

West Sussex Lived Experience Advisory Group Impact Report 2024-25

Tasha Barefield
Coproduction Lead

Jenny Kolda
Lived Experience Facilitator



Contents

- LEAG membership
- Activities from the last year
- LEAG and SCALE network topics
- LEAG aims for 24-25
- Key achievements in West Sussex and across Sussex
- LEAG impact and member feedback
- Next steps

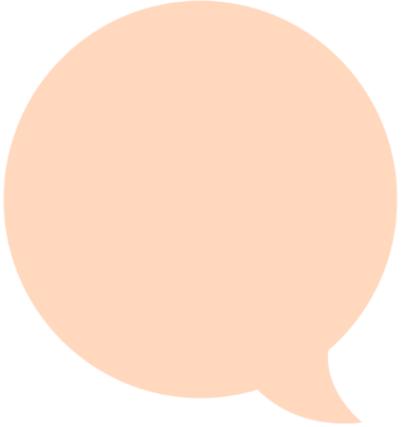


LEAG members

- 24 LEAG members (19 of which have been actively involved)
- LEAG members age ranges from 25-70 years old
- 25% of LEAG members are male
- 8 members are carers
- 2 have learning difficulties
- 4 are neurodivergent/neurological disability
- 7 have a physical disability
- 3 new LEAG members joined this year

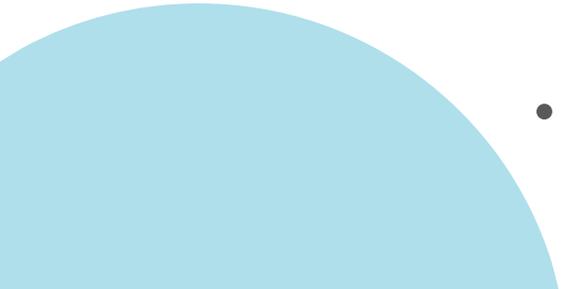


"It's been really great being part of the LEAG. The people I have met are amazing and so passionate about change. I am proud to be part of the LEAG and thankful for all the support and encouragement I have been offered. I am looking forward to seeing what we can achieve in the year ahead."



Quantative Overview



- Over **800 Lived Experience hours** supported in West Sussex this year
 - **169 meetings** with LEAG members attendance
 - **24** West Sussex LEAG members
 - Average of **9 LEAG members attending LEAG meetings** over the year
 - Average of **9 WSx LEAG members attending SCALE** network meetings
 - **6 LEAG representatives** attending strategic meetings
 - **90 people** attended the Sussex Co-production Conference in February 2025
 - **190 people** attended the webinar for the Mental Health Language Guide we co-produced
- 

LEAG meeting discussions

Pathfinder Services - Mary (United Response) Emma (SPFT) Siobhan (Mind)

Mental Health Support Services recommissioning
– Tasha Barefield and Josh Hall (ICB)

Right Care Right Person - Sarah Hall (SPFT)

Transformation of Crisis Resolution and Home Treatment Teams - Ollie Vantini (EbE SPFT)

ICB Data Review from LEAG & Engagement with Primary Care Group – Lydia Taylor

WSx LEAG Peer Facilitated Trauma Support Group
– Lydia Taylor and Sara Shepherd

Neighbourhood Mental Health Teams (NMHT) meeting plans - Amanda Walderman (ICB)

Crawley Hub proposal - Amanda Walderman (ICB)

LEAG meeting discussions cont.

Emotional Wellbeing Service (EWS) and Pathfinder reports - Amanda Walderman (ICB)

NMHT communications - Megan Gee (SPFT)

Emotional Wellbeing Service overview – Emma Logie (BHT) and Patricia Mendes (SPFT)

Operational Delivery Group feedback – Amanda Walderman (ICB) and Jenny Kolda

Joint Christmas Event with other LEAGs

Mystery Shopper exercise – looking at mental health signposting in WSx

Urgent Emergency Care Self Assessment Tool – Sarah Brennan and Louise Thomas (NHSE)

SCALE Network Topics Covered

- Future of participation in transformation – Christmas Musonza (SPFT) and Marian Guerges (ICB)
 - Co-production Conference Feedback
 - Mental Health Communications Working Group update and how to create system wide signposting – Justine Williams (SPFT)
 - NMHT model diagrams – Megan Gee (SPFT)
 - Place-based LEAG evaluations and the commissioner's highlights (Amanda Walderman, Leila Morley and Sara Candler (ICB)
 - NMHT communications – poster and letters to service users – Megan Gee
 - Updates about NMHT developments – Andrea Potter and Martin Dominy (VCSE transformation team)
 - NMHT milestones and metrics – Andrea Potter and Martin Dominy (VCSE transformation team)
 - Mental Health signposting update and materials - Justine Williams (SPFT)
 - Emotional Wellbeing Service updates – Jenny Edge (SPFT)
 - Mental Health Language Guide – Megan Gee (SPFT)
 - Electronic Patient Record – Lindsay Evans (SPFT)
- 

**Meetings
LEAG members
and/or the
facilitator has
attended and
supported**

Community Transformation Partnership Group

Operational Delivery Group

Mental Health Support Services recommissioning

Crawley Local Planning Group

Primary Care Group

West Sussex Pathfinder

Language Reference Group

CMHT Programme Board

Eating Disorder Steering Group

Co-production Discussion Forums

VCSE Mental Health Network

SPFT Lived Experience Feedback Group

LEAG Aims for 24-25:

- ✓ Support lived experience involvement in the Phase 2 Transformation Operational Delivery Group for the development of the Neighbourhood Mental Health Teams.
- ✓ Request lived experience representation on the MHSS recommissioning tender evaluation panel.
- ✓ Prioritise the workstreams we can support due to a reduction in our funding from the ICB in real terms.
- ✓ Streamline payment processes and monitor the budget for reimbursements for LEAG members to attend meetings.
- ✓ Continue Sussex wide Co-production networking and sharing resources to organise events and discussion forums.
- ✓ Explore the prospect of a Sussex wide lived experience programme of training opportunities alongside Possability People, Changing Futures and SPFT.

Key Achievements

- Set-up, delivered and evaluated a peer led trauma group for the LEAG
- Supported the co-production of the WSx Mental Health Joint Strategic Needs Assessment
- Created a LEAG presenter pack
- Challenged and highlighted issues around the development of NMHTs especially related to communications
- Involvement and influence over MHSS tender principles, specification and evaluation
- Challenged Pathfinder to consider how they are co-producing within their organisations and across with wider network



Key Achievements cont.

- SCALE and LEAG highlight reports now go to the monthly Programme Board and VCSE Mental Health Network meetings
- Two LEAG members attend the ODG to represent lived experience and LEAG feedback
- LEAG members visit other area ODGs and LEAG meetings to gain better understanding and share best practice
- Closer relationship building across other LEAGs – LEAGs supporting and encouraging each other
- Invitation for LEAG member to join the Mental Health Oversight Board



Sussex Wide Achievements

- LEAG member training – co-produced and co-delivered
- SCALE mental health network – recognition and increasingly the place to go for consultation
- Sussex Co-production Conference – attendee led agenda, we had amazing feedback
- Co-production Discussion Forums – 10-20 people attending these each month
- Sussex Co-production Trello Board launched – shared platform for all co-production resources
- 'Change The Language' project and guide – 2 years work launched and guide now being shared across the system



LEAG Areas of Impact

"a moment that made me feel really proud...I was at a system-wide meeting...They were talking about co-production and lived experience and service users feedback... a random individual, that has nothing to do with the LEAG said, where is the lived experience voice in this bit of work? **We have LEAGs in Sussex. Where are they? Why are they not sitting at the table with us?**"

"...back to the work that **Jenny led on in terms of the Crawley work** and how that's now become such a strategic piece of work and has led to the wider development for the neighborhood mental health teams."

"The **mental health needs assessment work** and what that meant for Capital and that's led into further development co-production work."

"about **Pathfinder and the fact that the status of the LEAGs and co-production** is really up there and on their agenda, that it wasn't at all when we first started three years ago."

LEAG Areas of Impact

"the **mental health support services retendering** that we've been talking about which includes LEAG and we should be really proud of the fact that we are principle number two. That the whole service or all the services should be co-produced."

"The **trauma group and the significant support for people** as well that this is a really supportive community supportive group and I think that the peer support sort of shines through from that."

"I was involved in the **communications mental health signposting**, how you're really feeling campaign. And it was really amazing to hear Justine talk about have we got lived experience? Has it gone to the different networks etc. And even like this week I was at the doctor's surgery and the leaflet was there and I was like, it's so amazing to see it there after all the work that's gone into it."



Wider Impact of LEAGs

Challenging stigma and preconceptions about people that use services and their carers

Working with transformation staff to influence changes to services, communications with the public

**LEAG/
SCALE**

Influencing wider system, public sector and VCSE organisations to do effective co-production

Involvement in commissioning, needs assessments, challenging decision making



Ripple Effect

- It's difficult to fully measure the wider impact of the LEAG and having LEAG members attending meetings and arranging events like the co-production conference.
- How can we get feedback from people we work with to fully measure our influence and impact across the Mental Health system?
- We can see and hear the change in meetings and when talking to people about how lived experience involvement and co-production is mentioned and attempted.

LEAG Members Survey (7 replies out of 18)

100% agree the West Sussex LEAG is committed to coproduction

100% of LEAG members feel that the LEAG is making a difference in getting lived experience voices heard in mental health service development

72% agree they feel supported to attend the LEAG meetings

100% think that meeting with other LEAGs in the SCALE meetings has been an important development in our influencing of mental health services

57% feel coproduction working in West Sussex, 28% said maybe and 14% said no it isn't working

LEAG Member Feedback

The LEAG is a safe space

"... I think a lot of the people are actually talking on something like this where they wouldn't anywhere else. There's no judgment so that helps."

"I may not always find the words to say it and I might struggle with that, but there's lots of support... I feel comfortable to say what I want to say and it's a marvellous feeling that you know you can come out and give your thoughts and opinions."

"... with the trauma groups...we're all so very unique and the inspiration is everybody in the LEAG brings something that's different to the other. I learn from everybody here...it's that lived experience and community."

"Capital provides a unique safe space for my voice to be heard. The meetings are warm, welcoming, non-corporate and non judgmental."

"I think the way that these groups are managed and led is really good as well."

LEAG Member Feedback

Building confidence & self-esteem and wellbeing of LEAG members

"It's helped me connect with others and recognise the value of what I've been through. It's improved my self esteem."

"It has built my confidence up and allowed me to feel valid in sharing my experiences. I feel more able to try new things and feel part of society again."

"Turning a negative situation into a positive, finding my voice, becoming more of an activist"

"These meetings have meant a great deal to me and have made a positive impact on my health. I am grateful for the opportunities to speak up and share without judgment and to be listened to and valued."

"It's stimulating work. It makes me feel mentally healthier."

LEAG Member Feedback

LEAG members have learnt new skills and actively participate

"Something I learned about myself is that I actually have a skill doing really effective presentations when we deliver them in person... I'm having a really positive impact and it's something I'm really good at."

"A goal where I also felt really supported and also proud was co-designing and co-delivering the training, which I think is just incredible...I was really pleased to be part of that..."

"Enabling me to learn and help others from my experiences and voice ideas in a productive manner. "

"I'm very proud of holding the five minute grounding sessions [at the end of each LEAG meeting] because they were really good. I really enjoyed doing that."



LEAG Member Feedback

LEAG as a source of information

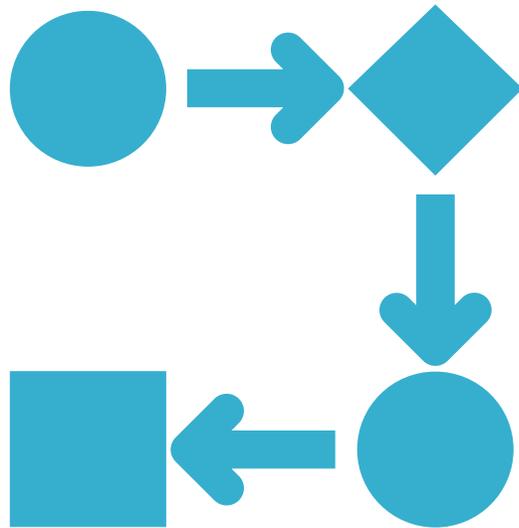
"... The way that LEAG has made a difference for me is giving me that hope that we still can do this, that we can really do the proper lived experience thing, the co-production thing, the peer support thing."

"Seeing all the other LEAG members who at first really didn't understand about the landscape, now really do and they're out there doing these things. When I see another LEAG member at a meeting... hear the sort of things they say. I think, yay we're getting there."

"The LEAG just gives so much insight. I think it's so fantastic the way that so many people are kind of invited along to our meetings and it's really helped me to have a much better kind of thorough view of what's happening really with mental health services"

" ...not just SPFT, but kind of broader and wider than that and just finding out about the different organisations and what they do. So, in terms of insight and broadening my understanding of what's going on it's been fantastic."

Making decisions together across the system and acting on LEAG feedback needs improvement



"Whilst we are working together, I don't feel that our opinions are taken into account; decisions are taken in spite of us, not with us. And/or they bring topics to us late in the day, when they have already decided something such as the posters/letters. Or not at all when it's a major change that they know we will be unhappy about (reduction in rehab hospitals and other cost cutting measures.)"

"Our voices are being heard, but I'm not sure how well they are being acted upon outside Capital"

What is one thing you think the LEAG could improve on in the future?

- Increase membership and funding by just carrying on with this great work.
- More diverse voices.
- More workshops and training.
- Training for people to work with lived experience experts – primary care.
- More hybrid meetings and in person meetings.
- Improved access - meeting times/days (evenings and weekends).
- Build stronger relationships with commissioners.
- Reach more people – the people that aren't listening yet.
- Good links with national LEAGs (do they exist?)
- Speaking at National Conferences.
- Be involved in the design of a service.
- I would also love to see some creative models co-produced and co-delivered for community-based options of treatment. We have a lot of creatives within our reach.

Next Steps



- The LEAG funding will be changing from October – it is unclear who will get the contract to support and facilitate the LEAG going forward and what our resources and priorities will be.
 - Reaching new LEAG members from minoritised communities.
 - Working with LEAG members to identify their development needs.
 - Training for clinicians and others about how to work with lived experience experts.
 - Work with the impact of the changes to the Community Mental Health Transformation Programme, NHSE and ICBs.
 - Look at how we can embed lived experience and co-production in the future of NMHTs.
- 
- 



Questions?