

Childhood Stroke Project Report





Background

Stroke Foundation is a national charity that partners with the community to prevent, treat and beat stroke.

Stroke Foundation delivers resources for survivors of childhood stroke and their families to improve recovery. This project will work with survivors of childhood stroke and their families to develop resources tailored to the needs they identify.

Stroke Foundation engaged Impacto Consulting to work with the Childhood Stroke Lived Experience Advisory Group to inform and support the delivery of resources and deliver a brief report of findings.

The outcomes we were looking to achieve included

- ▶ A set of project goals, vision and mission
- ▶ A co-designed project process
- ▶ Prioritisation of areas of need to inform focus for resource development
- ▶ Participants of the workshops feel equal, engaged, connected, supported, and working together. They should feel like they created good initiatives and had a good experience.
- ▶ Participants have learnt more about the Co-design process, which has removed the 'us and them' between staff and people with lived experience.

Linkages

The project aligns with the Stroke Foundation's mission of preventing strokes, saving lives, and improving recovery by raising awareness about childhood stroke and providing targeted support based on real-life experiences.

This project is also directly aligned with the strategic actions to "Better support people with unique needs (e.g. families of childhood survivors of stroke and young adult survivors and their families) by ensuring relevant information and support is available."

Methodology

Session one - project frame up & what we want to achieve

Session two - establishing project goals, creating a project vision and mission

Session three - co-designing principles and co-design approach, building our understanding of childhood stroke, the survey results and the lived experience of the participants, developing solutions and creating an action plan

Survey

In parallel with this work a survey was circulated to a wider stakeholder group to understand the needs of childhood stroke survivors, their families, friends, teachers, health and medical professionals and medical practitioners. The survey captured the barriers experienced, how they currently sourced information and their preferred format for resources to be delivered.



Session one

In the first session, we started by getting to know each other and outlining how the sessions would run and what was included in each session. Each of the participants shared their objectives for the project and how they wanted to feel about their participation.

The objectives identified as important to the project team in the first session were

- 1 Building support within the education system in the classroom
- 2 A positive experience for all participants supported by the Stroke Foundation working together as a team
- 3 Reach as many people as possible with education and awareness
- 4 Children have equal opportunity and access in all aspects of community and education
- 5 More support for stroke survivors and families outside of school
- 6 Resources that can be provided to Moyamoya families
- 7 Breaking down social exclusions
- 8 Equality of access regional/remote/metro - Connecting families to communities
- 9 Have young people be heard, increase education of teachers to support children following stroke
- 10 Add real life to the group and build support out in the community
- 11 Amplifying the voice of lived experience of stroke and raise awareness of what young people can achieve
- 12 Include a range of perspectives, including, parents & siblings
- 13 Self-sustaining
- 14 Sustainable achievements - long-term impact

How the members of the working group wanted to feel through their contribution to the project included

- ▶ Accomplished
- ▶ Empowered
- ▶ Privileged
- ▶ Proud
- ▶ Making a difference
- ▶ Impactful
- ▶ Change - ripples
- ▶ Aligned/collaborative with hospitals and Stroke Foundation
- ▶ Supportive
- ▶ Inclusive/accessible

Following this, we created a vision and mission to encapsulate what the project members shared.

Session Two

In the second session, we started with goal-setting methodologies. We created four goals encapsulating everything the working group was looking to achieve through the project and captured project performance measures for the next three years. We also discussed how we could measure progress on these goals.

In preparation for the face-to-face session, a working document was circulated for feedback on the goals, measurement, vision and mission.

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Lived Experience

“I've learnt more in one minute with Mitch than I have in 16 years”

During the face-to-face workshop, we recorded significant quotes and statements. One comment came from a parent referring to her time with one of the older childhood stroke survivors. This quote captures just how powerful their conversation was and the value lived experience provides.

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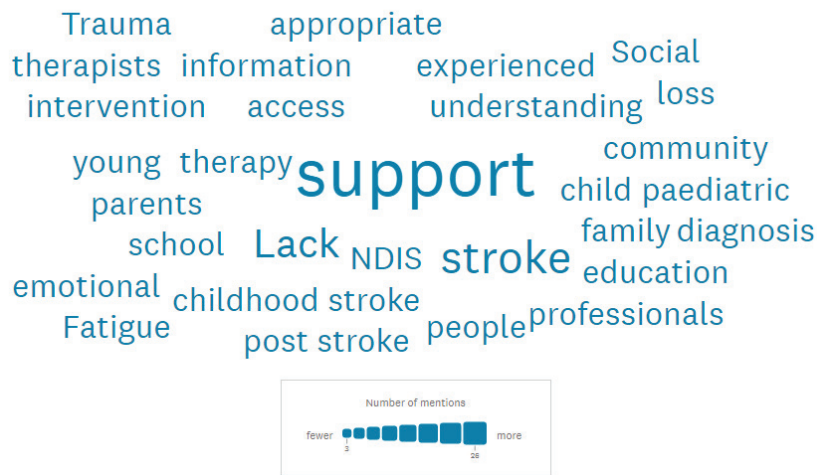
Session Three

Session three was a face-to-face workshop.

We started with an agreement on how the day would work, reviewed the progress so far and agreed on the vision for the project. We continued to workshop the mission to ensure that it was both inclusive, informative and meaningful.

Next, we co-created our co-design approach to the project by reviewing the five co-design stages in small groups and then sharing back to the larger group with a facilitated discussion.


Following this, we spent some time reviewing and discussing the survey results to understand what is important to the broader stakeholder group.



We then built on this with each person sharing their experiences and learning from various perspectives. Each group were then asked to distil this information into the three most important themes to ensure that the project is aligned with these insights.

The themes each group nominated as most important were:

- ▶ The value of lived experience from different perspectives
- ▶ Inclusion/Accessibility
- ▶ Awareness
- ▶ Clarity
- ▶ Navigating systems at all levels
- ▶ Access to resources and professional development across all sectors
- ▶ A diagnosis isn't the whole person, and everyone's recovery looks different



An ideation session followed to answer the question, “ How might we empower every child to reach their full potential following stroke?” Voting then allowed each participant to select their favourite idea to run through the prioritisation matrix to assist in identifying the most balanced ideas to take through to the next stage.

The most popular idea at this stage was to create a mentoring/buddy program to match childhood stroke survivors with other survivors.

Using the matrix, it was clear that there were some additional criteria to ensure that the ideas that had the highest impact, aligned most with the project's goals and had the highest likelihood of successful implementation and sustainability were identified.

The last session of the day was dedicated to identifying and documenting the following steps to set out what would be done next and who would be responsible.

We ended on a high note by acknowledging the gifts that each participant had shared and thanking them.

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Outcome vs process

“Every survivor has their right way of doing things”

Imagine the frustration when you live in a world that wasn't designed for you, you work out how to open your lunchbox around your abilities only to be told that you aren't doing it the right way. The shift from looking at the process to looking at outcomes is significant.

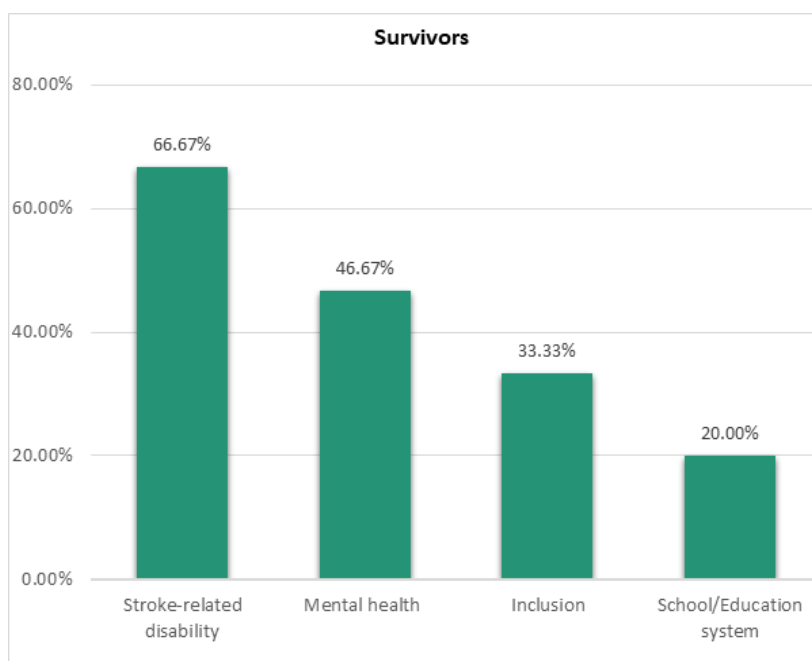
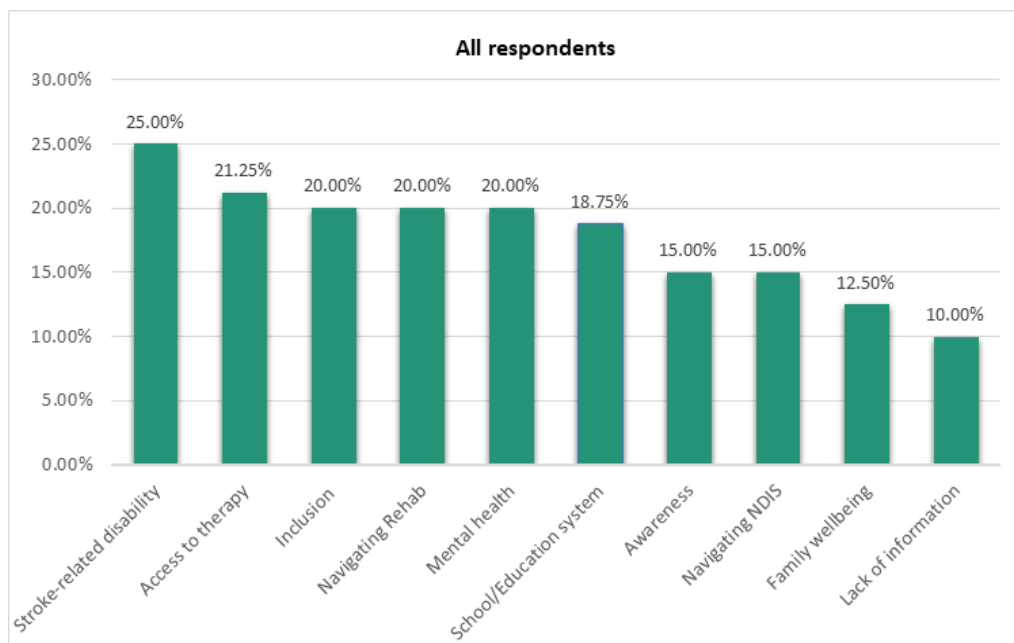
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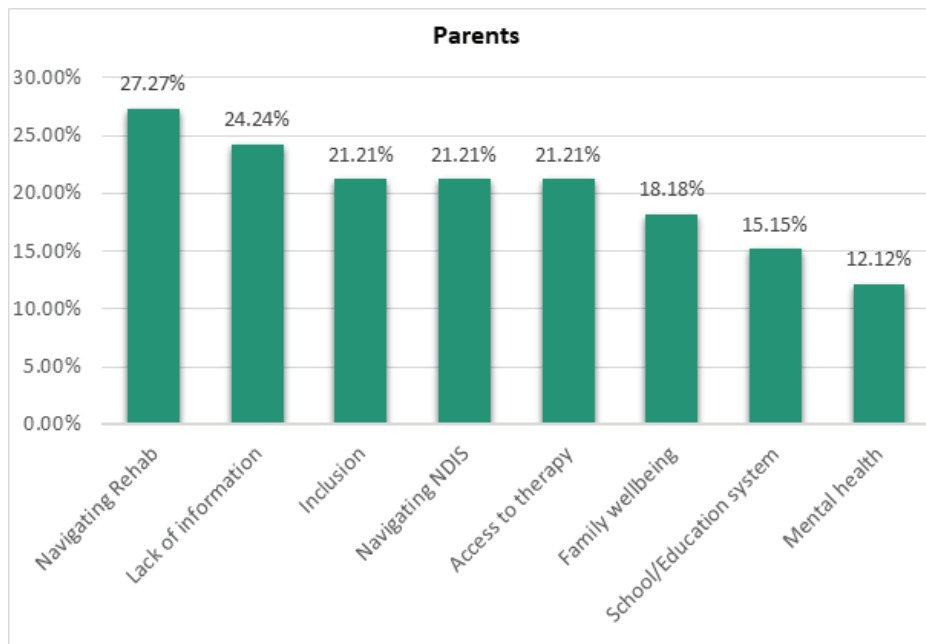
Childhood Stroke Survey Results

Survey Results

Eighty people completed the survey with parents making up 41% of respondents. Twenty-nine were health professionals, 19% were stroke survivors and the remaining were carers, educators, friends and other family members.

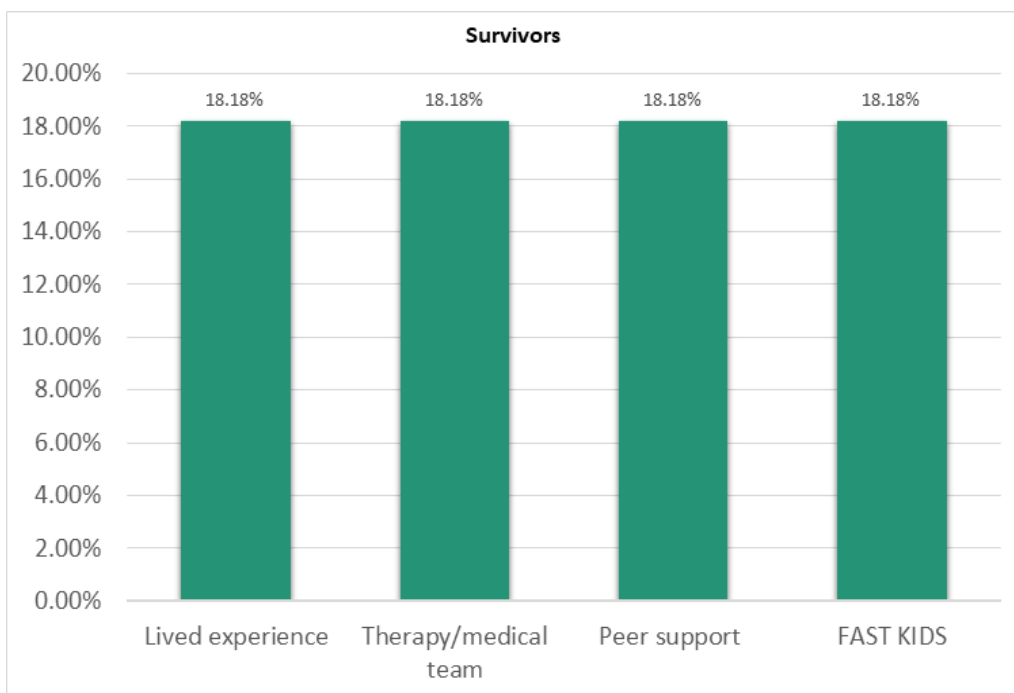
Results are presented for the whole sample of respondents and split to highlight the most important areas reported by survivors and parents.

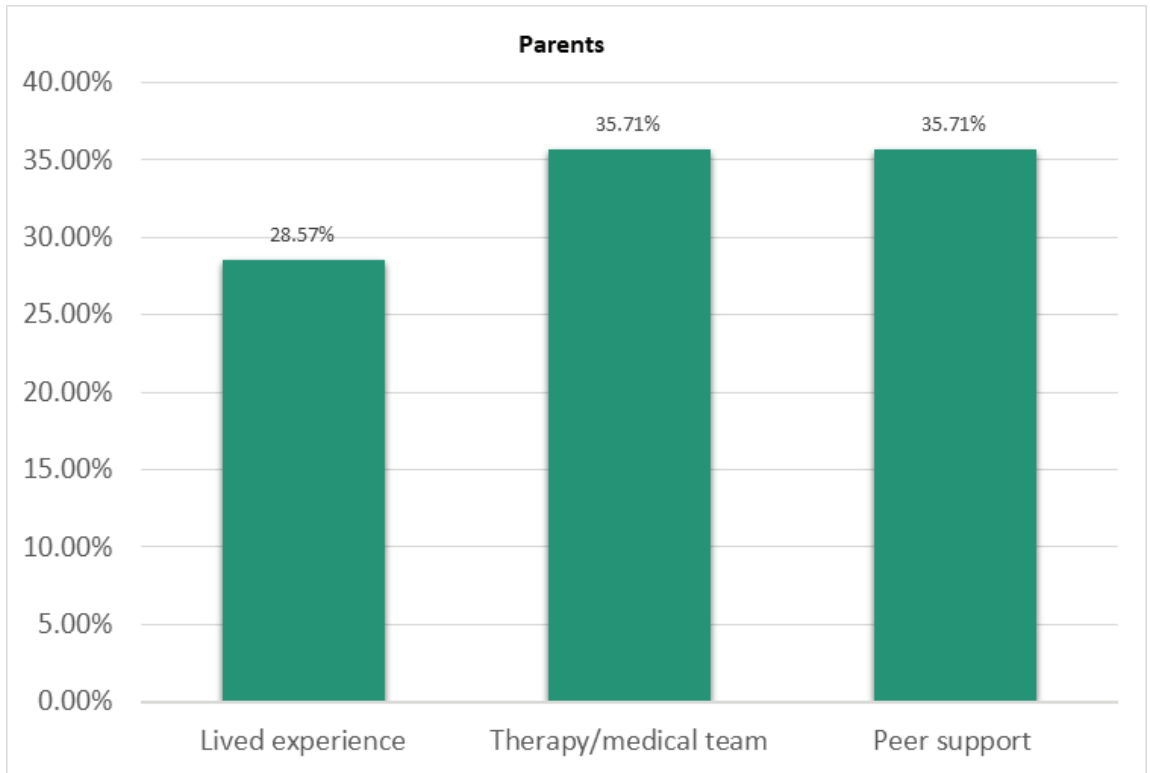




Most helpful information

The most helpful information again highlights the benefit of lived experience.





Survivors also shared the value of lived experience information along with therapy/medical team, peer support and F.A.S.T K.I.D.S (an initiative to increase awareness of childhood stroke)





Outcomes

Vision

Empower every child to achieve their full potential after stroke

Mission

We centre the expertise of lived experience, and together develop resources to support, create awareness and advocate for survivors of childhood stroke and their families.

Goals

The four goals that the project team have created are

- ▶ Build a sense of community, resources and knowledge for stroke survivors and their families
- ▶ Increase awareness of childhood stroke with the community and health/medical professionals and improve pathways to recovery
- ▶ Increase vs increased social inclusion and equal opportunities/participation for all children within the education system
- ▶ Participants in the project feel they have made a difference and built a sense of hope for the future.

Prioritisation of areas of need

A prioritisation matrix was created to ensure that all initiatives are prioritised with a balanced methodology and includes the alignment to goals, impact, viability, sustainability and safety. This tool also tracks barriers identified to ensure that all barriers are addressed.

Co-designed project plan

The participants co-created a project plan adapting the five stages of a co-design project specifically for the Childhood Stroke Project.

This plan is adaptable as the project progresses and the working group build on their co-design knowledge and understanding.



Participant experience

The participants appreciated the group conversations, working with different groups and interacting with each other.

- ▶ "Hearing survivors tell their stories and parents learning from their insight was powerful to witness."
- ▶ "Worked well with creating an environment where everyone was comfortable and feels more of a united team by the end."
- ▶ "Appreciated being put into different groups throughout the day to hear and work with all members."
- ▶ "I liked that Stroke Foundation staff were involved in the tasks and getting to know the community better."

What they would like to change about the workshop was more time spent on the actions taken moving forward, ensuring that everyone feels able to contribute equally and creating a roadmap towards achieving the goals.

- ▶ "I think we focused too much time on unpacking the goals rather than developing ideas."
- ▶ "Everyone has brilliant ideas; I feel some were shared, however, others weren't."
- ▶ "I was disappointed that by the end of the two days, I do not see that we have put together a clear roadmap on next action items to work towards achieving the 4 goals."

Additional feedback and comments provided were appreciative of the behind-the-scenes organisation of the project and working group.

- ▶ "Keep up the amazing work, young survivors need an army to survive, and all in today's workshop are the unsung heroes to those survivors of stroke."
- ▶ "It was a jam-packed day, and I believe we got through a lot. Thanks for organising and facilitating."

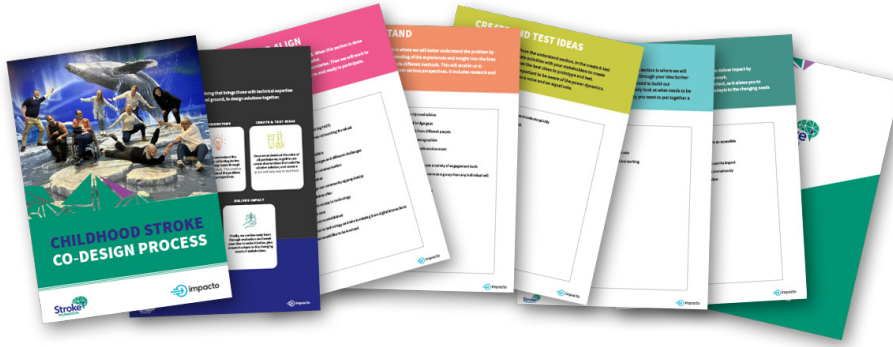
Next steps

- ▶ Identify which initiatives will be reviewed and prioritised first
- ▶ Create a timeline with goals broken down into yearly milestones and measurements

Deliverables

Co-design project plan

This plan was co-created by the participants specifically for the Childhood Stroke Project. It is adaptable, so will further develop as the project progresses.



Action Plan

The action plan includes all of the activity agreed and will ensure that the project progresses and everyone is clear on what is to be done and by whom.

Initiative	Activities	Owner	Measurements	Start/Finish	Risk Rating
Identify goals and commitments of LSCAC members	Conduct survey and send to all members	Neil	Completion of survey	1/18/22	Low
Developing relationships with stakeholders	Review what already exists within Stroke Foundation and possible connections	Michelle	Completion of stakeholder map	1/18/22	Low
Review with committees existing resources	Add agenda item to next LSCAC meeting to review	Michelle		1/18/22	Low
Goals	Review goals and measurements following connections, existing resources review	Michelle	Completed	1/18/22	Low
Meeting frequency	Agree on frequency and nature of meetings	Michelle	Completed	1/18/22	Low
Meeting Agenda	Agree on meeting agenda and roles for each meeting	Michelle	Completed	1/18/22	Low
Share Survey	Share survey on social media, share with schools, therapists, doctors, health together for A&P, & other groups	Michelle	Completed	1/18/22	Low
Review	Review and agree on intended changes to survey	Michelle	Completed	1/18/22	Low
Customise existing tool	Review existing tool and customise to meet needs of project	Michelle	Completed	1/18/22	Low
Share LSCAC story	How will we share the story of the project	Michelle	Completed	1/18/22	Low
Working Group	Following survey with professional interests and skills identify working group	Michelle	Survey results	1/18/22	Low
Call Log	Develop call log to track who has been contacted	Michelle	Completed	1/18/22	Low
Complete Feedback	Complete feedback survey	Michelle	Completed	1/18/22	Low
Outcomes	Higher form to be written	Michelle	Completed	1/18/22	Low

Prioritisation matrix

The prioritisation matrix was created to ensure that all initiatives are prioritised with a balanced methodology and includes the alignment to goals, impact, viability, sustainability and safety.

Initiative	Barrier	Goal	Alignment	Impact	Viability	Sustainability	Safety	Ease	Total
Mentor/buddy program	Peer support	Goal 3	Low	Medium	High	Low	Low	Low	9
Ask about assessment (supporting Major National sporting groups such as AFL, Tennis Australia, etc), The Aus Rugby and partner to build community awareness and a sense of inclusion	Awareness	Goal 2	High	High	Low	Low	High	Low	11
Guide to support families navigate education system, including information available and how to access it	Education/schools and lack of information	Goal 1 & 3	High	Medium	High	High	High	Low	15
Information about transition to adult services	Navigation/Health System	Goal 1							
Offer PDI for schools to support children and what school/therapist needs and links in schools - around inclusion and awareness	Education/schools lack of information	Goal 3							
Program needs to medical community	Awareness in medical profession	Goal 2							
Creating community groups in each state	Peer support	Goal 1							
Mentor/buddy program in Human Biome (Researcher/clinician)	Peer Support	Goal 1							
Medicare subsidised the services for families and carers	Family wellbeing	Goal 1							
CPD for clinicians to help and their own journey - sharing their own story	Lack of information	Goal 1							
Brochure for children about childhood stroke to be used in school, general etc	High appropriate information	Goal 1							
Spotlight letters for childhood stroke included in directory of ST	Inclusion	Goal 1							
Parenting after childhood stroke	Family wellbeing	Goal 1							
A plan for delivery which is personalised by team and a rough timeline when anticipated interventions and milestones can be achieved	Lack of coordination and follow-up	Goal 1							
EA&P RCT/CS	Awareness	Goal 2							

Key	Low	Medium	High
Alignment	Doesn't link directly to a goal & mission or barriers identified	Agreement that it will most likely contribute to achievement of a goal, support with an identified barrier & mission	Exactly the type of activity that is needed to fulfil our mission and direct linkage to a goal or barriers identified
Impact	Low impact may take time to see benefits	Medium impact with benefits within 12 months of implementation of initiative	High impact across more than one group within 12 months of implementation
Viability	Achievable within budget but will constrain other activity	Achievable within budget	Easily achievable within budget
Sustainability	Short term initiative	Immediate impact with ongoing effort to achieve	Impact now and into the future
Safety	Poses known safety issues in current format	Poses some safety concerns that are able to be resolved within the implementation of the initiative	Initiative is as safe as is reasonably possible
Ease	Requires co-ordination across a range of different groups with different needs	Can be implemented within the resources available to the group within 6-12 months	Could be implemented quickly with minimal engagement requirements
Value		1	2

Created for



By



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