was a really good lesson for me, as I was barking up the wrong tree by making more lists and wanting more control. But it was the human element that was really critical here – the program was encouraging me into lists. The SU health psychologist had flagged that mindfulness might be useful in the first interview for me, so I probably would have liked to get to it a bit quicker. I had seen a psychologist but she didn’t say anything about mindfulness, so perhaps it might have been easier just to see the SU health psychologist face-to-face and get straight to the mindfulness. (Spoke of psychologists having different areas of interest and expertise.)

She did things she wouldn’t normally do. She realised that if she did things she would probably feel a bit better. When she was over-doing things she would remember to not overdo things. She was able to change the way she goes about things.

It got things moving. I went back to pilates, I bought a new mattress (talked about this a lot). I am asking for help from friends, family instead of pushing them away because they were worried.
10. Can you tell me what you wanted to achieve?

I wanted to sleep better and get more exercise.

I am sleeping much better, by keeping pain under control (an extra dose of medication mid afternoon). I don’t have to drag myself out of bed in the mornings. Now I am not waking until 5:30, before it was 12, 1, or 2am.

I still haven’t got to as much walking as I would have liked. I am doing a bit at lunch time, but my back is still aching, sore all the time. The walking at lunch time is new. I still go to the pool nearly every day.

Improve fatigue/exhaustion and sleep habits.

Yes, as well as she can within the short period of time. Sleeping every now and again “stuffs up, but that’s ok” and fatigue depends on environmental stress/stress of the day, whether her arthritis is playing up or not. She is actively addressing these things now and that is a huge improvement because she wasn’t doing this before.

To lose weight but because it is so difficult to define the steps in losing weight successfully, we chose movement and strength training.

I’ve been able to set reasonable goals, and say to people I can’t do something. She spoke of being able to tell a friend she couldn’t do a walk. Previously, she would have had coffee and walked with her friend for 15 minutes, where she would need to push herself to do it, and so be in agony for the rest of the day.

It is an ongoing thing. I will have to practice every day. I need (this is not negotiable) to do meditation every day to calm me down/keep me calm – but I have still not been able to do this.

And to keep the positive thoughts happening, and question the negative thoughts – are they true and correct?

I am more accepting of my situation now, for example the doctor prescribed me pills for my headache (diagnosed migraine) and I will take them and see how it goes instead of resisting medication like I have done before.

To get more relaxed and to sleep better.

Yeah. Oh yeah. I’ve found another friend and we go to each other’s place. Now I make both cups of coffee. Before I’d make the first and he’d make the second when we met at my place. And we have coffee and tea together.

Sleep, improve it.

Some of it, I am falling to sleep a bit easier, and reading on the couch instead of in bed. I am using the strategies I can with the constraints I have, because you can’t help me with the pain and discomfort of my condition, this stops me sleeping properly. I wake up a lot of times in the night, this can’t change really. I know what not to do now, and I have changed my habits.

She started with 2 or 3 things and then got an email from the SU health psychologist saying to choose just one thing and this made it easier to write down all the things she needed to instead of adding 2 or 3 things together.

Yes. She got better at doing what she was doing and so she did more sessions per week than what she thought. (Started at 3 and then achieved 4 or 5)

Sleep or pain management. At the start I couldn’t decide which one to work on. I struggled during the program to work on the most important thing.

I have benefited from working on pain management.

What has changed? Way of thinking about pain, to do things in spite of the pain, and to put up with the consequences. Seeing exercise as important, that it is ok to hurt, it doesn’t mean it is making it worse.

I am now walking a bit, I didn’t do any walking before. And before I didn’t drive because of the pain. Now I am driving a bit when I need to, I did today. Before I was mostly housebound. The pain hasn’t changed, but my attitude has changed.

Going to sleep within 15 It is still a work in progress because occasionally life gets in the way (i.e., going to
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<thead>
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</tr>
</thead>
<tbody>
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<td>minutes; not waking up more than once in the night. Perhaps also sleeping for 8 hours, but he can't remember exactly.</td>
<td>dinner, occasional alcohol etc. He is still waking but no more than once. He is going to bed at a more regular time. He is confident that he will do more.</td>
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<td>She chose a lot of things. One of the key things was to worry less and engage in certain thoughts a lot less.</td>
<td>She has, but it is an ongoing thing. She is also doing some mindfulness training outside of S.U.</td>
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<td>It was an issue from consultations with previous people. I suffered from depression real bad. Now I don’t get it. I didn’t have ways of dealing with it. It doesn’t seem to occur. I’d just let it run over me.</td>
<td>I thought pain control would be a good thing if it was better. I’d fall over.</td>
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<td>To be more motivated.</td>
<td>Only marginal, if at all. My physical health status has got worse as I can’t walk so much. I think there is something wrong with me. I will see the orthopaedic surgeon and think also may need a neurologist.</td>
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<td>Yes, I achieved something, but I can’t remember my main goal. I have achieved. I think more about mood structured to illness; for me it is a subtle thing. I am able to reflect on the structure of my habits, where I was not dealing with disease, and was exacerbating my disease. I try to inculcate a habit to move forward and create new things. Changes: I have strengthened some habits and determinations and routines. For eg I take more original initiative of what I cook. I have also improved my golf swing (kinetic body structure) – the program helped me do this, but I didn’t do it because of the course. Have more intensified my trying.</td>
<td>It is a work in progress. I never really get to a point where it is complete because that’s life, but it was helpful for sure.</td>
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<td>She wanted to learn how to manage her worry, which in turn would help her to sleep and also reduce her stress levels.</td>
<td>She says, yes, sort of. It could still be better. It has helped a bit. Some of it is not in her control i.e her kids.</td>
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<td>To reduce fatigue.</td>
<td>“Not as much with de-sensitisation for exercise as I wanted.”</td>
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<td>She wanted “better management of pain to do more in life, to stand up for longer, walk for longer and driving – that’s managing fatigue”</td>
<td>Yes, given that I haven’t implemented my goals to the fullest, I have gained a lot. I get to sleep earlier.</td>
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<td>More sleep, I was going to bed too late. I sleep well when I sleep, I just need more.</td>
<td>Yes, he would like to thank them for telling him he had to do it step by step (he measured the number of houses he could walk to on his block) and to go slowly day by day and each time increase a little more. This was the right thing to do and was very helpful. He said he would have tried to go all around the block all at once if he hadn’t been on the program.</td>
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To increase the length of time that he can walk on his daily walks.
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<td>To manage fatigue better and have more balance in my life.</td>
<td>Yeah. Not totally. It's 7/10.</td>
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<td>Work on negativity, trying to be more positive.</td>
<td>Generally, yes, I have tried to be more positive, but I had a setback for a few weeks, soon after starting (family stuff) and I was bad for a couple of weeks. I thought, you can't stop what life throws at you, this was my negative response. Life throws things at you, family problems; they are not in my control. They are things I have never reacted well too. The program didn't negate this situation. I think if the same thing happens again, my reactions will continue to be the same. I don't trust my personality.</td>
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<td>I don't remember, a very broad goal.</td>
<td>I didn't go into the program with any real expectations. I didn't have anything, so the health psychologist &quot;created my goal for me&quot;, forced it upon me (interviewer- she said this in a nice way). I am happy I had the journey, it was worthwhile. It is good to have a new experience. We get stale, need to keep renewing. I am a bit afraid, that the printed out papers won't be enough for me to keep what I have gained.</td>
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<td>To reduce her worry.</td>
<td>She hasn't achieved it yet but she has strategies and understands better why it happens.</td>
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<td>This is not the precise wording of the goal, but it was to get better at accepting the uncertainty that came with the condition.</td>
<td>Yes. It has been achieved to a degree, and I have the ability to get closer to this goal as time goes on.</td>
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<td>To be able to deal with pain better.</td>
<td>Pretty much. The pain is a lot better. Better because of the strategies she's learned to manage better.</td>
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<td>About finding a structure to deal with my life/health/job/dad in chemo/emotions and try to let go of the stress attached. I felt helpless to be strong to everybody, not who I wanted to be - stressed out.</td>
<td>Yes, still work in progress. I do feel I have more stillness, calm. Created this step away, because the program put steps in place. I feel so much better than even a month ago. My health has improved, my dad's cancer has stabilized, and I am getting more used to my job.</td>
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