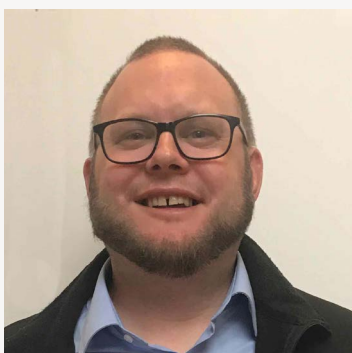


# Annual General Meeting and Members' Event – 2019

## The Value of User-led Groups

Thursday 24th October  
10.30pm – 4.30pm  
Priory Street Centre  
Priory Sreet  
York YO1 6ET



This report includes the minutes of the 2019 AGM and a detailed record of our Annual Members' Meeting 'The Value of User-led Groups'.

As well as this report we have two videos available on our YouTube channel:

<https://www.youtube.com/user/nsunformentalhealth>

**The Value of User-led Groups:**

<https://www.youtube.com/watch?v=XXYXRqZCOEw>

**AGM 2019:**

<https://www.youtube.com/watch?v=HrgRxv8WOQE&t=5s>

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**Company number:  
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2020**



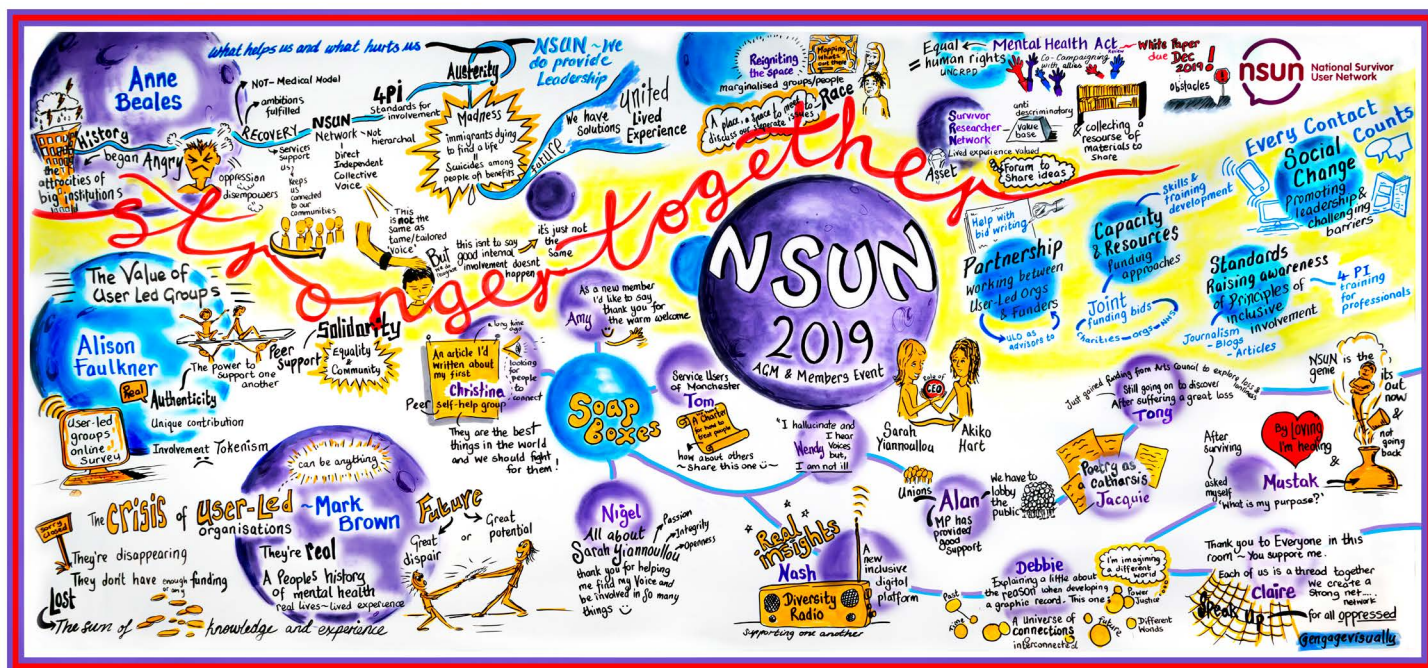




Sarah in her final AGM address talked about how difficult the last couple of years have been, but also how the process of saving NSUN from closure gave the organisation a renewed sense of purpose. She spoke about the ways in which independent user or lived experience voices had been edged out of discussions and the way that NSUN is now looking to protect and celebrate the history of lived experience of mental ill health to prevent that history being lost. Without this history and collective sense of who we are, lived experience can be co-opted and corrupted and used as a rubber stamp rather than being a political voice in itself. NSUN, said Sarah, will be safeguarding the past of the movement

Sarah acknowledged the support that Mind had provided for this year's event, particularly the Engagement Team, who NSUN continues to work with to strengthen and promote peer support in communities. ●

**Visual by Debbie Roberts**  
www.engagevisually.co.uk



**Mark Wood** (chair):

## **Apologies**

Trustees - Alisdair Cameron, Eleni Chambers, Joe Kelly

## **Item 1 –**

### **Approval of minutes for September 25th 2018 AGM**

Mark asked for approval of the minutes of the 2018 AGM, as a true record of that meeting. The minutes (within the 2018 AGM report) were previously emailed to attendees and a copy was included in attendees' information packs on the day. Mark asked for comments and if everyone agreed with the minutes.

**The minutes were approved.**

**Mark Wood** (NSUN Chair): I'd like to add my thanks to the board for their confidence in voting for me as acting chair and nominating me as chair which is certainly an honour. It's going to be an exciting time to become chair, at such a time of transition as I've said in my report. We've got quite a refreshed board with quite a few valued, longstanding stalwarts and very soon a new CEO to work with, so interesting times!

## **Item 2 –**

### **Trustees' Annual Report**

**Sarah Yiannoullou:** This is to give you a short overview of our work in 2018/19. We continue to have the ambition to be recognised as a diverse network but also to hold that diversity of user experiences in a respectful way, and we have got a very diverse membership. Also that our projects and partnerships are all developed to progress the intentions that are set out in the Members' Manifesto. Last year we took a steer from the AGM, not just in terms of refreshing and reviewing the manifesto but also in taking forward some of the things people said that were important to them. So lobbying and campaigning for what isn't working... For years, for decades, we've been campaigning to be heard, to be involved, and for peer support to be recognised, and we're now in a time when it is recognised but also things are being adopted and co-opted in a way that we now feel we don't recognise as what we meant originally. So we've been doing quite a lot of work around this in challenging some of the developments particularly around peer support because the theme of last year's AGM was 'the Future

of Peer Support', talking about the value of community peer support and also peer-led peer support. What we're finding is the development of peer support in the workforce has really raised some concerns and some challenges. It's ambitious and in some areas it's working well, but we really want to promote the importance and how valid our interpretation and experience of peer support is. So we've been part of the national peer workers working group taking forward some of the recommendations from the Five Year Forward View. We had to lobby to be on that group and what we found is that collectives are not automatically welcomed and invited to policy level discussions anymore. We seem to be reverting back to single representative model so that's been the challenge, we've experienced that with the Mental Health Act Review panel as well as some of the other work around peer support. We've also been working in Sussex looking at community peer support, also working in partnership with provider and user-led organisations and Sussex Partnership NHS Trust, which is where we developed the peer support charter and we will be continuing that work this year.

As you know the Value of User-led Groups has been our main campaign this year, and we co-ordinated and helped facilitate a meeting between funders with the support of Lankelly Chase and with other user-led groups - Shaping our Lives and People First. In the last couple of years, in the review of our membership, we've been realising that groups are not only struggling but disappearing, and other user-led networks have also reported the same kind of losses with their groups. So we're doing as much as we can to raise that as an issue with some of the larger membership bodies as well as other mental health organisations as well. Some of the issues are about other orgs moving into the space of user-led groups, but it's the political landscape, it's the changes that have been happening not only politically but economically, but it's also about the changes that we maybe need to embrace and adopt.

Thirdly, listening to and acting on what our members tell us. In your pack you have the reviewed and revised Members' Manifesto. As well as mainly reflecting what people have been telling us over the last year, it has been made more accessible in terms of language and accessibility and it's been edited down to six points. Thank you to everyone who's worked on it and sent in their comments and views. Emma Ormerod who couldn't be here today did a fantastic job of pulling all that together – to reflect the views and ambitions of our diverse network.

Then, moving forward, learning from the past, we talked

- ▶ last year about the work we've been doing, supported by Mark (Brown) and Debbie (Roberts), about our role, about being the narrator of our past but also being really proactive in the present and planning for our own futures as well.

Projects over the last year – the Survivor Researcher Network (SRN) continued to grow and recruited more people to the working group. We've continued to promote and use 4Pi and Angela Newton supported a piece of work for us in reviewing how 4Pi is used and referred to and we're going to be doing some more work taking that forward.

Dom (Makuvachuma) is going to be talking about Reigniting the Space later which is coming to an end this year, but we've worked quite hard to get that project up and running, again it's about finding that collective political voice for racialised groups.

'A Call for Social Justice' – the Kindred Minds' manifesto (NSUN hosted project), we have some copies left so please take one.

We also worked with other user-led groups in the wider disability world. So through our Health and Wellbeing (Alliance) work, we've worked with Disability Rights UK, Shaping our Lives and Change, looking at access to employment for people and the support you can get. We facilitated a 'Deep Democracy' day bringing together potential employers and employees and also many disability-led groups.

We ran a London Digital Leaders lab – our ninth leadership programme in ten years now. Each leadership programme has given birth to something new and quite unexpected and that was the case with this programme as well.

Dorothy (Gould) will be talking about the Mental Health Act review work and campaign that we've been doing later.

And of course our peer support work but also our hosted projects. We've hosted a number of user-led initiatives over the last couple of years – Kindred Minds, also North East Together – Mish (Loraine) is here from NEt so please ask her any questions about their work if you have any. North East Together has grown over many years and the efforts of many people and I think that the development of that original network demonstrated just how working together with different groups of people and the support that we all need to survive and thrive, that's a really good example of a regional network that has survived through these difficult times.

And of course Real Insight, but seeing how, given the space and the right support, groups can develop and actually achieve their ambitions. So hopefully very soon, in the next couple of weeks, the Real Insight radio station will be launched, watch this space! Nash will tell you more about that in the soapboxes and we will put information out about it.

So that's a quick overview, there's a lot more work that we've done so please have a look in the annual report and ask any questions of anyone here today.

Mark W: Any questions? (No). Then the next item is the approval of the annual accounts. I will invite Helen Oldfield, Treasurer, to run through the annual accounts - summary featured in the annual report and previously emailed out.

## Item 3 – Approval of Accounts

**Helen Oldfield** (Treasurer): I'm just going to give a few minutes on last year's accounts and also a bit about how we've done this year because it's important to tell the story in context.

So as you can see from the figures our income was down from last year from £273,301 in the year prior to £214,926 and our expenditure was also down, and I think it's fair to say that it's been a difficult couple of years, that the funding landscape has changed quite dramatically over the last five years, and over the last couple of years particularly grants have been awarded for an annual year rather than on a three-year cycle so that means the team have to work harder. It triples the workload effectively as they have to make funding applications every year and it also makes planning more difficult. In light of this there was a move last year to move out of the London HQ and that the core team would work remotely and with digital being as it is, that's easier these days. We also had to undergo an exercise to make some positions redundant and the core team had reduced hours in order to bring our overheads down as much as possible. That's given us a bit of a deficit last year of £43,274. Happily we did have some reserves from the previous year of £56k so we able to weather that storm but it was a little nail biting at some points but Sarah's been very diligent and very 'on it' in terms of forward planning and really understanding what NSUN needed.

So that was last year and we've got a breakdown in the annual report of what our income was made up of – some of our trusted grant providers still giving us some



► money. What has been undertaken is building up a bit of budget, it can never be the core, but a bit more budget from project work from getting individual grants for specific projects and that has helped make a difference but we will always be an organisation that's reliant on grants and so it's absolutely key that that work continues. So this year 2019/20 will see staff costs go down as will other expenses so that we are as tight and efficient as possible. That all make sense? Any questions?

**Floor:** What does 'strategic advocacy' mean?

**Sarah Yiannoullou:** That is the policy and involvement and influencing work – a catch-all term really but it's where, at a strategic level, that we're advocating on behalf of members, on the basis of what members have told us.

**Floor - Dominic Makuvachuma:** Given the changes you alluded to with the funding landscape over the last few years, do you have an idea as to what the next few years are going to look like, what are the plans etc?

**Helen Oldfield:** I'll come on to that next thanks. Any more questions?

**Floor -** Slightly inaudible, question about staff:

**Helen Oldfield:** There are two staff currently – Sarah Yiannoullou (full-time) and Zoe Kirby (part-time) = 1 ½ posts. Then around that we have NSUN associates who are employed on a contract basis for individual projects. Any more questions?

So that was last year, but there has been a big shift really so we wanted to give you a picture on the positive news around the funding landscape so Sarah and team have been working really hard to make bids for the bigger grants which are Esmee Fairbairn and Tudor Trust – so the top two have been secured. So Esmee Fairbairn is three years at £60k a year, and Tudor Trust is £20k a year for three years. So that core funding makes us more secure, plus we've got Lankelly Chase and Dept for Health and Social Care funds too. There's some really interesting applications including the National Lottery community fund, quite a big piece of work, but they are looking positively at peer support and so it looks quite promising. So, we've got a stronger base, there is a greater amount of project work, and we're also looking at moving our membership to a paid model which would start with our Ally members that have bigger budgets, and again it wouldn't be our core source of funding but it would help bring in some extra funds.

So it's been quite a difficult year last year but we've weathered the storm and there has been quite a reversal of fortunes in recent months with some nice grants coming in.

**Floor - Nigel Moyes:** Just building on Dominic's question. I know we've got Sarah in post at the moment and someone taking over from her. I've been involved in NSUN for a long time. Can you give us some reassurances about projects that you're taking on that will not be put on the shelf?

**Sarah Yiannoullou:** Last year we talked about the importance of strengthening the links with the regional networks again, so that's definitely something that's a priority looking forward, and not just strengthening relationships with member groups but what kind of infrastructure work there is locally, and as you said Nigel, capacity. It's not just about funds or resources, it's about people capacity and availability too – motivation as well. We've had people that have been active in various regions and for various reasons things have had to be put on the shelf or put on hold for a while. But yes the priority is to strengthen the network and particularly the local links.

**Helen Oldfield:** Any more questions? (none)

**Mark Wood:** Thank you Helen. Now I'm going to ask for a proposer and seconder for the motion that the annual accounts for the period April 2018 to March 2019 be approved. Please state your full names for the record.

**Proposer:** Nigel Moyes

**Secunder:** Clare Ockwell

**Mark Wood:** So I will put the resolution, that the annual accounts be approved to the vote.

Those in favour (majority show of hands); those against (none); abstentions (none).

**That motion is carried.**

## Item 4 – Election of Honorary Officers

**Mark Wood:** Our Articles of Association require that all Officers must be elected annually at the AGM and that all trustees must retire at the end of the third year following their election to serve. I will hand over to Sarah Y now (as can't chair his own election).

**Sarah Yiannoullou:** We have Nominations for Honorary Office as follows:

i. **Chair:** Mark Wood

ii. **Treasurer:** Helen Oldfield

iii. **Secretary:** Dawn Willis

i. **Chair:** Mark Wood

Can we have a proposer and seconder for the resolution that Mark Wood is voted into position as Chair.

**Proposer:** Julia Smith  
**Seconder:** Julie Jaye Charles

So we'll put that to the vote – Those in favour (majority show of hands), those against (none), abstentions (none)

**So that motion is carried Mark Wood has been voted in as Chair.**

## ii. Treasurer: Helen Oldfield

Can we have a proposer and seconder for the resolution that Helen Oldfield is voted into position as Treasurer.

**Proposer:** Mish Loraine  
**Seconder:** Alison Faulkner

So we'll put that to the vote – Those in favour (majority show of hands), those against (none), abstentions (none)

**So that motion is carried Helen Oldfield has been voted in as Treasurer.**

## iii. Secretary: Dawn Willis

Can we have a proposer and seconder for the resolution that Dawn Willis is voted into position as Secretary.

**Proposer:** Nigel Moyes  
**Seconder:** Timothy Dunton

So we'll put that to the vote – Those in favour (majority show of hands), those against (none), abstentions (none)

**So that motion is carried. Dawn Willis has been voted in as Secretary.**

## Item 5 – Election of Trustees

**Mark Wood:** The trustees nominated for re-election who have had their period of three years, are: Alisdair Cameron, who sends his apologies, and Julia Smith.

And new nominees are Zoe Bennett; Nic Murray; Emily Reynolds; Rachel Rowan Olive.

Our Articles of Association provide that nominated trustees, other than officers, may be voted for en bloc i.e. all together. If there is any objection to this, trustees will be voted for individually with a proposer and seconder required for each nominated trustee.  
Any objections? (none).

So can someone please propose and second.

**Proposer:** Jacqui Lovell-Norton  
**Seconder:** Nigel Moyes

So I'll put the resolution, that the nominated trustees be voted onto the board.

Those in favour (majority show of hands), those against (none), abstentions (none)

**So that motion is carried.**

I'll also mention that, in our latest trustee recruitment drive, even though we didn't have enough spaces on the board for everyone, there were candidates that we deemed very capable of coming into the board, and to try it out, so we have actually appointed co-optees, and I'd like them to make themselves known – Jonathan Rackham, Amy Rushton and Nick Kennedy.

## Item 6 – Appointment of Auditors & Remuneration

**Mark Wood:** I'd like to thank the Auditors Martin Morrison and Co Ltd. For their work during the year and recommend their re-appointment.

Can we have a proposer and seconder that Martin Morrison and Co Ltd be re-appointed as auditors.

**Proposer:** Mish Loraine  
**Seconder:** Nigel Moyes

So we'll put that to the vote that the auditors be re-appointed – Those in favour (majority show of hands), those against (none), abstentions (none)

**So that motion is carried.**

Now I'll recommend that the trustees be authorised to agree the amount of remuneration for this year with the Auditors.

Can I have a proposer and seconder for that.

**Proposer:** Dominic Makuvachuma  
**Seconder:** Clare Ockwell

So we'll put that resolution to the vote that the trustees be authorised to agree the amount of remuneration for this year with the Auditors – Those in favour (majority show of hands), those against (none), abstentions (none)

**So that motion is carried. ●**

Guest speaker:  
**Anne Beales MBE -  
NSUN Co-founder**



**"We still care and we still know what hurts and what works and we have the solutions and we now have to take the steps to believe in our leadership, to reach out to others who are service users and people who have lived experience and join forces with them and build a proper movement."**

*Anne Beales MBE -  
NSUN Founder*



# Guest Speakers

Anne Beales MBE, Alison Faulkner & Mark Brown

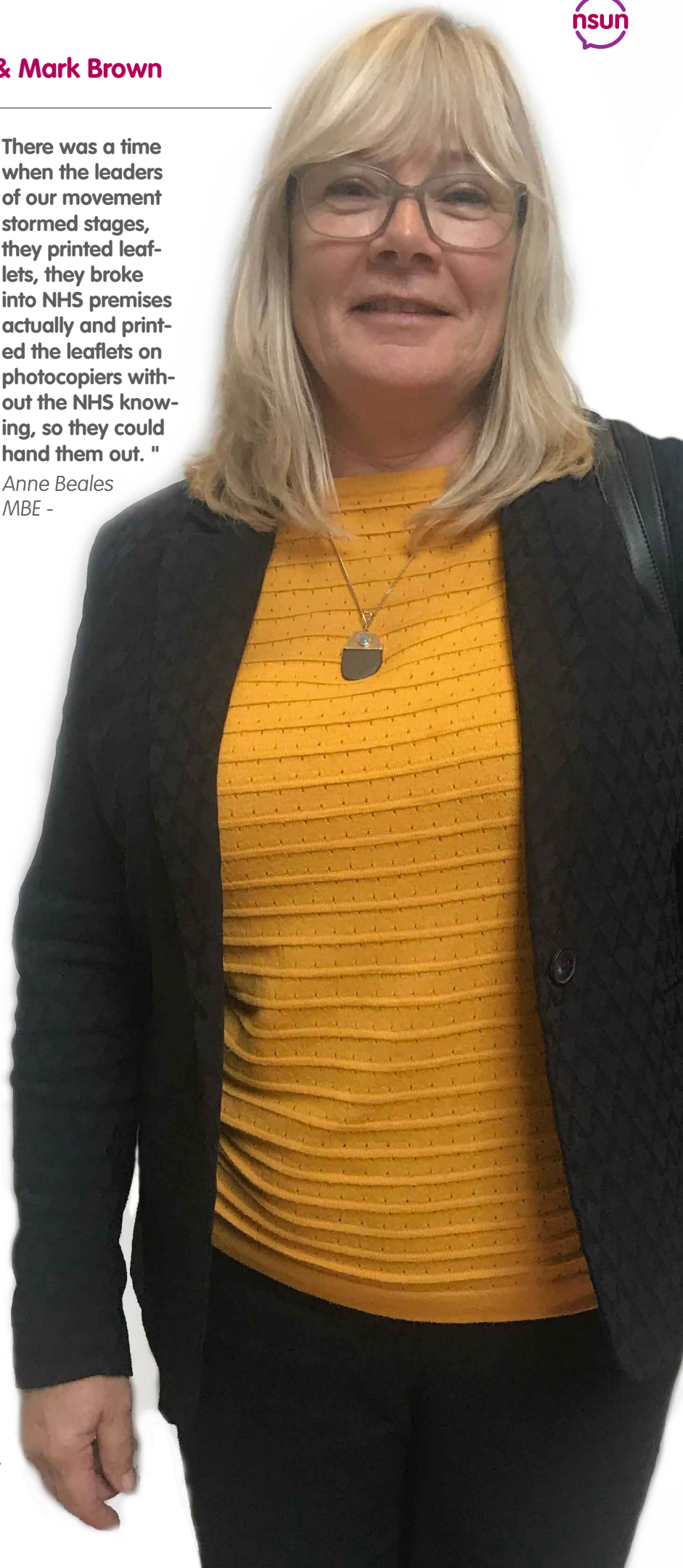


## Anne Beales MBE NSUN Co-founder

I wanted to start off talking about the history of NSUN because it's very important for people to understand where they came from. If you don't know where you came from, you don't know where your starting point is and you can't really measure where you are along the journey. So we started off as a very angry, sweaty and constipated group of people – no, but we were very angry. There was a time when the leaders of our movement stormed stages, they printed leaflets, they broke into NHS premises actually and printed the leaflets on photocopiers without the NHS knowing, so they could hand them out. And there are archives of badges that were made and placards, and that, in the 60s and 70s in particular, indicated how people had to be, and that was the kind of political climate and there was a mental health patients' union and in Hackney, people were actually hidden to avoid being sectioned and put in big institutions. That's where our roots lie. The atrocities that were inflicted on people because they had a diagnosis of mental ill health and learning disability in those big institutions should never be forgotten. And the point about how the medical model was able to deal with us as time progressed was they continued to segment us, so instead of having an institution where they would lock you up, check you had a bath, a different nurse then dried you and checked you got dressed, and a different nurse would see you in the day. You now have a certain outreach team, a community mental health team, you have the home from hospital team, and all throughout our lives and our journeys, that anger increases because we're not seen as a whole person, we're not seen as somebody who's got ambition, somebody who's got family,

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Anne Beales  
MBE -



## Guest speaker:

### Anne Beales MBE - NSUN Co-founder



somebody who's got history, somebody who's part of a community and we kept being segmented if you like and the way to put someone down, to suppress someone is to not see them as yourself. So the system, when we became active, we were very angry, we were very disempowered and it couldn't go on but also what couldn't go on was just being angry, you had to have a vision of what was possible and what NSUN did in its early days was start to talk about recovery, not the recovery that's spoken about now, but we talked about recovery meaning three things – and when I say this people think it's something new but it shows how far the concept of recovery has gone away from its roots. Recovery was always about if services can connect you to the best of yourself, if services can keep you connected to your chosen loved ones and if services can keep you in your community, then your recovery will be guaranteed, because from within you, you'll see the best of yourself, you'll feel the best of yourself, you'll start to know the best of yourself, you'll be shown the best of yourself, you'll be alongside people who know you, who trust you and really want you to be the best that you can be, and you'll be in a community, quirky though it may be, whether it's a religious community, a neighbourhood we happen to live in, a dialect that we speak, a racial background we come from, an ethnic group we're part of – we all are connected to a community. If services help us connect to that, then we will be ok in the end. And they talk about hope, but I'm always conscious of using the H word because it's used too often and misunderstood, and so NSUN's about people who use services understanding what it took to help us get better and sustain well. We didn't use that language, we wanted our ambitions to be fulfilled, we used language that was non-medical and I still tend to do that. And that's why NSUN was formed, it was formed as a network because we were sick of having nurses, doctors, people above us telling us what was wrong with us, we were sick of people not coming alongside us and if they did we had to be ever-so-

grateful - the network was formed as a network specifically because we didn't want a hierarchy. And the point about a network is no one part of a network is more or less important than any other part of the network. So for people who've been hospitalised, for people who've been sectioned, for people who've been separated from their communities, separated from the best of themselves, sometimes for years, for those people the idea of networking to get strength made absolute sense. That's why an organisation was not set up, a network was set up, and at that time we saw lots of service-user-led groups around the country, we had user focused monitoring groups in Bristol, we had Capital Project in West Sussex, I'm delighted to see Clare (Ockwell) here, we had all sorts of groups that were functioning and able to be part of a network and our overwhelming demand had to be shorthand, it had to be simple without being populist and we demanded that there should be a direct, independent collective voice at the table and how far have we come from that? And I'll come on to that in a minute as well. Our main demand was to have a direct, independent collective voice. Collectives of us got together with tiny resources and did amazing things. I remember when I was not so good in West Sussex, there was a group of people who were given about £200 to provide Sunday lunches for people who were isolated and lonely, and during that lunch people could find the best of themselves – friendship and community and that went on for about a year on £200, because people started to take turns, they go to know each other and they shared their houses and the whole concept of deliberate peer support started to come about.

So our history is a very proud history, because the people who did that weren't always well and weren't well respected and we fed into the myth that we weren't leaders – but I'll tell you now – we were. We were leaders and the people in this room are leaders, and I'll come onto that as well. Full of promises!



**"Recovery was always about if services can connect you to the best of yourself, if services can keep you connected to your chosen loved ones and if services can keep you in your community, then your recovery will be guaranteed, because from within you, you'll see the best of yourself, you'll feel the best of yourself, you'll start to know the best of yourself, you'll be shown the best of yourself, you'll be alongside people who know you, who trust you and really want you to be the best that you can be, and you'll be in a community..."**

Anne Beales MBE -  
NSUN Founder



## Guest speaker: Anne Beales MBE - NSUN Co-founder



► So, we started to work in partnership, we had a vision of what was possible and we started sharing that vision with the statutory authorities, with the status quo – the NHS, local authorities, large third sector organisations – and they liked it. Some of them liked it because they could see it was highly effective, they were humane, it was easy to sign up to; some of them liked it because they wanted to change the system themselves, and some of them liked it because it would be cost effective. But in including us, bravely we understood that you couldn't include us if there weren't some standards that were adhered to. Too many of us went to meetings, I remember the first time I went to a meeting, I went in a suit because I thought people took you more seriously and somebody couldn't believe that I could drive! Because I was a service user! They had no idea a service user could drive, it was very scary for them when they found out. And so we had to get rid of the tokenism, we had to get rid of the not being taken seriously. The 4Pi framework is absolutely essential and the NHS, which it targets, the whole NHS framework is in its essence to reach targets, so setting standards was something that was new and a framework like 4Pi was essential. And it's essential for all sorts of reasons, because for many decades, people who use services, people who don't use services, people who've refused the use of services – we know what works and we know what hurts. And Alison Faulkner's here and, looking back, Strategies for Living interviewed about 1800 people who were currently using services and the findings of Strategies for Living about what helps us and what hurts us has not changed. It was produced in 2000 – 19 years we've been trying very hard to be heard. So a network was needed, and we also formed an international group called Interrelate which is still going albeit underfunded and we found that I had more in common with a young native American Indian man who was a warrior against suicide than I did with some of the staff I had to work with. So we started to understand internationally

what we needed to do, despite language differences.

So we introduced the concept of recovery which was hijacked and misunderstood and now we have 'recovery-orientated' restraint techniques on our inpatient wards. How very dare they take the soul of what we were saying about what hurts us and what works for us and corrupt that, to fit in with their system, that does not keep us connected to our communities or our carers or enable us to see the best of ourselves

In the last 10 years, against the background of austerity and decreased funding, NSUN has grown in reputation and standing. What makes us mad in this room? We live in a country where 39 people have just died in a container. This is not right. We see division in our society and racism, bullying and abuse are on the increase and it's not right. What is maddening is that us vulnerable people are the ones who have to put it right because no one else is putting it right. Where have we come as a society when people are just abandoned? There's Windrush, homophobia, a tax on disability benefits. Our society and austerity is killing us. We see people who complete suicide because their benefits are taken away and people who are bumping along at the bottom of our communities living from day to day, who have no joy in their lives, no quality of life and it's not good enough.

But what austerity and the division in our society have given leeway to the establishment to say "We can now hear the voice of service users but they will be our service users. We will train our service users to come to our meetings. And we will train people and pay people to hear their voice." Saying that co-production is something that they can achieve, when they set the agenda, they pick who goes along, and when they don't like the outcome of consultations they can ignore them. We still need the direct, independent collective voice. Once you have that, when you have a voice that is not independent you hear it, you hear a different message. The system



**"So our history is a very proud history, because the people who did that weren't always well and weren't well respected and we fed into the myth that we weren't leaders – but I'll tell you now – we were. We were leaders and the people in this room are leaders, and I'll come onto that as well. Full of promises!"**

Anne Beales MBE -  
NSUN Founder



## Guest speaker: Anne Beales MBE - NSUN Co-founder



► has been able to bypass the voice of the user network to hear a voice that is more sterile, more tame. That is not to say I don't admire and I certainly do support people that work within the system, but the service-user-led groups and service-user-led leadership still needs to be in existence and to grow because we can't leave our friends and other people who use services alone inside the system having their say. I've been watching social media and to my horror I see people who are employed and paid by the system speak out about what's going on saying how good things are arguing with people standing independently outside the system saying no that's not right, that's not what's going on. I'm a non-exec director on an NHS board, and on the board you hear them say what things are like and you think that's suspicious, the wards didn't seem very busy to me, that's not my experience talking to people visiting their CMHTs. So the independence of the voice becomes a critical thing.

So, I'm not suggesting we go into conflict at all, instead of saying to the NHS and other organisations you've got it all wrong, in West Sussex we're saying give the people who want peer support a choice from a mapped out list - do you want that to be a part of your clinical team or would you like someone who is not part of your CT who's had a similar experience can see you at weekends and have conversations that will not get reported back to your clinical team? We need to make sure that when people are in the system they are safe and they can speak up.

Just imagine if the amount of money that was spent on an anti-stigma campaign was spent on the implementation of a modest manifesto. What does that tell the people in this room that NSUN had £13,480 in the bank and the establishment spent £40m on an anti-stigma campaign? The placing of resources speaks volumes.

So what's possible for the future. I think we should be filled with optimism because there are fantastic developments taking place across the country and

internationally. One of the mistakes we made as service users was we were too humble. We provide leadership around solutions and our leadership role can be resurrected because Sarah and others have done the work to get the funding because NSUN is still standing even though it was under resourced, even though we've not been invited to the table, even though we were disrespected.

So I'd like you to think about the future of lived experience, where we have gang members helping young people to avoid getting into gangs, where there are asylum seekers helping other asylum seekers. We used to talk about international networks and pan-disability networks. What I'm proposing today is thinking about pan-lived-experience networks. Wouldn't it be great if we used our infrastructure to help kinds in Manchester in gangs, or asylum seekers who are incarcerated.

And finally with our 1 ½ staff and our associates, we're still here ten years later. We still care and we still know what hurts and what works and we have the solutions and we now have to take the steps to believe in our leadership, to reach out to others who are service users and people who have lived experience and join forces with them and build a proper movement. We can push back and say we got up off our knees and we can see further than you and further than the status quo, we will be the leadership that will make the difference. ●



**"We still care and we still know what hurts and what works and we have the solutions and we now have to take the steps to believe in our leadership, to reach out to others who are service users and people who have lived experience and join forces with them and build a proper movement."**

*Anne Beales MBE -  
NSUN Founder*

I'm going to talk about raising awareness of The Value of User-led Groups, our main campaign for 2019, and to highlight the concerns we have.

For World Mental Health Day we spoke about the crisis facing user-led groups and the vital role they play in supporting people in their most distressing times. We knew from our membership the ULGs were closing and I'd also like to highlight the role of ULGs within marginalised and racialised communities who are made more vulnerable in these times of austerity and these are the groups that often close first. Also funding becomes more competitive in local areas and I'd like to stress how important it is to work in partnership on this.

I recently visited the ReCoCo collective in Newcastle and asked them how they have been thriving and they said how important partnership working was and how that when you share things in your local area you usually get it back tenfold e.g. free training to local voluntary sector organisations, sharing physical spaces etc.

In our survey, we asked lots of questions to ULGs e.g. what are your group's activities?, What is the value of the group to its members? How hard is it to get funding in the current climate? What are your concerns for the future? Racialised and marginalised groups e.g. BAME, LGBTQI+ groups were more likely to be struggling.

It seems more common at the moment to accept the views of large mental health charities in place of the authentic voice of service users and survivors, and that struggle is continual and even harder now.

What are the main concerns facing user-led groups at the moment? Funding, facing closure, running on the goodwill of volunteers, leaders and volunteers facing burnout, cuts to services and increased



- ▶ risk of hospitalisation and suicide. How do we better communicate with commissioners and decision makers to recognise the work we're doing?

### **So the key messages of what we want are:**

- recognise the value and unique contribution that ULGs make to individuals and communities
- involvement often continues to be tokenistic despite the language of co-production and the language of using that term has got louder while it is now less and less reflecting our authentic voice
- small ULGs losing out to larger voluntary sector charities at all levels
- don't lose sight of the user/ survivor movement's activist roots
- don't lose sight of the power that we have to support each other and to understand our own issues

### **More information on the survey results for our Value of User-Led Groups campaign can be found here:**

<https://www.nsun.org.uk/FAQs/the-value-of-user-led-groups-2019-campaign>

Also on the same page is information about a meeting we had with a variety of funders where we explained why ours is the authentic voice of service users and survivors which some of them really didn't understand before. ●



**M**ark gave an emotive speech titled 'User-led organisations are the people's story of mental health'.

"User-led organisations are vital in making sure that collective knowledge and experience can be passed on to younger and new activists..."

"User led groups are the unbroken thread of memory, experience, ideas and knowledge of life lived with experience of distress, trauma, mental health difficulty and difference."

"When a user led organisation ends, goes under or has to stop, what is lost is not just the service or support that it delivers to others, although that is important. What is also lost is the sum of the intelligence, the knowledge, the experience of what the world is like for the people who make up that group and have passed through it."

"Lived experience isn't just an additional special sauce for public services and charities to add to the recipe of service improvement, it's real people's lives as they live them." ●

### **Mark's full speech can be read here:**

<https://medium.com/@MarkOneinFour/user-led-organisations-are-the-peoples-story-of-mental-health-a6aa0291be80>

**"When a user led organisation ends, goes under or has to stop, what is lost is not just the service or support that it delivers to others, although that is important. What is also lost is the sum of the intelligence, the knowledge, the experience of what the world is like for the people who make up that group and have passed through it."**

*Mark Brown*



## Reigniting the Space

### Dominic Makuvachuma

Dominic began by drawing parallels between the struggles of his brethren in his native Zimbabwe for fuel, food and general survival and that of the struggles that the user survivor movement now faces. The feeling that our voices were so strong and now they are trying to be pacified, where we have to now focus on our basic survival.

NSUN is there to support its network and underserved communities and groups. And it also supports specific work for marginalised and racialised communities and Reigniting the Space is one such piece of work.

We knew there was work going on around the country by these groups but we didn't know exactly what that work was or where it was happening and that's what RITS set to find out.

One of the main issues that drove the Reigniting the Space project was racism. Somehow when the Equalities Act was reformed, race and equality seemed to have been diluted in their impact, and as a Black African man I felt that I didn't have the space to talk about the challenges that I felt.

So we made a strong business case to Lankelly Chase to pull together a group of people to recognise the work that was happening locally, to support the creation of a space where people could meet and decide what they were going to do with their lives, and to build a structure that would support people of colour.

We formed a steering group and initially focussed on mapping the work in two areas: East Midlands and London. In one



region there was no response from any group we had identified, they'd gone. But we knew there was some work going on, so it just made the work a bit harder trying to find this work that was going on under the radar. But we finally made contact with some groups and we'll be doing a report shortly. ●

You can read more about the Reigniting the Space project here:

<https://www.nsun.org.uk/FAQs/reigniting-the-space-for-bme-usersurvivor-voice>

**"So we made a strong business case to Lankelly Chase to pull together a group of people to recognise the work that was happening locally, to support the creation of a space where people could meet and decide what they were going to do with their lives, and to build a structure that would support people of colour."**

*Dominic Makuvachuma*

## Mental Health Act review campaign Dorothy Gould

The review's recommendations came out last December and since then the Department for Health and Social Care have been working on these. In theory they are meant to be working with the Mental Health Act review advisory group but there is a very low level of user group representation there.

We're continuing to base our campaign on NSUN's manifesto not only because of the injustice of coercion but also because of generally how unjust society is, how people struggle for the basics in life, how people face rising levels of discrimination.

Despite their preoccupation with Brexit, we've been trying to meet with ministers and others to try and make people aware of the issues. The signs aren't promising and I'd like to echo what was said before in that we need to be leaders on this. It seems like many of the professional groups and big charities involved are stuck in a culture of thinking some change is needed but a little bit but not the fundamental kind of change we are asking for in terms of the Convention on the Rights of Persons with Disabilities.

It has been a huge struggle to make ourselves heard and understood and I value the support of various people here. Some encouraging aspects are support from and the building of a network of ULGs such as those supporting people with learning disabilities and sensory impairment where we're finding we have a lot in common. We also found common ground with other organisations putting submissions in for the convention against torture e.g. incarcerated people, treatment of refugees. There is also encouraging work



**"Despite their preoccupation with Brexit, we've been trying to meet with ministers and others to try and make people aware of the issues. The signs aren't promising and I'd like to echo what was said before in that we need to be leaders on this."**

*Dorothy Gould*

going on around Article 19 of the Convention on the Rights of Persons with Disabilities (CRPD) by ROFA for example, to get this enshrined in law – e.g. deinstitutionalisation, bringing an end to compulsory hospitalisation and treatment, adult treatment units, CTOs – work that is also going on around the world.

We've also been trying to garner support from trade unions. The Trades Union Congress has a disabled workers' committee who voted in favour of the CRPD and who have started understanding these issues more e.g. cuts to the NHS. If we can get unions working with us more it would be great because politicians generally don't seem to want to engage.

You can read more about NSUN's Mental Health Act review campaign here:

<https://www.nsun.org.uk/news/mental-health-act-recommendations-campaign>

## Survivor Research Network

### Stephen Jeffreys and Dina Poursanidou

The key elements of the SRN are that it is user-led; it brings personal experience into research which we believe strengthens research; it has a holistic approach which recognises the social and economic context of mental health re: benefits issues etc.; the research is transparent and has a values base of social justice and being anti-discriminatory. It also aims to improve access to research and ULGs for marginalised communities and argues for research that explores and values different approaches to mental health research and knowledge in different communities.

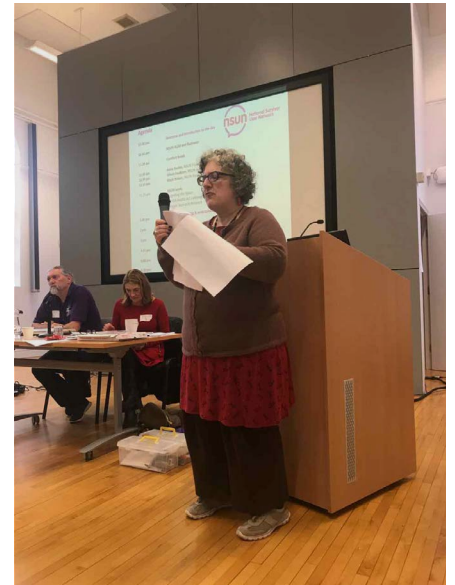
Over the last year, we have expanded the membership of the SRN working group, continued to produce the SRN bulletin, lobbied research bodies, contributed to a conference on intersectionality in higher education, and we're currently working on a chapter for an international handbook on service user involvement, as well as launched an SRN twitter account.

We are launching an online forum for people who are actively involved in survivor research where people can share ideas and find and then work with others with shared interests.

While there are already some resources on the NSUN website, I'm developing a resource collection of survivor research materials which particularly focusses on research techniques.

You can read more about the Survivor User Network here:

<https://www.nsun.org.uk/FAQs/survivor-researcher-network-srn>



**Dina Poursanidou**, a member of the SRN working group, read out a moving poem to which illustrated her struggle with her mental health over the years, the treatment she underwent and how she fought to regain her confidence and repair her life which continues today. Dina told how her experience and academic credentials has made her ultimately ideally qualified to be a service user researcher. "I went from being treated as somebody with diminished insight to being celebrated as somebody who has acquired unique insight, viable service user survivor knowledge... and expertise by experience." She also spoke of her struggle to survive as a service user researcher when facing issues working in a neoliberal university environment, such as caring for herself when having to maintain contact with the experience of madness; having to constantly recount her history to remain being considered as an authentic service user researcher; competing in a ruthless labour market with short-term contracts and lack of career development.

**"We are launching an online forum for people who are actively involved in survivor research where people can share ideas and find and then work with others with shared interests."**

*Stephen Jeffreys*



## Soap Boxes

**As usual, our soap boxes were a huge hit with attendees!**

The soap boxes ranged from talking about the importance of speaking up and working together, to making the most of the Freedom of Information act, to the stepping down crisis, to the advocacy of poetry as a cathartic release and much more.

You can find the videos of all the soap boxers on the AGM 2019 playlist on NSUN's Youtube Channel here:

<https://www.youtube.com/playlist?list=PLSccL5ZOPdoaUah8bkppYynH9QMtX6aiT>

The playlist also includes a summary video of the day and our farewell to outgoing MD, Sarah.

Please take a few minutes to watch – inspiring stuff!

## Discussions and networking

In groups, attendees discussed ideas around social change, promoting leadership and challenging barriers, partnership working between ULGs and funders, capacity and resources funding approaches, standards raising awareness of principles of inclusive involvement.

Ideas included linking older and younger activists together and learning from each other, leadership mentoring, help with bid writing for groups, employing ULGs as advisors to funders, sharing skills in policy and comms etc., challenge the current funding system, solidarity with other struggles, discussions around DOLS, stop services using CTOs, different ways of communicating e.g podcasts, texting, writing.



## Closing comments

Ending with a tearful farewell to Sarah and a collective embrace of the possibilities of the future, the NSUN AGM for 2019 sounded a positive note of warmth and human connection. Handing over to Akiko, Sarah said that she felt more excited for the future of NSUN than ever, even as times were getting harder. NSUN is nothing without its members, she said, and it's when we can come together that we really feel what it means to be amongst friends. Justice, hope, togetherness, history, solidarity, love for each other and practical actions is where NSUN has its value.

**END**

Top left: Debbie Roberts  
Top right: Alan Hartman  
Bottom Left: Tom Griffiths  
Bottom right: Amy Rushton

## 22 TOTAL RESPONSES

- Everyone who completed the feedback form agreed (or strongly agreed) that the purpose of the event was clear to them.
- 19 agreed or strongly agreed that they had felt able to participate in the event.
- 18 agreed or strongly agreed that they had felt listened to and their opinion had been valued.
- Everyone agreed or strongly agreed that they had learnt new information.
- Everyone agreed (or strongly agreed) that they had made new contacts.
- Everyone agreed (or strongly agreed) that they felt more connected to the wider NSUN network as a result of the event.
- 19 agreed (or strongly agreed) that they felt more prepared to get involved to influence others.
- Everyone agreed (or strongly agreed) that they felt they had received support from peers.
- 19 agreed (or strongly agreed) that they had provided support to peers.

## 1. THE PURPOSE OF THE EVENT WAS CLEAR TO ME

Strongly Agree	14
Agree	8
Disagree	0
Strongly Disagree	0

## 2. I FELT ABLE TO PARTICIPATE IN THE EVENT

Strongly Agree	10
Agree	9
Disagree	3
Strongly Disagree	0

## 3. I FELT I WAS LISTENED TO AND MY OPINION VALUED

Strongly Agree	9
Agree	9
Disagree	2
Strongly Disagree	1

## 4. I LEARNT NEW INFORMATION

Strongly Agree	10
Agree	12
Disagree	0
Strongly Disagree	0

- "Interesting but nothing new".

## 5. I MADE NEW CONTACTS

Strongly Agree	11
Agree	11
Disagree	0
Strongly Disagree	0

## 6. I FEEL MORE CONNECTED TO THE WIDER NSUN NETWORK

Strongly Agree	11
Agree	11
Disagree	0
Strongly Disagree	0

## 7. I FEEL MORE PREPARED TO GET INVOLVED TO INFLUENCE OTHERS

Strongly Agree	7
Agree	12
Disagree	2
Strongly Disagree	1

## 8. I FEEL I RECEIVED SUPPORT FROM MY PEERS

Strongly Agree	10
Agree	11
Disagree	0
Strongly Disagree	0

- "from the other NHS staff at the event".

## 9. I WAS ABLE TO PROVIDE SUPPORT TO MY PEERS

Strongly Agree	6
Agree	13
Disagree	1
Strongly Disagree	0

## What did you find most helpful about this event?

### SPEAKERS

- Powerful and inspiring speech by Anne Beales
- The inspirational speakers
- Anne speech knowing about root of NSUN.
- All of the talks – very motivating.
- Hearing the passion and ideas from all the speakers on the agenda and soapbox.
- Some inspirational speakers especially on social and equality issues.

### NETWORKING, CONNECTING WITH OTHERS, MEETING NEW PEOPLE & OLD FRIENDS

- To reconnect with NSUN as a whole, meet old and new faces.
- The overall catching up with NSUN's work and members.
- Solidarity – kindness, tolerance.
- Being among good company with a shared vision.
- Networking, making connections, shared thoughts.
- The feeling of Solidarity and support in the room
- The people and the information and sharing.
- Feeling part of a network.
- Met some old friends from previous meetings over the years.

### OTHER COMMENTS:

- Soapboxes (x2)
- Energy and inspiration (x2)
- Very well organised.
- Accessible venue
- Information overload!!!
- I have never seen so much leader led (?) speakers and clients.

- All of it – talks – soap box. Manifesto revisited.
- Sense of history
- Staggered, well-timed schedule.
- Find out more about what's happening in other areas.

## What did you find the least useful about this event?

### VENUE TOO SMALL

- Venue was too crowded
- Room a bit cramped.
- Room too small!
- The room was a little squashed at times and it was hard to hear people speak over the [???
- Not quite enough space / structure to meet others (though it's hard to fit in time, I know).

### PEOPLE WITH LIVED EXPERIENCE WHO WORK FOR LARGER CHARITIES FEELING UNCOMFORTABLE

- As a person with lived experience who works for a large mental health charity it was difficult. I felt some things expressed were useful but some were untrue and unfair. The manner some things were expressed felt very difficult.
- Felt uncomfortable coming from a national charity, with offhand comments being made to me directly. I have lived experience and am a service user but feel this is overlooked based on coming from London and not running a smaller charity.

### OTHER COMMENTS

- Soapboxes would have gone smoother if Zoe had kept the number...[???] of speakers 2 or 3

in advance so time wasn't wasted waiting on people to get to the lectern.

- Speakers immediately after lunch
- It could have been a bit longer. But not really – just because Sarah is leaving it feels a big change.
- The sandwiches, lol.
- Only one day together.
- Finally finishes for another year.

### ANY OTHER COMMENTS

- Please adjust the demographics box (minor details) Afro-Caribbean and list categories alphabetically eg. 'bisexual' first.
- The fact that despite being actively involved in mental health as a service user since 1996 I can't really say that things have evolved. What has been talked about at this event – service-user led groups closing down – pubs/shops/etc are also closing down. There needs to be a 'new' group. What about 'user led group by the phone'? Everyone has one!
- Not many opportunities to ask questions and give viewpoint.
- Same old format that other AGM/conference have. There needs to be an event that gets everyone involved rather than just sit, listen, eat lunch and go home.
- No mention of the new CEO in the welcome pack? Or an introduction to her to those attending?

### OTHER POSITIVE FEEDBACK

- Great event!
- Wonderfully chaired business section
- Enjoyed entertainment
- Good food
- Good lunch
- I will Sarah...
- Thank you to all at NSUN – felt well organised.
- End of an era! A new age begins!



- (Watch this space).
- Well done. Let's promote the Mental Health Charter across the NSUN movement.
  - Excellent – All.
  - Would like to know more about the work of the survivor researchers.
  - How can peer research influence policy without being guided/ constrained by policy makers or funders?
  - Great – thanks.
  - Love NSUN and the people in it, they are fabulous and thank you so much for all that you do!
  - Thank you! Felt v. welcome.
  - Great to hear about some of the excellent work taking place – Helping me to aspire to achieve more!
  - I'll be back!
  - A really well organised day with a clear and strong purpose.

# Demographic Information



REGION	
North East	3
North West	4
Yorkshire and Humber	2
East Midlands	2
West Midlands	3
East of England	0
London	8
South West	0
South East	0
AGE	
18-25	2
26-35	4
36-45	4
46-55	12
56-65	15
66 - 75	4

GENDER	
Male	17
Female	25
Transgender	0
Other	0
SEXUAL ORIENTATION	
Heterosexual	28
Bisexual	2
Lesbian	3
Gay	1
Other	6
NB: two people identified as 'celibate' under 'other'. One stated 'please put this. It's wrong to leave us out'.	

ETHNICITIES:	
Asian/Asian British	
Indian	1
Asian/Asian British Pakistani	2
Asian/Asian British other Asian background	1
Black British	2
Black British African Caribbean	1
White British English/Welsh/Scottish/ Northern Irish/ British Irish	30
White Other	4



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