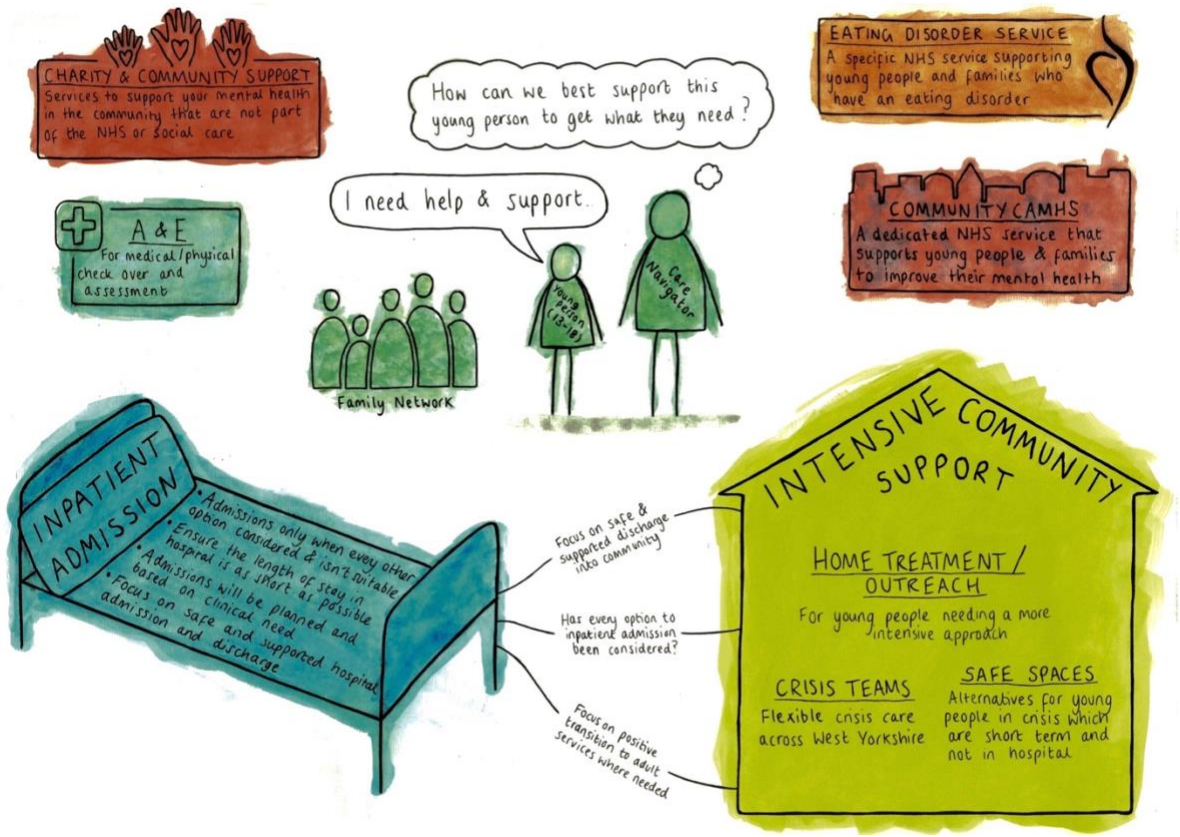
Conversations with young people and families about the West Yorkshire CAMHS New Care Model



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COMMON ROOM

“There’s nothing in hospital I couldn’t have got in the community”

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Introduction

In Spring 2018, Common Room Consulting were commissioned by Leeds Community Healthcare NHS trust as the lead provider for the CAMHS/Tier 4 New Care Model in West Yorkshire to carry out a series of discussions with children, young people, parents and carers who had recently received CAMHS inpatient and intensive community treatment in the region. The main brief for this engagement was to 'check out' the proposed New Care Model and gain insight into the benefits and possible pitfalls of such an approach from their perspective, including the introduction of Care Navigators, designated 'safe spaces' for crisis care and improvement to CAMHS Inpatient premises for the region. The discussions were intended to reflect on personal experiences of the existing systems and pathways in place whilst exploring the proposed NCM in order to steer new developments.

This report is complimented by a desktop review carried out by Common Room (March 2018) which explored, *"What do we already know from children, young people and their families?"*

Foreward

I felt truly privileged and excited to be a part of this project, to hopefully help incite such positive and necessary changes. From my own experiences of using services I can empathise with a lot of things the young people voiced. I feel incredibly passionate about trying to improve the current situation, but doing so with service user empowerment and their voices driving the changes.

It's not just the people I spoke to personally, but their friends, family and fellow patients, all sharing similar feelings of being let down and desperately wanting change. Hospital is definitely useful and needed, but for many young people who have been inpatients this could have been avoided. For some it may have exacerbated things, created new problems or prolonged issues. Many people felt strongly that an earlier intervention would have meant hospital admission may not have happened.

The young people using these services, and their families, cannot go home at the end of the day and 'switch off'. More likely, their life is consumed by their mental health and trying to cope. The NCM needs to remember this. It needs to remember to treat each individual as a human with a life that continues outside the walls of mental illness, and the literal walls of a hospital. Humans who have more to their identity than their mental illness, and cannot be left to fend for themselves in what has become a confusing minefield of accessing quality care. These people can be left to feel like problems, objects and ultimately abandoned.

These conversations made me feel a lot of things; disheartened, sadness, anger, but also pride, admiration, and hope… hearing the courage and passion in young people, and their vivacious energy to have their voices heard. We have a duty now to truly listen to what they've said and make it happen. I hope that not only the Care Navigators, but all relevant staff share my passion for positive change.

Megan, Common Room NCM Project Worker

Summary of key themes and messages.

Overall, and reassuringly, the messages and themes from our discussions with young people and parents were very consistent.

People we spoke to were overwhelmingly in favour of the New Care Model for CAMHS in West Yorkshire, and welcomed the new approach and its proposals. It made sense, and spoke to them in terms of their experiences of accessing CAMHS support in hospital and in the community.

In order for the new approach to be successful and to address the complex needs of children, young people and their families, people were concerned that the system requires the capacity to support people flexibly – and intensely where needed. Most people saw it as possible to support people in community settings as an alternative to hospital provision, but only if this support is adaptable and specialist enough to meet people's needs and offered in a timely and appropriate way to keep people safe. Intense support in the community, to be fit for purpose, needs to take young people's crises seriously and respond accordingly so that they feel validated. This may require a cultural shift for those providing - as well as using - services.

People we spoke to were clear that there needs to be consistency of care and better communication across trusts, teams and professionals in order to improve the experience as a whole but in particular during the transition between inpatient and community support services. In addition, people felt strongly that there needs to be more of an emphasis on the choice and accessibility of therapeutic interventions on offer, both in hospital and in community settings.

Young people and parents alike were generally complimentary about staff who had supported them and the good level of care they had received from individual practitioners, but felt the system was stretched in order to allow these staff to be able to give the level of care needed.

The introduction of specialist crisis services including 'safe spaces' out-of-hours provision was very popular. It was felt that these should not have a clinical emphasis, and should communicate with and respond to the individual in ways which suit them, enabling young people to feel in control wherever possible.

Young people want to be clearly informed at every stage of their care, and they want to be at the heart of their own care planning, enabled to have their say and being given choice about what is happening and who is involved. Parents were also in support of this.

In summary, the main messages from young people and families, explored further in this report, are

- We are very much in support of the new care model approach and feel positive about the changes proposed
- For this to be successful the whole system needs to work together with much more intensive community support options which are flexible and adaptable to individual need
- We want more access to therapy both in hospital settings and in the community
- We want services which communicate better – with us and with each other – and we want to be informed and involved wherever possible in a way we feel comfortable with

Throughout this report, direct quotes are indicated using italics and the following terms have been used;

YP	Children/young people
Parents	Parents and carers
CAMHS	Child and Adolescent Mental Health Service
NCM	New Model of Care for CAMHS West Yorkshire
IP	CAMHS Inpatient Units
CN	Care Navigator

Methodology

During Spring 2018, Common Room carried out a series of 1:1 discussions and one group discussion, about service users' perspectives on the proposed New Care Model for CAMHS in West Yorkshire. The majority were conducted in CAMHS Inpatient Units.

We spoke to 10 females and 2 males between 15 and 19 years; 9 of these had recently stayed or were currently staying in a CAMHS inpatient unit. We also spoke to 4 parents whose children had had at least one inpatient admission in the last year. With one exception, these parents and young people came from different families.

The participants' collective personal experience covered CAMHS inpatient and community services in Leeds, Sheffield, Doncaster, Huddersfield, Bradford, Airedale, Wakefield, York, Berry and Manchester. All participants gave formal consent to share their views in this report, and have been allocated random initials so as not to be identifiable.

The discussions began with an explanation of the approach and ethos of the NCM, using the illustration 'West Yorkshire CAMHS New Care Models' (see appendix 1). Participants were then asked a series of questions to gauge their thoughts and feelings about the new proposals based on their own experience (see appendix 3 for full list of questions). The discussions, where appropriate, covered wishes and hopes regarding the development of a key CAMHS inpatient unit.

NCM: Our first impressions

We spoke in detail to 14 young people, parents and carers, all of whom had first-hand experience of the current 'system' in different parts of the region. Their response on understanding the principles of the NCM was overwhelmingly positive about the proposed new way of working and the majority could see many benefits to introducing the NCM in this region. They told us;

- *Everyone knows something needs doing, but no one is doing it.* (YP)
- *The Care Navigator idea sounds good.* (YP)
- *We could manage in the community if support was not just 9-5*. (Parent)
- *It looks good, it makes sense.* (YP)
- *Yeah, I was in hospital so long…what was the point?* (YP)
- *Intensive community support would be amazing. To stop inpatient care for young people...it takes too long… there should have been intervention before, if there was would it have gone this far?* (Parent)
- *I get that I'm in but I'm not going to spend my whole life doing this. (*YP)
- *She could've come out earlier. She's now in a worse place mentally.* (Parent)

> ***I think the model is a great idea. To double check people are moving forwards not backwards… and it's freeing up space in the hospital.*** **(YP)**

Why we think the new approach might help and why we need the whole system working together

There was an overall feeling that hospital stays could be kept shorter or avoided altogether with the right community support. For example, one parent told us, *The BMI level needed for discharge is too much, it needs to be earlier. We thought it would be from red to amber, not red to green weight wise. But for her mental health,* (she) *needed to come out… she was eating just to get out of hospital, but they need to be prepared for it to not be the end of treatment.* (Parent)

> ***Too many young people are in hospital when it's not necessarily needed.***
>
> **(YP)**

Many young people and parents felt that staying in hospital long term wasn't always necessary and could in some cases make things worse. One YP felt it important that the reality of hospital is made clear to people who are receiving support in the community*; People think you'll get lots of support and it'll be nice … but in reality it's difficult, lonely and upsetting.*

Many aspects of the NCM were acknowledged as being positive:

- *I'd prefer more outreach than inpatient, it's too disruptive to my education. It's also too restrictive, I want to be able to go out more.* (YP)

- *I live too far from this unit, and if this worked I would get to see my family more because I would be at home – I would see more of my family and other people in my life and this would be a good thing.* (YP)

- *It's not as if as soon as you come out you're fine, it's not like that at all. Sometimes it's easier being in hospital because you've got to focus on getting better. But in the community, everything else comes first. There's nothing in hospital I couldn't have got in the community; someone to talk to 24/7, CBT, DBT, therapy, a call at 3 a.m. when urges are there…* (YP)

- *We had a care plan to see psychotherapists in the community whilst staying at hospital … but this didn't happen, and only just now is she seeing people in the community.* (Parent)

- *After my overdose, I didn't want to stay in hospital. Only one person came out ever to see me at home. They only stayed 20mins. Other than this I hadn't spoken to anyone, it helped to talk but longer would have been better. Maybe every 2 days. Ideally someone I've seen before… explaining everything over again is so difficult. They ask strange questions like "*what was your childhood like?*" or "*do you have siblings?*"* (YP)

A key theme from our feedback was the experience of systemic problems with referrals and pathways which got in the way of people's care and progress. It was felt that the introduction of the NCM would help communication and access across different trusts and professional teams. One young person suggested, *they should include this diagram, with a list of services and numbers and how to be referred, for different areas…* (with) *more than one option on how to access things. My GP was supportive and referred to CAMHS but school were not. You can hit a brick wall with it.* (YP)

There was a general feeling that inpatient care didn't live up to young people's and their families' expectations, and that the kind of specialised intensive treatment people expected wasn't their experience in reality. People described feeling bored and frustrated, with a lack of purpose or plan, where they would have expected and wanted more structured activities and intensive therapy.

People asked for a system with young people at the heart of it – which is flexible enough to fit with young people's support needs including more choice about appointment days / times. One young person described a positive experience and how they were supported *without me missing college as they knew it was important to me… and she drove out of area to attend the CPA meeting.*

What could make the new model more difficult?

There was from some a concern about safety and the capacity of services to be able to give intensive enough support, alongside an acknowledgement that sometimes people do need to stay in hospital. One young person was worried

that people may start to be prematurely discharged from hospital because services want to *try* new options, but that this may not be the best for young people. People questioned the capacity of the services which are alternatives to hospital to meet people's needs:

- *You say that the majority of support will be… done in the home/community… but home could be a trigger, a safe space might actually be inpatient unit.* (YP)

- *I don't get on with Mum so hospital will happen again. Mum doesn't understand. Why doesn't anyone listen? Mum can't cope, social care know, I'm on my 3rd admission. What if people don't have good parents?* (YP)

- *If I didn't get on with my Care Navigator or outreach team it would be really hard to do well. Also, if there aren't enough appointments I would struggle.* (YP)

What needs to happen to make the new model work?

Young people and parents alike were clear that the system would need the capacity and flexibility to see people as much and as often as is needed (every day, out of hours where necessary) with support which can respond appropriately to the level of need. Support in the community as an alternative to hospital needs to be able to deliver at an intensive level.

- *When you're in crisis there needs to be more appointments available.* (YP).
- *In my home treatment services, you may see someone twice weekly, but sometimes you need to see someone daily.* (YP)

> ***Doctors and staff often forget to inform me of what's going on. But this is important.*** **(YP)**

In addition, people described the benefits of openly reflecting and evaluating progress, i.e. *reviewing what's going on and explaining what's happening with treatment*. (YP). There was a clear feeling that review meetings could take place more regularly and that this should be based on individual need and relevance rather than standard protocol. We were also reminded that young people *are the most important people at those meetings* and that having regular feedback from the young people about their care is crucial, for example*, So they can say if a member of staff is not working for them without hurting their feelings.* (YP)

It was felt that the new model could also help to validate people's crises and very difficult episodes in the community, and that to acknowledge and be able to contain this without a hospital admission would be a positive step forward. One young person explained*; If you want to kill yourself enough you will. You not acting on it doesn't mean the feeling's not there. You have to hurt yourself for them to realise it's serious. It's a cycle, we need help before that point.*

Similarly, another young person told us*; My friend didn't feel like her illness was valid if she wasn't in hospital. Some people feel like they're not ill enough or the right kind of ill.*

We want it to feel easier when moving between inpatient and community support

Continuation of care came across as massively important. People felt strongly that, where possible, it would help to have the same therapists and mental health professionals working across inpatient and community services and, failing this, much tighter communication across the system to ensure a continuation of care. This would make transition in and out of hospital feel less daunting, and better enable people to move towards recovery.

For example, one young person explained; *I was put on a depot of anti-psychotics quickly after admission. If my home psychologist or someone was there who knew what I wanted, they could question this and say I don't need this. Decisions like this should be a joint discussion with other staff... Otherwise this is being decided by one person who's known you for a week.*

Another young person described how, *I was discharged the day before a four-week holiday. More contact time would be a lot better, it's the riskiest time, dangerous. I had no outreach that I can remember. There was no plan. I just wanted to say f*** you to everyone. I needed to be seen regularly, but it was all up in the air. I had to go see my CPN sometimes which was a 90min round trip. And no CAMHS support with school. School told me to sign in/sign out or we'll call the police, which was for their backs not for me. Like being threatened. They didn't ask me how to help, didn't understand the risks or my needs.*

> ***When I was in hospital I wasn't allowed to leave to continue with my CAMHS appointments.*** **(YP)**

Feeling *'abandoned'* and forgotten about in the system was a common experience described by young people and by parents. One parent told us, *CAMHS didn't attend the CPA or visit once, this was very disappointing …not even just a phone call.*

Another parent described how their child *was discharged with no schooling… she was too stressed but there was no home schooling or plan set up. This should've and could've been done earlier. There was no communication between* (IP unit) *and* (local) *CAMHS. Like a black hole.* (Parent)

In contrast, one example shows it *is* possible to get the transition process right; *By the time of discharge I was ready to transition and not stressed, as we were preparing for this* (YP)

Safe spaces: What we need in times of crisis

The provision of out of hours 'safe spaces' was welcomed, and it was felt this could help avoid the use of A&E services. Young people expressed the need for safe spaces which were accessible and contactable in different ways. They described wanting a non-clinical environment but with specialist help available in different ways – and choice about how to engage with the service.

- *Not everyone needs help in 9-5, it would be good to have help outside office hours.* (YP)
- *Late night opening, most crises are 9pm-1am. 24 hrs ideally. Also, the practicality of how to get there?* (YP)
- *If there are other poorly people there in crisis, this could make things worse for me - worsen my feelings because people can influence each other negatively. For me a safe space would need to be on a 1:1… I wouldn't want to go somewhere with other people in crisis.* (YP)

A young person described her experience of accessing a local safe space and how she was unsure of how risk was being managed; *It opened too late at 10:30pm... if it started at 5pm this would be better. There was only 2 rooms and I was the only person there. I felt pressured to socialise, talk to be polite. The whole focus was on me… I was quite ill, I made a plan to go to (*local store*) and buy medication to overdose. They needed to be aware of the risks…I could have easily run.*

So, to work well for young people, safe spaces need offer a variety of ways to engage and not have a rigid structure or strict criteria. One parent gave several examples of A&E not helping their daughter, and the feeling of having nowhere to go when in crisis; *They said,* 'go home and have a hot drink/bath etc." … *no, that's not going to work! We can't make a plan for the weekend. We've already tried everything and there's nothing else to do.*

A clear message from young people was about their wish to be in control – of information and of how crisis care was accessed:

- *It shouldn't be just "*parents are involved or not*" depending on circumstances, it should be the young person's wishes, like confidentiality* (YP)
- *There needs to be awareness, maybe a handbook, to empower people about their rights* (YP)
- *Discretion is important if someone has a fear of others knowing* (YP)
- *As simple a process as possible* (YP)
- *Not far from home* (YP)
- *Offer further support if I need it, but keep me up to date* (YP)

Young people welcomed an informal, reassuring approach with different options to engage -

- A *safe and calm space* (YP)
- *Not patronizing* (YP)
- *They need to treat you like an individual, not just your illness/struggle/risk. Think about my interests, for example art.* (YP)
- *There need to be relaxing things like music on, art activities, friendly staff and definitely not medical* (YP)

> ***'Safe spaces' is a good idea… A&E is not relaxing and it can be traumatic.***
>
> **(YP)**

Young people in general wanted options beyond having a helpline or having to make a phone call to access a safe space

- *If I was in crisis and needed out-of-hours care from the support teams I might not want to make a phone call, especially to a new person I'd never met. Unless the crisis was offered by a familiar face I don't think I would want to use it* (YP)
- *Having 24/7 support – phone, online chat, texting* (YP)
- *When I rang the crisis line, they suggested trivial things like seeing friends, self-care, suggestions… I couldn't brush my teeth let alone*

these. I just listened despite the cynicism… but please don't be patronising, I've heard it all a million times. (YP)

We want to have access to more therapy and more options

A strong, recurring theme from young people and parents was a wish for more therapeutic intervention – in hospital and in the community - alongside keeping people safe. It was felt that there was a missed opportunity, especially in IP settings, where people had lots of time and were expecting more intense support. For example, one young person explained how they would have liked *as many 1:1 sessions and as much therapeutic support as possible.* Another young person reiterated this; *It definitely needs a therapeutic approach, and to be really strong about this*. It was also felt important to have a choice about the way therapy was offered, for example; *I feel very on the spot in group therapy and it's hard to share some personal information in groups* (YP)

> ***Once a week for therapy was not at all enough. If you're in hospital then why not more? It takes time to build up trust and make headway with it, so why not?***
>
> **(Parent)**

One young person explained her inpatient provision had a good therapeutic offer… *but in Community CAMHS there was no group therapy, no DBT either. DBT is extremely important and helpful. Groups and 1:1 treatment are needed. Home treatment is important too. Also, more psychiatrists; there's only two, and often one is off so it's difficult to see my psychiatrist as she's busy and stressed.* (YP)
One parent described the same feeling about the IP unit where their daughter stayed: *If they had a more structured therapeutic programme, she would have learnt more skills to cope. It's all about medication, with no regular/consistent therapy. Nothing. It's disappointing as there was a real opportunity to learn about coping skills*. (Parent)

Young people and parents alike expressed wanting choice about when appointments were (e.g. *9 a.m. meetings aren't good!)* and whether appointments are attended alone; *Professionals often sweep you along and talk to mum rather than me* (YP)

We want clear information, good communication and services which are planned alongside young people

Where possible, young people said they would like to have input and a voice about their care and to play a part in how decisions are made:

- *You're our focus, we do what YOU want to… would be ideal* (YP)

Young people also told us that clarity of information is crucial - about what is happening to them and what has been decided – and that this is communicated well.

- *I just want to be well informed about my treatment* (YP)
- *…simple care plans that are understood by young people* (YP)
- *where I know the exact treatment plan and everything is kept simple.*
- *One doctor talks on and on, doesn't stick to the point and I find it confusing. I need clear information* (YP)

Young people said they would appreciate text or online options to enable them to cancel appointments or reschedule. One young person described being able to do this already with her CPN and it being the *easiest way of communicating.* There is a general feeling that phone calls aren't easy to make and letters in the post aren't welcome.

- *I'd only call when things are really bad*
- *To ring to cancel it can be like 'click here, do this, do that, or no one answers… it takes ages.*
- *letters at home are not great as parents read them, or know something is going on and want to know.*

> ***It would be good to have more information about what's going on and why!*** **(YP)**

Young people also asked for confidentiality issues in CAMHS to be clearer and less confusing - regarding who is deciding, where information goes and what is happening.

- (Staff) *need to check in with us before talking to parents, even if they're going to break confidentiality for safeguarding reasons at least let us know… also they don't need to tell parents everything. Be clear on what they're telling parents / not telling* (YP)

Our top tips for our Care Navigators

Overall people we spoke to were very positive about the introduction of Care Navigators into the system. They felt that a CN needs to be someone that they can trust who is *friendly, laid back* and can get a good balance between formality and a more *human* side e.g. be able to *have a laugh …not too stern/serious*. *Don't seem too professional. They need to be able to lead conversations, this is important. I'm not going to start a conversation, they need to come talk to me.* (YP)

One young person suggested that the CNs *have an information handbook to give out with who they are/ what to know/ and other info e.g. advocacy.* And that they are trained on autism as well as mental health *so they are more versatile and not excluding anyone.*

People were clear that CNs need to know the young people well and be able to act on their behalf;

- *they should…do what YOU want, not just what they think is right* (YP)

- *they need to actively be there for me, and have a clear understanding of me/my needs, make sure I understand too* (YP)

- *It would be great if the CN could be the key person in the middle, making sure everyone talks to each other and informs of what's going on… who ensures they know where to go and what's going on - not saying* "not today I've not got time*".* (Parent)

- *too much talking is bad. I need my own space. I don't want to repeat myself… this is really overwhelming. I need the CN/staff to know my history/needs/triggers* (YP)

> ***To have someone to stick up for you, who knows you…and knows about mental health.*** **(YP)**

Other messages from parents

A strong theme from parents was about poor communication and not feeling adequately informed. Parents expressed frustration at their lack of understanding about processes and decision making.

- *We're currently at big risk of readmission, and we have no idea what the plan is. Will it be all of a sudden or in two weeks? What weight will she be to be readmitted? I have to ask for all of the information, we don't get told anything.*

- *Only when we asked were we told information … they just assumed we knew what was going on. We had to ask. "*How do we help*?", "*What practicalities do we need to know*?". Knowing the team would've been a lot better.*

- *We weren't entirely aware of the risk, and didn't know how serious things were.*

Parents supported the idea of safe spaces and more out of hours options. Some felt the lack of crisis care had been very difficult at times, for example one parent explained; *The impact on me was big. It's so hard to admit I can't look after my daughter or keep her safe… I feel like a failure. I followed my daughter around and did everything I could… on the way to A&E she was pulling the steering wheel. A&E said* "let's make a plan for the weekend" *and I was just like 'NO, just help us!'*

One parent described feeling like they were fulfilling the role of their daughters' care coordinator, and questioned how the new model would help the situation; *Coordination between teams would've been great. I'm worried though that the Care Navigator may add an extra layer to this already complicated communication.*

Parents also felt the need for regular reviews, for example one parent talked about their IP unit experience; *It was scary not knowing how long. It's open ended. 28 days is a long time to review. Our lives are on hold.*

As outlined previously, parents said they would have appreciated more of an intense therapeutic offer from CAMHS, especially in IP units. In addition, they talked about the missed opportunity of not being supported and informed properly in order to be effective care givers. One parent described how, throughout five years being supported by CAMHS, they were never given any written information to help them know what to do and how to help their child. Parents also acknowledged the need to get support for themselves outside the care given to their children.

- *there was med and psych treatment for young people, but parents need help too. It's massively important. My life had to stop.*
- *(*IP unit*) had a parent group every week, with professionals too. We talked openly, felt like we weren't alone. It was fantastic. They taught me lots of things to use at home. I learnt a lot.* (They) *also kept me in the loop and up to date*.

Support is needed for the family. My wife and I benefitted from counselling with Relate to try and make sense of the crisis we were experiencing. **(Parent)**

CAMHS Inpatient support in an ideal world

The feedback and experiences touched upon above indicate that 'getting it right' for young people in inpatient care rests on developing elements of the whole system - across hospital and community settings. The final section of this report outlines specific feedback from young people and families about how they feel they would like CAMHS inpatient care to 'look and feel'.

The vast majority of young people we spoke to felt let down by the inpatient support they received. For example, one young person stated in the future that given the choice she would prioritise the quality of care in the unit over its location because the local provision was *'shockingly bad, pointless, no therapy and the building not fit for purpose. Also, eating disorders is the only criteria they can work with'.*

Young people often felt things hadn't been communicated very well, about what was happening to them regarding their inpatient stay and what was likely to happen next. For example, we were told, *there needs to be more info about how inpatient works, for example I had no idea about leave. When I was sectioned no one told me what was going on, I didn't understand… Legal? What? Someone needed to explain what was going on, explain that going voluntary was a lot easier. No one told me which hospital I was going to, just vague details of somewhere 90 mins away.* (YP)

Similar comments came from parents about their need to be informed; *So much was taken off her when she went in, it would have helped a lot to have a booklet before. We didn't know what to expect. Strait jackets? Padded cells? (*Parent)

Young people talked about boundaries and rules and generally understood and appreciated the need for them.

- *It was very regimented. However, this is what you need sometimes. Mobile phones were limited so we socialised more, computer use was allowed.*

- *Bedtime is fair, but don't lock off the whole ward at 8:30pm*

Several parents and young people talked specifically about education and the need for good communication, and encouragement; One young person suggested giving incentives for going to lessons and applying yourself *rather than punishments for not bothering.*

Likewise, another young person suggested this approach generally; *no punishments for bad incidents, just support*. And a further person suggested having *access to a computer or tablet which belongs to the unit so I can get on the internet and do school work or revision outside school classroom times…I might want to do this on an evening but might not have my own laptop.*

One parent did give a good example of how education was integrated well with their child's IP stay; *School were amazing. Her mentor visited whilst in hospital and teachers did too. They also supported her friends too. Teachers helped with exam papers, and sent invigilators to help.* (Parent)

We want access to more therapy and more activities (IP)

The majority of young people felt that there was a real lack of things to do to pass the time on the ward. More importantly perhaps they had expected - and would have appreciated - more therapeutic intervention. They also said they would have liked to be offered activities which reflected 'normal life', which enabled them to have fun and also more opportunities for time away from the ward. They felt they wanted things in place which help form a connection with the 'real world' and a sense they they were always moving towards transition.

- *A lot more normal things; baking, pumpkin carving, Xmas tree… more like a family… Nandos, cinema, farm, making a den in the lounge, making the best of a bad situation.* (YP)

- *I was told "*you're not here to have a good time*" and "*it's not supposed to be fun*" … but why? … it doesn't have to be so boring*. (YP)

- *More group leave, this was great.* (YP)

- *I wanted … just more things to do.* (YP)

> ***Cooking classes will equip you for life outside of hospital.*** **(YP)**

These messages were echoed by parents, for example, (*) *was only taken out once in her 9 months inpatient time. More outings would have been brilliant, and such a help for when she was discharged. She was taken to a café, and found it okay. Not going to these places while she was in hospital made it such a big problem when she was discharged. She can't go out anywhere now let alone a café.* (Parent)

A homely environment (IP)

When we asked about the look and feel of an ideal inpatient unit, a recurring theme was about it being comfortable, relaxing and welcoming, for example, *not like a hospital, more like a home… colourful, cosy, with comfy chairs, bean bags… really informal.*

Communal spaces were favoured if there was plenty of options to mix or to be alone within them;

- *Leave the communal spaces open right up until bedtime so we don't have to stay in our rooms, or go in lounges with other young people. Also, when family visit, it would be good to have a space for this.* (YP)

- *Social areas are important, sofa, TV, Xbox in one. Open plan would be best, it makes people interact more.* (YP)

- *More spaces we can use 'whenever' like chill out rooms, just more space that wasn't crowded. So, if you want to be on your own you don't always have to just be in your bedroom.* (YP)

> ***Options to go places to be by myself without going to my bedroom.***
>
> **(YP)**

Several young people talked about the idea of having a 'safe space' within the IP unit to go to in times of crisis or when things are feeling very intense *rather than the whole ward to be put on lock down… like a mindfulness /relaxation room. It might be a space which people could chill out in too… with lots and lots of beanbags!* (YP)

Some young people mentioned they would like to have creative spaces available, e.g. dance room, music, art and craft, alongside creative groups running. Several also mentioned internet access; *Wi-Fi everywhere! At the moment it's hit and miss, so some bedrooms work and some don't which isn't fair.* (YP)

Access to outside space was a recurring theme. One young person described how, *I'd often not been outdoors for a week. In summer this was really frustrating. Outdoor needs to be accessible all the time…plenty of light hours.* (YP)

IP: Food is important!

We didn't ask specific questions about food but it came up in the feedback discussions many times. Young people said they would like more appropriate,

varied menus where there was more choice, and also the chance to get involved in choosing and preparing food.

- *We could predict the menu, actually nice food and making meals would be good…cooking would be great, everyone can do it, you learn life skills.*

- *More kids' options on the menu like nuggets, pizza etc, and not steak & kidney pie!*

- *The food was awful. I lived off jacket potatoes and I hate them.*

- *Need more vegetarian options, more options generally.*

We want staff who genuinely care (IP)

A strong theme when we asked about staff was the feeling of being able to have authentic relationships with them beyond their professional roles and boundaries. Young people valued staff who *genuinely care* and *aren't just there because it's their job.*

- *Me and* (*) *would go out for a coffee, talk about everything - not just mental health, build up trust.* (She) *was human, talked about her own life and her own experiences.* (YP)

Parents also acknowledged this above and how this didn't feel consistent across different units;

- (IP unit) *had caring genuine staff who really knew the young person, but at* (*IP unit) *there was no connection with staff. No one would check on her even if she was in the social room.* (Parent)

- *…more chats would have been really good, more 1:1s. Staff would often come to* (*YP) *and say they'd see her later for a chat, and she would say "*it won't happen*".* (Parent)

As already mentioned, several people talked about the inconsistency of staff as being problematic, and wanting continuity of care wherever possible. *The staff*

on this unit were brilliant - all regular (rarely ever agency and bank staff). It was rare to see someone I didn't know, this made things a lot easier. We could see the rota so we knew who we could speak to. (YP)

> ***A lot of people don't get that …it's not in the job description, but such a big difference to know someone cares.***
>
> **(YP)**

Appendices

COMMON ROOM

Consent form for participants engaged with NCM West Yorkshire project

Thank you for volunteering to take part in a Common Room focus 1:1 discussion. We would like to use the things you say in reports we write and information we share which we hope will help develop services and improve them.

We will keep all your personal information anonymous. This means that we will not use your name, age or where you are from.

We need your consent to say that you agree to take part in the discussion.

Please tick the boxes and sign below to say you give your consent to take part.

	Yes ✓	No ✗
I am happy to take part in a Common Room focus discussion about New Care Models in West Yorkshire		
I understand that what I say may be used in written resources or formal reports – and these may be my direct quotes		
I understand that I can withdraw my permission at any time. This includes before, during or up to one week after the discussion has finished (I need to email kate.martin@commonroom.uk.com to do this)		
I understand that Common Room will not use my name or identify me in any way when they represent my views and opinions.		

Your name _____

Your date of birth_____

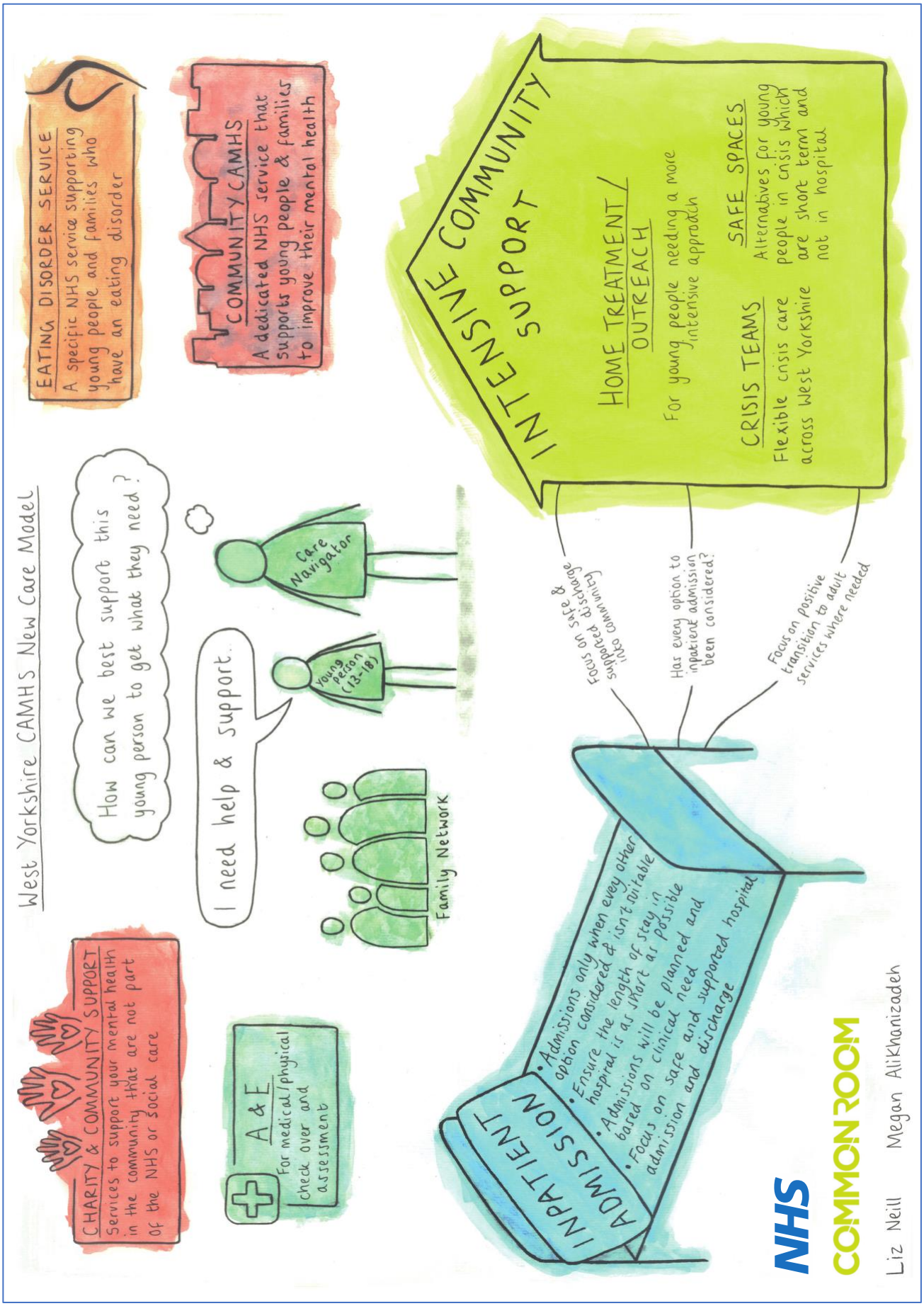
I am happy with the statements above (please sign)

_____

Date _____

Under 16? Please turn over

COMMON ROOM


West Yorkshire CAMHS New Care Model
EATING DISORDER SERVICE
A specific NHS service supporting young people and families who have an eating disorder
COMMUNITY CAMHS
A dedicated NHS service that supports young people & families to improve their mental health
How can we best support this young person to get what they need?
I need help & support.
Care Navigator
Young person (13-18)
Family Network
CHARITY & COMMUNITY SUPPORT
Services to support your mental health in the community that are not part of the NHS or social care
A & E
For medical/physical check over and assessment
INTENSIVE COMMUNITY SUPPORT
HOME TREATMENT / OUTREACH
For young people needing a more intensive approach
CRISIS TEAMS
Flexible crisis care across West Yorkshire
SAFE SPACES
Alternatives for young people in crisis which are short term and not in hospital
Focus on safe & supported discharge into community
Has every option to inpatient admission been considered?
Focus on positive transition to adult services where needed
INPATIENT ADMISSION
•Admissions only when every other option considered & isn't suitable
•Ensure the length of stay in hospital is as short as possible
•Admissions will be planned and based on clinical need
•Focus on safe and supported hospital admission and discharge
NHS
COMMON ROOM
Liz Neill Megan AliKhanizadeh

NCM engagement – discussion outline for young people / parents

Intro

Thank you for agreeing to meet with Common Room to discuss the 'New Care Model' in West Yorkshire. We are going to explain to you what is being proposed in the region to redesign the CAMHS and community services, and ask for your comments about a new way of working across the region. We want to check this model fits with what feels helpful to young people and families.

What you tell us in this discussion will be confidential and you will remain anonymous (we will not share your name or identify you in our report). We will be talking to several young people and parents and carers during Spring 2018, and will write a report based on these discussions. The report will go to the NHS 'decision makers' and help inform the staff who are delivering services.

(gain signed consent)

1. Your age and gender (if young person) OR your relationship to YP

Use the illustration to explain/describe the NCM which is being put into place this year)

2. What are your initial thoughts about the NCM?

3. Do you think this new approach might address some of the difficulties with the way the services work at the moment? How?

4. Do you think this new approach might make anything harder or worse for young people / their families?

5. How do you think the Intensive Community Support service will need to work to help young people avoid long stays in hospital?

6. Do you have any top tips for our Care Navigators?

Do you have any other comments about the model and approach?

Inpatient unit (if relevant)

We are currently planning a new location for the CAMHS inpatient unit in this area. Please tell us what elements you think would make an excellent unit – in terms of

7. The look and feel
8. The staffing
9. How information should be shared / communicated

Is there anything else you would like to say? e.g. if you could change one thing with how things are now, what would it be?

(give voucher)

About Common Room

Common Room is a consultancy led by lived experience. We promote collaborative practice and connect the expertise of children, young people, researchers, practitioners and policymakers across disability, health and mental health to find the best ways of

- involving young people in decisions about their lives, services and support
- improving support services to ensure they can best address and respond to the CYP experience

- We do this through
  - offering training and service improvement support to professionals and services
  - involving children and young people as partners in research, policy, and service improvement projects
  - learning from lived experience through consultation and research with children, young people and families

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Thanks to all children and young people, parents and carers who took part, including the Stairways group (through Y&H Strategic Clinical Network) ☺

September 2018