

Preparation Star™

The Outcomes Star for living well right to the end

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Please contact info@triangleconsulting.co.uk to enquire about buying a licence and training.

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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.

Acknowledgements

Many people have contributed to the development of the Outcomes Star over its long evolution and we would like to thank all the patients, workers, managers, funders, academics and commissioners who have generously given their time and expertise.

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We would particularly like to thank North London Hospice, Jewish Care, St. Joseph's Hospice, MacMillan Cancer Support and the London ADASS EoL network, the collaborators for the development of this version of the Star.

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Introduction

The Outcomes Star tools

The Outcomes Stars are a suite of person-centred tools for supporting and measuring change when working with people. They are both keywork and outcomes tools, supporting effective interventions and 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 data management for departments and between commissioners and service providers.

All versions of the Outcomes Star have five- or ten-point scales arranged in a star shape. Each point on each scale has detailed descriptors setting out attitudes, behaviour and sometimes skills or circumstances typical of that point on the scale. 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.

The Outcomes Star tools are different to other approaches to assessment and outcomes measurement¹. They are designed to empower service users within a collaborative process of assessment and measurement that supports a positive conversation and is integrated with support work, rather than being a separate activity. The Star is closely aligned to person-centred, strengths-based, co-production and trauma-informed approaches and can support people and organisations to put those values into practice:

- Person-centred: The Star encourages and enables workers to listen to the perspective and priorities of service users and to work with them collaboratively. It helps engage service users to develop realistic action plans based on where they are on the Journey of Change
- Strengths-based: The Star is holistic and enables people to focus on aspects of life that are going well rather than have an assessment focused entirely on areas of difficulty. The scales focus on what service users can change, rather than the severity of their problems or circumstances

¹ The Outcomes Stars share the core principles of Participatory Action Research (O'Brien, 2001; Carr & Kemmis, 1986) – empowerment, collaboration and integration – extending these 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. The Outcomes Stars seek to empower service users within a collaborative process of assessment and measurement that is integrated with support work rather than being a separate activity.

- Co-production: the collaborative approach to completion means that the service user and worker produce the assessment and measurement together and build a shared perspective as a basis for action. This is in contrast to expert assessment or self-report approaches in which the two perspectives remain separate
- Trauma informed: the collaborative nature of the Star helps to give the service user control, which has been shown to be important in building a sense of safety for people who have experienced trauma. The focus of the tool is primarily on how things are now, rather than past experiences that might trigger someone's trauma and put them outside their safe "window of tolerance". In addition, the guidance for use emphasises the importance of building of a trusting relationship and a shared perspective as an essential foundation to moving forward.

For a fuller description of the values and approach underpinning the Outcomes Stars suite of tools, see MacKeith (2011).

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

The Preparation Star

The Preparation Star is the Outcomes Star for living well right to the end. It supports conversations about what is important to people when they consider their final years or months. It may be most relevant for people following a diagnosis, or for those who are elderly or have a health condition but is also relevant to all of us at any point in our lives.

The Preparation Star includes the following resources:

- The Preparation Star Chart, Notes and Action Plan
- The Preparation Star User Guide, with both brief visual scales and detailed scale descriptions
- Short illustrated scales and flashcards
- Guidance for professionals completing the Preparation Star collaboratively with service users
- Self-completion guidance for people choosing to complete it alone or with family/ friends
- A web application for online completion and analysis at www.staronline.org.uk

This Development Report provides a detailed description of the development process of the Preparation Star.

Development process for the Preparation Star™

Methodology

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.

The development process comprises four main stages:

Stage 1: Exploring the scope and need for the tool

Stage 2: Creating the pilot version of the new Star in consultation with the working group

Stage 3: The pilot and revising the Star

Below we describe how this process was applied to create the Preparation Star.

Stage 1. Exploring the scope and need for the tool

North London Hospice approached Triangle to develop a new version of the Outcomes Star for people they support with End of Life care, both in the hospice and community. They then worked with Triangle to find additional collaborators – Jewish Care, St. Joseph's Hospice, MacMillan Cancer Support and the London ADASS end of life network.

Triangle then carried out a scoping process, involving:

- An exploratory review of the literature including existing measures and frameworks including the Kübler-Ross model (1969)
- Checking prior interest and enquiries from other services for a similar or the same version.

As with any new version of the Star, this phase also included scoping the capacity for both Triangle and the collaborators to undertake the development within the budget and timescale needed. Based on this, Triangle's conclusion was to proceed with a version of the Star specifically for people approaching the end of their lives, designed to encourage best practice across the sector.

Stage 2: Creating the pilot version of the new Star in consultation with the expert working group

An expert working group was formed to collaborate in the development of the new Star, comprising commissioners, consultants, managers and practitioners from North London Hospice, Jewish Care, St. Joseph's Hospice, MacMillan Cancer Support and the London ADASS end of life network. A patient group at North London Hospice also provided feedback.

This expert group played a central role throughout the development process, providing in-depth knowledge of the issues faced by people approaching the end of their life, the intended outcomes of service delivery and the process of change towards those outcomes. The working group's input was organised around four workshops. The first two contributed to the creation of the pilot version of the tool, and the third and fourth workshops reviewed the results of the pilot and contributed to refining the tool to create a final version (see Stage 4).

Workshop 1 (November 2016): A one-day workshop was held to identify intended outcomes and processes of change in work supporting people approaching the end of life. The workshop included a series of focus groups to provide insight into workers' experiences and to understand the outcomes that services aim to help service users achieve.

The key questions explored in Workshop 1 were:

- What are the main areas in which services and the people they support 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 people 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 was 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 in their process of change

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

Triangle compiled all the material gathered from the working group at Workshop 1 and reviewed it to allow meaning and common strands to emerge. On the basis of this, combined with the literature review carried out in Stage 1, a provisional model of change and outcome areas for the Preparation Star were developed. These were then used as an outline or “skeleton”, from which the first draft of the Preparation Star was created.

Once the first draft was 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 client group and workers participating in the development process. The process included checking that the first draft took into account key themes that emerged from the literature review, and a second workshop with the expert working group.

Workshop 2 (March 2017): A one-day workshop was held to present the first draft of the Preparation Star to the expert working group and to hear feedback to inform the pilot version of the Star, including from the patient group. On the basis of this feedback and the other activities listed above, the early draft was refined to create a pilot version of the Preparation Star with the Journey of Change and outcome areas listed below:

The pilot Preparation Star Journey of Change	<ol style="list-style-type: none"> 5. As good as it can be 1. Finding what works 2. Trying things out 3. Finding out 4. Not yet dealing with this
The pilot Preparation Star Outcome Areas	<ol style="list-style-type: none"> 1. Pain management 2. Other medical needs 3. Care and dignity 4. Family and friends 5. Doing what matters to you 6. Finances 7. Legal and practical aspects 8. Advance wishes 9. A sense of completion (renamed “How you feel” for the second part of the pilot)

Stage 3: The pilot and revising the Star

Triangle trained 59 workers from the collaborating organisations to use the Preparation Star in May and June 2017. Refresher training was provided in 2018 as the pilot had to be extended until May 2019 due to additional time needed to obtain NHS ethics approval and additional data. A total of 43 service users completed the Preparation Star during the pilot.

Service users and workers were asked to complete brief feedback forms on their experience of using the Star and to submit the Star data to Triangle for initial exploration of the psychometric properties of the pilot Star.

Summary of analysis of patient feedback forms

Triangle received 12 completed questionnaires from service users who had used the Preparation Star during the pilot period, all of whom reported finding “the process of completing the Preparation Star positive” and that the “completed Preparation Star is a helpful picture of how things are for me at the moment”. Eleven out of the 12 service users said that “the scales helped me to understand what I can do and how others can support me”.

Service users provided written feedback indicating that they appreciated the holistic approach offered by the Star. For example:

“Found helpful as fairly isolated – helped with who to go to with a holistic view”

“Like the topics on the points- helped generate thoughts”

“Good. Pulls together a broad spectrum of where you are at”

“Easy to see improvement since last review”.

Summary of analysis of worker feedback forms

Triangle received six feedback forms from workers completing the Star with people they support, of which five agreed that “Using the Star helped me to get an overall picture of people’s situation and needs”. All of those who had completed review stars agreed they “found it encouraging to see how things had improved between Star readings”. Workers provided positive written feedback about the benefits for understanding and supporting the people with whom they completed the Star:

“Really helped the service user to open up and have daunting conversations with his family around”

“I feel I got to know the patient better by using this tool”

“He clearly benefitted from using the tool and spoke about it giving him a focus and to stay motivated”

“He responded well to the structure and visuals – no longer abstract concepts”

“It helped pick apart what was going on and then prioritise”.

Psychometric analyses of the pilot Star data

Analyses of the Star data from the 43 Star readings showed the following:

Distribution: Four outcome areas had readings that were normally distributed, three were moderately skewed and the “Pain management” area was severely skewed towards the top of the Journey of Change (see Appendix). It is important to note, however, that service users may have been receiving support for some time before they completed first Stars and if readings had been completed on arrival they would probably have been more normally distributed.

Internal consistency: Cronbach’s alpha was .79 – above the threshold of .70, suggesting good internal consistency.

Further research into the psychometric properties of the final published version of the Preparation Star was initiated following publication. For the latest information on this, please contact info@triangleconsulting.co.uk.

Revising and finalising the new Star

Workshop 3 (November 2018): The third meeting of the expert working group gathered feedback on the process of using the tool from a wide range of people in different contexts. It also focused on the detail of the tool itself – the areas covered, Journey of Change, scale descriptions and range of materials. Changes needed before the pilot continued were also discussed, including self-completion guidance of the Preparation Star.

The working group was asked some specific questions about the Preparation Star and the responses are briefly summarised below.

What worked in the pilot Preparation Star?

The Preparation Star worked well as a holistic needs assessment for an outpatient or day hospice environment and for people who are not immediately facing end of life (in other words, who have at least several months left).

Feedback from patients was positive – they liked the visuals and found that the Star helped them to see that they are progressing (without seeing that visually the many wouldn't have believed they'd made progress). For example, attendees at the workshop said:

“It really helped her focus on how we could help her – she came in a muddle and it helped us prioritise”

“The topics interested him and included things he hadn't yet considered”

“She found it a good reflection tool for the different aspects of her life”.

Professionals also felt they benefitted when they were able to use the Preparation Star:

“It is very useful for getting to know people. It's a really good way to talk to patients and hear where they are. I like doing the action plan with them and showing them where it relates to the Star Chart”

“I like the visual element. It was the springboard and trigger for conversations that people find hard to acknowledge are there”

“It's really interesting to get to know the patients on different levels”.

What didn't work in the pilot Preparation Star?

The Preparation Star did not work well when people were very close to the end of their lives or for palliative care social workers in the community as they often only see people a few times (sometimes once), often when they are in crisis or need support with a narrow range of issues. It was thought it could work well for palliative care social workers in an inpatient setting with people getting help for symptom control and who were not immediately at the end of their lives.

Attendees also discussed that there was often not time to complete the Star when visiting people in the community and that it would be helpful for some people to self-complete the Preparation Star or take it home to do with family. However the conversation with a worker was also seen as valuable.

There were difficulties with the “Sense of completion” area. Inpatients often don't have a sense of completion but are too ill to do anything about it. Those who are further from the end of their lives are thrown by it and the implication that they are at a completion stage.

Changes made to finalise the Star based on learning from the pilot

On the basis of the worker and patient questionnaires, psychometric analyses and workshop feedback, a number of changes were made to the pilot version of the Preparation Star to create the final version. The main changes are summarised below:

- The “A sense of completion” area was renamed “How you feel” to make the Star more appropriate for people further from the end of their lives
- Guidance for self-completion was revised so that it was on one side of A4 and used bullet points
- Brief scales were written as a more accessible option where appropriate.

The decision was made to carry out a further, brief pilot, focused on encouraging self-completion of the Star by people attending outpatient and well-being services, particularly that run by NLH. After the end of this final pilot, **Workshop 4** was held in May 2019 to draw together any further conclusions and finalise the Star prior to publication later that year. There was positive feedback about the Preparation Star overall when used in the appropriate context:

“Most tools are for clinicians. This can be used by anyone. It’s not just for the clinicians – it’s about starting conversations and getting to the issues”

“If we can manage some of those things that there isn’t a pill for, that is important. I feel it was a gap in our service – we weren’t having those conversations and people weren’t starting them themselves”

“I’ve found it a real joy to work with and very, very clear”

“The Star has given credibility to the service. People are telling me more than they would have before”

“I feel I know patients better. I wouldn’t have got to know them anything like as well without the Star”

“We have much more meaningful conversations with people – not just “have you had a good week?”

“For me the main thing is about conversations – to enable people to have those conversations. Staff don’t know how, so if the Star can help start the conversation, that is enough”.

Some small additional changes were made as a result of this final round of feedback:

- The “Other medical needs” scale was renamed “Symptoms and side effects” and some minor changes made to the content to reflect a range of possible side effects

- Minor changes were made to the “How you feel” scale to include reflecting on your life and legacy.

The final Preparation Star Journey of Change	1. As good as it can be 2. Finding what works 3. Trying things out 4. Finding out 5. Not yet dealing with this
The final Preparation Star Outcome Areas	1. Pain management 2. Symptoms and side effects 3. Care and dignity 4. Family and friends 5. Doing what matters to you 6. Finances 7. Legal and practical aspects 8. Advance wishes 9. How you feel

Completion

The draft version of the Star went through final checks:

1. The expert working group was invited to review and comment on the final draft
2. It was reviewed again by Triangle to ensure clarity of descriptions and distinctions between each stage of each scale
3. It was edited and proofed before being typeset

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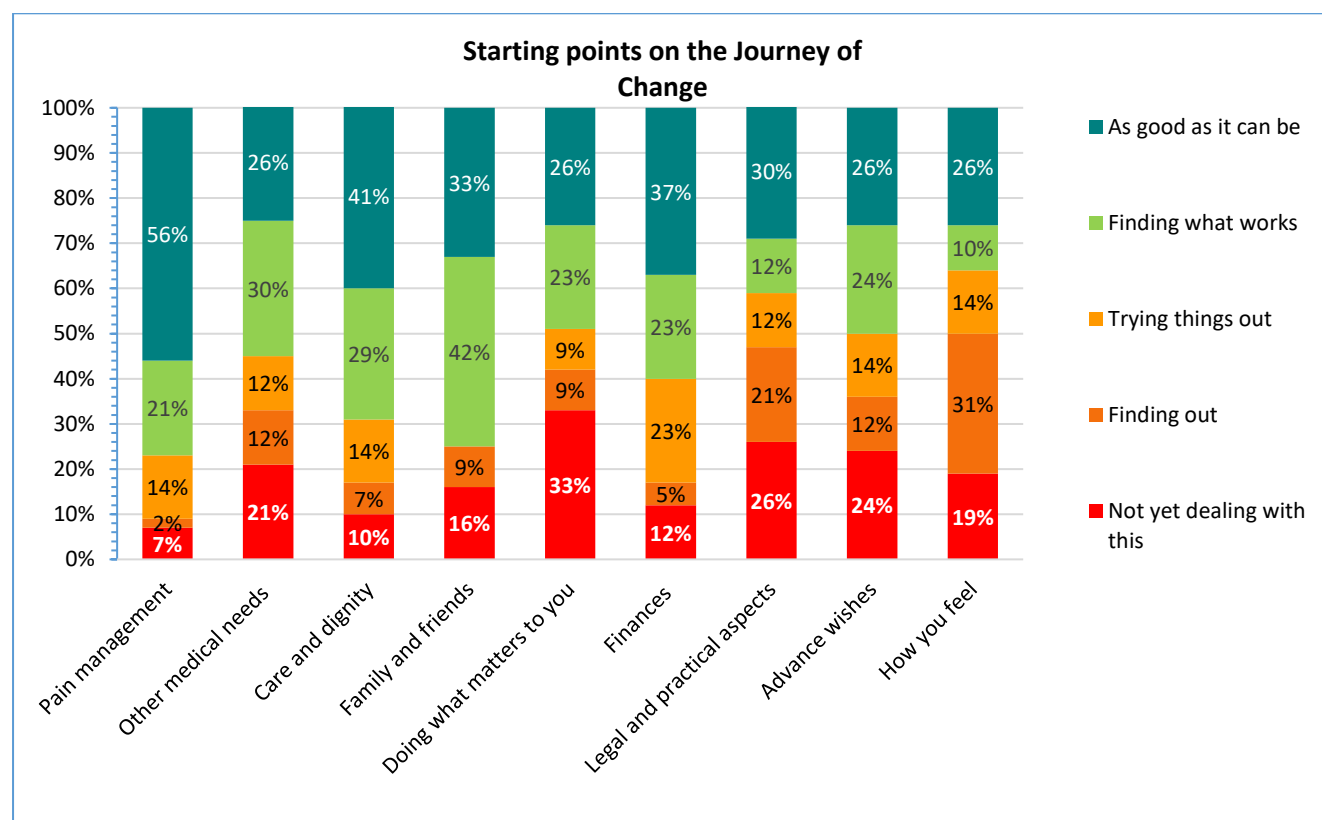
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Appendix

The distribution of initial Star readings across the Journey of Change stages during the pilot of the Preparation Star™



	Skewness statistic	Result
Pain management	-1.46	Highly skewed
Other medical needs	-.48	Moderately skewed
Care and dignity	-.97	Moderately skewed
Family and friends	-.99	Moderately skewed
Doing what matters to you	-.15	Approximately symmetric
Finances	-.74	Moderately skewed
Legal and practical aspects	.12	Approximately symmetric
Advance wishes	-.26	Approximately symmetric
How you feel	.22	Approximately symmetric

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