

OUTCOMES STAR

My Brain Star™

The Outcomes Star for life after a brain injury

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Please contact info@outcomesstar.org to enquire about buying a licence and training.

About Outcomes Star™

This Star is part of a family of Outcomes Star tools. Each tool includes a Star Chart, User Guide and Guidance for Practitioners and some have visual and other resources. For other versions of the Outcomes Star, good practice and further information see www.outcomesstar.org.uk

Acknowledgements

Between 2003 and 2023, Joy MacKeith and Sara Burns co-created the Outcomes Star, authored over 50 versions, and founded Triangle to support their development, validation and implementation in the UK and around the world. We are grateful for their vital contribution.

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Contents

Introduction	3
The Outcomes Star tools	3
My Brain Star	4
Development process for My Brain Star™	4
Methodology	4
Stage 1. Exploring the scope and need for the tool	5
Stage 2: Creating the pilot version of the new Star with the expert working group	5
Stage 3: The pilot and revising the Star	7
Stage 4: Revising and finalising the new Star	30
References	33
Appendix: Details of the psychometric properties of the pilot My Brain Star™	34

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 measurement¹. 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 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

¹The 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.

- 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 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

My Brain Star

My Brain Star is the Outcomes Star designed to support people who are recovering following a brain injury – perhaps due to an accident, stroke, brain tumour, aneurysm or other cause. My Brain Star is intended for use where there is holistic one-to-one support for recovery or improvement after brain injury. It is designed to be completed after any initial acute hospital phase is over.

It includes the following resources:

- *My Brain Star Chart, Notes and Action Plan*
- *My Brain Star User Guide*, with brief visual scales and detailed scales
- *Short illustrated Scales*
- *Flashcards*
- *Guidance for practitioners* completing My Brain Star collaboratively with the people they are supporting
- Star Online – a web application for online completion and analysis at www.staronline.org.uk

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

Development process for My Brain 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 My Brain Star.

Stage 1. Exploring the scope and need for the tool

Headway approached Outcomes Star to develop a new version of the Star for people recovering from a brain injury. We then carried out a scoping process, involving:

- A market scoping to assess the likely uptake of a Star in this area
- Checking prior interest and enquiries from other services for a similar or the same version
- An exploratory literature review examining the possible outcome areas.

As with any new version of the Star, this phase also included scoping the capacity for both Outcomes Star and the collaborators to undertake the development within the budget and timescale needed. Based on this, the 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 Headway managers, rehabilitation co-ordinators, trustees, staff with lived experience and people being supported by Headway. This expert group played a central role in the development process, providing in-depth knowledge of the issues faced by people with an acquired brain injury, 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, Outcomes Star formed an internal reference group, which met to review changes.

Workshop 1 (September 2023): This workshop was held to identify intended outcomes and processes of change in work supporting people with an acquired brain injury. It included a series of sessions to provide insight into the experiences of practitioners and service users and to understand the outcomes that services support people 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 discussing 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.

The Outcomes Star team 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 My Brain Star were developed. These were then used as an outline or 'skeleton', from which the first draft of My Brain 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 and service user group (November 2023): A one-day workshop was held to present the first draft of My Brain Star to the expert working group and to hear feedback to inform the pilot version of the Star. In addition, a separate focus group was held to hear feedback from seven service users, two volunteers and two rehabilitation assistants. Based on this feedback and the other activities listed above, the early draft was refined to create a pilot version of My Brain Star with the Journey of Change and outcome areas listed below:

The pilot My Brain Star
Journey of Change

1. Things are not OK
2. Getting help
3. Exploring new ways
4. Finding what works
5. Finding fulfilment

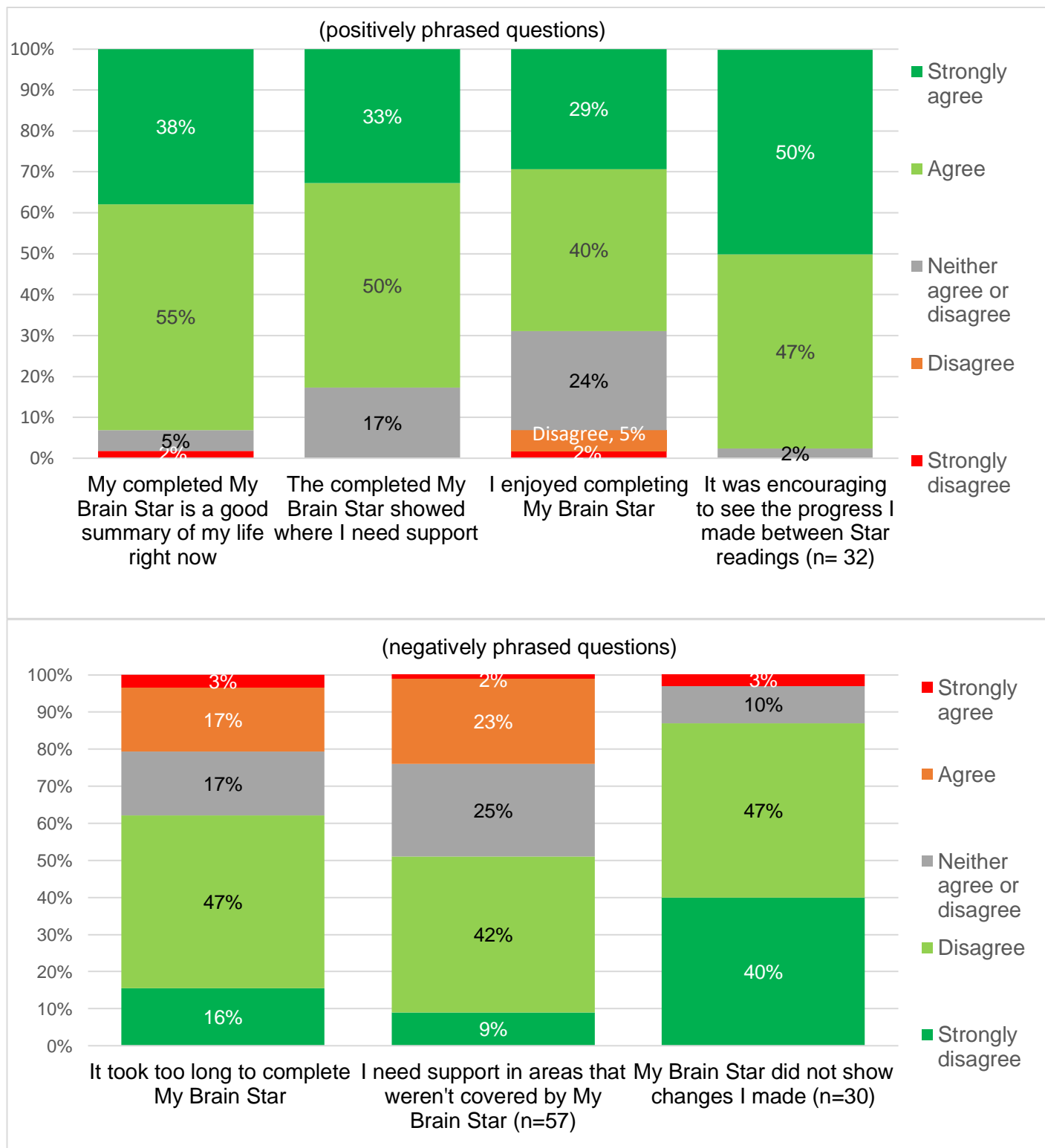
The pilot My Brain Star
Outcome Areas

1. My thinking skills
2. My daily life
3. Communication and social skills
4. My safety
5. Social and support networks
6. How I spend my time
7. My physical health
8. How I feel

Stage 3: The pilot and revising the Star

The Outcomes Star team trained Headway practitioners to use the pilot My Brain Star, who then completed the Star with 136 service users during the pilot period. At the end of the pilot, Star readings were sent to Outcomes Star for analysis of the psychometric properties of the pilot Star as well as feedback forms from 58 service users and 17 practitioners.

Feedback from 58 service users



Service users also gave the following feedback:

General positive feedback

- *I really enjoyed doing this. It felt it was about me as a person for once, not just a patient with symptoms. Often the term 'the new you' is used – this felt like 'the real you' because it was about how I actually feel about me and the life I am now living*
- *Enjoyed the moment of reveal to show how much progress I have made – in Olympics week I felt like I'd won a gold medal*
- *I am struggling to cope with my brain injury and I sometimes feel that I am not really making any progress. But some things on the Star are OK and I can see what I can do to improve. I also liked being able to discuss it properly*
- *Doing the Outcomes Star helped me set my goals and along with my caseworker break down what I needed to do, step by step to achieve a good result and change my life for the better*
- *For the Star I liked how many areas that it covered and it really related to me with my head injury. I also liked that we chunked up the time to go through this and didn't do it all in one sitting as that would have been very hard*
- *Due to my visual problems, having the Star to look at was very helpful, rather than the writing*
- *It's a very useful and easy to view graphic showing how far we've come along. Maybe we could provide this to people starting on their journey, but provide useful websites, support groups where people select a 1 or 2 response (i.e. give proactive help)*
- *I liked the visual picture of the Star. I liked the gap between the two My Brain Stars because it gave me the opportunity to see what worked and what didn't, and I could think of goals in the second Star. I loved seeing how far I've come; it really surprised me how much progress I have made. It gave me the confidence to try new goals and plans and look forward to my progress in the future. I am very impressed with myself*
- *Like the visual aspect of seeing my improvements and I can see how much I have improved. Prior to this I had no understanding of my improvements*
- *I liked being able to have a 1:1 chat and speak freely*
- *I think having a review will help me. I know I need help with identifying what I need and how to say it*
- *It helped see where people may need more help in life*

- *Completing it is fine, it is not too intrusive*
- *It was alright, and covered everything important happening in my life right now*
- *Good to see areas for improvement*
- *I liked everything – chance to think and see how well I am doing*
- *I liked the fact that I could see my improvement over the last four years*
- *I liked the visual Star of where I was/where I am now*
- *I enjoyed the visual of the Star. I enjoyed the support from (the practitioner) to go through and explain and support me*
- *Really helpful. Glad I did this*
- *I feel good when I see my progress on the Star*
- *I really liked seeing the progress I had made. The questions were easy to follow, and I liked being able to check my understanding using the flash cards*
- *Not sure – I don't mind it*
- *It helps you to see positive progress and moving forward*
- *It was a very positive experience. It showed me the areas that I still need to work on but was very encouraging to see what I had achieved and how far I have come in other areas*
- *It was an interesting exercise and very good not to have to use medical terms or diagnoses*
- *It was important to understand my key points of my brain injury in my life*
- *It's perfect & covered everything*
- *Liked: colour system was relatable – good visual display*
- *Very helpful to highlight for myself to take a good look at where I am regarding my TBI and to focus on where I need support and help with recovery*
- *The detail in the My Brain Star gives me a solid foundation to make progress. We talked in short steps one Star point at a time this gave me the time I needed to answer and reflect upon next steps*

- *The flashcards are helpful. Completed, the Star helped me to look at what goals to work towards and areas that needed support*
- *The Star helped me understand what I could do. I'm fine with the Star the way it is*
- *The value of My Brain Star is the conversation that takes place between those involved = ideas and thoughts and shared experiences lead to new actions*

Different issues covered in the same area

- *Sometimes I found it difficult to score the categories because it was too general. I struggle with some elements, but I am independent in others. The score did not capture it fully. For example, in the 'my daily life' category I would be a 3 or 4 for personal care but 2 in shopping, cooking and cleaning because of fatigue*
- *I felt too many things were in each category so difficult to have a meaningful 'average' score in many*
- *Only part of each card – some overlap made it difficult to decide*

Comments on the Journey of Change

- *Levels 2/3 were too similar to each other*
- *Some were a combination of one or two*
- *Some of the wording in the questions could be clearer as some of the scores are very similar and have cross over*
- *I don't think anyone could be a 5 – no-one can be perfect, always room for improvement*

Time and energy to complete and complexity of language

- *I think doing this with a head injury is difficult and chunking it up really did help, however there is still a lot of reading and information to process and I don't know if there is any way to put this in other formats (e.g. audio) to reduce the processing power our brains need to use given that is limited for us*
- *It took too long*
- *I did find it took a long time to complete*
- *It is time consuming when I only attend Headway for a morning*

- *Completing the Star was confusing/tiring and I didn't feel the numbers really showed what my life is like*
- *Time, time, time = you need lots of time to construct the Stars. The sessions should be bitesize to combat tiredness and fatigue*
- *Make wording simplified, easier to understand*
- *On my first Star I found it difficult to think of goals or plans. Everything was overwhelming. In the beginning I was too anxious to listen to suggestions or advice*
- *I struggle to remember what I've done. I don't remember the Star well. Staff had to tell me and show me what we spoke about.*

Comments on it being upsetting

- *It was sometimes upsetting – with the realisation of what I have lost/been through etc.*
- *I could see where I progressed, although it also showed where I believed I had not improved and I found this difficult*
- *Doing My Brain Star brought back some memories I would rather forget*

Suggestions for specific outcome areas

- *I have considered an extra Star point which I am calling Orientation (which is related to how I choose the actions = prioritise)*
- *Could include something about education on brain injury*

Communication skills:

- *Some categories were too general. For example, in 'Communication' I would score 4 but 1 or 2 in person*
- *The communication skills did not really give enough depth to convey how difficult communication is and I'd like more options for speech vs writing vs reading. I can read but speech is very limited*

Daily life:

- *In 'Daily life', 'self-care' is used – 'personal care' more common term in Scotland social care etc.*

How I feel:

- *'How I feel' – more emphasis needed on specific mental health, especially as the brain injured much more likely to suffer serious depression*
- *Talk about mental health more. Set more targets*

My physical health:

- *I never 'feel ok physically' (term used in 'My physical health') = I have brain injury caused by chronic fatigue*

Suggestions for the wording

- *I didn't like the wording of some of the questions – i.e. accept how I am now / spend my time/ physically – prefer another word – i.e. live with*
- *Wording needs to be different – I have not accepted how my daily life is I but have reconciled how it is now*

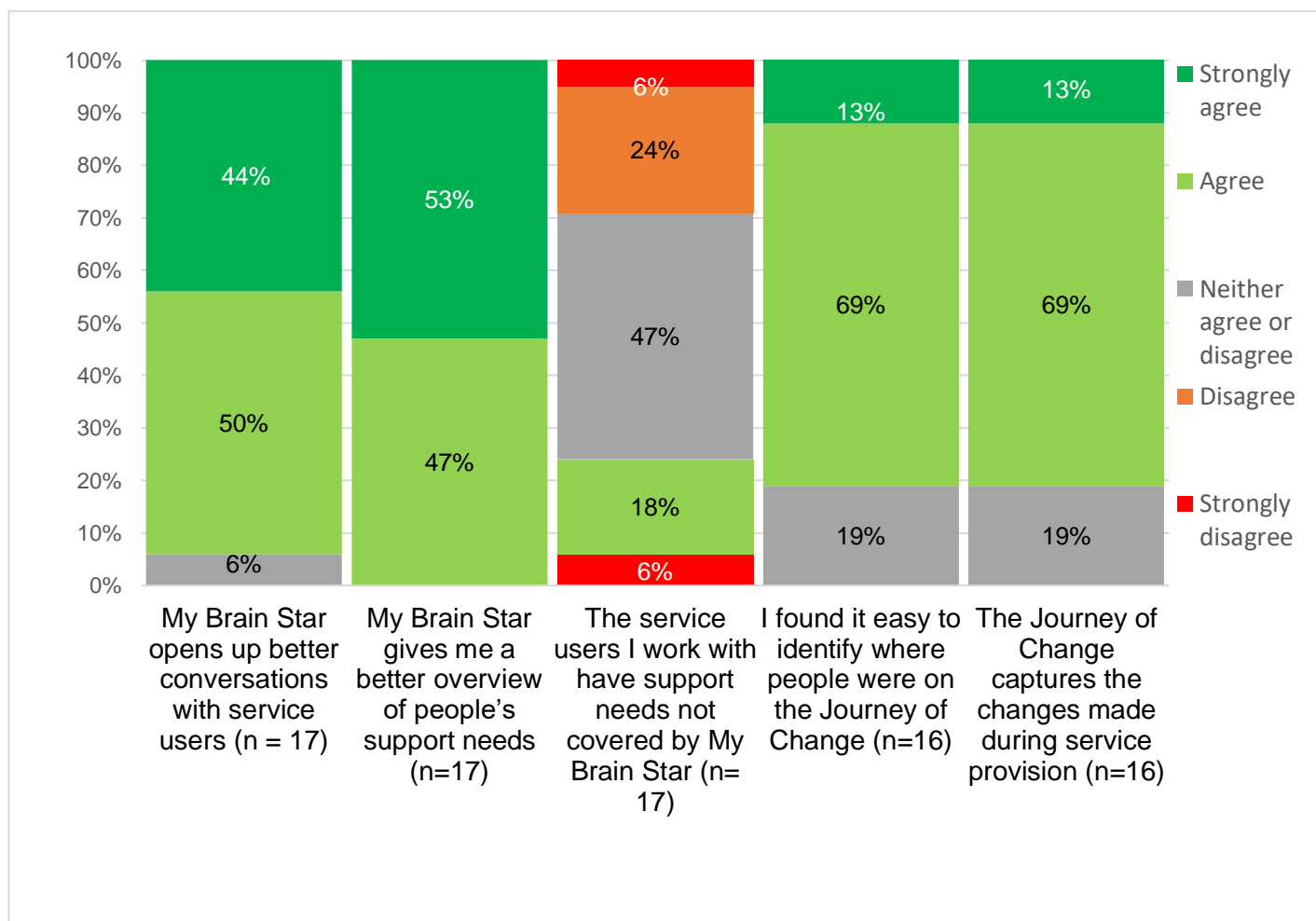
Colours/accessibility

- *Text should be black and white for ease of reading*

Other feedback

- *It's OK – not much different to Headway's reviews. The Star is fun but doesn't make a difference*
- *There was just one question with regard to how I felt four years ago, for which none of the options were relevant*

Feedback from 17 practitioners



Practitioners also gave the following feedback:

General positive feedback and answers to 'What works well with My Brain Star?'

- *I feel that the My Brain Star will be a very effective and evidence-based tool to support clients to progress in their rehabilitation over the long term. The clients who participated in the retrospective and review Star showed progress that clients could relate to, and it gave the clients a sense of achievement*
- *Once I got going, I was really inspired by it to see that we can make our individualised support far more structured and manageable than it currently is!*
- *Clients could identify easier where they felt they are on the journey. The 5 points gave clients a good range of where they feel they are on their journey*

- *The Flashcards were a superb resource – the descriptors cover most options and are worded well to let clients choose them without feeling they are ‘fixed’ if they choose a 5 – it allows for ‘good enough’ and ‘well enough’ etc which was appreciated by most*
- *On the whole, covers everything*
- *Covers all aspects and opened up conversations well*
- *Overall, it is a nice measurable tool to use within the service and clients valued the conversations the Star had opened up*
- *I enjoyed the ease of the format as I was able to use it without the need of using any of the additional material provided. I think if I was to use the supporting material it would make the process a lot longer*
- *The visual element – the images of the person in the hole was very powerful and helped most make a definitive and clear decision about the stage they felt they were at – without that they would have struggled and felt confused*
- *Clients felt that the assessment was a collaboration – they were being heard. The opportunity to discuss sensitive topics such as risk-taking behaviours, financial matters and relationships in a non-threatening way, i.e. using the Flashcards, clients could see these topics were part of an overall assessment and not directed at them personally. The resources made the assessment easy for clients to follow and complete at their own pace. Clients were able to stop and return to it later if necessary*
- *The Star itself is a good visual aid and potentially could boost someone’s confidence when they see the changes on the scales. However, I think this is for someone new to the service rather than an individual who has been with the service for many years*
- *Covers all aspects of their life and structures and focuses them well for staff and service users. Good tool for action planning*
- *Starting conversations, working collaboratively for solutions, getting a deeper understanding of the person’s needs*
- *The eight themed areas of reflection are relevant to my service. I liked the Scales and used them with all my clients, and I found them user-friendly and less confusing than sitting with a Star sheet. As they clearly define the difference between the individual number in each area helping the participant to reflect where they are on the scale*
- *The Flashcards worked well with clients. It gives staff a good understanding of the areas the clients are struggling with and how to support them to move forward/how they want to be supported*
- *Fairly easy to follow with diagrammatic form*

- *It gives us an easy measure of change over time*
- *It opens conversation! The Flashcards were brilliant in terms of assisting clients with their memory*
- *The visual aspect of being able to see what stage a person is at any point on the Star*
- *The statements attached to each Scale helped if they weren't sure, but these weren't always needed – I used it to clarify and sum up once they had made their decision – on only a few occasions someone changed their mind. They were all quite long-standing clients who I know well; they were very honest and showed good awareness and all were very satisfied with the process and felt empowered. I didn't have a situation where I disagreed – so can't comment on how it works with those who have lack of insight but the opportunity to record a service user and a practitioner level would appear to address this issue if it arises*
- *The live completion was brilliant - I found the process easy to navigate and empowering for the clients – they felt this too*
- *The 'reveal' of the completed Star was quite an event! It demonstrates clearly the connection between how they spend their time and how they feel – pointing this out helped some to make statements of intent about how they would like this to change*
- *Clients responded well to the visual impact of the outcomes represented, particularly as the scoring indicated their strengths as well as their 'weaknesses'. As we worked through the My Brain Star clients often commented that they were surprised at the number of areas where they were doing better than they initially thought*
- *It opens up a conversation on key issues in a structured way*
- *It is the constructed conversation between user and practitioner that delivers a detailed focus on the actions to be taken to achieve the goal on moving along the Star profile. The visual Star is a good way for the user to see the progress they are making - if you know where you are that's powerful to set the actions and goals to take place*
- *My Brain Star is a comprehensive review of our service users and is formatted in a way that allows them to easily see the progress they are making. Our service users report that they find the Star engaging and much more easily accessible than previous models. Having an online reporting system also makes it easier for practitioners to monitor their client's progress*

What could be improved about My Brain Star?

Time consuming and demanding for the service user group

- *The length of time it takes to complete the Star. Sometimes you have to keep going over aspects for people to be able to understand it - due to the nature of the Star and clients, this can be demanding, hard and very time-consuming*
- *Takes too long to complete and needs to be done over a few sessions for most service users. Difficulty fitting it in with members' activities and staff availability*
- *The Outcomes Star can take a while to complete, and some clients only attend for a half day which probably means them missing most of the session. This does depend on the client you are supporting to complete the Star with because some clients who have a good understanding of how their ABI has impacted their lives complete the Star easier taking less time*
- *I think the clients I worked with struggled to understand the Journey of Change ratings at times*
- *The Scales were a little confusing to service users at first and required effort on my part to explain 4 and 5. People were actively choosing to put themselves on 4 with the idea that you can't be good at everything. This was something that I had to explain a few times and it made me mindful with the other reviews I did afterwards*
- *While I understood the Journey of Change and it worked well for me, I think for clients it was a lot to consider, as well as all aspects within priority areas*
- *It can be very time consuming and fatiguing for clients because of this, often requiring My Brain Star to be completed within steps*

Reduce repetition

- *There is repetition within their answers for different aspects*
- *I also found a lot of the Stars very repetitive with the choices, particularly if you are just reading directly from the Star and not using any additional material*

How I feel area

- *Re-focus some areas, e.g. expand mental health*
- *Some clients felt the descriptions of what was happening for them to be able to choose a particular level didn't always fit – some felt (when completing a retrospective Star) that they would have chosen a level 0 if it were possible – level 1 didn't always describe enough how bad things were, especially in the 'How I feel' section*

How I spend my time

- *Re-focus some areas, e.g. expand work and volunteering, e.g. ability to enter/remain in the labour market*

New things to include

- *I feel we somewhere need to include vision and hearing as a few Stars I completed were influenced by poor vision and hearing*
- *Possibly including insight and perception, as this can impact the whole view of My Brain Star*

Name of final stage

- *Stage 5 'Finding fulfilment' I would be tempted to use the phrase actualisation (like the Maslow's hierarchy of needs)*

Colours

- *My thoughts on this are based on the Star is a system for creating change and closing gaps. I would say it's a traffic light system red to green and the 5 stages need defining colours 1 darker shade of red, 2 red, 3 yellow, 4 orange, 5 green*
- *When scoring, most of my clients tended to prefer numbers rather than the colours. They saw the numbering system as a way to check their progress. The colours were more useful when inputting on the Star as they found it easier to draw a line from category to category*

Feedback on the Journey of Change

- *Maybe use a 10-point Journey of Change?*
- *I have a concern regarding change - the system seems to use a large measure to identify change. In reality, the journey through a stage can be small steps that collectively indicate notable change. I believe bitesize stepping stones in the change zone are more effective and confidence boosting for the client*

Name of final stage

- *'Finding fulfilment' left my candidates a bit cold. They liked 'Got as good as it gets' but still trying*

Different issues covered in the same area

- *Each Star point is multifactorial, so their journey may remain the same on review but for different reasons. So, any progression may only be shown in the notes written rather than on the actual Star e.g. in My Physical Health their mobility may have improved a lot but then it may have had an impact on their levels of fatigue, so the position in their journey is unchanged. Some service users still saw it as a number scale*

- *Many of my assessments struggled with the Journey of Change. Each point on the Star had so many elements it was hard to decide which bit to rate on*
- *For some clients it was clear where they were on the Journey of Change, others struggled because they may be at a 3 or 4 or in one area but a 2 in others in the same category. For example, in 'My daily life' category one client scored themselves a 4 on self-care and cooking and cleaning but 2 for money, paperwork and shopping. This was frustrating for them*

Readings perceived as an indicator of self-worth / upsetting

- *Some ABI-experienced individuals focused on the 'score' and perceived self-worth rather than the dynamic nature and personalised aspect of the placement*
- *A few members found it hard as it brought back memories they would rather forget - this in turn left them deflated even when they could see how much they had come on over time*

My thinking skills

- *Many were confused - some had significant issues with memory but fine with attention- so overall score seemed vague*
- *Can be problematic if person ponders on where they were pre brain injury - many members found it hard dealing with where they were now and needed reassurance on this matter*
- *Clients were able to group these topics together easily in this category, Score between 2 and 3 needed the most verbal explanations and examples. Fatigue was reported as being an important factor, particularly the impact on memory*
- *I feel like this title could be changed. Most of my service users needed this one explained to them and then still found it confusing*
- *This works well, all service users highlighted this as an area in which they would like to see improvements as their brain injuries have affected them with memory, attention and problem solving. As I have expressed before, our service already looks at this outcome area in our current reviews.*
- *Seemed to be generally accepted as relevant in current form*

My daily life

- *Wording on this one in particular was difficult - members have not/will not accept how life is now - reconciled/put up with etc. Also brought back memories they did not want to revisit*
- *Self-care used whereas personal care more commonly used in Scotland*
- *Hard to rate difference between what the service user could do and what they had help for*
- *Useful outcome to include. Gives an insight in to an individual's day to day life*
- *Worked well*
- *Generally, no difficulties scoring self-care, shopping, cooking and cleaning. Often found money and paperwork more challenging. Fatigue was also discussed in this category*
- *Sensitivity to the approach is very important (non-threatening)*

Communication and social skills

- *A very wide range of issues in one 'arm' e.g. social situations may be avoided but the person is very conversational - may be the noise factor*
- *Many 'managed' with poor communication. Doctors have said no more improvement so rated as 5 even though they clearly have significant problems*
- *If people have communication issues you may not fully get whole picture as family/ support etc may vary from what member actually wants.*
- *Additional verbal explanations and examples required. Clients report following conversations -particularly in groups can be exhausting. Fatigue mentioned*
- *If a client has communication issues, recoding and capturing what is being said can be difficult*
- *Useful outcome – many service users have expressed an interest in improving communication and social skills post brain injury*
- *Worked well*

My Safety

- *Clients found this section a bit more difficult*

- *Most were clear on this - but many are totally dependent on others - I would have liked to show this*
- *Overall member accepted they may have safety issues but were reluctant to admit this at first*
- *Users commented that some issues can predate the ABI and affect the general population*
- *This is an outcome area which is not currently used in our review process and one that is worth implementing. When speaking with individuals it highlighted worries of online safety, telephone scams and safety in the home*
- *Topic area worked well - positive feedback from clients*

Social and support networks

- *Fatigue was commented as being a factor affecting friendships and family connections. Not recognised as its hidden or misunderstood*
- *Lots of discussion over the meaning of 'belonging'. Often user saw belonging to be membership of Headway Glasgow*
- *Worked well for both self and member to see what was missing/working for the individual*
- *Useful outcome. Helping individuals connect with others*
- *Worked well*
- *This was clear to use*

How I spend my time

- *Second most contentious area – we have many users who still work or wish to re-enter labour market and felt it was very under-represented*
- *The concept of volunteering could be added to the descriptors at Level 3 – it states gardening, housework etc or work as 2 quite extreme ends of the scale – volunteering as an option in here would make the jump less stark – maybe even instead of work which many of our clients aren't doing at level 3*
- *Useful outcome – helps to think of ideas of things to do if an individual gets bored or lonely at home*
- *Worked well*

- *This was clear to use*
- *Worked well – made it easier to fill in any support required*

My physical health

- *These are four major aspects within one point here and each one can affect the other, so maybe difficult to track progress. Their physical health may also be affected by health issues unrelated to their brain injury*
- *This was complicated for some – as while they had been stable in physical health, it was far from ideal. Most has significant problems in some ways, but it could not show on the Star*
- *Useful outcome – helps to plan centre activities*
- *Generally felt to be appropriate as it is at the present*
- *Worked well – this is a good indicator for member's health needs requirements*

How I feel

- *Most contentious area – a lot of feedback saying 'mental health' should be more explicit and have greater focus/ coverage*
- *Again, some felt they could not decide on the Journey of Change number*
- *Useful outcome*
- *Worked well – useful for how member is at this time*
- *Outcome area, a good starting point if concerned about client's mental well-being. It's non-threatening and part of an overall assessment*
- *Conducting and mapping the Star needs to be in a non-threatening environment like client's own house. Best when all others involved in care are involved especially family members*

Other feedback on the outcome areas

- *For the client, if they don't know they can't make the change – e.g. cleanliness, if you're unaware that this is an issue approaching, this can be difficult and lead to relationship damage. Caveat for all outcome areas – I think clients are reluctant to commit to an answer because this is/can be seen as a weakness. Some clients said that's not for me because others draw a conclusion that the head trauma is viewed as a deficit to getting on at work?*

- *Fatigue was described as having an impact in all outcome areas by clients. I think that this topic should either have its own outcome area or be added to the other areas. Fatigue is often a hidden challenge for our clients, if the only area this is discussed is physical health, then the psychological, social, emotional and cognitive elements will be missed*
- *I would have liked it to show how much support someone had vs how much they could do themselves – to help identify how they can become increasingly independent of support*
- *Some service users struggled with the multifactorial aspect of each point when trying to plot where they were overall on their journey*
- *Just the time it takes to cover the Star, on the whole, is very long/time consuming and holding members' concentration for this length of time is problematic*
- *I think they are all key outcomes and help to reflect the person, who they are and where they need further help*
- *While insight and perception is a thinking skill, it can impact how clients envision each area*
- *On the whole, all worded and graded well*
- *All outcome areas worked well and led to an open and frank conversation. There was a real sense of achievement*

Comments on the language

- *The difference between standard and retrospective Stars is difficult to distinguish. It is difficult to know which one is the most appropriate for the situation*
- *Wording used – the word 'accept' – a lot of members said they have reconciled/lived with the way they are now but have not/will never accept*
- *All ok apart from 'finding fulfilment'!*
- *Some of the terms seemed to overlap*
- *Use of retrospective Stars needs to be used with care and selectively to prevent retraumatizing the person*
- *Language was good*
- *Easily able to adapt use of language to suit each client*
- *Suitable for all client groups*

- *Language seems suitable and non-offensive. Can be adapted or rephrased by the member of staff supporting. Works well as a baseline then it can be tailored to the individual if needed*
- *Was suitable for all of the clients I worked with and all of the above (sensitive, non-confrontational, well received and understood)*
- *The various resources available are sensitive and inclusive to my client group. The visual logos are neutral, the grey colour tone and outline make it user friendly. One of my clients is colour blind and they had no difficulty following the Flashcards. At times the clients asked for clarification of certain sentences or words, but a verbal discussion and examples resolved it*
- *The language used was good*

Accessibility of the resources

- *Accessibility for poor sight is a problem. They could not distinguish the numbers on the main Star despite my enlargement*
- *Visually impaired clients were able to Zoom in and read for themselves – can imagine, if having to use a paper copy in a coffee shop, this may prove an issue*
- *Two clients are neurodiverse, both required additional time and explanation particularly when trying to determine a single score for different categories*
- *All good – prompt cards need to be better produced and in a binder*
- *I found the online resources excellent and easy to use*
- *The resources were helpful. Flashcards supported clients with communication issues*
- *Need to acknowledge that it will not cover every individual's requirement – some of these will come to light the more it is used and then Headway will need to update/revamp its resources*
- *I used this online with a client for whom English is a second language who managed very well to answer everything; another who is under the LD&A ASC team managed to understand using the Flashcards only, with the level descriptors read out loud to him to clarify*
- *I feel like the Star is very accessible and all my service users were able to engage with it well in different ways. The people with limited English did need additional support but were still able to engage with the overall process because of the visuals*

Feedback on the Guidance for practitioners

- *The many different ways I was sent information made it feel like there were reams of pages of information to read through – in practice this wasn't the case, and I needn't have worried as it was largely self-explanatory*

- *Comprehensive guide to read first and clarify any issues later*
- *Practical and informative*
- *Very comprehensive*
- *The guide for staff was helpful*
- *Clear*
- *I found this useful in the early stages*
- *Quite lengthy but on the whole easy to follow*
- *Straight forward and user friendly. The ideas and tips were very useful*

Feedback on the service user guide/leaflet

- *Once I had talked service user through it, they were fine – but found if they then went away and read it at a later date, they were unable to grasp it*
- *Clients generally found the User Guide overwhelming, wordy and difficult to follow. particularly if they had reading and memory problems*
- *I didn't use as too many words for service users*
- *The small A5 leaflet was useful for service users to take away*
- *Not many service users wanted this*
- *Useful and easy to follow*
- *Good resource*

Feedback on the User Guide

- *Didn't really refer to this – the Flashcards and live completion were sufficient*
- *Useful for practitioner to clarify each level of journey with examples if necessary*
- *Easy to follow*

Feedback on the Short Scales

- *Easy to use but would have preferred a bit more detail at this stage instead of having to go to the Flashcards*
- *Some preferred this format to the Flashcards*
- *Excellent and easy to follow*
- *Clear*
- *This was most helpful for the majority of service users*
- *Used occasionally when the internet lagged and we needed to move to the next Star – helped to keep within the 1-hour window I'd tried to stick to so I could go back and fill in when the system caught up rather than break the momentum*
- *Clients liked the images coupled with the short sentence descriptions*

Feedback on the Flashcards

- *Need improving and placing in a binder of some sort. Got messy (might be me!)*
- *Perhaps a simpler scale would have been useful for people I worked with*
- *Useful in picture form to simplify each area for some service users*
- *Good resource but did not use them*
- *Useful visual aid*
- *Really helpful for clients*
- *These were most helpful for those with visual issues*
- *Brilliant!*
- *Excellent for members to use / prompt them.*
- *All clients referred to the Flashcards as memory prompts, it anchored them to the point being discussed. They were less likely to be distracted and go off the topic*

Feedback on the Star Chart, Notes and Action Plans

- *There was just enough space when handwriting the notes with some service users, but I do have small writing*
- *The Star Chart and Notes were good. I feel with the Action Plan there could be space to record outcome – i.e. did they meet the goal*
- *Action Plan used only once but concept good and reminders/setting deadlines would be very useful going forward*
- *Excellent resources, practical and easy to use*
- *Having visual prompts works well for staff and clients*
- *Good use of graphical representation*
- *Once I had gone through it, and if you are used to Action Plans – good resource. Action Plan training for those that are not used to doing them*
- *Great visual representation – notes weren't used initially but I eventually started to record what clients said to capture the information*
- *I liked the simple format and structure of My Brain Star. It is user friendly*
- *The goals and action plan can be incorporated in care plans*

Additional resources

- *More resources for the goal setting and monitoring the attainment of goals*
- *Information on how to integrate database with Salesforce*
- *Printing out the Flashcards was a bit of a task – they are very useful to help clarify/focus, and I think they could be printed and issued with the project*
- *I had a very good experience using the tools and support resources during the My Brain pilot*
- *The step-by-step guide on completing a Star is helpful when training staff to use the Star*

Final things respondents wanted to add

- *Clients new to the service would not necessarily be able to see progress within the time restrictions of the pilot. It did however provide a visual baseline of areas that they could choose to work on*

- *We must keep working on this and get it embedded in what we do to track our clients' journey after brain injury*
- *Memory was a key negative in the retrospective phase*
- *Not sure how much it will impact on proving quality of service provision and funding, as any progression may only show minimal change on the actual Star if any. More useful for in-house to identify these small changes and to action plan individually for each service user*
- *I think it is a useful tool for monitoring outcomes and change over time. I think it could benefit from a 'clinical notes' section to record information like: poor vision, noisy environment when completing, that they were well/unwell, that someone spoke mostly for them, how engaged in the process they were*
- *The Scales work well with some people and not others, especially people who have been in the service for a long time and already have the full support and a routine they are happy with. As it were our Headway branch provides reviews and goal setting to our service users, one that is similar (without the software) to the Star when it comes to engaging service users about themselves, interests and support needs*
- *I think it is important for practitioners to note that this is a snapshot of how their members are at this exact time and these could change at any time due to illness etc*
- *The Action Plan layout, I don't like having to scroll to view it all and how it is laid out*
- *I am looking forward to using this Star instead of the The Well-being Star with all clients. It helps to really get to know the client and how their injury has impacted their lives*
- *Overall, very useful for members to have their Star for meetings with service providers to show where support is needed, what's working well etc as some of the topics discussed under each heading members may not associate with – i.e. physical health – may focus on mobility and forget about fatigue, exercise, nutrition etc*

Overall, how well does My Brain Star meet the needs of your service?

- *Overall, it does meet the needs but with some changes it would be much more useful to our ABI community and demographic*
- *Once an understanding of My Brain Star is gained it met the needs of the service/service user*
- *The categories are like the ones we already use in our service and therefore we know those are important areas in an individual's life. At the moment it seems to offer the same service that we currently provide*
- *It could provide a good overall assessment for use with our service users, looking at the changes in all aspects of their life since their brain injury*

- *Very useful for targeted work with clients who have a good degree of awareness*
- *From my experience, I feel that My Brain Star meets the needs of the service as its themes are relevant to the service and the user. It allows an opportunity for the practitioner to sit down with the service user and begin to identify issues or barriers that might be holding the person back as well as supporting and map their Journey of Change, which over time they can reflect upon and benefit from recognising the distance they have covered or issues that have been preventing them from moving forward and achieving their goals*
- *The Star is more suitable to the needs of our clients we support. It's easier to support the clients to look at areas that they need support with and support them to identify goals*
- *I have been happy with how it has worked, it was able to demonstrate their journey within the My Brain Star*
- *Overall, My Brain Star is a useful addition to our initial assessment and review process*
- *My Brain Star has been extremely well received by clients – we have a 'self-designed' goal setting process that is based on SMART goals but does not have the depth of detail that allowed for the conversations I had during the Star process*
- *From the small number of clients, I was able to assess, the My Brain Star was very effective in meeting the needs of the service particularly as the action plan was easily incorporated into the care plans.*
- *It will be a highly useful tracking tool for my support co-ordinator to use on a rolling basis*
- *The My Brain Star is not only a powerful tool to drive discussion and action for clients using Northumberland Headway, it is an essential process to achieving 'closing the gap' in where a user experience is and where they want to be on the journey from 1 'Things are not OK' to 'Finding fulfilment'. I believe the My Brain Star is a game changer*
- *My Brain Star meets the needs of the service users. It covers all the key areas that we focus on within rehabilitation, so we can easily set appropriate goals*

Psychometric analyses of the pilot Star data

Analyses of 136 first Star readings showed the following:

Distribution: Readings were normally distributed for all outcome areas (see Appendix).

Item redundancy: Most of the inter-item correlations were in the desired .3 to .7 range, but four of the 28 were just over this (See Appendix for full details):

- My daily life –My thinking skills
- My daily life –How I spend my time
- Social and support networks –How I spend my time
- How I feel –How I spend my time

Internal consistency: Cronbach's alpha was .94 – above the threshold of .70, indicating very good internal consistency.

Factor structure: A unidimensional factor structure was advised, with one factor explaining a good proportion of the variance (76%).

For an explanation of these tests please see: http://www.outcomesstar.org.uk/wp-content/uploads/OS-Psychometric_Overview.pdf

Further research into the psychometric properties of the final published version of My Brain Star was initiated following publication. For the latest information on this, please contact anna@outcomesstar.org

Stage 4: Revising and finalising the new Star

Workshop 3 (October 2024): The third workshop gathered further information needed to finalise My Brain Star, resources, and guidance.

The Journey of Change stages and outcome areas in the final version of the My Brain Star are as follows:

The final My Brain Star Journey of Change	<ol style="list-style-type: none"> 1. Things are not OK 2. Getting help 3. Exploring new ways 4. Finding what works 5. Managing well
The final My Brain Star Outcome Areas	<ol style="list-style-type: none"> 1. My thinking skills 2. Everyday tasks 3. Personal admin 4. My physical health 5. How I feel 6. How I spend my time 7. Communication and social skills 8. Social and support networks 9. My safety

Based on all of the post-pilot feedback, a number of changes were made in creating the final version. The main changes are described below:

- **My daily life was broken down into two separate areas:** Everyday tasks (covering personal care, shopping, cooking and cleaning and travel) and Personal admin (covering money, bills, applications, financial safety)
- **Difficulties communicating over the phone** were added to the Communication and social skills area
- Additional notes were added to the *Guidance for practitioners* to emphasise **that lower readings are not a bad thing** – e.g. ‘being at things are not OK or getting help isn’t a negative thing, it shows you where you need support’
- The final Journey of Change stage was changed from **Finding Fulfilment to Managing well** and small changes were made to the language at this stage to make it clearer that things might not be perfect
- The term **‘self-care’** was replaced with **‘personal care’**
- A section on ‘adapting to different needs’ was added to the *Guidance for practitioners*, explaining that the Star can be **completed over several sessions** if needed and the resources can be used flexibly
- In the *Guidance for practitioners*, it was explained that worker only retrospective readings may be more appropriate in some cases (e.g. if completing these with a service user would be distressing for them)
- **Education about/understanding of brain injury** was made more explicit in My thinking skills (e.g. ‘you may be finding out learning more about brain injury and how it has impacted on the way you think. You may be learning about how fatigue can impact on this too). A section on insight was added to the *Guidance for practitioners*
- In the How I feel area, **more attention was given to serious mental health conditions** and how bad someone may feel. For example, the phrase ‘mental health condition’ replaced mental health issue – and being in crisis and struggling with mental health conditions was added
- **Fatigue was added** into My thinking skills, Social and support networks and in the Things are not OK stage in the overall Journey of Change
- Mentions of **accepting the effects of the brain injury** were replaced with acknowledging and understanding them. Acceptance of ‘how life is now’ was only retained in the How I feel area
- Poor vision and hearing was added into the Things are not OK stage for My Physical health

- A section on insight was added to the Guidance for practitioners. This explained that the Journey of Change 'does not mention insight explicitly as we wanted to avoid making this a condition of reaching the Managing well stage. Instead, at Managing well there is an acknowledgement of how things are – this is about having an understanding of the impact of the brain injury, how things have changed and where support is needed. This could go hand-in-hand with having insight, but it could be that others have helped them with acknowledgement and understanding of their limitations but they still don't have self-awareness'
- Being **as independent as possible** was added to the Managing well stage for outcome areas where this is relevant. A section on recording level of independence was also added to the *Guidance for practitioners* (e.g. using Star Notes)
- **The Managing well stage of My Safety** was adjusted to set a higher bar given skew towards the top of the Journey of Change in the pilot data (e.g. changed from 'mostly feel safe' to 'you are safe')

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 Outcomes Star 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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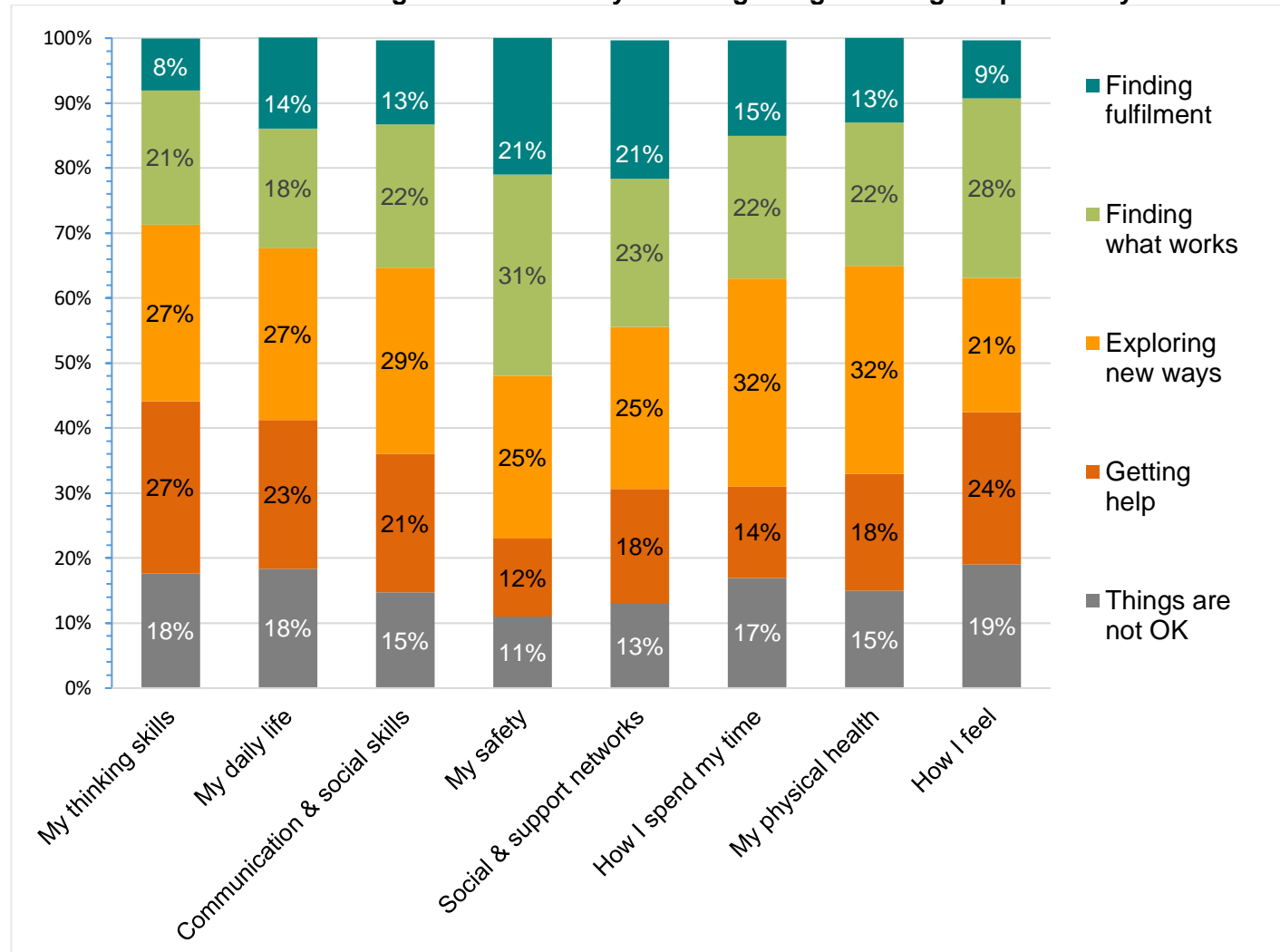
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Appendix: Details of the psychometric properties of the pilot My Brain Star™

The distribution of Star readings across Journey of Change stages during the pilot of My Brain Star™



My Brain Star outcome areas	Skewness statistic	Result
My thinking skills	0.16	Normally distributed
My daily life	0.13	Normally distributed
Communication & social skills	0.00	Normally distributed
My safety	-0.47	Normally distributed
Social & support networks	-0.19	Normally distributed
How I spend my time	-0.13	Normally distributed
My physical health	-0.06	Normally distributed
How I feel	0.00	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

Polychoric correlation matrix

	2	3	4	5	6	7	8
1 My thinking skills	.72	.60	.63	.55	.54	.60	.60
2 My daily life	-	.61	.62	.60	.65	.70	.58
3 Communication & social skills		-	.62	.63	.64	.59	.59
4 My safety			-	.60	.63	.60	.68
5 Social & support networks				-	.70	.56	.68
6 How I spend my time					-	.66	.73
7 My physical health						-	.65
8 How I feel							-