

HOW DOES IT FEEL FOR ME?



Sophia's story summary report



Context

This work is part of a wider approach being taken in Leeds to understand people's experiences as they move around health and care services, called the 'How does it feel for me?' programme. As well as the real time journeys that we are following, there are three additional components to the programme: case note reviews, understanding what citywide complaints tell us, and developing a set of metrics (data measures for tracking progress) that will be used to measure joined up health and care services. The project involves all health and care partners, including representatives from Healthwatch Leeds, Leeds Teaching Hospitals Trust, Leeds Community Healthcare NHS Trust, GP Confederation, Leeds and York Partnership NHS Foundation Trust, Leeds City Council, Carers Leeds, Age UK and St Gemma's Hospice. It is designed to support them to understand what people's experiences are like as they move through 'the system'; identify what is working and what is not; and to think about how they can plan and deliver services better. Increasingly, as health and care services work more and more in partnership, this work will feed into the Integrated Care Partnership for Leeds.

For more information on this project, please visit our website

<https://healthwatchleeds.co.uk/our-work/how-does-it-feel-for-me/> or contact harriet@healthwatchleeds.co.uk

Background

Sophia is a young woman who has a diagnosis of complex PTSD (Post Traumatic Stress Disorder) which massively affects her day-to-day life. She also struggles with severe migraine episodes, insomnia, and IBS which affect both her physical and mental health.

She wanted to take part in the How does it feel for me? video project as she wanted to be listened to when providing feedback on services. Her experience in the past has sometimes been that she hasn't been taken seriously when she has tried to give feedback, particularly when she has been in crisis.

Sophia is not her real name. We have used it to protect her identity.

We followed Sophia's journey between April 2022 and April 2023 through a series of audio recorded updates.

Themes and key messages

Below we have summarised some of the key themes arising in Sophia's journey. We start with the '3 Cs'- communication, compassion, and co-ordination - essential building blocks for good person-centred care, but also cover some other themes that come up in Sophia's experiences.

Co-ordination

As someone who uses a lot of different mental health services, Sophia's experiences frequently touch on the need for good co-ordination both within and between services.

She shares some good examples of co-ordination (mainly involving her care co-ordinator at Emerge) but also recounts poor experiences, particularly around discharge.

Sophia describes how the three professionals that she sees from Emerge (care co-ordinator, youth worker and occupational therapist) work together to co-ordinate her care.

“They all kind of seem to communicate, so I haven’t really got to say the same thing twice too much, which I think is a good thing because saying the same thing three times a week is just really, really irritating. And also, especially if the thing you need to say is difficult you don’t want to have, to have that difficult conversation three times... I think it just makes the care feel a bit more joined up.” (Nov 2022, part 1)

She also describes how them all being up to date with how other sessions have gone means that they can tailor their approach better and provide better care. She explains how good co-ordination means that they can cover for each other during staff absence (e.g., when her occupational therapist stands in for care co-ordinator at her benefits review).

Sophia has a good relationship with her care co-ordinator whom she sees regularly, knows her well, and recognises when she needs more support. Her care co-ordinator also acts as an advocate for Sophia when she is not well. In April 2023, part 2, we see her care co-ordinator explaining to the male police and paramedics how to not to further antagonise Sophia by touching her unwarrantedly. Her experiences demonstrate the importance of continuity of care, and the resulting trust that is built up over time.

Her care co-ordinator also organises a Multi-disciplinary Team (MDT) meeting with all the professionals involved in Sophia’s care with the aim of sharing her history and the best ways to support her (April 2023, part 2).

Repeatedly from Sophia, we hear about poorly co-ordinated discharges where there appears to be no clear plan and that often happen at very short notice:

- In April 2022, she describes being discharged from A&E by the Acute Liaison Psychiatry Service (ALPS) without any support.

“The next day, my care coordinator from Emerge came round the house, to speak to me and she agreed to refer to ISS, which is something that, you know, ALPS could have done the night before. I would have preferred to know what the plan was, last night when I was in crisis.” (April 2022)

- In the May-Sept 2022 update, she describes being told about her discharge on the day of discharge.

“When I was being discharged from Oasis I was literally told on the day, with no real warning that that was going to happen, and that was quite stressful, because obviously you go from having all the support around you to nothing.” (May-Sept 2022, part 1)

- In February 2023, she describes discharge from A&E without a plan or mental health review despite being deemed to not have mental capacity earlier on in the day.
- In February 2023, she also recounts discharge from Oasis with no plan because she refused to engage with the person from ISS who they “kept sending”, despite her previously having a bad experience with them in terms of the detrimental way she had been spoken to. In this instance, she reflects on the impact of not having a structured plan for discharge:

“I think if I'd have had a discharge plan, I don't think it would have escalated to how it escalated, but because they made me feel so unsettled with like, what was happening next, and it was stressing me out, that's why I was just like, 'Well, nothing is going to get better then, so may as well just die'.” (Feb 2023)

- In April 2023 part 1, Sophia talks about her discharge from the 136 suite. She feels pressured to leave immediately because the taxi was waiting outside, leaving her no time to check for her house keys (which turned out not to be in the bag she was given). This resulted in her having a panic attack in the taxi and having to be brought inside again to be calmed down and medicated.
- In April 2023, Sophia is given mixed messages about what day she will be discharged from Becklin which “***** around with your head when you're mentally preparing yourself”. She says that she is given one day's notice which didn't give her enough time to arrange someone to come and pick her up. Ideally, she would have liked to have three- or four-days' notice so that she could get things in place and also to mentally prepare herself for going home. When she does get home on this occasion, poor communication and planning from ISS resulted in no face-to-face support after discharge, just a short phone call.

Sophia's care co-ordinator does unsuccessfully try to push for better co-ordination of discharge, and on more than one occasion advocates for her to stay a couple more days and have a structured plan that works towards discharge (May-Sept 2022, parts 1 and 2).

Sophia's experience with the Intensive Support Service (ISS) is a good example of the variation that can happen in a service over time in terms of co-ordination, but also in terms of communication and compassion. When we first meet Sophia, she describes ISS as a good service:

“They're always really good, just got a really nice bunch of people. They're not very judgemental and they don't tend to ask you too many annoying questions that don't make sense... You get seen once a day. You can also ring the duty line as well, which is open 'til 9pm. And they also really try to get you to see people that you've seen before, so when I've been under the service, I've always got the same like, three, four people that I know already, so that helps.” (April 2022)

Six months later in September 2022, her view of the service feels very different and continues in this vein until our last interview with Sophia in April 2023.

“They were sending round a male worker when I had specifically said, “Don't send round a male worker because I'm not going to engage.” And then they wouldn't tell me what time they were coming.... Before, they'd supported me for a bit longer and like, had always been a bit more consistent... telling me in advance. You know, they'd tell you the day before, “Okay tomorrow we're going to come roughly at about 3 o'clock.” But this time it was like, “We could come anytime between 11 and 4”, which is like a big chunk of time. You're already really isolated and then you... can't even just go outside to go for a shop.” (May-Sept 2022 part 1)

She also describes how she feels the support has become too short-term. On one occasion she describes only two visits from ISS, and on another just a 13-minute phone call (May-Sept 2022, part 2) before discharge.

When Sophia is in hospital following an overdose, she doesn't feel confident that staff from different services are clear about who is responsible for keeping her safe if she "walks off" or "does something daft".

"When I was on the general ward at Jimmy's it felt like there wasn't really a plan of like, who was in charge of my care... because technically I was under the care of the Becklin Centre, but then I was also under the care of Jimmy's." (May-Sept 2022, part 1)

This example highlights the need for services to be clear about roles and responsibilities and the potential impact on patient safety if this doesn't happen effectively.

Finally, Sophia highlights the link between good record keeping, information sharing, professionals reading her notes and how this impacts her care.

"It's just not joined up. Everybody is working on a different system, and it does more harm than good." (April 2022)

She also indicates how this can affect how safe she feels when receiving care.

"If they'd have read my records properly, they would have realised that... I feel very unsafe around men." (April 2023, part 1)

Compassion

Compassion, or lack of it, is another key theme of Sophia's experiences. Her experiences demonstrate clearly that when professionals prioritise compassion, trust, co-operation and recovery are more likely to happen.

Sophia shares many examples of individual compassionate staff across the different services that she accesses. Often when asked about what she most valued about her care in each update, Sophia gives an example of compassionate care, which is often something as simple as a hug or someone holding her hand when she is in crisis.

“When I was at CAU (Crisis Assessment Unit), this nurse who I'd met previously on Ward 5, happened to come to this ward that I was on, told me off, and then she gave me a hug. So, I valued that.” (Feb 2023)

Professionals that stand out for her as being consistently compassionate are staff from Oasis, an A&E doctor, the ambulance service and her care co-ordinator.

“Usually when the ambulance crew sees you're really, you're still quite really distressed so they're seeing you when you're really not in a good way at all, but then they're still able to speak to you like a person and they're still able to have some compassion.” (April 2022)

Her care co-ordinator is a “nice person” but also what makes Sophia like her is that she “understands how to talk to me and get the best out of me,” and offers appropriate challenge and boundaries (Nov 2022 part 1).

Sophia experiences a huge variation in compassion from the crisis team. More than once, she describes not feeling heard by the crisis team who she reports saying things like, “have a cup of tea,” “go for a walk” or “have a bath”, when she has called them in crisis.

“It's just so demeaning when they say things like that.” (May-Sept 2022 part 2)

She describes one crisis team staff member saying to her, “We don’t think you’re going to kill yourself.” (May-Sept 2022 part 1). This has a lasting impact, when this same person gets repeatedly sent out to see her several months later during a stay at Oasis, resulting in her refusing to engage and being discharged without any kind of plan (Feb 2023).

She compares this kind of attitude to the “best response I’ve ever had from the Crisis Team”, where the person on the phone, “just listened to me with a bit of like, compassion”. The result is that Sophia trusts her enough to be open with her about her suicide attempt, and then co-operates when an ambulance is sent out to do her observations.

“Because of how nice she’d been to me, it meant that I was really honest with her and told her what I’d taken.” (April 2023, part 2)

Compassion is shown in the ‘trauma-informed’ practice Sophia experiences from a doctor in A&E, who by listening and understanding what might be behind her behaviour very skilfully de-escalates a very difficult situation.

“I felt like they listened to me, and they also got what they wanted out of the situation without it, escalating into a big kerfuffle.” (April 2023, part 1)

Sophia says that the one thing that would make her experience of crisis services better would be more of this kind of trauma-informed approach:

“I would say that they should be looking at someone as a whole person, rather than just looking at a someone’s behaviour right now, in the here and now and being like, ‘what is wrong with them?’ Like, ‘what has that person been through? What is that person’s circumstances?’” (April 2022)

Stigma

“The one thing that I would really like to see improved in services... is the way that people with personality disorders or complex trauma... are treated in the system. So just treating people with like, dignity and respect and actually like they’re worth treating, because most of the time we’re written off and we need people to fight for us, and nobody is.” (Nov 2022 part 1)

In her audio recordings, Sophia touches on the stigma surrounding Emotionally Unstable Personality Disorder (EUPD) or complex trauma and how this can affect how she feels treated.

“We’re always labelled as attention seeking.” (April 2023 part 2)

She describes a doctor at the 136-suite diagnosing her with EUPD after having only just met her and asking her “three questions”. She states that the doctor also didn’t read her records, where she would have seen that Sophia had recently had this diagnosis removed.

“She wrote me off as just like untreatable and discharged me.” (May-Sept 2022 part 1)

Communication

Much of Sophia’s experiences of communication has already been covered under ‘Co-ordination’ and ‘Compassion’. However, a notable exception is the language used by the Acute Liaison Psychiatry Service (ALPS) both verbally and in her medical records. She describes them as nearly always “condescending”:

“The way they speak to you, I feel like I’m being told of by my schoolteacher.” (April 2022)

Contrast that with how she later describes her care co-ordinator:

“When she talks to me, I don’t feel like she’s talking down to me like I’m a child.” (Nov 2022 part 1)

More than once Sophia also describes what she feels is judgemental rather than descriptive and factual language used by ALPS in their reports. She cites the example of using language such as “refused” as opposed to “didn’t want to” (April 2022). On another occasion she feels that she is being labelled as attention seeking when she says that an ALPS states, “I always bring myself to the attention of services in order, so that I can be saved.” (April 2023, part 2).

“It really infuriates me, because it basically makes me look like an attention seeker, and that’s not what happened.” (April 2023, part 2)

Sophia also highlights the need to get initial communication right when being contacted by a service. She describes how the phone ‘induction’ with Live Well Leeds felt invasive and unnecessary, and that it could have been done more sensitively and appropriately via a questionnaire at the first session of the art group she was attending.

“I’d just come out of hospital. I didn’t really want to talk about what had happened because I just tried to kill myself. It’s not really the conversation you want to have with some bloke that you don’t know on the phone. It just didn’t feel very safe.” (Nov 2022, part 2)

Importance of Community support

Sophia is under the care of Emerge Leeds and gets three visits a week from different professionals within the team – her care co-ordinator, occupational therapist and youth worker. In addition to this, she often accesses other services such as Dial House, Well Bean café as well as creative and community sessions run by Live Well Leeds and Inkwell Arts. She enjoys the arts and crafts sessions run by Live Well Leeds which she says are “high quality” and likes the peer support element of being able to relate to other people in the room who all have lived experience of mental health (Nov 2022, part 2).

She values this community-based provision as a key factor in preventing her health from deteriorating....

“If that stuff wasn’t there, I’d probably be at home or be somewhere doing daft things.” (May-Sept 2022 part 3)

...and keeping her out of hospital.

“I’ve avoided hospital thus far because I have been using other services like Dial House and Well Bean café” (Feb 2023)

Despite this, Sophia sometimes finds it difficult to understand which service to access when she is unwell or in crisis, and it would be helpful for there to be a really clear message about this.

“I always find it hard to know like, ‘Which level of crisis am I on today?’ Like, ‘Am I at Dial House level? Or am I like, Well Bean Cafe level?’ (May-Sept 2022, part 3)

Interplay of physical and mental health

In her introductory video, Sophia describes her various health conditions – complex PTSD, insomnia, migraines and Irritable Bowel Syndrome (IBS), and how they interact with each other. For example, how insomnia affects her mood and IBS flares up when she's anxious.

“I also have IBS... I feel that gets worse when I'm anxious, so I feel like they're kind of interconnected, to what I experience with my mental health.” (Intro, April 2022)

Mental health and employment

Sophia describes the impact that unpredictable changes in her mental health have on her employment. Working as a freelancer, she describes the stress and embarrassment that becoming very unwell on a job can cause. She also describes the difficulty around deciding whether or not she is well enough to work as well as the impact on her of deciding not to work.

“It's really hard to not work because obviously like, money. And also like you just feel like you're failing... From work like, you you're engaging with people, you're meeting new people... You're going to places... And like, it can be fun... and like, by going to work you also gain more work, especially as a freelancer because like word of mouth is probably the biggest advertisement for you.” (May-Sept 2022 Mental health and employment)

Involvement of person receiving care

Sophia says she doesn't always feel like a partner in her own care and we see multiple occasions where her wishes are not acted upon regarding gender preferences, medication and discharge. However, she says that with the Community Mental Health Team (CMHT) and Emerge she has felt more actively involved.

“...with CMHT and Emerge, I've felt like I've had a lot more control about what's happening with me, and my care and treatment.” (April 2022)

We know that having a female worker is important to Sophia. She tells us, “I don't have a great history with men.” (May-Sept 2022, part 1).

“I would like to be asked my preference, that's never actually been asked [by ALPs]. That's been asked with ISS, and...with Emerge and with CMHT [Community Mental Health Team]” (April 2022)

The impact of gender preference not being taken on board can really be felt when Sophia describes a situation that happens in the 136 suite.

“I was quite confused, and the doctors came in to assess me literally about half an hour after me getting there, and I just dropped off to sleep because I was knackered, and then the next minute I woke up and there was like five people standing around my bed, and then one doctor sat really close to me. And I think the majority of them were all male as well... and that freaked me out.” (April 2023, part 1)

The second time is better because staff have understood what trauma - informed care looks like for Sophia.

“So, the second time was better because it was two females and one male. And they'd also, what helped is, that they'd, like, sat down a little bit, like on the floor. So, then they weren't like, like, looking over at me, like, from a height. It felt less confrontational.” (April 2023, part 1)

Her wishes around medication are not always listened to. For example, despite her repeated request for ISS to action a prescription for Diazepam as agreed by her GP, it never happened. She feels that had it been, further crises could have been prevented.

“It was just like a domino effect of things, and that could have... been the one thing that just changed the path, but it didn't, because I wasn't prescribed it.” (May-Sept 2022 part 2)

Environment

What Sophia had to say about Oasis was really striking and provided a good example of how therapeutic she found a much less 'clinical' homely environment, and a relationship with staff with lived experience which felt more equal.

“Oasis feels a bit more like staying at like a hotel, it's not clinical. It looks more cosy... You've got proper duvets... and they refer to you as patients or service users, they refer to you as guests, which I think is quite nice... They prioritise the actual supporting people, talking with people, even just sitting with people... Whereas at Becklin, the staff were just constantly updating paperwork, that's why you never got any time with them. So Oasis... definitely made me feel more supported.” (May-Sept 2022 part 3)

The Becklin Centre, on the other hand, she describes as “meds focused”, with little meaningful activity (e.g. group therapy) for the times when people are not in crisis (April 2023). She said that she knew from talking to staff at Oasis that part of their induction was to visit the Becklin Centre to see how it operated. She suggested that could be helpful also for Becklin staff in terms of learning to visit Oasis as part of their induction.

Digital and phone

The majority of Sophia's interactions with services are face to face. However, there was one occasion where Sophia felt that an opportunity was missed by a GP in communications via e-consult and phone.

“This whole shenanigans could have potentially been avoided... obviously I wrote that E-consult, the GP that rang me isn't the one that knows me very well. If it had been the one that knows me very well, she would have got me to come in, and then she would have assessed whether she needed to call the police, or whatever else, or try and get the crisis team to her... I think doing things over the phone, in general, especially if it's like mental health, and somebody is literally talking mumbo jumbo at you, like, be concerned.”
(February 2023)

How this report should be used

The insights from this report should be used by all health and care organisations in Leeds as part of their ongoing Quality Improvement work. They should also be used by relevant Population Boards to inform their thinking. In addition, the reports will feed directly into the Leeds Health and Care Partnership, including the citywide Person-Centred Care Board and the Quality and People's Experiences Committee.

Please do let us know by emailing harriet@healthwatchleeds.co.uk how you have used this report and any improvements it has prompted within your services or the wider system.

Questions for Leeds Health and Care Partnership:

The Leeds Health and Care Partnership is made up of health and care organisations that work together and use their resources collectively to improve people's health and reduce inequalities by delivering joined up person-centred care. We would like the Leeds Health and Care Partnership to consider the following questions:

1. At a system level what needs to happen differently for all our services to co-ordinate well?
2. What do Sophia's experiences tell us about the importance of having a culture of compassionate care, and how can we ensure that this is consistent across the system?
3. What do we need to do as a system to improve communication so that people like Sophia will always have a good quality experience and good outcomes?

4. How might Sophia's experiences have been different if services had been operating to the principles of an integrated care model – i.e. co-designed, jointly commissioned and delivered in partnership to achieve shared outcomes?

Questions for individual organisations and Population Boards:

We would like health and care services to use this report and Sophia's videos within their teams as a learning and development tool. Below are a series of questions that could be used as conversation starters in conjunction with this report and the videos:

1. What would your services need to do differently to make sure Sophia was always felt like she was treated with compassion and empathy and without stigma?
2. What would your services need to change to ensure that Sophia was always involved as an equal partner in plans and decisions about her care, and make use of any skills and knowledge she brings?
3. How can you work with other services to ensure better co-ordination of care and reduce the risk of negative impacts for Sophia?
4. How will you make sure that people like Sophia are kept informed and involved in their discharge planning so that they feel in control?
5. What opportunities exist for staff to work across organisational boundaries so that they acquire new skills, adopt ways of working and communicate better with each other?
6. Within your service what's the smallest change that could make the biggest difference to people like Sophia?

Appendix 1: Actions from Partners

Organisation	What actions have you taken, or will you take as a result? And where will you share the videos or updates?
<p>Leeds and York NHS Partnership Foundation Trust</p>	<p>Videos have been shared and discussed at the following groups:</p> <ul style="list-style-type: none"> • Patient Experience and Involvement Strategic Steering Group (PEISSG) <p>This group is co-chaired by the Director of Nursing, Professions and Quality alongside a lived experience partner. The purpose of this overarching meeting is to make sure that priorities identified by service users and carers in their three sub-groups; Experience, Carers and Involvement, are actioned and progressed.</p> <ul style="list-style-type: none"> • Experience Sub-Group <p>This group is co-chaired by the Deputy Director of Nursing and a lived experience partner.</p> <ul style="list-style-type: none"> • Unified Clinical Governance Meetings <p>These meetings are held monthly and are attended by Heads of Services (or their representatives) to share good practice and to escalate any barriers to delivering care.</p> <ul style="list-style-type: none"> • ALPs and Crisis teams' clinical governance forums (April 2022) <p>In Jan 2023, the Operations and Clinical Team managers of ALPS (Acute Liaison Psychiatry Service) met with Sophia where they were able to listen first hand to her experiences. The meeting resulted in the following set of learning points being identified by ALPS that were shared with the wider ALPS team:</p> <ul style="list-style-type: none"> • Use a trauma informed approach to care; ask people about a preference for a male or female worker (whenever possible and if not possible, explain why)

	<ul style="list-style-type: none"> • Ask people if it is okay for a second assessor to be present during assessments. In circumstances where ALPS have assessed that a second assessor is required – an explanation should be provided to the person receiving care as to why. • Be transparent about meeting people's expectations – be explicit about what can and cannot be offered. • Include carers (wherever possible) • Ensure notes/assessments are written in a clear, jargon free and non-judgemental way, that can be easily understood. Write notes as if service users are reading them. <p>The links to all Sophia's videos, along with the above learning points have been emailed to all Heads of Services who have been encouraged to share the videos and learning points with their teams and implement into everyday practice.</p> <p>May-Sept 2022 - Food provision at Becklin Centre</p> <p>This video was shared with the matrons and clinical lead of the acute inpatient wards. The matron of the ward also shared the video at their clinical governance forum to remind staff that service users should be offered menus the day before and that they do have the choice to eat their food in their rooms should they wish to do so.</p> <p>The acute inpatient leadership team apologised that this had not been the case for Sophia.</p>
<p>Leeds Community Healthcare NHS Trust</p>	<p>Videos will be shared with:</p> <ul style="list-style-type: none"> • Clinical/Quality Leads to be shared within services/ teams. • The LCH services referred to within them directly with an ask to review and consider where improvements can be made/feedback to share.

	<ul style="list-style-type: none"> • Trust Boards meetings where appropriate as part of the Patient Story agenda item. • They will also consider how else the videos can be used across the organisation as part of current Engagement principle development work. • Learning will be highlighted in newsletter/reporting structures.
Carers Leeds	Videos have been shared with the Carers Leeds team as a learning and reflection tool.
Leeds Teaching Hospitals NHS Trust	<p>Videos have been shared at the Trust Patient Experience Group. They have also been shared with the following:</p> <ul style="list-style-type: none"> • April 2022 – shared with the Emergency Departments as the ALPs service is hosted by LTHT and often present in the Emergency Department. • May-Sept 2022 – Positive feedback regarding experience in emergency department and inpatient stay at St James Hospital will be shared with the urgent care clinical service unit. • Feb 2023 - shared with the urgent care clinical service unit for learning about discharge without plan or mental health review. • April 2023 – positive experience of compassionate care at St James Emergency Department shared with the urgent care clinical service unit
Other places the videos have been shared.	<p>Videos have been shown and discussed at the following groups:</p> <ul style="list-style-type: none"> • Leeds Integrated Care Board subcommittees: Delivery; Quality and Patient Experience; Finance • Person-centred care expert advisory group • Mental Health Partnership Board

Appendix 2: Index of Sophia's updates

All Sophia's updates are available at <https://healthwatchleeds.co.uk/how-does-it-feel-for-me-sophia/>

Video/ update title and link	Summary of content
Intro – April 2022 https://youtu.be/-Ry-hu3R0xw	<ul style="list-style-type: none"> • Complex PTSD and how it affects day to day life and relationships with other people. • Migraines can also impact mental health. • IBS affects what she can eat and also flares up when mental health gets worse. • Insomnia and how this affects mood. • Would like to try and raise awareness as feels that feedback as an individual to services often doesn't get back to the right person.
April 2022 Update https://youtu.be/X6gLcsxRc8U	<ul style="list-style-type: none"> • Recent experience of mental health crisis – crisis team, Acute liaison Psychiatry (ALPs) in A&E, and Intensive Support Service (ISS). • Felt let down by ALPs as discharged with no further support when other professionals had expressed concern. • Didn't know what the plan was until next day Care-co-ordinator from Emerge referred to ISS. • Positive experience of ISS • Feels that language used by ALPs team both verbally and in reports is "condescending" and "judgemental". • Compares this with a positive experience from ALPs in a different geographical area. • Never been asked preference about whether she would like to see a male or female member of staff in ALPs which causes issues for her when presented with a male member of staff. Has been asked preference when accessing Community Mental Health Team (CMHT), ISS and Emerge.

Video/ update title and link	Summary of content
	<ul style="list-style-type: none"> • Feels that her patient information is out of date. Records not joined up. “Everyone working from a different system.” • Doesn't feel like an active partner in own care in A&E. • CMHT and Emerge – feels like has much more control and say in own care. • Positive experience of Care Co-ordinator from Emerge. Good relationship. • Would like crisis services to look more at a person as a whole person rather than someone's behaviour right now. Also need to record information more accurately.
Paramedic experience – April 2022 https://youtu.be/lyBf6R1fvL0	<ul style="list-style-type: none"> • Positive experience of paramedics when in crisis.
May-Sept 2022 Part 1 https://youtu.be/bOH84SvZENY	<ul style="list-style-type: none"> • Recent experience of mental health crisis: A&E, ALPs, crisis team, Becklin Centre, Oasis, ISS, 136 suite. • Didn't feel that crisis team listened to her or her care co-ordinator in terms of discharge from Oasis. • Impact of not respecting gender preferences of workers. • Positive and negative experiences of assessment at 136 suite by mental health act assessment staff. • Positive experience of A&E staff. • Uncertainty about responsibilities when under care of both Becklin Centre and LTHT whilst on general ward following overdose.

Video/ update title and link	Summary of content
May-Sept 2022 Part 2 https://youtu.be/Fvqs5jglpw4	<ul style="list-style-type: none"> • Discharge from Becklin Centre with no notice and didn't feel involved in decision. • ISS - Importance of being clear about which worker is coming out and when. Also supporting people for an adequate length of time and involving them in and giving more advance notice of discharge. • Feels it is 'belittling' to be told things like to have a cup of tea when in crisis. • Impact of prescriptions not being sorted.
May-Sept 2022 Part 3 https://youtu.be/5rNzcXB5UnE	<ul style="list-style-type: none"> • Dial House and Well Bean café – difficult sometimes to self-assess what level of crisis you are in order to access the right service. • Emerge – 3 visits a week - OT, care-co-ordinator and youth worker. • Live well Leeds – been on waiting list for year – finally accepted onto art group. • Probably be at home or “doing daft things” if I wasn't at these groups. • Sometimes difficult to find out about these groups etc. • Really valued Oasis. Support from individual staff, lived experience of staff, feels less clinical and cosier. Refer to people as 'guests' not 'patients' or 'service users.' • Feels like staff at Oasis have more time to be with people rather than doing paperwork like at Becklin Centre. • “I don't think telling somebody that they're not going to kill themselves in neither helpful nor appropriate.”
May-Sept 2022 Employment	<ul style="list-style-type: none"> • Sophia is self-employed. Can't always predict when mental health is going to mean she is too unwell to work.

Video/ update title and link	Summary of content
<p>and mental health https://youtu.be/oBuZ45dayKA</p>	<ul style="list-style-type: none"> • Can cause a lot of stress and sometimes isn't in a place to communicate with employer or person you have contract with. Has been helpful to have an advocate to help her do this. • Not all employers are going to understand, especially if they don't know you really well. • Currently not working. Difficult financially, emotionally and for career progression. • Huge contrast in capabilities when well and unwell – this can be frustrating. • Gets enhanced PIP and universal credit which makes things less stressful.
<p>May- Sept 2022 Becklin centre https://youtu.be/0lvFg90ClQ8</p>	<ul style="list-style-type: none"> • Experience of food at the Becklin centre
<p>Nov 2022 – Part 1 https://youtu.be/Tp09l88J994</p>	<ul style="list-style-type: none"> • Experience of working with the different professionals from Emerge. • Why she likes her care co-ordinator. • How they work well and communicate to each other and how this has a positive impact on her. • Importance of the Emerge team when having intense flashbacks – “good at calming me down”. • Wants the way that people with “personality disorder” or “complex trauma” are treated in the system to improve. Need to be treated with dignity and respect, as currently often feels “written off”.
<p>Nov 2022 – Part 2: Live Well Leeds</p>	<ul style="list-style-type: none"> • Experience of attending art group with Live Well Leeds. • Importance of sensitive first contact. • Need for more efficient waiting list system.

Video/ update title and link	Summary of content
https://youtu.be/Ws-M5UDc9XM	
Feb 2023 https://youtu.be/ZVjtAx52hkl	<ul style="list-style-type: none"> • Period of crisis over Christmas and new year. • Phone conversation with GP. • Discharged from A&E after being found unconscious and became very agitated. • Stay at Oasis where she was visited by person from Crisis team who she has had problems with, in the past, resulting in her refusing to engage. • Planned discharge without adequate discharge plan in place. Mixed messages from Dial House about whether could accept her referral. • Lack of support made her feel unsettled and suicidal. • Taken to 136 suite and voluntary admission to Crisis Assessment Unit (CAU). • Difficult environment – scary and unable to sleep. • Discharged because risk deemed to have increased in CAU, which she feels was not the case. • One phone call and visit from ISS then discharged to Emerge's care. • Accessing support from Well bean café and Dial House. • Feels telephone GP consultation with someone in crisis isn't appropriate for someone in crisis. Also feels that opportunities missed in A&E when discharged without a plan and wasn't seen by ALPS. • Appreciated kindness of a nurse in CAU.
April 2023 part 1	<ul style="list-style-type: none"> • Experiencing mental health crisis • Contact with Crisis team, care co-ordinator at Emerge, police, A&E and 136 suite.

Video/ update title and link	Summary of content
https://youtu.be/GKtpJMOWCs	<ul style="list-style-type: none"> • Varied experiences of communication and compassion at 136 suite, with crisis team and at A&E and impact it has on Sophia. • Trauma informed communication and response from doctor at A&E.
<p>April 2023 part 2</p> https://youtu.be/zVS1lj5g094	<ul style="list-style-type: none"> • ALPs assessment – doesn't feel involved in process. • Stigma of EUPD, complex PTSD etc. • Good communication with ambulance crew and compassion from Emerge care co-ordinators whilst in crisis. • Feels that poor communication and not enough support from ISS on discharge following being sectioned and inpatient at Becklin Centre. • Positive experience of MDT organised by Emerge. • Positive experience of crisis team.
<p>April 2023 – Becklin Centre and Discharge</p> https://youtu.be/wn2EWDm2p4c	<ul style="list-style-type: none"> • Experience of the Becklin Centre and discharge process
<p>Evaluation – April 2023</p> https://youtu.be/V2Zu-Jf07YA	<ul style="list-style-type: none"> • Sophia shares her thoughts on what has gone well being part of the How does it feel for me? project and her ideas for how it could be made better.