Lancet Psychiatry Commission Lived Experience in Mental Health Research

Lived Experience Advisory Board (LEAB)

Role Description

Context

Lived experience* involvement and leadership are essential for mental health* research to be meaningful, for practice and policy to effectively serve the people concerned, and for inequities to be identified and addressed appropriately. While lived experience involvement in mental health research is becoming more common globally thanks to the many people with lived experience who have made this happen, there are disparities in practice and many questions yet to be answered. How can research truly integrate, honour, and reflect lived experience? How do we avoid tokenism and exploitation? How do we negotiate power? What cultural, structural, and systemic changes are needed? How do we sustainably serve epistemic and social justice?

Traumascapes and the Service User Research Enterprise (SURE, King's College London) are teaming up to co-lead the development of a *Lancet Psychiatry* Commission on Lived Experience in Mental Health Research. Lancet Psychiatry Commissions bring together experts from across the world to synthesise knowledge on a key issue in mental health and build the way forward with co-defined next steps and recommendations. We anticipate that the Commission will;

- reflect on the history and evolution of lived experience involvement in mental health research;
- assess existing knowledge and knowledge gaps, considering diverse knowledge and practices;
- establish key principles for lived experience involvement in mental health research;
- explore and embrace difference and debate; and
- provide recommendations and next steps for the field.

The Commission will be overseen by a **Lived Experience Advisory Board (LEAB)** of around 12 people who will help shape the development and structure of the Commission. Guided by the LEAB, we will appoint up to 20 Commissioners (or co-authors) from across the world who will write the Commission.

The Commission will be produced over two years, followed by a third and final year during which we will work with the LEAB and Commissioners to produce a range of resources to accompany the Commission. Examples include illustrative artworks; podcasts; blogs; tailored resources for key stakeholders (e.g. people with lived experience, funders, journal editors); and exhibitions, conferences, and other events.

Given the influence of *Lancet Psychiatry* Commissions, we hope that the Commission will significantly increase the status, standard, and impact of lived experience involvement and raise the quality of mental health research and practice.

*A note on language

We have elected to use the terms 'lived experience' and 'mental health' because they are broadly recognised, yet we acknowledge their partiality. We hope that these terms can be understood loosely as encompassing people who work in other ways, honouring inner wisdom and doing research on our inner worlds and our individual and collective experiences of being. The terms we have used here may not be those we collectively agree to use in the Commission.

About us

The Commission is being supported by two project coordinators (Lou and Dylan, Traumascapes), a survivor artist-researcher (Sully, Traumascapes) and an administrator (Paolo, King's College London). The Commission is co-led by Laura (Traumascapes) and Angela (Service User Research Enterprise, King's College London), with support from the Centre for Society and Mental Health (King's College London), *The Lancet Psychiatry* and Wellcome. You can find out a little more about these organisations here.

Co-lead <u>Traumascapes</u> is a survivor-led organisation dedicated to changing the ecosystem of trauma and creating new horizons for survivors through art and science. We exist to comprehensively respond to trauma and mental distress, support survivors, and protect people's rights to safety, freedom, and joy. We do this through research, education, consultancy, advocacy, and healing provisions.

Co-lead <u>Service User Research Enterprise (SURE)</u>, based at King's College London, is a unique academic research group comprised predominantly of Patient and Public Involvement Coordinators and researchers with direct experience of neurodiversity, trauma violence and abuse, mental distress, and/or (ref)using mental health services.

Partner <u>the ESRC Centre for Society and Mental Health (CSMH)</u> brings together a unique mix of disciplines and expertise to conduct innovative research on the impact of rapid social changes on mental health. Research within the Centre aims to improve understanding of

the complex interrelationships between society and mental health, and to work in partnership with people with lived experience.

Publisher <u>The Lancet Psychiatry</u> is a scientific journal and an internationally trusted source for original research within psychiatry. It publishes original research that advocates change in, or illuminates, psychiatric practice. The Lancet Psychiatry is keen to amplify voices of lived experience.

Funder <u>Wellcome</u> is a global charitable foundation established in 1936. Wellcome supports science to solve the urgent health issues facing everyone by bringing together expertise across science, innovation and society, including lived experience expertise. Wellcome has expertise in lived experience in mental health in particular.

Our ethos

At the very start of our work together, we (co-leads, coordinators, artist-researcher, and LEAB members) will co-define the values and principles that we would like to guide our work so that we can ensure each person's needs are considered and everyone feels valued and heard.

Both Traumascapes and the Service User Research Enterprise (SURE) are intentional about doing work that is values-based, purpose-driven, and led by lived experience. The Commission's values will be shaped by the people who are part of it (rather than us) but you may find it useful to know where we're coming from and what values we hold: you can find out more about Traumascapes' values and beliefs <u>here</u>, and SURE's approach <u>here</u>.

The Lived Experience Advisory Board (LEAB)

We are seeking up to **12 people** to join the Lived Experience Advisory Board (LEAB) to help guide the development and growth of the Commission.

It is essential for the LEAB to have global membership. Though multinational, our team is based in the UK and it is important that we widen the group to include people from across the world so that a breadth of different experiences and perspectives shape the Commission. This means that we actively encourage people from around the world to apply, particularly people from the Global South.

The LEAB will **meet five times** across the duration of the Commission, from approximately July 2024 to approximately June 2026. Each meeting will last approximately **three hours** with a mid-way break (members will be able to come and go from the meeting space, as needed for additional breaks etc.).

Some meetings will take place online and some will take place in **London, United Kingdom**, with the option of joining **online**, depending on preference. A budget is available for travel

(including national and international travel), accommodation, and subsistence for those who choose to join in person.

The table below outlines the **key meetings and milestones** of the LEAB, the date and likely focus of the meetings, the progress of the Commission at that time, and the role of a survivor artist-researcher who will capture our process.

Approximate	Meeting focus & milestone	Commission	Evaluation &
date		progress	reflection
2 July 2024	LEAB Meeting 1: consider	The Commission is	A survivor-artist
	the aims of the Commission	up and running	researcher will
	and our underpinning values		attend all
23 July 2024	LEAB Meeting 2: finalise	We have agreed a	meetings to
	core values and principles;	path forward	record and
	agree key content of the		evaluate
	Commission; identify		process, and
	potential Commissioners		capture key
	(co-authors)		learning on the
May/June	LEAB Meeting 3: review	There is a final	values and
2025	progress of writing;	draft of all the	principles for co-
	problem-solving	Commission	working on lived
		sections	experience
March/April	LEAB Meeting 4: review	A final draft of the	projects.
2026	edited draft; consider	Commission is	
	supporting resources;	submitted for peer	
	develop dissemination plan;	review	
	reflect with survivor artist-		
	researcher		
June 2026	Joint LEAB / Commissioner	Edits based on	
	(i.e. co-author) meeting:	peer review	
	agree supporting resources;	feedback are	
	reflection; celebration	agreed,	
		Commission is	
		resubmitted	
September	Commission launch with ongoing dissemination of accompanying		
2026	resources		

Access and support

We will hold conversations with each LEAB member about their access and support needs so that we can do our best to meet individual needs and make this work as safe and comfortable as possible for everyone. We will also work with LEAB members to develop self-care and safety guidelines for our meetings and our work together.

Peer support will be available before, during, after, and in between meetings, if needed. Peer support will be provided by <u>Survivors Voices</u>, a survivor-led organisation with expertise in supporting people with lived experience involved in research. If a different form of support would be more suitable to you, you will be able to discuss this with us and we will do our best to make it happen.

Payment and expenses

LEAB members will receive £150 per person per meeting (of approx. 3 hours). There will also be opportunities to get involved in generating and disseminating additional resources, also paid at £150 per half-day or £300 per day.

There is also a budget for travel, accommodation, and subsistence. This includes national and international travel.

Role description and criteria

LEAB members can be based anywhere in the world.

LEAB members will contribute to the Commission through:

- shaping the development of a values-based process led by lived experience;
- gently and kindly holding ourselves and one another accountable to that process;
- embracing the messiness and complexity of lived experience in mental health research, and finding ways to discuss this with integrity, openness, mutual respect, and compassion;
- using our knowledge of lived experience in mental health research (including good practice, issues, and gaps) to shape the structure and content of the Commission;
- drawing on our knowledge and experience to recruit potential Commissioners (i.e. co-authors who will write key content for the Commission);
- contributing to problem-solving if and when issues arise, seeking to make reparations where necessary, and engaging in co-learning;
- sharing the Commission among our communities;
- commenting on a near-final version of the Commission;
- guiding the development of associated resources.

Skills and experiences: essential criteria

All LEAB members should have:

- direct (personal) lived experience of mental health struggles, mental distress, psychosocial disability, madness, and/or using or refusing mental health services (Please note that we operate on the basis of self-identification and no one will be asked to share their experiences at any point);
- a deep understanding of the role and value of lived experience in mental health research and a commitment to amplifying this;
- an excellent understanding of lived experience involvement and leadership in mental health research (either locally or globally, including existing good practice and/or important issues and/or gaps and needs);
- significant experience working collaboratively towards a common goal;
- a commitment to mutual care and shared learning;
- an ability to sit with discomfort and hold differing opinions with openness and respect;
- a commitment to anti-oppressive work;
- a readiness to challenge traditional approaches and think creatively;
- experience of sensitively working with people from different cultures and backgrounds, and with different kinds of lived experiences;
- connections with wider networks of people with lived experience in mental health, particularly communities, grassroots initiatives, and organisations led by people with lived experience;
- access to the internet / email / online meetings (we may be able to support with the costs of these).

Skills and experiences: desirable criteria

The following skills and experiences would be helpful, but are not essential:

- familiarity with social movements of people with lived experience, including madness, mental distress, trauma and violence, psychosocial disability and using or refusing mental health services;
- experience of working as a lived experience researcher, practitioner or advisor;

How to apply

Please complete the Application Form and send it to Lou (<u>lou@traumascapes.org</u>) by the **2nd** of June at **11pm GMT**.

If written applications are difficult, you can send us an audio or video application instead (of up to 4 minutes in total for all questions).

Please read the tips at the start of the application form on how to produce a strong application.

We will select applicants based on how they meet the essential criteria **and** based on how we can ensure the LEAB comprises people with a variety of expertise and interests, a range of identities and backgrounds, and who are based in different parts of the world.

Selected applicants will be invited to interview on the 18th or 19th of June.

The first two LEAB meetings will be held on the 2nd of July and the 23rd of July (online).