Ethical principles and practice for involvement of people with lived experience of stroke in Stroke Foundation projects and activities

Safe, Supportive and Positive Engagement

Contents

1. Introduction

Stroke Foundation is a leader in the involvement of and co-design with people with lived experience which is reflected in the ‘Voice of Lived Experience’ guiding principle underpinning our **Strategy 2024 Empowering | Supporting | Connecting.** Involvement of people with lived experience ensures our activities, products and services meet the needs and preferences of survivors of stroke, families and carers.

To incorporate the voice of lived experience, Stroke Foundation engages people with lived experience of stroke in different ways. At a governance level we have our Consumer Council. A project example is the Young Stroke Project, a three-year Department of Social Services funded project co-designed with young survivors of stroke. For our research activity, we have developed an education resource on best practice for including people with a lived experience of stroke in research projects.

In research there are strict procedures and processes to ensure and enforce ethical conduct in research practices. However, there is currently not such rigour for involvement of people with lived experience in project development and other activities (collectively referred to in this document as Projects). This guide provides a framework for ethical principles and practice for involvement of people with lived experience of stroke in Stroke Foundation projects and activities. It can also be used by researchers to supplement the information provided as part of the ethics approval process.

Applying ethical guidance in Projects is an ongoing matter of judgment and good practice and in all of our work we should be living our values of *Courage, Excellence, Compassion, Integrity, Leadership*. Irrespective of what an activity is (quality improvement, program development or research) the activity must be conducted in a way that is ethical.

Stroke Foundation employees and Project participants need to be mindful of the various issues that can arise in the context of their individual Projects and the aim of this guide is to provide support by providing ethical principles and practices for involvement of people with lived experience in Stroke Foundation Projects to ensure people have a safe, supportive, and positive experience of engaging with us.

2. Definitions

Term	Definition
Child or Young Person/Vulnerable Adult	A child or young person under the age of 18. Adults aged 18 and over have the potential to be vulnerable (either temporarily or permanently) for a variety of reasons and in different situations. An adult may be vulnerable if he or she: › Has a learning or physical disability › Has a physical or mental illness, chronic or otherwise, including an addiction to alcohol or drugs › Has a reduction in physical or mental capacity › Is in the receipt of any form of healthcare; or › Is detained in custody › Is receiving community services because of age, health or disability › Is living in sheltered or residential care home or his homeless › Is unable, for any other reason, to protect himself/herself against significant harm or exploitation › Has communication barriers eg because of language and culture › Has been exposed to persecution in the past e.g. refugees. It is recognised that people who meet one or more of the criteria above may not be vulnerable at all, or all the time.
Conflict of interest (COI)	A situation in which someone's personal (financial, political, professional, social, sexual, family, etc.) interests could influence their judgment or actions in a financial or other decision, in carrying out their role, or in their relationships with participants. A COI occurs when a Stroke Foundation Person's personal, institutional or business interests conflicts with their responsibility to act in the best interests of Stroke Foundation. If a particular decision is likely to benefit a Stroke Foundation

	Person in any way, or benefit a Related Party, that Stroke Foundation Person is considered to be no longer in a position to make an impartial decision and is therefore considered to have a COI. It also includes a conflict between a Board Member's duty to Stroke Foundation and another duty that the Board Member has (for example, to another board). A COI may be actual, potential or perceived, and may be financial or non-financial.
Ethics	A code of thinking and behaviour governed by a combination of personal, moral, legal, and social standards of what is right. In the context of Projects, ethics covers topics such as the overall harms and benefits of the Project, the rights of participants to information, privacy, anonymity, and the responsibilities of Stroke Foundation employees to act with integrity.
Ethical principle	A general standard or norm that promotes what is regarded as worthy or valuable for the flourishing of humans and/or the whole ecosystem. Ethical principles may relate to right/wrong conduct, good/bad qualities of character and responsibilities attached to relationships. A principle does not tell us how to act in each situation we encounter, but is broad in scope, and needs interpreting in the light of particular circumstances.
Project	The umbrella term in this document used to describe any activity undertaken by Stroke Foundation involving the participation of people with lived experience of stroke excluding research. Examples of activities classified as a Project include: › A Stroke Foundation Council, Committee, or Working Group › Little Stroke Warriors activities › Development of a Stroke Foundation Service.
Risk	An exposure to the chance of harming oneself or other people. We have a duty of care to people at risk of self-harm, and there is a duty to warn where we receive information that someone else may be harmed.

3. Ethical principles

This section outlines some general ethical principles but is not meant to be an exhaustive list.

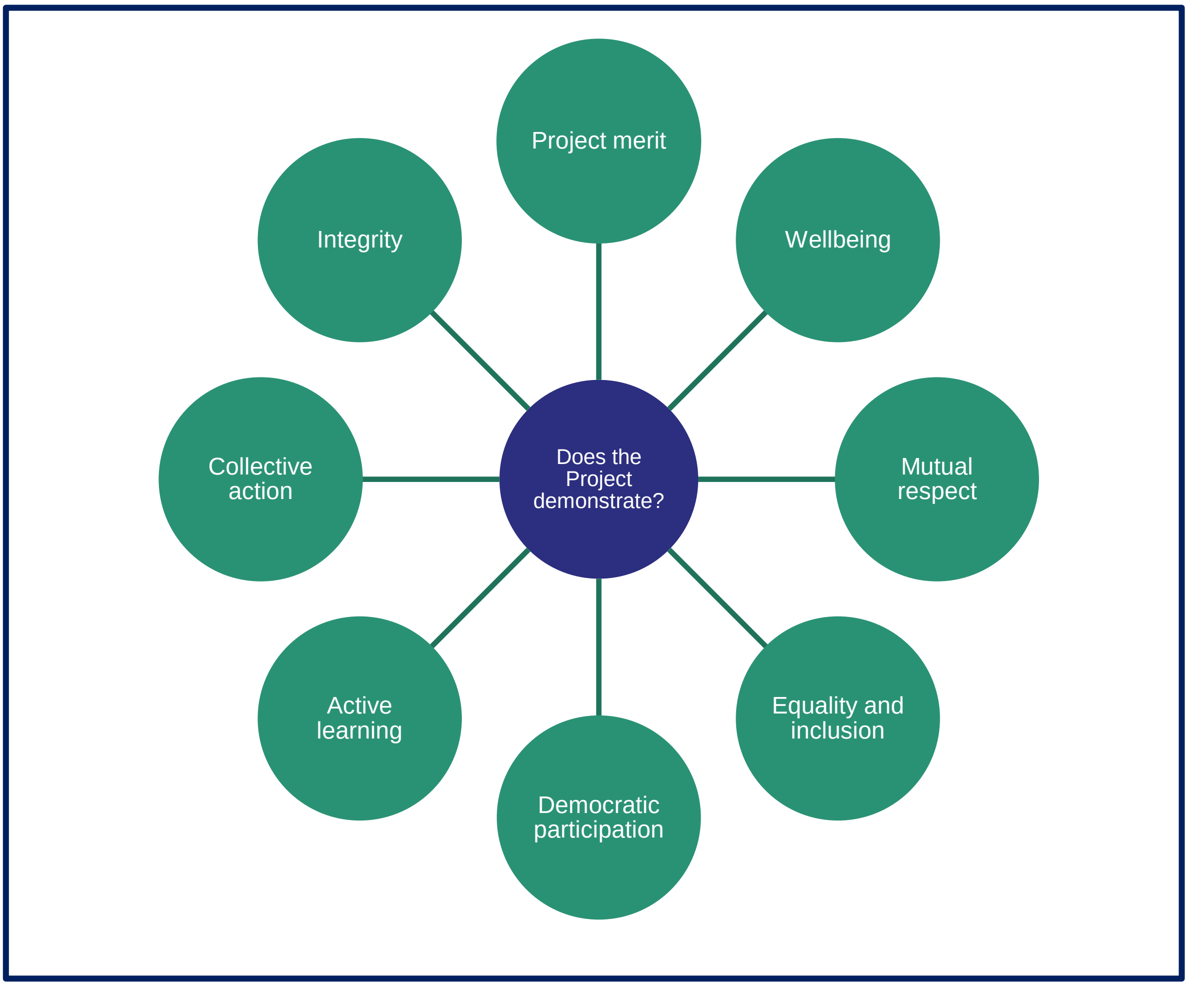
1. **Project merit:** only developing and implementing Projects that are likely to have potential benefit, including a commitment to:
    - use an evidence-base from current or previous literature and data where relevant
    - ensure the Project is managed by persons or teams with relevant experience, qualifications and competence.
2. **Wellbeing:** ensuring the wellbeing of those participating, involved in, or affected by the project is at the centre of the process, including a commitment to:
    - uphold the rights of participants and the values and principles that flow from or are a consequence of these rights
    - acknowledge that the planned or expected benefits of the Project must never be at the cost of respect for the rights of individual participants.
3. **Mutual respect:** developing relationships based on mutual respect, including a commitment to:
    - a respect of privacy, confidentiality and cultural sensitivities
    - agree what counts as mutual respect in particular contexts
    - build and maintain an environment of psychological safety so that people can respectfully share their views without fear of negative consequences
    - being prepared to listen to the voices of others
    - accepting there are diverse perspectives
    - allowing scope for people to make their own decisions.
4. **Equality and inclusion:** encouraging and enabling people from a range of backgrounds and identities (ethnicity, culture, faith, class, education, gender, sexual orientation, (dis)ability, age) to lead, design and take part, including a commitment to:
    - actively include people whose voices are often ignored
    - challenge discriminatory and oppressive attitudes and behaviours

- ensure information, venues and formats for meetings are accessible to all.

5. **Democratic participation:** encouraging and enabling all participants to contribute meaningfully to decision-making and other aspects according to skill, interest and collective need, including a commitment to:
    - acknowledge and discuss differences in the status and power of Project participants, and working towards sharing power more equally
    - communicate clearly using language everyone can understand
    - participatory Project methods that build on, share and develop different skills and expertise.
6. **Active learning:** viewing collaboration and the process of Project development as an opportunity to learn from each other, including a commitment to:
    - ensure there is time to identify and reflect on learning during the Project process, and on the ways people learn, both together and individually
    - offer all participants the chance to learn from each other and share their learning with wider audiences
    - share responsibility for interpreting the Project findings and their implications for practice.
7. **Collective action:** individuals and groups working together to achieve change, including a commitment to:
    - identify common and complementary goals that meet partners' differing needs for the Project
    - work for agreed visions of how to share knowledge and power more equitably and promote social change and social justice
    - recognise and work with conflicting rights and interests expressed by different sections of communities or by different communities.
8. **Integrity:** participants behaving reliably, honestly and in a trustworthy fashion, including a commitment to:
    - work within the principles detailed in this document
    - be open to challenge and change and prepared to work with conflict.

Figure 1 below summarises the general ethical principles for Projects. Use this summary as an easy reference to refer to during your project.

Figure 1: General ethical principles for Projects



4. Practice, Principles and Guidance

This section focuses on how to put the ethical principles presented in Section 3 into practice and offers some brief guidance on some of the ethical issues that those involved should think about. Table 1 on page 18 provides a checklist to help you integrate ethical practice and principles into a Project.

4.1. Preparing and planning

4.1.1. Type of involvement

When thinking about a Project it is first useful to consider what type of involvement is appropriate for a Project. Some options are listed below:

Consultation

Consultation ensures our products and services meet the needs and preferences of people with lived experience of stroke. Consultation includes:

- Stroke Foundation and Project Councils and Committees
- One-to-one interviews and conversations
- Surveys
- Workshops.

Story gathering

Story gathering is used to share stories through interviews, podcasts and videos.

Stroke Foundation employees:

- Identify people suitable for storytelling
- Think carefully and seek advice about approaching anyone who is vulnerable or at risk, to ensure the approach is appropriate and if so, managed well
- Approach people about storytelling, providing information about the process
- Attend recording sessions and follow up with people after their session about their experiences.

- Provide people with access to their stories before they are published, so that they can make changes and confirm consent.

The Storytelling content consent form is used for recording consent, including any limitations or conditions agreed to. People are provided with a copy of this form, along with The Sharing Your Story and Getting Support Statement.

Evaluation

Evaluation ensures we understand people’s views and experiences of our products and services.

We commonly use a ‘three quick questions’ survey. The questions are:

- How helpful was X?
- Would you recommend X to others?
- Do you have any feedback for us?

Projects that include engagement beyond simple surveying will have an evaluation framework. Stroke Foundation’s Young Stroke Project Evaluation Framework provides a good guide to developing an evaluation framework. More detailed evaluation on a Project can be done in partnership with an academic research organisation.

4.1.2. Working together

Before starting a Project together, it’s helpful if the parties involved go through a preliminary phase of checking out expectations, including considering whether the proposed Project is a good idea at all.

Why work together? At the start, it is a good idea for everyone involved to get to know each other, discuss their hopes and fears for the Project and share what they want to get out of it. What are the commonalities and differences? Is it going to be practical and productive to work together? At this point it might be decided that the Project is not going to work or that some expectations need to be changed. Sharing experiences and stories can be a useful part of the process to find out common values and aspirations.

Who should be involved? Given the purpose of the proposed Project, are there certain people or groups with expertise, experience or interest in the topic who should be invited and what might be the barriers to their participation? Is there a group of people that deliberately or unintentionally excludes others for no good reason? Some people may have the capacity and desire to be heavily involved whereas others may dip in and out. Individuals might also decide that the partnership or Project is not the right fit for them and not continue with the Project. Anticipating and managing the different levels of involvement is important to ensure nobody feels either pressured to contribute, or deliberately excluded.

What are the aims and objectives of the Project? Are all parties clear about why they want to do the Project and what they want to get out of it? It is important to involve as many people as possible in the process of designing the Project and to take account of different expectations of the purpose of the Project – being clear which aims and objectives can be agreed by all and which may need to be modified or changed.

4.2. Doing the Project

4.2.1. Terms of Reference

A first step is the development of a 'Terms of Reference' (ToR) which is essentially a document providing guidance on how to work together. This need not be regarded as fixed or unchangeable, as Projects will often develop in unexpected ways, and can be reviewed and revised on an ongoing basis.

The ToR may include practical details of working relationships, as well as an outline of how to ensure that people who participate data are protected and credited. Things to consider include:

- **agreed ethical principles,** such as those listed in Section 3
- **protocol for communications and meetings**, including preferred ways of communicating and meetings (e-mail, Zoom, Teams, face-to-face meetings), expected frequency of communications and meetings, main point of contact from Stroke Foundation, how to ensure that a few participants do not dominate and that people speak in plain language
- **protocol for safety**, including procedures for providing support if participants feel that a meeting content raises personal health and wellbeing issues. This includes Stroke Foundation employees attending workshops to:
    - Ensure information on support is provided including the *Getting Support Statement* (Box 1) at the beginning and end of every meeting and:
        - Notice if someone is distressed, vulnerable or at risk
        - Consult with colleagues and managers as needed
        - Ensure the person is followed up as needed.
    - The Stroke Foundation Children and Vulnerable Adults Protection Policy provides guidance on keeping children and vulnerable adults safe.

- **protocol for handling difficulties and conflict**, including ways to sort things out if people disagree, fall out and things go wrong
- **agreed aims and objectives** of the Project
- **management of Project**, whether by Stroke Foundation team, partnership, steering or working group or other means, including acknowledgement that leadership roles may change throughout the process
- **what contribution fees and expenses are available** to whom, for what, how much and in what form (e.g. money or vouchers) and the process for claiming fees and expenses
- **any training and policies required** for the Project partners including mandatory Stroke Foundation training and policies
- **practical details** of who will take responsibility for what, e.g. minute taking, meeting organisation, administration of contribution fees and expenses, Project planning etc
- **processes for reflection, evaluation and learning** from each other and from the Project throughout the process
- **confidentiality, informed consent, personal information, anonymity** and how these are handled are important considerations covered in more detail in Section 4.2.2
- **conflict of interest** must be discussed at the beginning of any Project and regularly at governance level meetings (eg Steering Committee meetings). A mechanism for addressing and recording any potential or actual conflicts of interest needs to be established.
- **recognition of involvement of all participants** needs to be acknowledged and how this will be recognised throughout the Project and any Project outputs.

Box 1: Getting Support Statement

Sharing your story will get you thinking about your own experiences. If you feel any distress, talk with someone you trust—perhaps a family member, friend, or your health professional.

StrokeLine's health professionals provide information and support. They take the time to listen. They can help you find the support and services you need.

- StrokeLine is available 9am to 5pm, Monday to Friday, AEST. Call StrokeLine on 1800 787 653 or email strokeline@strokefoundation.org.au
- Lifeline is available for anyone experiencing a personal crisis. LifeLine is available 24 hours a day, seven days a week. Call 13 11 44 or visit lifeline.org.au

4.2.2. Information and confidentiality

Confidentiality

When collecting communications, data and other information from people with a lived experience of stroke in the course of a Project it is important to be very careful about confidentiality. When sharing information it is important to be explicit about the confidential nature of the information and the boundaries around that information.

Depending upon the situation confidentiality may encompass a range of possibilities:

- **Information is not confidential** and can be used internally and externally
- **Information is not confidential but needs to be deidentified** before the information can be used. In this case people's names and other identifying features of the situation should be removed.
- **Information is confidential within a Project** but is submitted to funding sources as documentation of services provided. Information in this case can be deidentified.
- **Information is confidential within a Project** but may be shared among team members or other Stroke Foundation employees for purposes of developing the

Project. It might mean the information can be used, but people’s names and other identifying features of the situation should be removed.

- **Information is completely confidential** so that no one but the individual sharing the information and the team member that information is shared with will have access to the shared information without express permission. If someone tells you something that is personally compromising or that they do not wish to be passed on to others, it is important to honour this. It may mean that information cannot be directly used in the Project and should not even be passed on to other members of the team.

At an early stage it is worth discussing the ways in which using social media (e.g. Facebook or Twitter) affects issues of confidentiality. It is important to be as clear as possible about how confidentiality will be handled to avoid causing harm or embarrassment to people.

A limit is placed on confidentiality in circumstances where team members get to hear about unlawful or risky behaviour, suspected child/ adult abuse and/or where there may be a risk of serious harm to other people. The circumstances of disclosure should be made clear to those participating in the Project in advance.

Informed consent

There are two situations to consider:

1. **Individuals giving consent to participate in a Project** – enough information needs to be provided about the purpose of the Project so that people are fully informed, and can ask and have answered any questions, and are able to decide whether to participate (or for their parent/guardian/contributor to agree). Be honest about your intentions and to try to attend to people's objections or concerns.
2. **Project participants giving consent to share information or allow access to aspects of their lives as part of the Project** – enough information needs to be provided about the uses of any data (see also Confidentially above).

Sometimes it is not only the consent of individual people that is required, but also collective consent (e.g. of a community, group or organisation).

It is also important to acknowledge that the Project may change and develop over time, so consent may need to be continually reviewed and renegotiated, especially if specific plans for publication and dissemination are developed.

Anonymity

It is a good idea to discuss in the Project team the advantages and disadvantages of identifying people, places and organisations (by their real names, appearances or voices in written, visual or audio records or social media) – whether this is in team discussions or dissemination of the Project. If the Project relates to sensitive topics or contexts (e.g. household debt, mental health, domestic violence), it is often important not to name or give identifying features of individuals. It may also be advisable to give organisations and places different names, as using real names may help identify people. However, in some cases, individuals and organisations may wish to be named, to have their opinions, achievements or challenges credited or highlighted. Yet naming some people needs to be discussed fully and consideration given to the implications for the anonymity of others.

Handling personal information

Stroke Foundation policies on privacy and complaints provide guidance on how we collect, manage and use people's personal information, and on how we manage complaints.

These policies are available on our website:
https://strokefoundation.org.au/Privacy

https://strokefoundation.org.au/Contact-us/Feedback

4.2.3. When is formal ethics approval required for a Project?

Formal ethics approval is needed for all research involving human participants. This approval must be obtained before research participants can be approached and before data collection can begin. This process helps research participants be confident that possible risks of the research project have been considered, minimised and deemed acceptable.

Exemptions from ethical review can be granted for research that carries negligible risk – where the only foreseeable risk from the research is no more than inconvenience (eg time spent filling out a survey). Anything more than this (eg risk of discomfort) is not considered negligible risk.

Routine clinical audits, quality improvement or assurance activities, and health service program development, delivery and evaluation are not usually considered research and may not require research ethics approval. However, if part of the health service program development involves research, for example comparing two methods of delivering a service, then ethics approval will be required. In addition, if the intent is to publish findings from a Project in a peer reviewed scientific journal then ethics approval is likely to be required. When in doubt seek advice from the Stroke Foundation Research Advisory Committee via research@strokefoundation.org.au.

Irrespective of what an activity is (quality improvement, program development or research) the activity must be conducted in a way that is ethical.

4.3. Sharing and learning from the Project

During the Project, or once the Project has been completed, the team will usually want to share the Project process and outcomes with others – people in the locality, community organisations, policy makers, politicians, academics and others.

4.3.1. How to analyse and interpret research data and findings?

There is often a tendency for Stroke Foundation employees or more experienced community members to take responsibility for analysis and interpretation of the Project data. However, involvement of a range of people in analysis and interpretation of findings can be an opportunity for the development of new skills.

It may require more time, training and creative thinking about inclusive processes, but may add valuable alternative perspectives on what some of the findings mean and contribute to the thinking about problems and solutions.

4.3.2. How to share the Project?

The process and findings may be shared with others as the Project progresses, and there may be a wide range of different audiences to consider.

What to share? Sharing Project outputs can have both positive and negative effects on communities. For example, sharing accounts of personal stroke stories may have social problems of particular groups or neighbourhoods might be expected in a report to research funders or service providers, and may result in heightened awareness of inequalities and/or improved services. But this may have a negative effect on the self-esteem of community members. Open, honest discussions and negotiations about what to share, how to share it, desired outcomes and possible negative impacts should be an ongoing part of the Project.

Formats for dissemination: If a range of different audiences is anticipated, it is important to consider the most accessible format to reach people, e.g. visual materials (videos, cartoons photos); written materials (blogs, articles, books); conferences and workshops, or audio (podcasts). It is also important to consider what formats may suit the skills of different members of the Project team, and several different types of outputs geared to different audiences might be produced.

Authorship and credits: It is a good idea to discuss in advance who will be responsible for compiling or writing the outputs, when decisions will be made about the nature and formats of outputs and how the responsibility can be shared and skills developed by those who are not used to doing this. Agreeing who will be credited and how is also important – ensuring that the variety of contributions is recognised.

4.3.3. How to make an impact?

Once a particular Project has been finished or when the funding runs out, this is not necessarily the end of the process.

Implementation: It can be useful to think about how to use or implement the findings and follow-up any recommendations for change in practice, policy and ways of working.

Producing useful outputs: Consideration should be given to ensuring that any reports or other products of the Project or research are made accessible to the wider Stroke Foundation community, researchers, policymakers, service providers, community members and other organisations for future use. Additionally it is important to ensure that the skills and knowledge gained by all of the partners is capitalised upon in Projects.

Learning from the Project: It can be very productive for the Project partners to reflect on what they have learnt. Not just from the Project findings, but also from the process of doing the Project and working together. If the relationship has gone well, or has potential to go well, then a longer-term partnership may develop.

Good endings: At some point the relationships that were formed around the Project may have to end (funding ends, people move on). So, it is worth thinking about how endings should be negotiated to ensure the benefits of the Project can continue into the future and some participants do not feel let down.

Table 1: Ethical Projects Checklist

Project phase	Activities to consider	Notes	
1. Preparing & planning	What **type of involvement** would be useful for the Project?		
	Why work together?		
	Who should be involved?		
	What are the aims and objectives of the Project?		
2. Doing	**Terms of Reference**	**Item**	✓
		agreed ethical principles	
		protocol for communications and meetings	
		protocol for safety	
		protocol for handling difficulties and conflict	
		management of Project	
		what contribution fees and expenses are available	
		any training and policies required	
		practical details	
		processes for reflection, evaluation and learning	
		confidentiality, informed consent, personal information, anonymity	
		conflict of interest	
		recognition of involvement of all participants	
	Information & confidentiality	Has the level of confidentially for information been discussed and documented?	
	Informed consent	Have participants provided consent to participate in the Project?	
		Has consent been given to share information?	

	Anonymity	Have you discussed the balance of identifying verses anonymity and have preferences been clearly documented?	
	Handing personal information	Have all team members read and understand Stroke Foundation policies on privacy and complaints?	
	Ethics	Do you need to apply for ethics for the Project?	
3. Sharing & learning	**Analysis** –how will the whole team be included?		
	What Project outputs will be shared?		
	How will the Project outputs be shared?		
	Who is responsible for compiling outputs?		
	How are the individual team members to be **credited** for their contributions**?**		
	How will the Project outputs be used to **implement** change?		
	What has been **learned** from the Project?		
	How will the Project **wrap-up?**		

5. References

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