The Support Stars

Support Star (Young People)™
The Outcomes Star for young people facing serious illness

Support Star (Parents)™
The Outcomes Star for parents of children facing serious illness

The Outcomes Star™
This Star is part of a family of Outcomes Star tools. For other versions of the Outcomes Star, good practice and further information see www.outcomesstar.org.uk.

Contents

1. Introduction

The Outcomes Star is a suite of a suite of person-centred tools for supporting and measuring change when working with people, including versions for young people, families and people with learning disabilities.

There are two versions of the Support Star. The Support Star (young people) has been developed to help young people facing serious illness to talk about the impact of their illness on different aspects of their life and to identify any support they may need. The Support Star (parents) is a tool to support parents of children facing serious illness to help them to talk about the areas of life that may be affected by their child's illness and to think about what support they may need.

All versions of the Outcomes Star have several five- or ten-point scales arranged in a star shape. Each point on each scale has detailed descriptors setting out the attitudes and behaviour typical of that point. Underpinning these scales is a model of change (the Journey of Change) describing the steps towards the end goal that both the service and service user are trying to achieve.

In the case of both versions of the Support Star, the end goal is **managing well**, where things are as good as they can be for the service user, under the circumstances.

Like all versions of the Outcomes Star, the Support Stars are both keywork tools, supporting effective interventions, and an outcomes tools, giving management data on progress towards the end outcome. Because of this dual role, they bring together measurement and service delivery and can provide a shared language and framework across operations and performance management departments.

Both versions of the Support Star have the following resources:

- The Support Star Chart, Notes and Action Plan for completion by workers with service users
- The illustrated short scales for use with young people and parents
- The Support Star User Guide, containing the detailed scales, which can be shared with young people and/or parents as needed
- The Guidance for workers, providing guidance on how to use the Support Star
- A web application for online completion at www.staronline.org.uk.

Background and further information about the Outcomes Star suite of tools can be found at **www.outcomesstar.org.uk**.

About this Development Report

This report outlines the theoretical foundations for the Support Stars, the process of their development and the research that supports them. The report includes analysis of the psychometric properties of the pilot version of the tool and further research into the psychometric properties of the final tool is planned. For the latest information on this please contact info@triangleconsulting.co.uk**.**

2. Theoretical foundations of the Outcomes Star™

A new approach to outcomes measurement

The approach underpinning the Support Stars, and all versions of the Outcomes Star, is an original way of dealing with assessment and outcomes measurement. It draws on the core principles of Participatory Action Research (O'Brien, 2001; Carr & Kemmis, 1986) – empowerment, collaboration and integration – and extends them beyond research into assessment and outcome measurement. Participatory Action Research seeks to empower the subjects of research, collaborate with them and integrate research into practical action to improve people's lives. For a fuller summary please see MacKeith (2011).

In the same way, the Support Stars seek to empower service users within a collaborative process of assessment and measurement that is integrated with support work rather than a separate activity.

Empowerment

Underpinning the Star is the belief that, in order for change to take place in people's lives, service providers need to harness the motivation, understanding and skills of the person themselves to create change. In the context of the Support Stars this means enabling the young person and their parents to manage as well as possible in the challenging context of serious illness.

The principle of empowerment recognises that whilst serious illness, societal or other external factors are beyond the control of the individual, there are things that can change for the better. In line with this principle, the Support Stars are designed to facilitate young people and parents of children in talking about the impact of the illness on different aspects of their lives and identifying any support they need. Through this process, parents and young people can highlight external factors which are beyond their control and focus on things they are able to change.

In other contexts, including mental health, parenting and work with young people, service users and front-line workers have reported that the Star provides an empowering context for keywork as service users are active participants in the process rather than having an assessment 'done to them'. Being involved in their own process of change – and the validation of their experiences and perceptions – is often critical in helping service users make the changes they seek (Burns, MacKeith & Graham, 2008). In contrast, when the assessment and measurement process require service users to be passive in submitting to the expertise of others, it can reinforce the disempowerment and lack of self-worth that may have contributed to their need for help in the first place.

Collaboration

When using the Support Stars, the worker and service user assess the service user's needs together. The service user bases their assessment on their knowledge and understanding of themselves, and the worker applies their professional training and experience of working with others to observe and reflect on the service user's situation and needs. The assessment emerges through a dialogue between service user and worker and this may result in a change in the perceptions of each person.

The Star makes the model of change explicit and the information that is collected is immediately presented back to the service user as a completed Star. This allows the service user and worker to take an overview together and to reflect on the completed Star as a basis for deciding what actions are needed. The service user takes an active role in defining issues, identifying actions and thinking about consequences for themselves. As a result, they are much more likely to be behind the plan that emerges from the completed Star.

This contrasts with extractive approaches to assessment and measurement in which the expert collects "data" from the service user and takes that data away to make an assessment on their own. The expert may then decide what course of action is most appropriate and try to persuade the service user that this is the best way forward for them.

Integration

Completing the Star is an integral part of working with the service user and is intended to support as well as measure change. For the service user, the process of participating in the assessment, engaging with the model of change and reflecting on the data the Star presents can of itself result in change. It can also have the same impact on the workers and carers working with the person. In addition, the assessment dialogue and the Journey of Change that underpins the Star naturally leads to discussion of next steps and action planning. The assessment is therefore an integral part of the intervention.

This contrasts with traditional approaches in which the collection of data is seen as a separate process to the intervention and may be regarded as intrusive by workers and service users.

The differences between the Star and traditional approaches to measurement are summarised on the next page.

	Support Star	Many traditional approaches
Empowerment	• Servicer users are seen as active co-producers of change • Their motivation, understanding, beliefs and skills are often key to creating change, while recognising external factors beyond their control • The focus is on the service user's relationship with the issue	• Service users are seen as passive recipients of help, with "experts" having the knowledge to devise solutions • The focus is on the severity of the issue
Collaboration	• The worker and service user collaborate in assessment, with the potential to build a shared perspective on issues and the action needed	• These employ either self-report measures or professional assessment measurement tools that don't build a shared perspective
Integration	• Assessment and measurement are an integral part of keywork	• Assessment and measurement are additional tasks that can be resented by workers as a distraction from "real" work

Values shared with other approaches

The values that inform the Support Stars are similar to those of person-centred (or 'patient centred'), strengths-based and co-production approaches:

- The Star places importance on the service user's perspective and priorities, as in a person-centred and patient-empowerment approaches

- The holistic assessment offered by the Star focuses on aspects of life that are going well in addition to areas of difficulty, as in a strengths-based approach

- As in co-production, the service user is seen as an active agent in their own life and a valuable source of expertise and knowledge rather than a passive participant who is wholly dependent on the professional, with their expertise and knowledge, for change.

As a result, implementing the Support Stars can provide an effective way of putting these values into practice.

3. The development process for the Support Stars

The methodology for developing all versions of the Outcomes Star is based on Action Research (O'Brien, 2001) and the Existential Phenomenological research method (McCall, 1983). Action Research is a collaborative process of identifying issues, trying out solutions and assessing what works. This phenomenological method places a strong emphasis on understanding the subjective experience of the person or people being researched and the meaning of the experience for them.

In order to ensure that patient and parent perspectives were central to the development process, the Support Stars were developed in collaboration with CLIC Sargent. CLIC Sargent are a charity providing support to young people with cancer and their parents. There was an expert working group overseeing the process which consisted of managers, workers and service users from CLIC Sargent, though participants varied between the different stages of development.

The development of the Support Stars consisted of five main stages:

Stage 1: Establishing the need for the Support Stars

Stage 2: Identifying model of change and desired outcomes for service users

Stage 3: Data analysis and drafting

Stage 4: Consultation, piloting, and refining

Stage 5: Relating to existing research and frameworks

This section of the report sets out the process involved in each stage. The findings are set out in Section 4.

Stage 1. Establishing the need for the Support Stars

CLIC Sargent provide support to children, their parents, and young people to maximise their quality of life following a cancer diagnosis. The organisation needs to be able to routinely evidence the difference their services make. Following a 12-month pilot and external evaluation of the Well-being Star (a version of the Outcomes Star designed to support people with long term health conditions to improve their quality of life), they approached Triangle to develop two new versions of the Outcomes Star that would more specifically support their work with both young people with cancer and parents of children with cancer.

Triangle's research team then conducted a scoping review to explore existing tools of adaptation to serious illness. Further details of this are provided later in this report.

Stage 2. Identifying the model of change and desired outcomes for service users

Workshop One (May 2016): A one-day workshop was held to identify intended outcomes and processes of change in support work with both young people with cancer and parents of children with cancer. This workshop was attended by an expert working group made up of professionals, young people and parents and included a series of focus groups to provide insight from about their experiences and the criteria needed to determine whether the support that CLIC Sargent provides results in positive change.

The key questions asked in Workshop One for all versions of the Outcomes Star are as follows:

- What are the main areas in which services and service users are seeking to create change? *These areas become the points of the Star*

- What is the desired outcome of the change process? *This becomes the end point on the Journey of Change that underpins all the scales*

- What model of change describes the steps that service users take on the journey towards that end point? *This is described in a series of steps – the Journey of Change – showing a clearly discernible, qualitative difference between each step of the journey.*

A range of techniques were used to draw out participants' subjective experience and knowledge including:

- Using the Outcome Triangle tool to identify the overall aim of services, the specific outcomes they are trying to achieve and the activities they carry out to achieve these changes

- Bringing to mind an individual who has undergone a substantial change and identifying the key steps involved in their process of change

- Hearing feedback about suggested outcome areas and discussing how they would work in different situations and with different service users.

Stage 3. Data analysis and drafting

Triangle compiled all the material gathered from the focus groups at Workshop One and reviewed it to allow meaning and common strands to emerge. An initial review of the literature was also conducted to examine outcome areas used in other tools for coping with serious illness. On the basis of this learning, the provisional model of change and outcome areas for both of the Support Stars was developed. The provisional model of change and outcome areas were then used as an outline or 'skeleton', from which first drafts of the Support Stars were created.

Stage 4. Consultation, piloting and refining

Once the first drafts were completed there was an iterative process of sharing, listening, refining and sharing again to hone the outcome areas, Journey of Change and descriptions of the steps towards change in each outcome area until they resonated with the young people, parents and professionals participating in the development process. This stage also involved testing the psychometric properties of the tool. In the development of the Support Stars, as for other versions, this process included the following four steps:

1. **Workshop Two (August 2016):** The first drafts of the Support Stars were presented to the expert working group to capture views on the Star's face validity. An additional workshop was also held in August to gain more feedback from parents on the Support Star (parents) first draft as it was important to gain more service user feedback. The feedback was collected from the workshops and, in the light of this, improvements were made to the Support Stars to create the pilot versions.

2. **Training**: CLIC Sargent was trained to pilot the Support Stars across their services.

3. **Piloting**: The Support Stars were tested by CLIC Sargent with workers and service users over a four-month pilot period. Data gathered during this period was analysed to test the tools' psychometric properties and feedback forms from workers and service users were used to inform the need for further changes. More information about the pilot process and feedback is included in Section 4 of this report.

4. **Workshop Three (March 2017):** Further feedback was gathered on the pilot versions of the Support Stars through focus group discussions at this final workshop. This workshop also provided an opportunity for reviewing the format of the tool, its scope (for example, whether it was unsuitable for any of the service user groups it was piloted with), the guidelines for use and the value of the data generated to the pilot services. This informed the final version of the Support Star (young people) and the Support Star (parents).

After Workshop Three further revisions to the Support Stars were made followed by editing and design to ensure the tool was clear, accessible, and user-friendly in advance of the first edition being published.

Stage 5. Relating to existing research

A literature review was conducted to validate the Support Star journey of change and outcome areas as key factors in supporting young people and parents of children. This review supported the inclusion and comprehensiveness of the Star areas and did not identify any that were missing.

Triangle published the final version of the Support Star (young people) and the Support Star (parents), including guidance for its use, in August 2017.

4. Findings from the development process

Why is there a need for an Outcomes Star in this sector?

CLIC Sargent piloted the Well-being Star for one year within their services for young people and parents of children diagnosed with cancer. An external evaluation of the Well-being Star pilot showed that using a version of the Outcomes Star had the following benefits for CLIC Sargent:

1. Using the Star improved the quality of the service that was delivered

2. The Star helped young people discuss things that mattered to them

3. The Star helped workers and young people to create action plans for support

4. The Star helped young people realise how far they had come since diagnosis, giving them a sense of achievement and empowerment.

However, the evaluation concluded that the Well-being Star was not an appropriate outcomes measurement tool for CLIC Sargent for several reasons:

1. The Well-being Star is not designed to be specifically used for young people with cancer so some of the outcome areas in the Star were not relevant to CLIC Sargent's service users

2. The Journey of Change underlying the Well-being Star does not specifically reflect the journey of CLIC Sargent's service users.

CLIC Sargent therefore approached Triangle to develop a new version of the Outcomes Star which would both support and measure the impact of support provided to young people with cancer or for support provided to parents of children with cancer.

A scoping review by Triangle further confirmed the need for two new Stars that could be used to support service users experiencing cancer and other life changing illnesses. Appendix 4 provides a summary of measures most related to the Support Stars, and highlights that although there are many measures of coping/adaptation to illness, the majority are self-completion tools using simple Likert Scales anchored with basic descriptors such as 'Not at all' and 'Very much'. They are also predominately designed as outcome measures, in contrast to the Star which also serves as keywork tool and is completed collaboratively to guide service delivery. The Patient Activation measure (PAM) is closest to the Star in terms of having clearly defined stages of change and measuring engagement with the issue and self-reliance. However, the Outcomes Stars are more holistic and are tailored specifically to the target service user group; they also link specifically to the action plans that are most suitable at each stage.

Identifying the model of change and desired outcomes for service users

Detailed analysis of the data collected during the initial consultation and Workshop One led to the development of a Journey of Change which describes the journey of young people and parents of children with cancer, or other life changing illnesses.

The Journey of Change and outcome areas for both versions of the Support Star that emerged from the analysis are shown below:

The pilot Support Star (young people) **Journey of Change**	5 Acceptance and choice 4 Finding a way through 3 Trying to respond 2 Taking it in 1 Not able to respond
The pilot Support Star (young people) **Outcome Areas**	1 Health 2 Emotional well-being 3 Managing side-effects 4 Positive use of time 5 Money 6 Relationships and social life 7 Home and family 8 Goals and plans
The pilot Support Star (parents) **Journey of Change**	5 Acceptance and choice 4 Finding a way through 3 Trying to respond 2 Taking it in 1 Not able to respond
The pilot Support Star (parents) **Outcome Areas**	1 Confidence as a carer 2 Supporting your child 3 Managing practicalities 4 Finances 5 Your child's education 6 Being a family 7 Your emotional well-being

Pilot findings

The Support Stars were piloted from November 2016 – March 2017 in Principle Treatment Centres and their connected shared care or district hospital across the United Kingdom. The Support Star (young people) was completed with 55 service users. The Support Star (parents) was completed with 38 service users.

To get feedback on the both the Support Stars, a short questionnaire was provided to all workers and service users who participated in the pilot (see appendix 1 for more detail) and further feedback was gathered at Workshop Three.

Feedback questionnaires

Feedback questionnaires were received from workers and services users. These included questions with dichotomous (yes/no) and Likert-scale response options, as well as allowing open-ended feedback about what was particularly good or needed improvement.

Support Star (young people)

Service user feedback:

- Triangle received 18 completed questionnaires from young people who had completed the Support Star (young people)
- Over half of the young people thought the Support Star was a good summary of their life with an additional 43% reporting that it went some way to summarising their life
- 94% found it helpful to complete the Support Star with their worker
- Only 22% felt that the Star took too long to complete
- Over two thirds of the young people agreed that the scales helped them describe how life was for them at the moment
- Over two thirds of these young people agreed that the scales helped them identify what support they need
- 70% thought the Star helped them see their progress or where things had improved
- 70% found it encouraging to see the progress they made between two Star readings.

Worker feedback:

- Triangle received 15 completed questionnaires from staff members who had used the Support Star (young people)
- Over half of respondents indicated that they thought the Star described the situation, strengths and needs of the young people they work with
- Over two thirds of respondents agreed that the Star helped them get an overall picture of the service users situation and needs
- 47% of these staff members did not think that completing the Star took too long, and one third indicated they were unsure about this
- Over two thirds of respondents indicated that the Star helped focus the support to be focussed on
- 70% of these staff members found that progress that clients had made on the Star encouraging.

Support Star (parents)

Service user feedback:

- Triangle received 15 completed feedback forms from parents completing the Support Star (parents)
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- All parents felt that the Support Star (parents) was a good summary of their lives at the moment
- 93% of parents found completing the Support Star with their worker helpful
- 87% were happy with how long the Star took to complete
- 87% of parents fed back that the scales helped describe how life was at the moment. The remaining 13% of parents either were unsure about this or disagreed.
- 87% of parents agreed that the Star helped them understand what they needed in the way of support
- 80% of parents suggested that the Star had helped them see where they had made progress or things had improved

Worker feedback:

- Triangle received 10 completed feedback forms from staff members completing the Star with parents
- All respondents reported that the Support Star (parents) described the situation, strengths and needs of parents either fairly well/very well
- Over half of respondents agreed the Star helped them get an overall picture of parent's situation and needs, with only 10% disagreeing with this statement and 30% saying they were unsure
- Only a third felt that it took too long to complete the Star with parents
- 46% agreed that the Star helped them focus work with parents, with 36% unsure about this and 18% disagreeing
- Over two thirds of respondents found it encouraging to see the progress parents had made

Workshop 3 feedback:

The workshop participants were asked some specific questions about the Support Stars and the answers are summarised below.

What did you think of the pilot Support Stars?
The overall reaction of the working group was positive. Some of the working group commented that at the beginning of the pilot it had taken a long time to complete a Star reading but, as they became more familiar with the tool, it became easier and quicker. The participants further explained that using the Support Stars had helped to open up a lot of discussion with service users and that they had worked well to show what support CLIC Sargent was able to offer young people and parents using their service.

The working group also commented that the Support Stars worked well for three-month reviews, that the short action plans had been useful and that it was a flexible tool which could have a positive effect on the way people work.

When did the Support Stars work well and not so well?
The working group gave examples of situations in which completing the two versions of the Support Stars had worked well. For example, one worker explained how completing the Support Star (young people) had worked well with a young person and her sister, giving them insight into how well they had coped since diagnosis and giving them a sense of pride when looking at how far they had come. Another worker commented that completing the Support Star (young people) had helped prepare the young person around the anxieties of moving to a new hospital and it was good for them to visualise the progress made.

The working group also commented that it was more difficult to complete the Support Stars with people where there are language barriers. Further, that it may not be appropriate to complete a Star when a family is dealing with a crisis situation.

There was discussion about whether it was appropriate to use the Support Stars with service users receiving palliative care. Although the wording of the scales is designed to fit for people in a palliative phase, not all workers were confident about using it in those circumstances and it was concluded that this would have to be decided using professional judgement on a case by case basis. Some workers suggested it may be easier to complete a Star reading if a previous Star had been completed before a service user had reached a palliative phase or if they were in palliative care for a long period of time, so a relationship of support was well established.

Where can the Support Stars be completed?
The working group felt that the Support Stars were best completed in private spaces where service users felt comfortable to talk, however it was possible to complete a Star on a ward or in a day unit if the worker planned for this, checked the service user was comfortable with this and was responsive to the service user's needs whilst completing it.

Can the Star be completed over the telephone?
The working group discussed whether the Support Stars could be completed with service users over the telephone. It was suggested this method of completion was best suited for the Support Star (parents) as this may be the only opportunity to have an in-depth conversation with a parent without their young children present. For young people, it was suggested this was a more difficult way to complete a Star reading; it was found that young people were less open on the telephone, and that they may not want to be disturbed when they are at home.

Which areas of the Star do you think need some changes or more refining?
The working group thought all areas of the pilot Star were important and that there was no duplication between areas. Some changes were suggested regarding language and small alterations to the detail within the scales.

What would you like to change about the Support Stars?
The working group agreed that the working title (Guiding Stars) of the pilot Support Stars was not suitable and did not reflect the work that CLIC Sargent does. The colours of the pilot tool were not popular, and it was thought the Journey of Change colours drawing on a 'traffic light system' were not suitable for this Star. The working group discussed some wording within the Star that should also be changed, including the names of the Journey of Change Stages. Feedback also highlighted the need to be very clear that the Journey of Change underpinning the Stars did not follow the diagnosis and treatment journey, but was focused on the change that CLIC Sargent can help bring about for service users, regardless of the prognosis or stage of treatment.

Analysis of the pilot data

The Star data collected during the pilot of the Support Stars was analysed to provide an initial assessment of the psychometric properties of the pilot Stars. A larger sample and longer time-period will be used when formally evaluating the psychometric properties of the final versions of the Support Star (young people) and Support Star (parents), including testing for responsiveness.

Support Star (young people)

Distribution
Analysis of the data showed that across the Star scales there were service users with readings at all stages of the Journey of Change, indicating that that all stages are meaningful in capturing a service user's current situation (see Appendix 2).

However, as is often the case for ordinal data, there was some skew. As a rule of thumb, if more than 20% of service users fall into the highest category there is a ceiling effect, making it harder to demonstrate change. This was the case for the *Money, Relationships and social life and Home and family* scales. These results could be partly explained by the fact that the Star was piloted with service users who had in many cases been receiving a service for some time.

For the scales, *Health, Managing side effects, Positive use of time and Goals and plans,* the data was skewed towards the lower end of the Journey of Change.

Internal consistency
The Support Star (young people) was found to have excellent internal consistency (Cronbach's α = 0.92), with a Cronbach's α of 0.7 taken as indicating good internal consistency. Further analysis on a larger data set is needed to confirm the internal consistency of the final version of the Support Star (young people).

Item redundancy

There was evidence of item redundancy (correlations above 0.7 indicating repetition) in the Support Star (young people). High correlations were found between the scale *Health* and the scale *Emotional well-being* and between *Health* and *Managing side-effects.* There was no evidence of heterogeneity (all correlations between domains were above 0.3). See Appendix 3 for inter-item correlations.

Support Star (parents)

Distribution

Analysis of the data showed that across the Star scales there were service users with readings at all stages of the Journey of Change, indicating that that all stages are meaningful in capturing a service user's current situation (see Appendix 2).

The data was skewed with more service users at the higher end of the Journey of Change. For the scales, *Confidence as a carer, Supporting your child, Managing practicalities* and *Your child's education* more than 20% of service users fell into the highest category which could make it harder to demonstrate change in these areas. Similarly, across all Star areas the data revealed that less than 20% of service users were at **not able to respond** on their first Star reading. However, both these results may be partly explained by the fact that the Star was piloted with service users who had in many cases been receiving a service for some time.

Internal consistency

The Support Star (parents) was found to have excellent internal consistency (Cronbach's α = 0.92). Further analysis on a larger data set is needed to confirm the internal consistency of the final version of the Support Star (parents).

Item redundancy

There was evidence of item redundancy (correlations above 0.7 indicating repetition) in the Support Star (parents). High correlations were seen between the following scales:

- *Confidence as a carer* and *Supporting your child*
- *Confidence as a carer* and *Managing practicalities*
- *Supporting your child* and *Managing practicalities*
- *Supporting your child* and *Your emotional well-being*
- *Your emotional well-being* and *Managing practicalities*

These high correlations suggest that there was overlap between the content of these scales (see Appendix 3 for inter-item correlations).

Conclusions from the pilot

The feedback from the pilot shows that parents, young people, workers and managers were generally positive about the Support Stars. The feedback from young people and parents was particularly positive. Improvements to the Support Stars were agreed at Workshop 3 in the light of the feedback gathered, discussion in the workshop and the psychometric evaluation of the Support Stars.

The names 'Support Star (young people)' and 'Support Star (parents)' were chosen as the working title 'Guiding Stars' was not liked by workers, young people or parents.

The main changes agreed for the Journey of Change underlying both of the Support Stars were:

- To change Stage 5 *Acceptance and choice* to *Managing well,* as there is no choice in a child or young person's illness and young people and parents may not always accept the illness

- To ensure it is clear that the Journey of Change doesn't map the treatment journey of the child or young person, and that moving along the Journey of Change isn't dependent on the stage of the illness or the response to treatment

The changes agreed for the Support Star (young people) in response to the pilot, the feedback and psychometric testing were:

- To combine the area *Health* with the area *Managing side effects* and to include the physical impact of illness on fertility in this scale and to rename this scale *Physical health*

- To add in the emotional aspect of side effects to the scale *Emotional well-being* and to make wording changes to ensure this scale doesn't follow the treatment journey

- To rename the scale *Positive use of time* to *Study and work* to focus on education, work and training but to emphasise that having a break in education, work or training is not a problem. It was decided that young people's use of time would then be reflected in the scale *Goals and plans*

- To ensure the scale *Friends and Relationships* is more explicit about how much a young person's illness impacts on their friendships and relationships and how they are supported in this. Further, to change the wording at 1-3 to make young people more comfortable about placing themselves there

- To add in more about emotional impact in the scale *Home and family* and to include detail relating to young people moving back in with parents, acknowledging that this is a difficult and common thing which can cause a lot of anxiety. Further to change the wording at 1-3 in this scale to help to make young people feel more comfortable about placing themselves there.

- To ensure the scale *Goals and plans* is about the young person having meaning in their life, feeling like themselves and doing what matters to them at that time. It was decided to change name of this scale to *Doing what matters to you*.

The changes agreed for the Support Star (parents) in response to the pilot, the feedback and the data analysis were:

- To remove the *Confidence as a carer* scale, putting the emotional aspects of this scale in *Your emotional well-being* and the practical aspects in the *Supporting your child outcome area*

- To clarify the difference in the Stages 4 and 5 in the outcome area *Supporting your child*

- In the outcome area *Finances,* to rename this scale *Money* and to change to the phrase 'getting to grips' in Stage 4 as parents may not be getting to grips with finances but still having to deal with financial implications of child's illness

- To clarify the difference between stages 4 and 5 in the outcome area *Your child's education*

- In the scale *Being a family* to avoid the phrase 'normal family' although this scale is about the family trying to retain as much normality as possible

- To amend the scale, *Your emotional well-being,* as Stage 5 was considered to be too positive and it should reflect that the parent is just holding it together.

5. Literature review findings and relationship to other tools

The Support Stars reflect the many facets involved in coming to terms with and learning to live well with cancer or another serious illness. Each of the outcome areas were developed and refined alongside professionals working directly with young people and families experiencing this challenge and are supported by published research. A summary of this evidence is presented here.

Frydenberg (2008) observes that "stress and coping are arguably the most widely researched area of psychology" (p.21), therefore an exhaustive list of tools relating to adaptation to stressors is beyond the scope of this report. Appendix 4 provides a summary of measures most related to the Support Stars, and highlights that although there are many measures of coping/adaptation to illness, the majority are self-completion tools using simple Likert Scales anchored with basic descriptors such as 'Not at all' and 'Very much'. They are also predominately designed as outcome measures, in contrast to the Star which also serves as keywork tool that is completed collaboratively to guide service delivery. The Patient Activation measure (PAM) is closest to the Star in terms of having clearly defined stages of change and measuring engagement with the issue and self-reliance.

However, the Support Stars are more holistic, going beyond managing health and are tailored specifically to young adults and parents of children with serious illnesses; they also link specifically to the action plans that are most suitable at each stage.

The collaborative and action-focused approach

The Support Stars for young people and parents are collaborative, person-centred tools, which measure and facilitate the progress of clients in case-managed services. Their role as both outcomes and keywork tools provides 'a unique innovation in human service delivery' (Harris & Andrews, 2013, p.17).

The collaborative process of understanding clients' situations and making action plans is important in the context of families experiencing serious illness, given that such families strive to 'feel hope and have a positive focus, to gain control, and to feel close to other people' (Björk, Wiebe & Hallström, 2005, p.265).

Empowering service users in this way also fits with best-practice for encouraging positive adaptation amongst young adults experiencing serious illness (Evan & Zeltzer, 2006). Involving adolescents and young adults in decision-making and goal-setting during this vulnerable time can help to re-establish their burgeoning sense of autonomy and purpose (Atkin & Ahmad, 2001; Wiener et al, 2012).

The Journey of Change

The Journey of Change underlying both final, published versions of the Support Star consists of five stages a service user may progress through: **not able to respond**, **taking it in**, **trying to respond**, **finding a way through** and **managing well**.

These stages of change correspond broadly to those outlined in other models of adaptation to serious events, namely the initial shock and defensive retreat, which give way to acknowledging the issue and beginning to deal with it (cf. Elrod & Tippett, 2002). However, the Support Star's Journey of Change is very much tailored to the experience of young people and parents dealing with cancer. The stages were identified through extensive discussion with service users and those supporting and measuring change in this field.

Some previous conceptualisations of the stages individuals in these circumstances go through have described coping strategies typically engaged in at each stage from diagnosis to post-treatment (e.g. Miedema, Hamilton & Easley, 2007). However, it was found that the Journey of Change for the Support Stars does not necessarily map the "treatment journey" - for example a child may have a relapse but the parent may be more resilient second time around. Moving along the Journey of Change is not always dependent on the illness or how treatment progresses, and movement between the stages is not always sequential.

Moving from "not being able to respond" to "taking it in"
The first stage on the Support Star's Journey of Change is **not being able to respond**. At this point the service user has not yet taken in what is happening and may be feeling numb or overwhelmed by the situation. Once they can move beyond this initial reaction, a phase of **'taking it in'** begins, in which the implications and adjustments needed in the short-term are processed and individuals begin to feel ready to accept help.

This process of movement towards being able to take the illness on board fits with theoretical frameworks and research showing that patients are often traumatized and unable to recall information given around the time of diagnosis (Lally, 2010; McCaughan & McKenna, 2007), but then move beyond the initial reaction and transition to a phase of trying to 'take it on' (McCaughan & McKenna, 2007, p.2096). Similarly, Lally (2010) describes a second phase of women with cancer 'surveying the situation in which they now found themselves and attempting to define the meaning of the diagnosis and fit it into an understandable, mentally manageable framework' (p.272).

Progressing to "trying to respond"
Both Lally (2010) and McCaughan and McKenna (2007) describe the next stage as moving beyond taking the new situation on board to 'taking action' or 'taking control'. This is a phase of adaptation, in which individuals begin to proactively develop emotion-focused and problem-focused strategies to deal with the condition and treatment regimes (Miedema, Hamilton & Easley, 2007). At this stage, support is often needed to overcome barriers and cope when things don't work out.

Beginning to "find a way through"
Movement to the next stage of Finding a way through is characterised by more effective coping and more independence in dealing with any difficulties. Frydenberg's (2008) review of coping in young people identifies this stage of appraising coping strategies, and this appraisal generally becomes more positive over time (Sen & Spring, 2013). Confidence in finding the way through grows as people become more informed about the illness, gain experience in dealing with it and find more effective practical solutions (Sen & Spring, 2013). Reaching the point of **"managing well".**

The main goal for many people affected by cancer, other serious illnesses or injuries is to regain a level of normality and managing well with circumstances (Miedema et al, 2007). Miedema and colleagues emphasise that this may involve acceptance of a 'new normal'- their research showed that for young people diagnosed with cancer 'feelings of invincibility and naiveté were gone, and the cancer journey had matured them in comparison with their peers, and in some cases transformed them'. Parents of children with cancer also appear to be able to adapt and accept the diagnosis, with interviews showing that they relatively quickly reach a stage of 'confronting the reality and establishing a new perspective' (Wong & Chan, 2006).

The Support Star (young people) outcome areas

The seven areas of the Support Star for young people are well-aligned with existing psychological adaptation measures and frameworks for adolescents and young adults, such as the Survivorship Quality of Life Scale (Park, Wortmann, Hale, Cho & Blank, 2014) and the Resilience in Illness Model (Haase, Kintner, Monahan & Robb, 2014). A summary of these and other related tools is provided in Appendix 4.

It is important that the Support Star (young people) is specifically tailored to the needs of older adolescents and young adults, since it has been emphasised that serious illness must be contextualised in terms of the broader themes of 'growing up' and life transitions (Atkin & Ahmad, 2001). Young adults with cancer, for example, have concerns unique to their stage of life such as fertility and financial issues (Roberts, Piper, Denny & Cuddeback, 1997). These issues and others included in the outcome areas are discussed below.

Physical health
Medication, treatment, fertility and other side effects, healthy lifestyle

Compliance with treatment and other health behaviours are critical to recovering from, or living well with serious illnesses, but peer group concerns, the struggle for control and avoidance can make these behaviours difficult for young people (Koocher, McGrath & Gudas, 1990; Pfeffer, Pfeffer & Hodson, 2003). Adolescents and young adults with cancer, for example, often fail to adhere to their treatment plans, especially when they involve self-administered treatments (Kennard et al., 2004). As adolescents get older, they are given greater responsibility for disease management and even more support is needed to encourage adherence (Martin et al., 2007; Williams et al., 2006).

The physical side effects of treatment can also be particularly important for adolescents and young adults. For example, research shows that reduced fertility is often a concern, and that both genders want this to be raised proactively by professionals in the years following diagnosis (Crawshaw, 2013; Roberts et al, 1997). Support may also be needed to cope with the effects on body image and intimacy (Landon & Rosenfeld, 1987; Pfeffer et al, 2003).

Study and work
Education, work, training, volunteering, goals for the future

Adolescents and young adults with serious illnesses have similar concerns to their peers in terms of doing well at school or in employment, but can face disruption of these plans and discrimination in the workplace (Pendley, Dahlquist, Dreyer, 1997; Richardson, Nelson & Meeske, 1999).

Goals for the future may no longer seem realistic (Lee, 2008), and young people may feel that they must reappraise how they fit into society (Lee, Cohen, Edgar, Laizner & Gagnon, 2004). For example, interviews with young adults diagnosed with cancer revealed that over two thirds of young people were worried about the impact of their illness on their education and employment prospects (CLIC Sargent, 2012).

Services that assist patients and survivors in returning to being a student or gaining employment have been shown to help young people to overcome the detrimental effects of their health condition (Zebrack, 2011). Positive use of time can help young people living with serious illness gain more enjoyment, achievement and social significance, all of which are critical ingredients for emotional stability (Allison et al, 2013).

Doing what matters to you
Activities that make life meaningful, social life, enjoyment, feeling like yourself

The psychological impact of the illness can also be reduced if young people are supported to feel like themselves – to live as normal a life as possible, including going through developmental milestones with their peers (Atkin & Ahamd, 2001; Kyngäs et al, 2001; Morgan, Davies, Palmer & Plaster, 2010). Activities that make life meaningful are understood to have a 'powerful role in maintaining a familiar, positive identity in cancer, and providing a resource for coping' (Reynolds & Prior, 2006, p.333).

Social activities may be particularly advantageous, with evidence that they can reduce the stress of coping with an illness and enhance wellbeing (Zebrack, Bleyer, Albritton, Medearis & Tang, 2006). Supportive services that address the difficulties that illness can cause in maintaining a normal social life have been reported as an important need by young adults and adolescents with cancer (Warner et al, 2016).

Money
Benefits, grants, student loans, debts, bills and paperwork, budgeting

Gaining financial independence is often a key priority in late adolescence and early adulthood (D'Agostino, Penney & Zebrack, 2011), but financial difficulties are common amongst young adults with conditions such as cancer due to reduced income and a variety of out-of-pocket costs, (Bleyer, 2010; Timmons, Gooberman-Hill & Sharp, 2013).

Interviews with cancer patients and oncology social workers have shown that loans are often needed to deal with the direct and indirect effects of illness, and that support is needed to assist with this financial burden (Timmons et al, 2013). This is increasingly the case given the advent of new, expensive treatments and improved survival (Pfeffer et al, 2013; Roberts et al, 1997).

Friends and relationships
Friends, partners, feeling connected

Being accepted and feeling connected with peers is important to adolescents and young adults with serious illnesses, just as it is for their healthy counterparts (Atkin & Ahmad, 2001). A sense of connection and belonging has been identified as one of the main contributors to resilience amongst young people with illnesses such as cancer (Rosenberg, Yi-Frazier, Wharton, Gordon & Jones, 2014). Consequently, best-practice recommendations emphasise the need to facilitate social support and peer relationships as part of meeting patients' needs (Bleyer, 2007; Pritchard, Cuvelier, Harlos & Barr, 2011).

One of the reasons for the positive effect of social support on adaptation is the opportunity for emotional expression, which can help to reduce distress, increase self-confidence and help with understanding what is happening (Cho & Park, 2015; Pfeffer et al., 2003; Zebrack et al, 2015). Further to these benefits, when peers engage in sensible health behaviours this can encourage compliance with treatment (La Greca, Bearman & Moore, 2002).

Home and family
Where you live, who you live with, adapting to home life

Being diagnosed with a condition such as cancer often forces adolescents and young adults to become more dependent, and can involve remaining in, or moving back into in the family home into adulthood (Zebrack & Isaacson, 2012). It has been found that mothers of those in this situation are often over-protective (Patterson, McCubbin & Warwick, 1990), and 'infantilization' and loss of autonomy can lead to resentment and negative effects on self-esteem and mood (Corey, Haase, Azzouz & Monahan, 2008). Conversely, serious illness can also lead to problems with independence by causing fear of moving away from home (Kollberg, 1982).

Despite the potential for negative effects within the home and family, when household members adjust well to the new situation and there is good communication and cohesion, this can be one of the best sources of support and normalcy (Barrera et al, 2003; Kyngäs et al., 2001). It is therefore important that the appropriate support is available to enable positive adaptation to living arrangements.

Emotional well-being
Feeling OK, coping with ups and downs, dealing with fear, stress, anxiety or uncertainty

Young people diagnosed with serious illnesses experience ongoing challenges that can give rise to difficult emotions such as fear, anxiety and stress (Hockenberry-Eaton, Dilorio, & Kemp, 1995). Young adults with cancer, for example, often experience poorer well-being and quality of life than their peers as well as symptoms of post-traumatic stress (Kazak et al., 2010). Symptoms and changes in appearance can be embarrassing and distressing, often leading to isolation, fatigue and depressed mood (Corey et al, 2008). Insomnia is also a common side effect of repeated exposure to stress (Nordin, Knutsson, Sundbom, & Stegmayr, 2005).

Developing the resilience and skills to manage these difficult situations and emotions is essential to positive adaptation (Rosenberg et al, 2014). Indeed, adaptive coping and acceptance have been shown to be important to emotional well-being and to encouraging adherence to treatment (Abbott, Dodd, Gee & Webb, 2001; Pfeffer et al, 2003).

There is also strong evidence for the social support element of this outcome area, with support from counsellors, family and friends predicting positive self-image and adaptation (Cho & Park, 2015; Zebrack et al, 2015). Support from health care providers has also been shown to reduce uncertainty amongst young people with cancer (Decker, Haase & Bell, 2007).

The Support Star (parents) outcome areas

As was the case for the Support Star for young people, the six areas of the Support Star for parents were identified through a bottom-up process of discussion with service users and providers. The importance and validity of these areas is further supported by research evidence and their inclusion in related tools such as self-completion questionnaires assessing coping/needs associated with having a child with a chronic illness (e.g. Coping Health Inventory for Parents; McCubbin et al, 1983; Impact on Family Scale; Stein & Riessman, 1980). The evidence supporting the importance of each outcome area in the Support Star (parents) is summarised below.

Looking after your child
Practical care and emotional support, helping your child to cope with their illness

A child becoming seriously ill has a profound effect on the whole family, with parents often struggling to coming to terms with the situation themselves alongside supporting their child practically and emotionally (Monterosso, Kristjanson, Aoun & Phillips, 2007).

There is increasing recognition of the key role that parents play in providing support and continuing care, and parent participation is a key element of care delivery models, such as family-centred care (Curtis, Foster, Mitchell & Van, 2016). Nevertheless, research has shown that some of the most important unmet support needs relate to helping their children adapt to the disease, keeping them comfortable and dealing with medication and dietary requirements (Monterosso et al, 2007). Parents often feel helpless and lack confidence about how best to help their sick child (Kai, 1996), and it can be hard to hand over responsibility for the safety and care of a child to the medical team (Davidson et al., 2007).

Managing practicalities
Appointments, travel, work, childcare, a suitable home, running your home

The care burden associated with a child's serious illness has wide-ranging effects on family life (Monterosso et al, 2007), and it is often challenging to balance domestic responsibilities with medical care (Tong, Lowe, Sainsbury & Craig, 2008). In addition to "normal" parental roles, families are often required to make frequent and long journeys for appointments (Yantzi, Rosenberg, Burke & Harrison, 2001). Research has shown that for repeatedly hospitalised children this travel can have significant effects on family relationships and the ability to keep the child at home (Yantzi et al, 2001).

Parents are often required to reduce their hours, take time off work or give up work altogether to care for their child (Eiser & Upton, 2006). A study examining the costs of caring for a child with cancer found that more a third of working mothers left all paid employment after diagnosis and a further 29% reduced their hours (Eiser & Upton, 2006).

These additional practical demands come at a time when families are already experiencing physical tiredness, uncertainty, and disruption to peer support (Tong et al 2008).

Money
Money issues related to your child's condition, earnings, benefits, grants, debts

Financial strain is common in families with children with serious illnesses (Monterosso et al, 2007). In the UK, most parents of children with cancer are entitled to government benefits, but professional help is generally needed to navigate the application process and extra costs create money worries for more than two thirds of families (Eiser & Upton, 2006).

Frequent travel for appointments contributes to these costs and it often comes alongside loss of income as discussed above (Eiser & Upton, 2006; Longo, Fitch, Deber & Williams, 2006). Greater distance from the hospital is predictive of economic hardship, as are single parenthood and lower household income (Heath, Lintuuran, Rigguto, Tikotlian & McCarthy, 2006).

Qualitative research has indicated that parents of children with cancer may not think about the financial impact because they are focused on diagnosis, treatment and recovery. Consequently, early support with these issues is important to reduce the risk of long-term debt and bankruptcy (Amir, Wilson, Hennings, Young, 2012). Financial assistance is also a major unmet need in most parents of children with other life-threatening conditions (Monterosso et al, 2007).

Your child's education
Catching up, continuing lessons, coping at school, learning, early development

Growing up with a serious illness can have a significant detrimental effect on a child's education and attainment. Research has consistently demonstrated links between childhood cancer, educational achievement and cognitive functioning (Mitby et al, 2003). Chronic illness in childhood has also been linked to poorer educational outcomes (Maslow, Haydon, McRee Ford & Halpern, 2011).

Special educational support can mitigate some of these effects (Mitby et al, 2003), but many parents report difficulties accessing this support (CLIC Sargent, 2013). Research suggests that primary schools often fail to maintain contact with children absent for longer than a few weeks and while 70% of children with cancer receive some form of education in the home or in hospital, parents often doubt its quality (CLIC Sargent, 2012).

In addition to the potential adverse effects on learning, there can be wide-ranging social and emotional consequences. In research conducted by CLIC Sargent (2010), children reported that disruption in their attendance at school was one of the most devastating impacts of cancer, second only to the effects on their health. When children are able to attend school, they can find it hard to reconnect with friends and even experience bullying because of their diagnosis and treatment side-effects (CLIC Sargent, 2012).

Being a family
Making time for families or friends, doing things together, family routines and boundaries

Research has documented the profound effect of caring for a seriously ill child on the ability to maintain a 'normal family life' (Monterosso et al, 2007; Patterson et al, 1990).

Positive outcomes within the family are more likely if normal routines can be maintained (Grootenhuis & Last, 1997), but this can be difficult, for example because hospital visits may require parents to miss work and pick other children up from school early. These changes in routine have even been associated with poorer school performance amongst healthy siblings (Alderfer et al, 2010).

Against the backdrop of a severe or life-threatening illness, the significance of everyday issues such as diet or appropriate discipline can change (Young, Dixon-Woods, Findlay & Heney, 2002). Understandably, parents of seriously unwell children can lower their expectations and find it more difficult to provide consistent boundaries (Lohnberg et al., 2008). There is evidence however, that family organization and control increase over time following the diagnostic period (Grootenhuis & Last, 1997).

Making time to be a family and spend time with friends is also important, with social support buffering the impact of the stress- especially after diagnosis and during treatment (Grootenhuis & Last, 1997). There is potential for increased closeness between parents and between siblings following a child being diagnosed with a serious illness (Grootenhuis & Last, 1997; Lavee & Mey-Dan, 2003). However, support may be needed given the well-documented strain on spousal relationships and the risk of negative effects on siblings (e.g. Da Silva, Jacob, & Nascimento, 2010; Grootenhuis & Last, 1997; Monterosso et al, 2007).

Your emotional well-being
Dealing with fear, stress or anxiety, making time for yourself, friends or other support

High levels of parental distress are experienced at the time of their child's diagnosis, during early treatment and for at least a year afterwards (Grootenhuis & Last, 1997; Sawyer, Antoniou, Toogood, Rice, & Baghurst, 1993). Research has shown that caring for a sick child 'evokes an intense emotional interdependence' and comes at a high cost to parents' emotional well-being (Young et al, 2002, p. 1835). Although emotional consequences can sometimes reduce over time and once treatment has ended (Fife, Norton & Groom, 1987), the end of treatment can also trigger increased anxiety. Parents often need help to deal with fear of relapse, uncertainty and post-traumatic stress symptoms (Grootenhuis & Last, 1997; Lewis & LaBarbera, 1983).

Research documenting high levels of fear, stress and anxiety in parents of seriously ill children highlights the importance of providing support and facilitating parents in accessing support from friends and other sources (Sloper, 2000). Social support is a key predictor of positive coping with a child's illness (Mastroyannopoulou, Stallard, Lewis & Lenton, 1997). but has been identified as an area of unmet need for parents of children with cancer and other serious illnesses (Hopia, Tomlinson, Paavilainen & Åstedt-Kurki, 2005; Mitchell, Clarke & Sloper, 2006).

Both dissatisfaction with support and caregiver burden is associated with greater anxiety and depression amongst parents of child with serious, life-threatening conditions (Monterosso et al, 2007). Parents often spend much of their time with their sick child to 'comfort' and 'keep-watch' (Young et al, 2002), but making time for themselves is extremely important to their own emotional well-being and capacity to provide continued support (Davies, Steele, Collins, Cook & Smith, 2004; Merluzzi & Martinez Sanchez, 1997).

Conclusions

To conclude, there is a strong evidence base for the domains measured by the Support Stars in terms of their importance for parents and young people and the value of providing services that address them. The inclusion of the domains within other related tools, such as those assessing family well-being or functioning further validates their inclusion.

6. Appendices

Appendix 1: Worker and service user feedback following the Support Star pilot

Support Star (young people) worker feedback

Triangle received 15 completed feedback forms from workers on using the Support Star (young people).

How well did you feel the Support Star (young people) described the situation, strengths and needs of the people you work with?	Using the Star helped me to get an overall picture of people's situation and needs
53% Very well, 27% Fairly well, 20% Not well	73% Agree, 20% Unsure, 7% Disagree
I found the process of completing the Star with people too long	**The scale descriptions help me to understand where to focus next with the people I work with**
20% Agree, 33% Unsure, 47% Disagree	73% Agree, 14% Unsure, 13% Disagree

I found it encouraging to see the progress that clients had made (for those who completed a 'retrospective reading')

- Agree
- Unsure
- Disagree

70% / 20% / 10%

Summary of workers open-ended feedback in response to the Support Star (young people): What did staff members like about using the Support Star (young people)?
Shown in order of frequency

The Support Star (young people) helped workers get an overall picture of support needs
Staff members commented that the Support Star (young people) helped them gain a good picture of where the service users were in their life, allowing them to focus on the areas in which support was most needed. It was also suggested that the Star gave staff members a perspective on the impact of cancer on service users' lives and that it allowed staff members to work in a more solution focussed way.

The Support Star (young people) generated a good conversation
The feedback suggested that the Star helped to generate good conversations between service users and staff members, helping service users to reflect on the impact of cancer and to open up conversations about how things may change in the future. The topics were said to be relevant and the sections useful. Further, one staff member commented that having the 8 headings gave the conversation some structure and enabled the service user to know what they were asking and why.

It is a visually attractive tool
Staff members commented that service users liked the visual nature of the tool, that is was good that service users could see the Star as they talked and this made the process seem very transparent.

What improvements to the Support Star (young people) did staff members suggest?
- To include space for an analysis section in the Star notes
- To have a different name (*the pilot Star was called the Guiding Star*)
- To ensure the Journey of Change was not linked to the cancer treatment journey
- To have some guidance as to how to complete a Star over the telephone.

Support Star (young people) service user feedback

Triangle received 18 completed feedback forms from service users on using the Support Star (young people).

Do you think that your completed Support Star (young people) is a good summary of your life and needs at the moment?

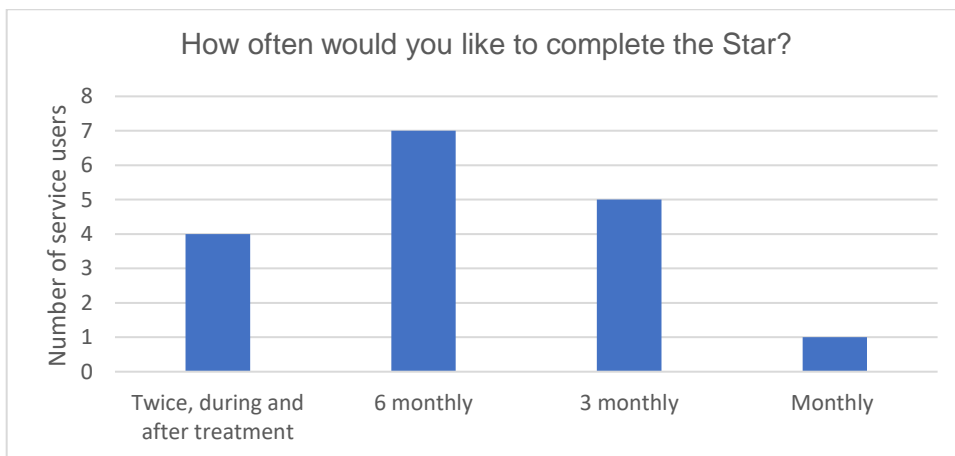- 57% Yes, very
- 43% Yes, a bit

■ Yes, very
■ Yes, a bit

I found completing the Support Star (young people) with my worker helpful

- 94% Agree
- 6% Unsure

■ Agree
■ Unsure

I found the process of completing the Guiding Star too long

- 22% Agree
- 33% Unsure
- 45% Disagree

■ Agree   ■ Unsure
■ Disagree

The scales helped me to describe how life is for me at the moment

- 72% Agree
- 28% Unsure

■ Agree   ■ Unsure

The Star helped me see where I had made progress or things have improved

70% Agree, 10% Unsure, 20% Disagree

■ Agree ■ Unsure ■ Disagree

The scales helped me understand what I need in the way of support

72% Agree, 28% Unsure

■ Agree ■ Unsure

How often would you like to complete the Star?

Number of service users (y-axis, 0–8)

Twice, during and after treatment: 4; 6 monthly: 7; 3 monthly: 5; Monthly: 1

Summary of service users' open-ended feedback in response to the Support Star (young people)

It is good to see where you are and what support you need
The main positive responses from service users were that the Star helped them see where they were at and where they were before. Some service users found it reassuring to see that most things in their life were on track. Service users commented that the Star allowed them to talk through things and gave points that could guide conversation about things they wouldn't normally have spoken about. Service users further commented that this allowed them to help get things off their chest and doing the Star made it possible for their worker to refer them on to other professionals.

I liked the areas of my life it covered
Service users commented that the Star allowed them to break down aspects of their life into more manageable sections.

Ownership
One service user commented that the Star allowed them to have ownership of their support.

Service users were also asked what improvements to the Support Star (young people) they would suggest (shown in order of frequency)

Improvements on the wording
- Service users suggested that in the Friends and relationships scale the phrase "I wish I had more" did not sound very positive. It was suggested this scale should focus on the quality of existing friendships

- Service users commented that some of the description in the scale Positive use of time suggested that if service users were not doing much in their free time that they were being lazy. Service users pointed out that young people may not be using their time positively because they were not feeling well enough to be able to.
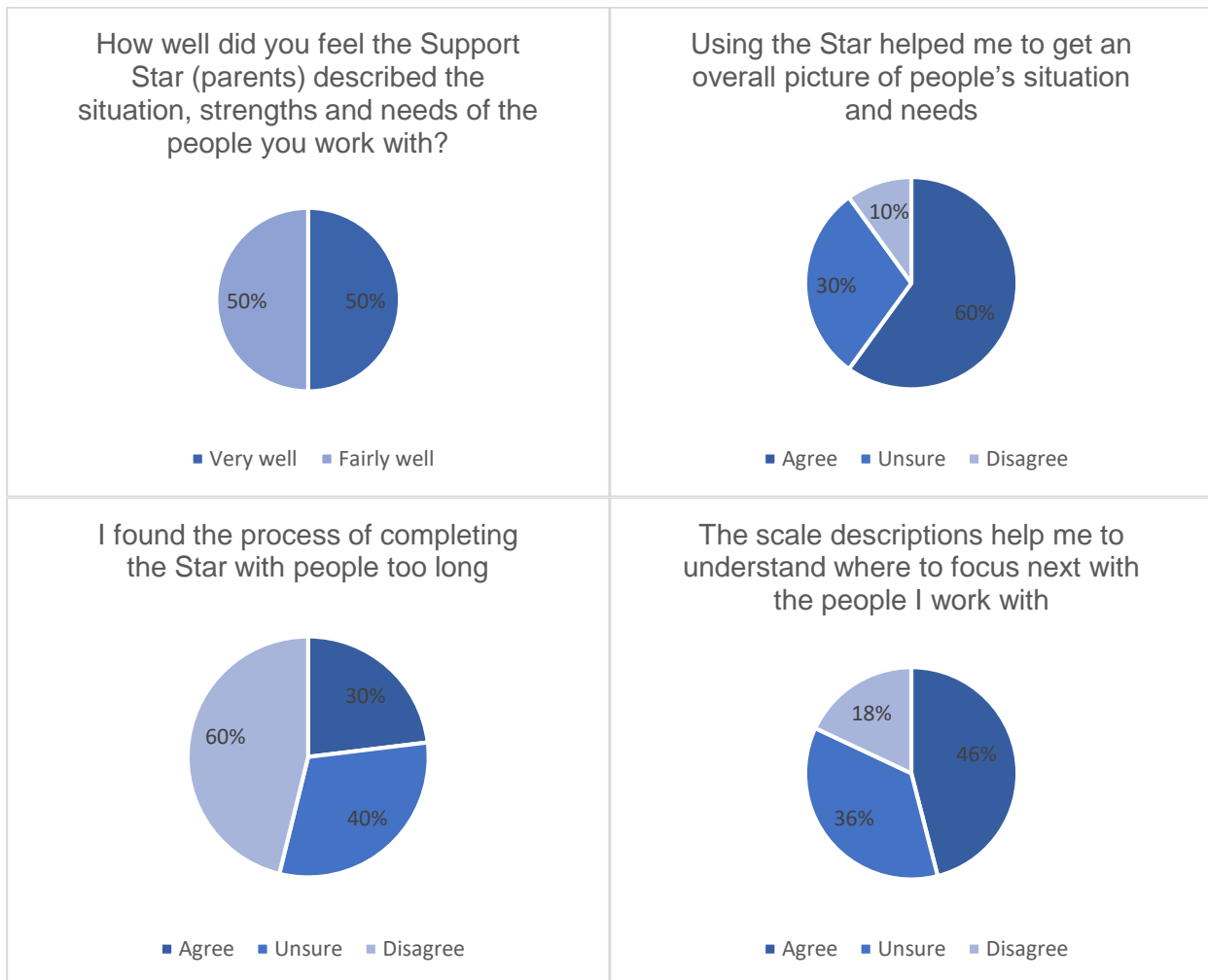
The name
- It was suggested that the name was not a good fit to the service user group, that it didn't have much meaning and was childish *(this Star was previously called the Guiding Star).*
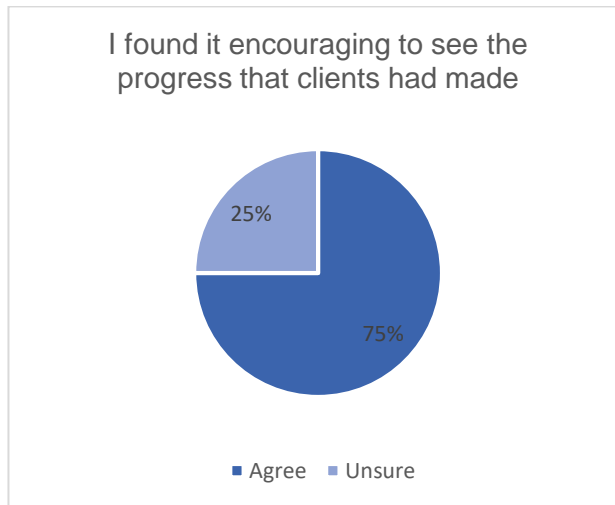
The length
- It was suggested that the Support Star (young people) and some of the detailed scales were too long and it would be better in a shorter format.

Support Star (parents) worker feedback

Triangle received 10 completed feedback forms from workers on using the Support Star (parents).

How well did you feel the Support Star (parents) described the situation, strengths and needs of the people you work with?

- Very well 50%
- Fairly well 50%

Using the Star helped me to get an overall picture of people's situation and needs

- Agree 60%
- Unsure 30%
- Disagree 10%

I found the process of completing the Star with people too long

- Agree 30%
- Unsure 40%
- Disagree 60%

The scale descriptions help me to understand where to focus next with the people I work with

- Agree 46%
- Unsure 36%
- Disagree 18%

I found it encouraging to see the progress that clients had made

25%

75%

■ Agree ■ Unsure

Summary of workers open-ended feedback in response to the Support Star (young people): What did staff members like about using the Support Star (parents)? Shown in order of frequency
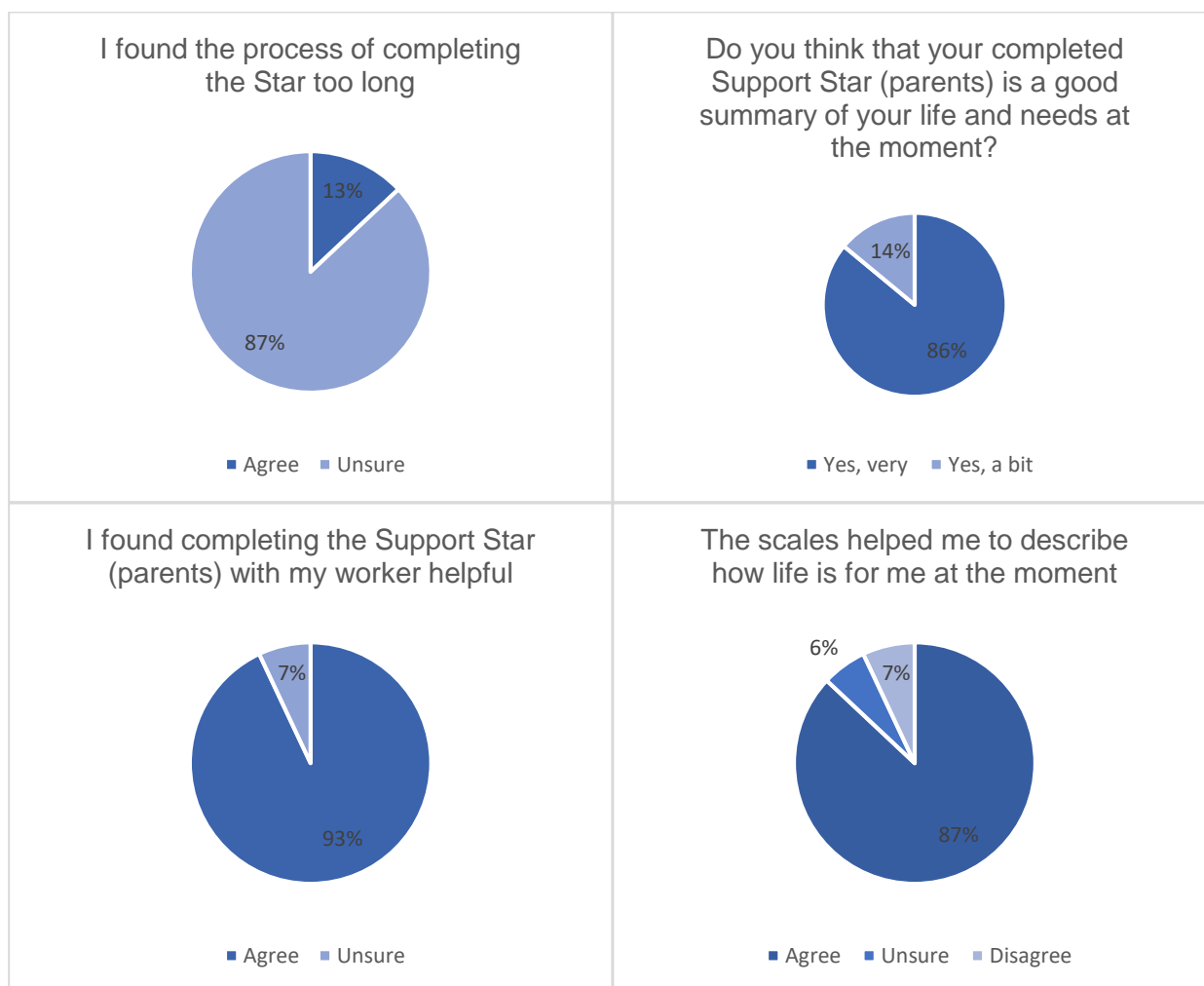
- The Star prompts useful discussion and allows conversation to be explorative as well as focussed and directed
- Completing the Star was empowering for the service user
- Completing a retrospective Star reading allowed service users to feel pride for how well they had done
- The Star helped highlight how parents of the same child can cope differently and can have different support needs
- It allowed workers to provide good emotional support
- The Star covered the relevant and key areas for supporting parents of children with serious illness.

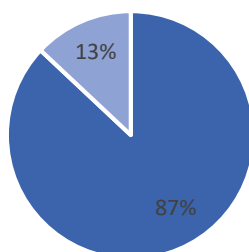**What improvements to the Support Star (parents) did workers suggest?**

- It was suggested that the Star should be shortened as in some cases it took a long time to complete
- For the Star to be available in different languages
- It was suggested that the Star should be designed so it could be integrated with CLIC Sargent's other assessment tools for all the information they collected to be in the same place.

Support Star (parents) service user feedback

Triangle received 15 completed feedback forms from parents completing the Support Star (parents)
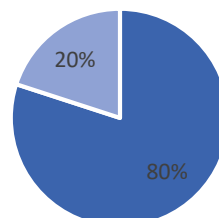
I found the process of completing the Star too long

13% Agree
87% Unsure

- Agree
- Unsure

Do you think that your completed Support Star (parents) is a good summary of your life and needs at the moment?

14% Yes, a bit
86% Yes, very

- Yes, very
- Yes, a bit

I found completing the Support Star (parents) with my worker helpful

7% Unsure
93% Agree

- Agree
- Unsure

The scales helped me to describe how life is for me at the moment

6% Unsure
7% Disagree
87% Agree

- Agree
- Unsure
- Disagree

The scales helped me understand what I need in the way of support
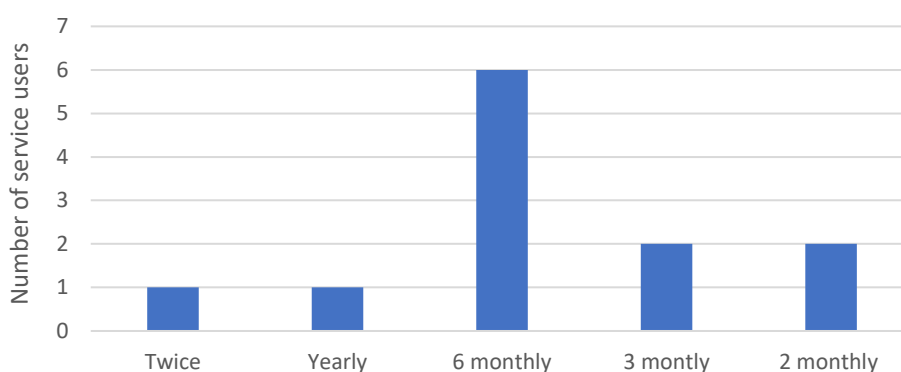

13%

87%

■ Agree ■ Unsure

The Star helped me see where I had made progress or things have improved

20%

80%

■ Agree ■ Unsure

How often would you like to complete the Star?

Number of service users

Twice | Yearly | 6 monthly | 3 montly | 2 monthly

Summary of service users' open-ended feedback in response to the Support Star (parents)

The Star helped describe their distance travelled
Service users commented that the Support Star (parents) allowed them to see progress and positives, helping them realise how far they had come. One service user commented that completing the Star helped them to see how far they had come as a family and that the illness was not taking over normal family life.

The Star highlights service users' support needs
Service users commented that the Support Star (parents) helped them look at their situation and identify the areas in their lives that they could benefit from some support. One service user commented that it helped them to understand what more could be done to help their situation.

The Star aids conversation between worker and service user
The feedback suggested that the Support Star (parents) provided parents with the opportunity to openly discuss their journey and experiences. One parent explained that it allowed them to talk about their emotions more openly than they had previously.
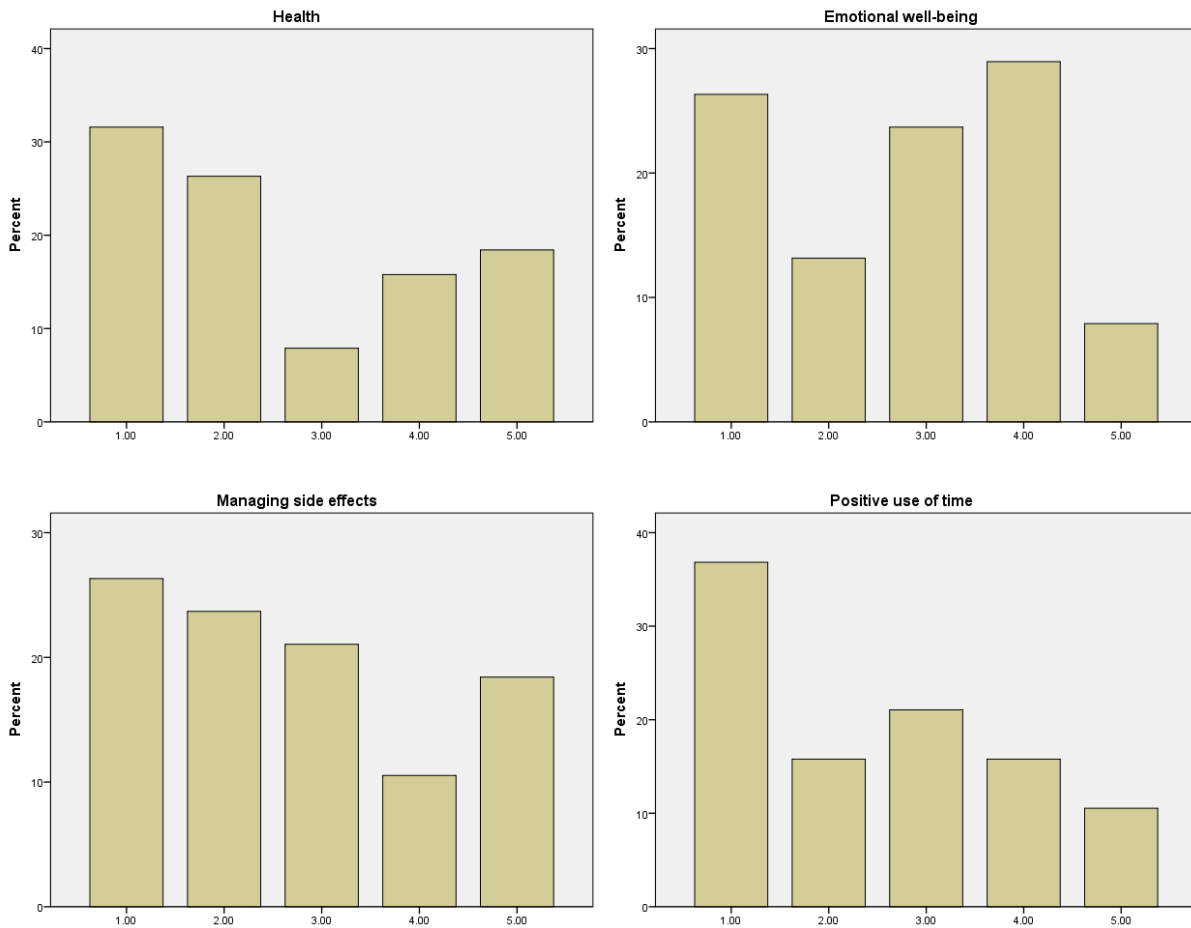
The Star is simple
The feedback showed that parents found the Support Star (parents) to be clear, simple and easy to understand and use.
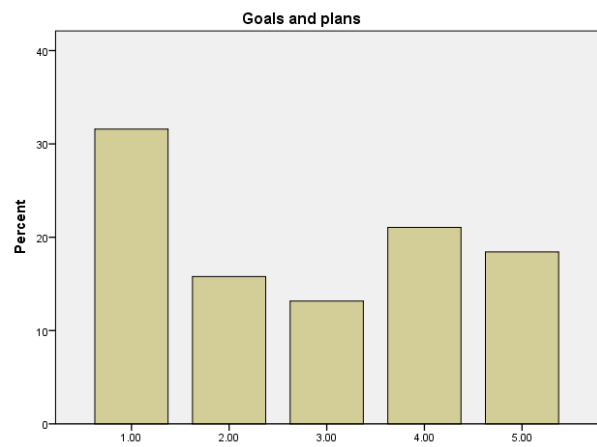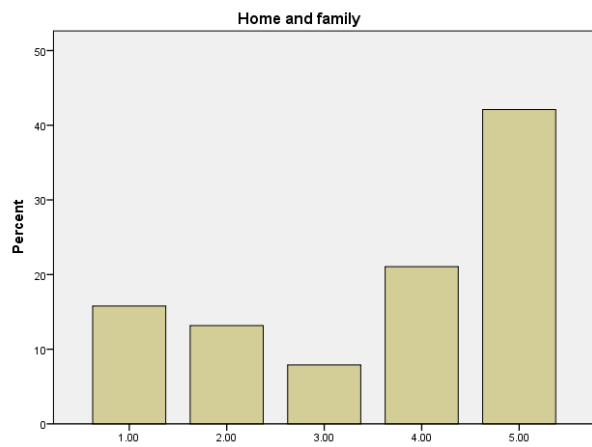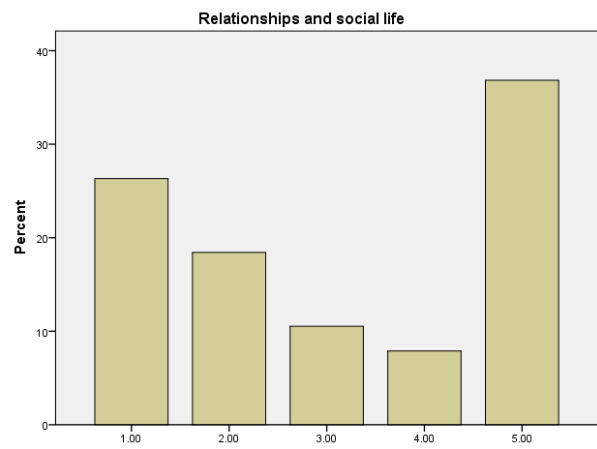
What improvements to the Support Star (parents) did service users suggest?

- To include a measure of the emotional impact of the child's illness on the family in the Star
- To include guidance for the Support Star (parents) to be used more frequently by workers at the start of treatment when things are most chaotic.

Appendix 2: Graphs showing the distribution of initial Star readings across the Journey of Change stages during the pilot

Support Star (young people)

Health

Emotional well-being

Managing side effects

Positive use of time

Money

Relationships and social life

Home and family

Goals and plans

Support Star (parents)

Confidence as a carer

Supporting your child

Managing Practicalities

Finances

Your child's education

Being a family
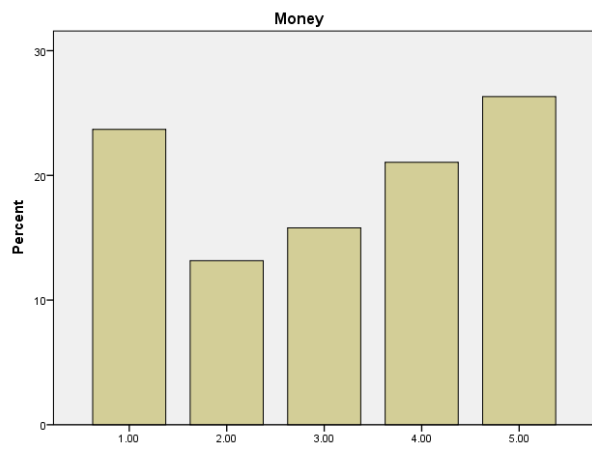
Your emotional well-being
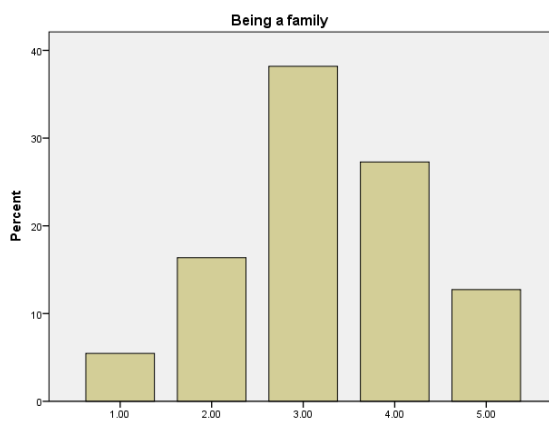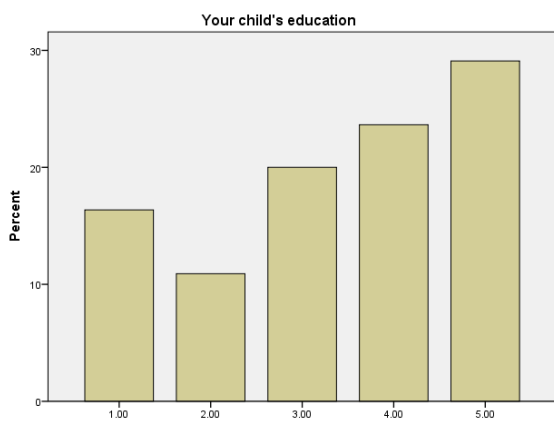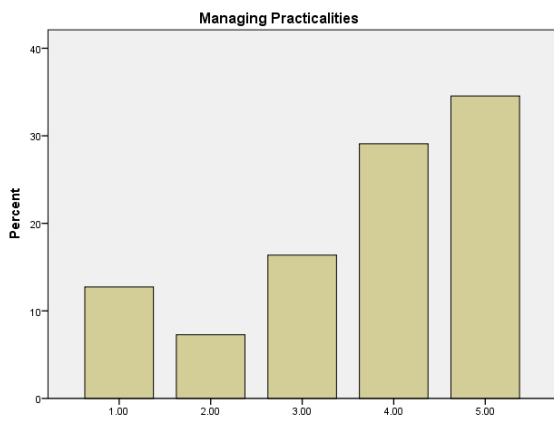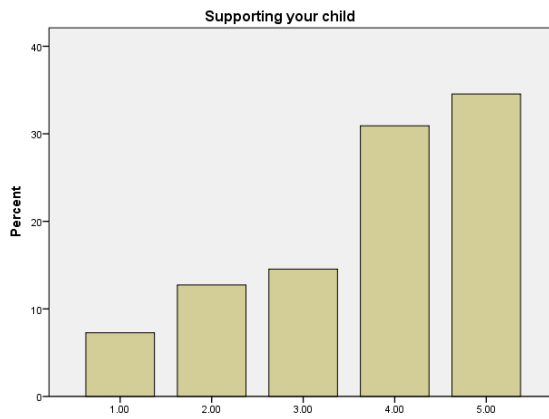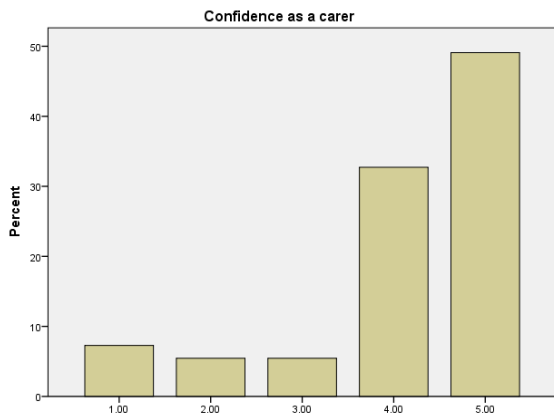
Appendix 3: Table showing the pilot Support Star's inter-item correlations

Support Star (young people)

Inter-Item Correlation Matrix

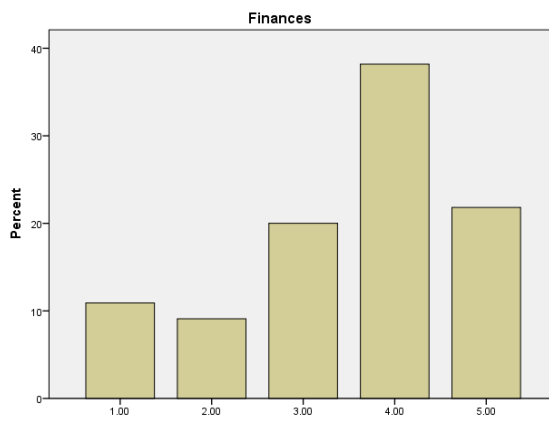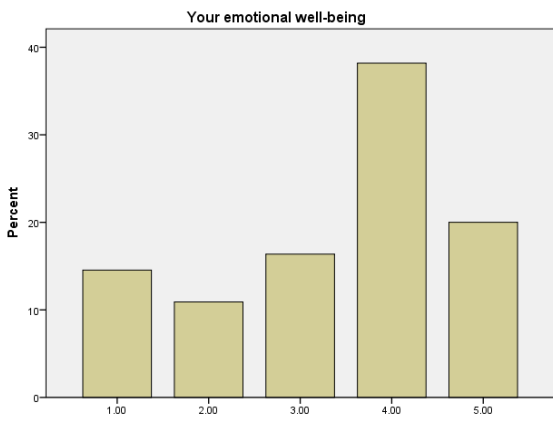|	Health	Emotional well-being	Managing side effects	Positive use of time	Money	Relationships and social life	Home and family	Goals and plans
Health	1.000	.778	.851	.571	.535	.611	.500	.743
Emotional well-being	.778	1.000	.692	.556	.340	.608	.564	.710
Managing side effects	.851	.692	1.000	.571	.524	.609	.494	.636
Positive use of time	.571	.556	.571	1.000	.566	.421	.401	.655
Money	.535	.340	.524	.566	1.000	.471	.513	.521
Relationships and social life	.611	.608	.609	.421	.471	1.000	.496	.713
Home and family	.500	.564	.494	.401	.513	.496	1.000	.614
Goals and plans	.743	.710	.636	.655	.521	.713	.614	1.000

Support Star (parents)

Inter-Item Correlation Matrix

	Confidence as a carer	Supporting your child	Managing Practicalities	Finances	Your child's education	Being a family	Your emotional well-being
Confidence as a carer	1.000	.740	.750	.596	.634	.607	.638
Supporting your child	.740	1.000	.801	.535	.629	.687	.767
Managing Practicalities	.750	.801	1.000	.607	.646	.691	.770
Finances	.596	.535	.607	1.000	.605	.518	.486
Your child's education	.634	.629	.646	.605	1.000	.557	.497
Being a family	.607	.687	.691	.518	.557	1.000	.563
Your emotional well-being	.638	.767	.770	.486	.497	.563	1.000

Appendix 4: Relationship to other tools measuring adaptation to serious illness

Frydenberg (2008) observes that "stress and coping are arguably the most widely researched area of psychology" (p.21), therefore an exhaustive list of tools relating to adaptation to stressors is beyond the scope of this report. The table below provides a summary of measures most related to the Support Stars.

Name and reference	Target demographic	Dimensions	Journey of change / response options	Mode of completion
Patient Activation Measure (PAM; Hibbard, Stockard, Mahoney & Tusler, 2004)	Patients managing chronic conditions and individuals engaged in disease prevention efforts	Knowledge, skills and confidence a person has in managing their own health and care.	(1) believing the patient role is important, (2) having the confidence and knowledge necessary to take action, (3) actually taking action to maintain and improve one's health, and (4) staying the course even under stress.	Interviewer-administered / self-completion
Survivorship Quality of Life Scale (Park, Wortmann, Hale, Cho & Blank, 2014)	Those diagnosed with cancer in late adolescence and early adulthood	Existential/spirituality; Coping; Relationship, Dependence, Vitality, Health care, Education/career, Fertility, Intimacy/sexuality; Cognition/memory.	1-7 Likert scale: Completely unsatisfied to completely satisfied	Self-completion
The Resilience in Illness Model (Haase,	Adolescents and young adults with	*Illness-related Distress; Social Integration; Family Environment; Defensive Coping; Derived Meaning;*	1-5 Likert scale	Self-completion

Kintner, Monahan & Robb, 2014).	chronic illness, especially cancer			
Herth Hope Index (HHIndex; Phillips-Salimi, Haase, Kintner, Monahan & Azzouz, 2007)	Adolescents and young adults with cancer	Temporality and future; Positive readiness and expectancy; Interconnectedness	1-4 Likert Scale: Strongly disagree to Strongly agree	Self-completion
*The Benefit and Burden Scale for Children (*Currier, Hermes & Phipps, 2009)	Paediatric cancer patients	Affect; Self-confidence; Relationships with peers; Family relationships	1-5 Likert scale: Not at all true for me to Very true for me	Self-completion
Adolescent Quality of Life Instrument (AQoL; Ward-Smith, McCaskie, & Rhoton, 2007)	Adolescents with cancer	Normal activities; Social/ family interactions, Health status; Mood; Meaning of illness.	1-5 Likert scale: Not at all to Very much	Self-completion
The Cancer Needs Questionnaire - Young People (CNQ-YP)	Adolescents sn young adults who have been diagnosed with cancer	Treatment Environment and Care; Feelings and Relationships; Daily Life; Information and Activities; Education; Work	1-5 Likert scale: No need to Very high need	Self-completion

The Cancer Module of the Pediatric Quality of Life Inventory™ (Varni, Burwinkle, Katz, Meeske, & Dickinson, 2002)	Children and adolescents with cancer	Physical, emotional, social and school functioning	0-4 Likert Scale: Never to Almost always	Self-completion
The Pediatric Cancer Quality of Life Inventory (Varni et al, 1998)	Children and adolescents with cancer	Disease and Treatment-Related Symptoms; Physical Functioning; Psychologic Functioning; Social Functioning; Cognitive Functioning	0-3 Likert Scale: It is always a problem to It is never a problem	Self-completion
The Royal Marsden Hospital Paediatric Oncology Quality of Life Questionnaire (Watson et al, 1999).	Children and adolescents with cancer	Functional status; Global health; Physical symptoms; Emotional status; Social functioning; Cognitive functioning; Behavioural problems; School/Educational progress	1-4 Likert Scale: Not at all to Very much	Self-completion
Chronicity Impact and Coping Instrument: Parent Questionnaire (CICI: PQ; Hymovich, 1984)	Parents of children with chronic illness	Coping with problems and concerns related to the child's health; Coping when upset with a spouse; Parent's perception of how one's spouse copes when upset with the parent completing the instrument	1-4 Scale: Does not apply; Do less; Do about the same; Do more	Self-completion

The Impact on Family Scale (Stein & Riessman, 1980)	Parents of children with chronic illness	Financial burden; Familial/social impact; Personal strain; Mastery	1-4 Scale: strong agreement, to strong disagreement.	Interviewer-administered
The Coping Health Inventory for Parents (CHIP; McCubbin et al, 1983)	Parents/caregivers of children with serious or chronic illness	Maintaining family integration, cooperation, and an optimistic definition of the situation; Maintaining social support, self-esteem, and psychological stability; Understanding the medical situation through communication with other parents and consultation with medical staff	0-3 Likert-scale: not helpful to extremely helpful	Self-completion
Family Inventory of Needs-Paediatric II (FIN-PED II)	Parents of children with cancer	The importance of care needs; The extent to which needs were met; The need for more information	1-5 Likert-scale: not at all, to extremely	Self-completion
The Parent Perception of Uncertainty Scale (PPUS; Mishel, 1983)	Parents of hospitalized children	Ambiguity; Lack of Clarity; Lack of Information; Unpredictability	1-5 Likert-scale	Self-completion
Parent Experience of Child Illness (PECI; Bonner et al, 2005)	Parents of children with chronic illness	Guilt and Worry; Emotional resources; Unresolved Sorrow and Anger; Long-term uncertainty	0-4 Likert Scale: Never to Always	Self-completion

Pediatric Inventory for Parents (PIP;	Parents of children with serious illness	Medical care; Communication (with child and health care team); Role functioning; Emotional functioning	1-5 Likert-scale: not at all, to extremely	Self-completion

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