



# Development Report

## **The Discovery Star™**

**The Outcomes Star for living with fatigue or other persistent physical symptoms**

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Please contact [info@triangleconsulting.co.uk](mailto:info@triangleconsulting.co.uk) to enquire about buying a licence and training.

Licences may be available for those wishing to translate this report into other languages.

**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](http://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, practitioners, managers, funders, academics and commissioners who have generously given their time and expertise.

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We would particularly like to thank Betsi Cadwaladr University Health Board - North Wales NHS long Covid service, for collaborating with Triangle to develop 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 providing 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 the people they support are trying to achieve.

The Outcomes Star tools are different to other approaches to assessment and outcomes measurement<sup>1</sup>. They are designed to empower people receiving services within a collaborative process of assessment 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 practitioners to listen to the perspective and priorities of people being supported and to work with them collaboratively. It helps engage people 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 being focused entirely on areas of difficulty. The scales focus on what services and the people they support can change, rather than the severity of their problems or circumstances
- **Co-production:** Services and the people they support are involved in the development of the tool, and the collaborative approach to completion means that the practitioner and the

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<sup>1</sup> 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 people being supported by services within a collaborative process of assessment and measurement that is integrated with support work rather than being a separate activity.

person they are working with produce the readings together and build a shared perspective as a basis for action. This contrasts with 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 individual receiving support 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 Star suite of tools, see MacKeith (2011).

Background and further information about the Outcomes Star suite of tools can be found at [www.outcomesstar.org.uk](http://www.outcomesstar.org.uk)

## The Discovery Star

The Discovery Star is the Outcomes Star for people with persistent physical symptoms which are complex to identify and treat such as fatigue, breathlessness, ongoing pain, autonomic dysfunction such as PoTS or palpitations. Symptoms may be present due to a number of conditions, including post-viral presentations such as long Covid, ME/CFS, or other persistent physical symptom presentations such as FND or fibromyalgia. There may not be a specific diagnosis or label. It charts the journey of discovery towards finding fulfilment, whatever that means for you, and a sense that things are stable and sustainable.

It includes the following resources:

- The Discovery Star Chart, Notes and Action Plan
- The Discovery Star User Guide, with detailed scales
- Short illustrated Scales and Flashcards
- Guidance for practitioners completing the Discovery Star collaboratively with the people they are supporting
- A web application for online completion and analysis at [www.staronline.org.uk](http://www.staronline.org.uk)

This Development Report provides a detailed description of the process of creating the Discovery Star.

## Development process for the Discovery 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 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

Stage 4: Revising and finalising the new Star

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

### Stage 1. Exploring the scope and need for the tool

North Wales NHS Long Covid service approached Triangle to develop a new version of the Outcomes Star for people with long Covid and other forms of post-viral, chronic or disease related fatigue. Triangle then carried out a scoping process, involving:

- A market scoping to assess the likely uptake of a Star for those with long Covid and other fatigue related conditions
- A literature review examining the possible outcome areas
- 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 this version of the Star.

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

An expert working group was formed to collaborate in the development of the new Star. Members of this group included patients, GPs, cardiac rehabilitation nurses and occupational therapists, consultant leads, therapy leads, operations managers and researchers working in or supported by North Wales NHS service for those with long Covid and other fatigue-related conditions.

This expert group played a central role in the development process, providing in-depth knowledge of the issues faced by patients, the intended outcomes of service delivery and the process of change towards those outcomes. The working group's input was organised around three workshops. The first two workshops contributed to the creation of the draft version of the tool. The third workshop reviewed the results of the pilot and contributed to refining the tool to create a final version (see Stage 4). In addition, Triangle formed an internal reference group, which met three times to review changes.

**Workshop 1** (June 2022): This workshop was held to identify intended outcomes and processes of change in work supporting people with fatigue. It included a series of focus groups to provide insight into the experiences of practitioners and people with lived experience and to understand the outcomes that services aim to help the people they are supporting to achieve. The key questions explored 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
- Practitioners and people with lived experience pairing up to discuss 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 Discovery Star were developed. These were then used as an outline or 'skeleton', from which the first draft of the Discovery 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 practitioners 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** (October 2022): A one-day workshop was held to present the first draft of the Discovery Star to the expert working group and to hear feedback to inform the pilot version of the Star. Based on this feedback and the other activities listed above, the early draft was refined to create a pilot version of the Discovery Star with the Journey of Change and outcome areas listed below:

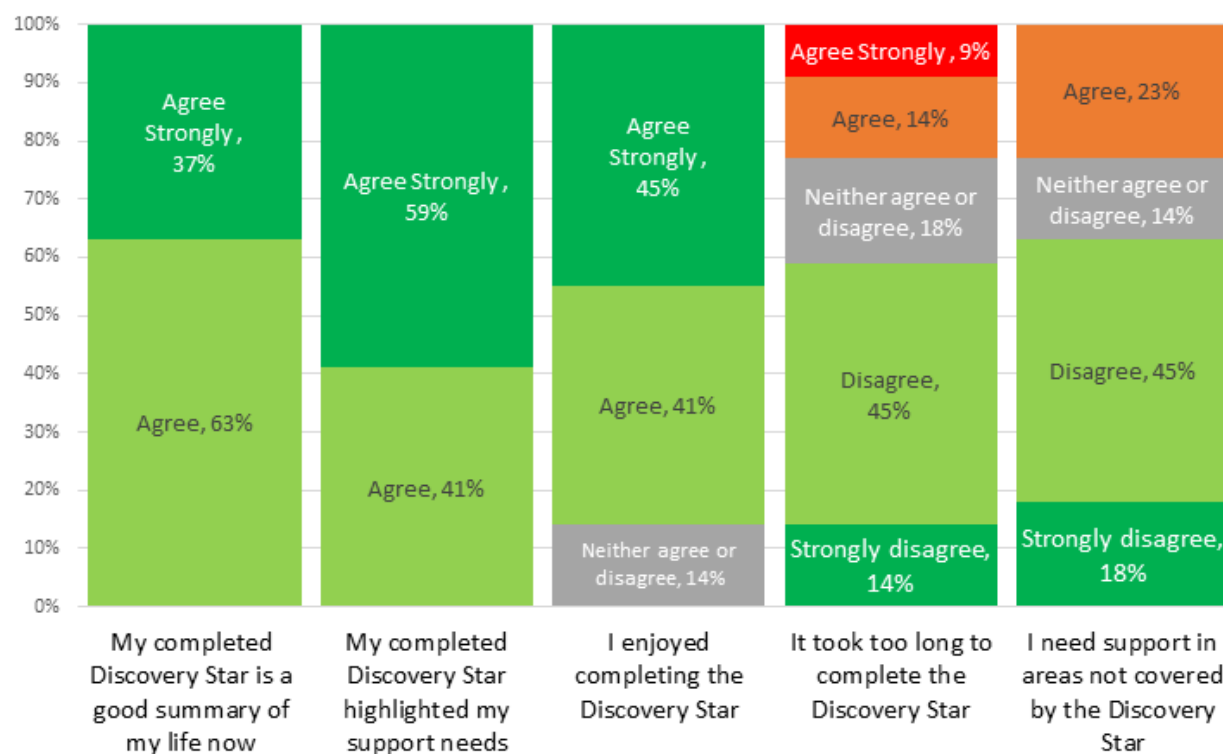
The pilot Discovery Star <b>Journey of Change</b>	<ol style="list-style-type: none"> <li>1. Crisis</li> <li>2. Taking it in</li> <li>3. Acceptance</li> <li>4. Discovering what works</li> <li>5. A fulfilling life</li> </ol>
The pilot Discovery Star <b>Outcome Areas</b>	<ol style="list-style-type: none"> <li>1. Daily living</li> <li>2. Pacing and priorities</li> <li>3. Managing symptoms</li> <li>4. Calming the body</li> <li>5. Responsibilities</li> <li>6. Family and friends</li> <li>7. Healthy lifestyle</li> <li>8. Emotional well-being</li> </ol>

### Stage 3: The pilot and revising the Star

Triangle trained practitioners in North Wales NHS Long Covid service to use the pilot Discovery Star, who then completed the Star with 318 patients during the pilot period. At the end of the pilot, Star readings were sent to Triangle for analyses of the psychometric properties of the pilot Star as well as feedback forms from 22 patients and 16 practitioners.



## Feedback from 22 patients



Six patients responded to questions about review readings, and the numbers selecting each answers were as follows:

- 'I found it encouraging to see the progress I made between Star readings': 'Neither agree or disagree' (2), 'Agree' (3), 'Strongly agree' (1).
- 'The Discovery Star did not reflect the progress I had made': 'Disagree' (4), 'Neither agree or disagree' (1), 'Agree' (1)

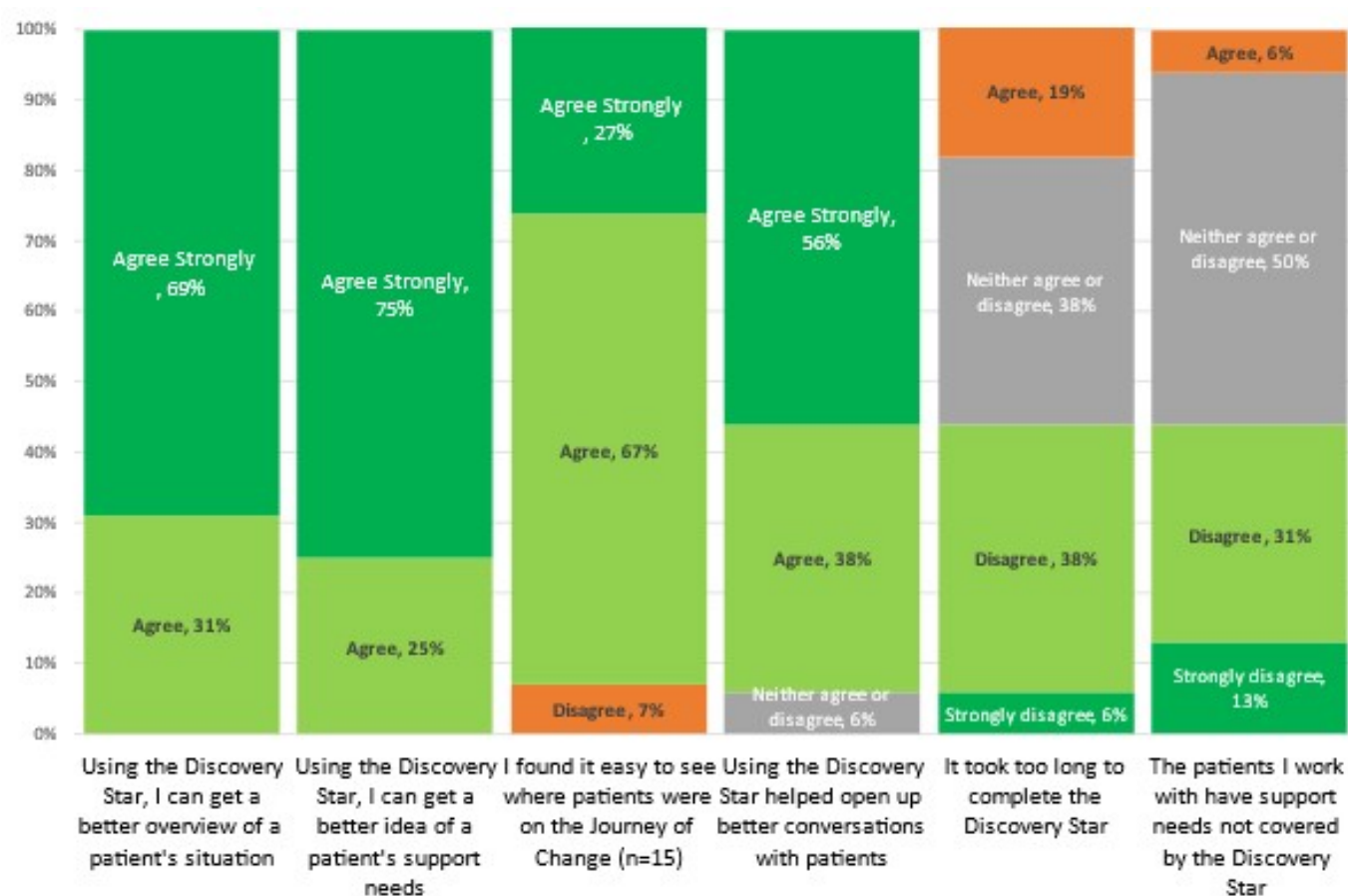
In terms, of qualitative feedback, there were a number of general *positive comments*:

- All positive and helped me see my needs and what I'm going through. Can't see anything negative.
- I think the Discovery Star covers mostly what's relevant.
- I was quite happy with everything, no further comments.
- Enjoyed it, speaking to a health professional as I tend to bottle things in.

- I liked that it showed I was tackling any problems I have and finding solutions to help myself and my long Covid. Little steps.
- Thinks it went well, nothing to compare it to.
- The Discovery Star is useful in focusing on all areas impacted by a long-term condition such as long Covid. It does provide a holistic overview and certainly helps to look at managing symptoms.
- The Discovery Star as a framework to use in support of those with long Covid IS beneficial. It helps highlight the different areas but can entail some explanation of descriptions. Using alongside the service's workshops is helpful and provides a greater understanding of the condition. Empathetic staff and a listening ear has been important
- and continues to be so. How this is delivered is key.

There was also one suggestion – to rename emotional well-being 'mental and emotional well-being'.

## Feedback from 16 practitioners



Six practitioners responded to questions about review readings and the numbers selecting each answers were as follows:

- 'The Discovery Star reflected changes service users made': Agree' (3), 'Agree strongly' (3)
- 'I found it encouraging to see the progress that service users made between Star readings': 'Agree' (2), 'Agree strongly' (4)

*Practitioners also gave the following feedback:*

### **General positive feedback**

- It allows open conversations with others and provides an opportunity to think about aspects of their lives we have perhaps not thought about. Overall, I think the Discovery Star is a very useful tool to help support patients make sense of their situation and move forward.
- By making sure to discuss each Journey of Change it ensures nothing important is missed out and helps layout the conversation with the service user (I found that some things that were not covered/ missed during the initial assessment were covered in the

Discovery Star). It was really helpful to create SMART goals with the service user and I could tell it helped them feel more positive/ hopeful for the future and gave them something to think about before starting the Discovery Programme. I really like how collaborative it is and its layout and user guide made the whole process simple and quick.

- I feel it gives a more complete picture of the patient. It also helps the patient identify areas where they can work on to improve their symptom management.
- It's pretty fab to be fair. Collaborative focus, co-production emphasis in its genesis. Flexibility of focus.
- I like how much the Discovery Star covers - it helps the person to explore each area and think about what support is needed moving forwards.
- I think the Discovery Star provides an excellent opportunity to collaboratively work with patients to help them identify needs and set goals. It is very visual so patients can pinpoint at what stage they are in their recovery. I also like the way it plots progress between stars.
- I find the Discovery Star very comprehensive, I think it provides a good snapshot of the service user's circumstances and helps us identify areas of strength and barriers to implementing certain strategies such as pacing. I think a lot of people also resonate with the Journey of Change, which can help make the Discovery Star a positive experience as they reflect on their quality of life rather than focusing purely on symptom reduction as a goal.
- It is laid out well and easy to use. It covers pretty much every aspect of the affected areas, with lots of information to hand. It is nice to use the 10 point scale, as it helps the service user if they are unsure where they are on the journey of change to have a bit more freedom in each section.
- I did two versions of the Outcomes Star concurrently with one service user – It was really useful to talk in such depth with them and allowed them to reflect back on how bad things were for them and actually how far they've come. I thought it was a great way to prompt conversations on all aspects of someone's life and reflect on what they would like to change that they be impacting on their mood. It was also so lovely to see the service user realise how such a long way he'd come from when he was at his worst. I instantly noticed a positive change in his attitude and he was filled with hope.
- I like that though it looks very structured but it's actually easy to make it into a conversation and patients are usually very comfortable and open to the process. It's a good balance of giving time for patients to talk but also has structure to keep them on track and to ensure we get a good overview of their situation. The goal setting is also very effective as patients can see the links to their life and making goals at the end.
- Good tool to open up a conversation to patients.
- This gave me a better understanding of the patient's symptoms as well as areas to focus on when it comes to group interventions.

- When service users come in for the appointment, they can sometimes look at their life as a whole and can be overwhelming. What the Discovery Star does well is it breaks life down into more smaller changes. This allows service users to recognise that actually some aspects of their life are going well and then can identify areas that aren't going so well.
- Co-produced with patients, well thought out.

### **Suggested changes to the outcome areas**

- Calming the body: I felt 'calming the body' the most difficult to talk about as a standalone topic and felt it may be better linked in with 'emotional well-being'.
- Covering functional aspects/mobility might be a useful point on the Star alone.
- I think there is some overlap between some of the items of the Star, namely 'pacing and priorities', 'managing symptoms' and 'your lifestyle'. I find that we cover sleep twice – under 'pacing' and 'your lifestyle', also certain conditions come up twice – we discuss diagnostic tests and medication under 'managing symptoms', but they can also be relevant to 'your lifestyle', especially diabetes, sleep apnoea or any conditions affecting mobility.

### **Journey of Change stage names**

- I think the term '**living a fulfilling life**' could be changed – patients have reported they would prefer something along the lines of 'I am happy with that'.

### **The order of the outcome areas**

- 'Calming the body' and 'emotional well-being' are similar points of the Star and so I think it would be better to put those next to each other (rather than leaving emotional well-being to the end).
- The layout of the topics could benefit from being rearranged e.g. 'emotional well-being' would be better placed near 'calming the body'.
- Most patients want to do the Star starting at the top and going around clockwise. This tends to mean we end on 'emotional well-being' which can bring the mood down. I think having this in the middle would be better.
- Most service users opt to start at the top (daily living) and go clockwise, which leaves 'emotional well-being' as the last item to review. If this is something they struggle with, it is then difficult to finish the appointment on a positive note as they are still visibly upset even after finishing the Action Plan. I think it would help to place it somewhere in the middle, maybe around 'calming the body' or 'responsibilities', which would allow to

emphasise the physical nature of long Covid and build rapport with the service user while being able to finish the Discovery Star on a more positive (or at least less emotionally charged) note, such as with 'your lifestyle'.

- Also, as each area is often done in order it would be good to have 'emotional wellbeing' nearer the start as it often requires more time and focus and can't be rushed or cut short if you run out of time.

### **Resources**

- I think it might be useful to have more explanation of what each stage of the Journey of Change refers to on the worksheet – so that if the service user wants to keep a copy, they can recall what each stage means.

### **Differentiation between scale points**

- I liked using the 10-point scale as it allowed for more specific scaling - however, I struggled having to pick 1-5 and then further pick between 2 within that scale.

### **Recording risk**

- Sometimes conversations about risk would arise and there often wasn't the space and time in the Discovery Star to accommodate it.

## Taking too long

- The time spent completing the Discovery Star was quite long, but I think that was more to do with the service user as an individual, so I don't think that it is a reflection on the Star itself and will hopefully improve with regular use. I think having prompt questions to help clarify what each section is about may help service users decide where they are on the Journey of Change, as there is a lot of explanation into each section but it can be quite lengthy. There are shorter statements but again I think a question may help by asking the right things.
- We managed to complete the Journey of Change and Action Plan in one session, however, I felt that the majority of time is taken up getting familiar with the service user and their experience (especially because I hadn't spoken to this service user before). This left only a small amount of time to complete the Action Plan, which led to it feeling almost rushed at the end. I also feel like the session would benefit from having a break in-between the Journey of Change and Action Plan.
- Regarding the length of time it took to complete the Discovery Star – I felt it depended on the service user. Some did not engage well and therefore didn't take long to complete but some service users really engaged in the task and enjoyed reflecting so would go a lot over the time period.

## Psychometric analyses of the pilot Star data

Analyses of 318 first Star readings showed the following:

*Distribution:* Readings were normally distributed for all outcome areas apart from 'responsibilities' which was slightly skewed towards the top of the Journey of Change – but it should be borne in mind that some patients were completing first Stars when they had been in the service for some time (see Appendix).

*Homogeneity and item redundancy:* All correlations are all within the desired range of .3 and .7.

*Internal consistency:* Cronbach's alpha was .87 – above the threshold of .70, suggesting very good internal consistency.

*Factor structure:* A unidimensional factor structure was advised, with one factor explaining a good proportion of the variance (70%).

For an explanation of these tests please see: [www.outcomesstar.org.uk/wp-content/uploads/OS-Psychometric\\_Overview.pdf](http://www.outcomesstar.org.uk/wp-content/uploads/OS-Psychometric_Overview.pdf) Further research into the psychometric properties of the final published version of the Discovery Star was initiated following publication. For the latest information on this, please contact: [anna@triangleconsulting.co.uk](mailto:anna@triangleconsulting.co.uk).

## Stage 4: Revising and finalising the new Star

**Workshop 3 (July 2024):** The third workshop gathered further information needed to finalise the Discovery Star, resources, and guidance. The responses to specific questions about the Discovery Star, as well as decisions made are briefly summarised below.

*Is 'Crisis' the right name for the first Journey of Change stage – did the naming/descriptor explain the small number of patients with first readings at this stage?*

- There was general agreement and strong feedback that 'crisis' is the right word - from both patients and practitioners - it was good to recognise that this was where they were, names and validates their experience and it shows progress. We offered more neutral options such as 'Not yet able to respond' but they were rejected.
- The service uses the Star after initial assessment, before starting the group programme, so a patient may have had medication and an OT, and many will have moved beyond 'crisis' by the time they do the Star. However, other services may have more people doing a Star in crisis in at least some areas and a retrospective Star would show crisis.
- There was a useful discussion of the stage description – the kinaesthetic sense/ feeling is of being immobilised, overwhelmed, stuck, maybe panic-stricken, at breaking point, no answers - not able to start to move forward. Even if it doesn't feel like a crisis, that's a good description. Don't know where to turn.
- **The decision was to change the stage name to 'Crisis or overwhelm' and edit the description using the above.**

*Is 'Acceptance' the right name and sentiment for the second Journey of Change stage?*

- There was general agreement that this stage name and word is problematic and needs to be changed. However, people did recognise the stage as described (verbally) so it seemed to be about the language and the name not a change to the Journey of Change.
- One patient said 'I struggle with this word. What it means to me is way apart from what psychologists think.' There was a view that a psychologist might say they're doing well but doesn't have acceptance so it's a block that's not allowing them to move on. Also, acceptance feels continuous and ongoing.
- The essence of this stage is what acknowledgement makes possible - an openness to new ways, exploring new ideas, being open and ready to change. It unfreezes that sense of being immobilised/ stuck and enables people to start taking steps in spite of what's going on. More of a sense of control comes in. Whereas when people are not yet at this stage they might say, 'Until I get tests to show what's going on I am not moving forward'. One patient said 'If you don't have acceptance you struggle to try to be where you once were before which is not possible. It's about making different steps and choices'.



- The groups felt that the Star should avoid using 'open' or 'moving forward' as the opposite feels negative or blaming.
- **The decision was not to use 'Acceptance' as a name or in the description – and to change it to 'Acknowledging and exploring'.**

*Are any changes needed to the 'Discovering what works' stage?*

- The group noted that 'Adapting' felt like an important word to build into the description and that this stage should include having periods of being OK but these are not stable until stage 5. **Small edits were made to the descriptors, and the stage name was changed to 'Discovering'.**

*Are any changes needed to the 'A fulfilling life' stage?*

- It was felt that 'fulfilling life' sounded too holistic – the whole of life rather than the scale under discussion – and agreed it needed to be changed. However, people identified with the long description. We suggested 'Finding fulfilment' and this was well received. There was feedback that it felt more realistic and makes it a process not an end point - it's not the best it can be as there's always hope it can be better.
- 'Managing or coping well' were discussed and some liked it 'You're never going to get back to how you were, you are managing with it'. One practitioner said, 'the feedback I get is more 'managing' or 'being okay with it' or 'good enough' – not specific enough to this Star/ journey or sufficiently aspirational but build into stage descriptor more'.  
*Female patient – 'I'm finding fulfilment in different places. Like learning to crochet, or I've started painting which I never would have dreamt of before. Or I learn to cook something new for my family.'*  
*Male patient – 'I've moved house and now I'm doing gardening in short spurts. My life has changed, I am finding fulfilment in what I do. I am missing the workplace though.'*
- The group felt that at this stage things are sustainable – not fleeting, relative stability. There's confidence that they can adapt to changes with the tools they need and overcome obstacles. **The decision was to build that more into the description, along with enjoyment.**
- **There was a decision to change to 'Finding fulfilment'** and to take the word 'recovery' out of this stage and the whole Star (this term was avoided by the collaborator).

*Are any changes needed to the 'Managing symptoms' outcome area?*

- There were reports of difficulties assigning readings as the area combined severity of symptoms and management of them. **It was agreed to remove any reference to 'strong' symptoms/ symptom severity or improvement in symptoms to have a clear focus on how well people are managing symptoms.**
- **Changes to the descriptors/ things to ensure are emphasised for this area at each stage:**

'Crisis' is about being overwhelmed by symptoms.

'Taking it in' is about starting to make sense of them.

'Acceptance' doesn't work as it implies accepting there isn't a medical cure, where they do still hope there may be one (the change to 'Acknowledging and exploring' solves this).

'Discovering what works' - change 'medical or other advice' to 'health professionals' advice (the collaborators try not to overly focus on medical).

'Finding fulfilment' – change the bold statement to 'At the moment I manage any symptoms well'/ 'I am managing any symptoms at the moment' - mostly people still have lots of symptoms.

*Are any changes needed to the 'Responsibilities' outcome area?*

- It was reported that people can find it shaming to acknowledge that they don't/ can't meet their responsibilities – even more so when that means not being able to care for their children – leading to more people placing themselves in stages 4-5.
- There was concern that some of the language is blaming and that the intersection between responsibilities, identity and values needs to be considered. People want to be reliable and responsible, and their identity may be tied into that to such an extent that they prioritise this above their own health to the detriment of themselves. We need to ensure the Star language doesn't imply that people are not doing enough/ good enough and can support discussions on choices and potentially the need to prioritise self-care over meeting responsibilities.
- **The scale name was changed to 'Roles and responsibilities'.**
- **The language in the first Journey of Change stage was changed so it no longer stated 'I'm not meeting my responsibilities'.**

*Are any changes needed to the 'Calming the body' outcome area?*

- There were some comments in the feedback forms and in the room were that this scale was hard to discuss and suggestions to combine it with 'Emotional well-being' or broaden to self-care. However, those leading the service, Triangle and some practitioners and patients emphasised that this area is the key to the Star and to managing or improving long Covid and other conditions.

- We concluded that problems with this scale in the pilot Star are largely due to attempts to make a specific, technical area accessible, leading to language and a scale name lacking in specificity.
- **The suggestion to change the name to 'Nervous system regulation' was followed, as well as to use technical language and be specific to explain what it is about in the detailed scale introduction.** One patient said this language would feel more validating to them, that they could be treated more seriously and professionally.

*Are any changes needed to the 'Family and friends' outcome area?*

- This scale had a high proportion of people at stages 4-5 and where the feedback was that people tend to place themselves higher out of loyalty to their partner or to close friends and family, and because they were supportive, but the condition was having a detrimental effect on the relationship. **There was a decision to remove references to being supported by family and friends and make the focus more clearly about the aspect that is the impact of long Covid/ fatigue on relationships and about how people can mitigate the impact.**

*Are any changes needed to the 'Pacing and priorities' outcome area?*

- Based on feedback the decision was taken to **change the bold statement in the first stage from 'I keep getting exhausted' as this can continue throughout the Journey of Change – to reflect the situation of being overwhelmed by exhaustion and struggling to take in what's happening/manage it.**
- **At Stage 5 we needed to ensure it was clear that someone may still get exhausted but can manage it.**

*Are any changes needed to the 'Healthy lifestyle' outcome area?*

- **Following feedback, we decided to change the word 'exercise' to 'activity' – which is used in services and sounds more achievable. We also changed the name of the outcome area to 'Your lifestyle' to avoid potentially different interpretations of the word healthy.**
- There was some discussion about the reference to 'avoiding unhealthy habits', as potentially subjective and blaming. One practitioner gave an example of how this could be interpreted as e.g. eating microwave meals. The intention is more about avoiding drinking too much alcohol or using drugs – **we decided to make the wording both clearer and softer.**

The final Discovery Star  
**Journey of Change**

1. Crisis or overwhelm
2. Taking it in
3. Acknowledging and exploring
4. Discovering
5. Finding fulfilment

The final Discovery Star  
**Outcome Areas**

1. Pacing and priorities
2. Daily living
3. Roles and responsibilities
4. Family and friends
5. Emotional well-being
6. Nervous system regulation
7. Your lifestyle
8. Managing symptoms

## 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.

## References

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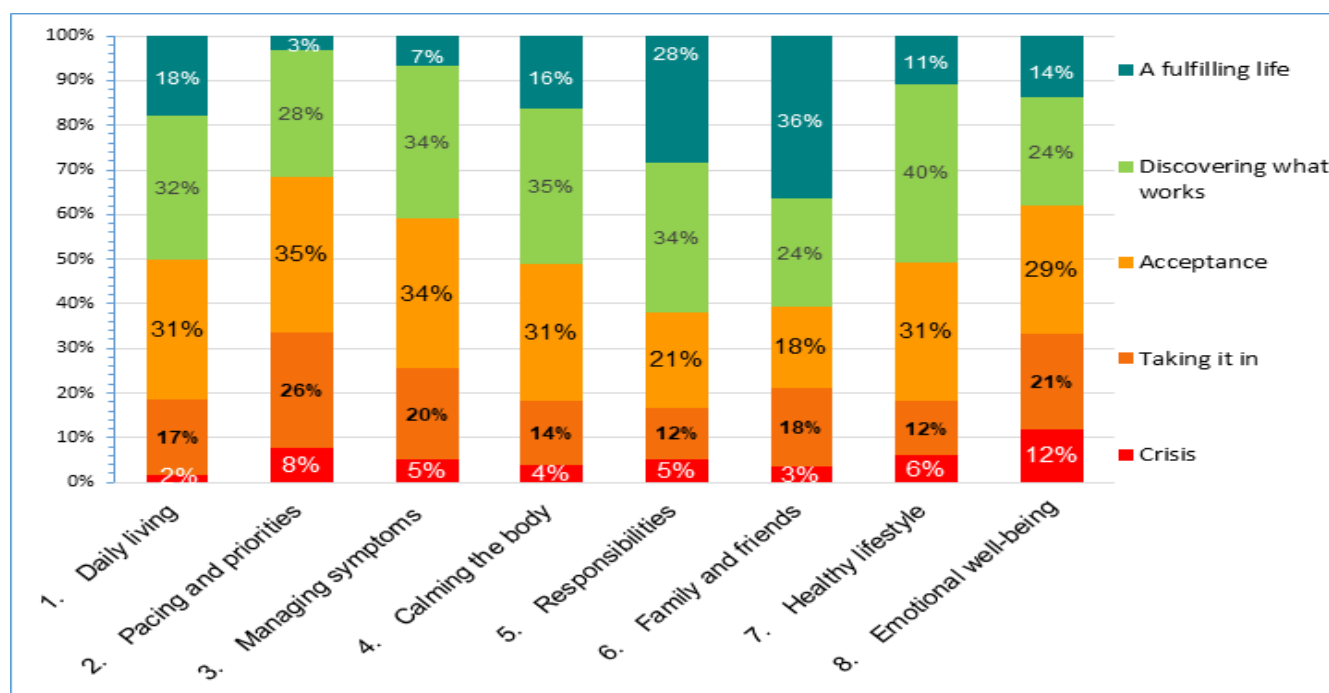
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## Appendix: Details of the psychometric properties of the pilot Discovery Star™

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



	Skewness statistic	Result
Daily living	-.08	Normally distributed
Pacing and priorities	-.14	Normally distributed
Managing symptoms	-.09	Normally distributed
Calming the body	-.28	Normally distributed
Responsibilities	-.53	Moderately skewed
Family and friends	-.43	Normally distributed
Your lifestyle	-.42	Normally distributed
Emotional well-being	-.04	Normally distributed

Less than -1 or greater than 1 = highly skewed. -1 to -0.5 or between 0.5 and 1 = moderately skewed. -0.5 to 0.5 = normal

### 3.1 Pearson correlation matrix

Correlations were all within the desired range of .3 and .7.

	Outcome area number						
	2	3	4	5	6	7	8
1 Daily living	.51	.52	.38	.51	.43	.52	.45
2 Pacing and priorities	-	.56	.49	.47	.44	.43	.53
3 Managing symptoms		-	.44	.38	.43	.42	.48
4 Calming the body			-	.39	.36	.35	.50
4 Responsibilities				-	.36	.35	.50
5 Family and friends					-	.47	.48
6 Your lifestyle						-	.53
7 Emotional well-being							-

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