

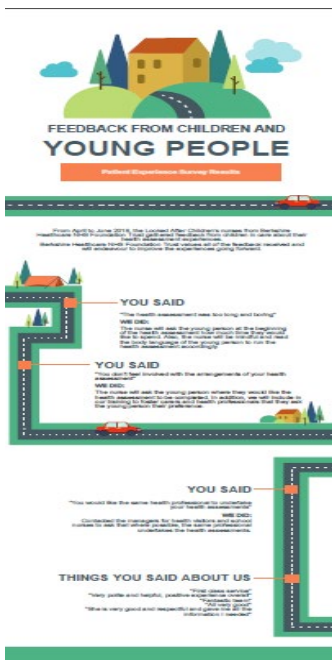


## Quarterly report: Participation and Feedback in Children, young people and family services (CYPF). April, 2019.

By Daryl Nicholas, Service user experience and participation lead for CYPF

We are pleased to welcome Becca Bird (CAMHS) and Tani Prindiville (Willow House) to our team of participation champions. Our participation champions have continued to work hard in their progression towards achieving the participation levels, outlined within the Participation strategy, this quarter. A growing focus has been given to 'You said, we did' outcomes and many services having now developed effective methods of feedback, response, and action. The depth and wide ranging nature of actions, taken in response to service user participation and feedback, has been pleasing to see. We have also witnessed a growing ownership of participation across individual services. A new reporting template has been developed to reflect the growing emphasis on outcomes and also to ensure our services are mindful and progressive in their endeavours to ensure their participation and feedback structure meets the equality, diversity, and inclusion agenda. Collectively, the team have met for a participation champion's workshop and for a 'catch up' meeting during the quarter with several 1:1/service specific meetings also taking place. Our network meeting included an emphasis on Equality, Diversity and SEND, and the use of Devices and tablets to aid feedback.

### Looked after Children Nursing



Data from feedback forms, which are completed by Looked After Children and Young People and their Foster Carers, following Review Health Assessments, is discussed at LAC nursing monthly team meetings where themes are identified and solutions considered. 'You said, we did' posters are displayed to service users and their Foster Carers. LAC Nurses have also demonstrated that they have taken on board and acted on the suggestions made by Foster Carers in regards to improving the training sessions that the LAC Nurses deliver.

The 'Participation Champion' within the LAC team is regularly rotated to keep engagement fresh and enthusiasm high. There is a whole team approach to the Participation process with everyone's input being valued.

LAC Nurses consulted Young People via 'Children In Care Councils' in regards to developing the feedback form they would prefer the team to use following health reviews. The service is waiting for an electronic version of this form to be finalised. This will then be downloaded to the LAC Nurses' smart phones and hand held devices for ease of use and to

improve date collection.

Foster Carers were also asked, via focus groups, or during regular support meetings/coffee mornings that are facilitated by LA's, for their thoughts in regards to ways the service could improve the training sessions the LAC Nurses deliver. The feedback has now been acted on and training packages revamped accordingly.

YOU SAID....	WE DID.....
<p><u>Foster Carers:</u></p> <p>You would like training that was interactive and relevant</p>	<p>Held focus groups, gathered feedback of carers' views and arranged further training for nursing staff through Learning and Development to improve our training delivery. Individual training 'packages'/health topics were then revamped by LAC Nurses.</p>
<p><u>Children &amp; Young People:</u></p> <p>The health assessment was too long and boring</p>	<p>The nurse will ask the young person at the beginning of the health assessment how much time they would like to spend. Also, the nurse will be mindful and read the body language of the young person to run the health assessment accordingly.</p>
<p><u>Children &amp; Young People:</u></p> <p>Our feedback forms are too long to complete</p>	<p>We changed the feedback form for young people and asked for your input in the new design (the new feedback form will also be downloaded to our smart phones to make it a more 'young person friendly' way of gathering feedback data).</p>
<p><u>Children &amp; Young People:</u></p> <p>You don't feel involved with the arrangements of your health assessment</p>	<p>The nurse will ask the young person where they would like the health assessment to be completed. In addition, we will include in our training to foster carers and health professionals that they ask the young person their preference.</p>

## CAMHS

Service users, parents, carers, and other family members, share their experience of the service via monthly participation meetings, which have taken place in Reading, Wokingham and Slough in recent months. This allows for both consultation and co-production.

These groups allow young people and families to provide their view on various developments of the service for example, updating the BHFT CYPF website. Young people and families were able to identify ways the website could be improved, areas not to change, as well as comment on the content and design of the website.

Young people and parents have also:

- Reviewed the recently published ‘You said, we did’ final document.
- Advised on ‘what would service users like to know about CYPF and the senior management team?’
- Service users have put together a paragraph to describe the role of the care-coordinator to other service users.
- Reviewed the consent to treatment and Sharing of Information.

CAMHS offered the participation groups several opportunities to report back on their experience of their ‘service journey’

and to highlight areas for improvement or concern. CAMHS continues to receive a substantial amount of feedback responses via the Experience of Service Questionnaire, completed by 95% of service users, and the Friends and Family Test cards which are distributed on a six weekly cycle.

The service user’s priorities were taken to the monthly CYPIAPT meeting for exploration and action. The feedback is taken to the CAMHS leadership meetings to discuss decisions further. “You said, we did” posters are then developed which are displayed in waiting rooms at all site locations. Hand-outs are also put in waiting rooms for people to read through. Discussions are also held at the monthly participation group meeting in order to hear young people feedback on the decisions made.



YOU SAID....	WE DID.....
It is often difficult to get through to CAMHS on the phone.	Berkshire Healthcare recognise the difficulty that people sometimes have in contacting some of the CAMHS teams by phone and understand how frustrating that is. The Trust’s Children, Young People and Families directorate have been working to review the administrative needs and resources across all services over the last 6 months and have allocated dedicated reception staff to some areas of particularly high need. They have also updated their telephone phone systems at several specialist CAMHS sites with the aim of making it easier for service users to get through. The impact of these changes will be monitored over the coming months.
The waiting times we can expect to experience before entering CAMHS are unclear.	Whilst it is challenging to give precise waiting times due to the fact that we have to prioritise those young people most at risk at any one time,

	<p>and that this changes frequently, all teams within the CAMH service try to give clear information on the likely waiting times for appointments. We regularly review waiting times and have processes in place to provide support and communicate with people while they are waiting but we are working with our service users to think about how we can communicate these more effectively in the future.</p>
<p>It is often difficult to get a referral to CAMHS from GPs.</p>	<p>Berkshire Healthcare CAMHS are active members of the Berkshire East and Berkshire West CAMHS transformation partnerships and have worked closely with the Clinical Commissioning Groups and other partners to promote the message that the best person to make a referral is someone who knows the young person and their needs and difficulties well. That is often not their GP, but could be a teacher, youth worker, parent/carer or if over 16, the young person themselves. It takes time for this message to be embedded but we continue to promote it, through our website, our single on-line referral form, in our training and meetings with schools, through GP forums and via information on the GP IT systems.</p>
<p>Clinicians tell us they are going to do something (such as make a referral to another pathway), but it does not happen. We have to chase them.</p>	<p>We agree that this is not acceptable. Fortunately, it happens infrequently however we would encourage any young people or families who may have experienced this situation to contact the relevant clinician and if unable to do so, to contact the service manager so that they can resolve the issue quickly. If a referral has not been made when it should have been, when the young person is transferred to the new pathway/team, the referral is backdated to the initial referral date so that families are not disadvantaged by potential errors by the Service.</p> <p>We are keen to ensure that the service that we provide is the best that it can be and want to learn from when things do not work well, so that we can make changes. Information about how to make a complaint is clearly displayed in all CAMHS clinics and on the CAMHS website and if necessary, young people and families can make a formal complaint. However we hope that will not be necessary.</p>
<p>We feel that the anxiety and depression pathway</p>	<p>The anxiety and depression pathway is a specialist</p>

<p>needs an autism specialist for incidences of co-morbidity.</p>	<p>service that offers cognitive behavioural therapy (CBT) – based treatments to young people with moderate to severe anxiety, depression, OCD and PTSD. There is good evidence that these treatments can be successful for those with autism, if adapted appropriately and the team frequently see young people with neurodevelopmental difficulties, including autism, and do offer one-to-one CBT that is adapted to young persons’ needs. Members of the anxiety &amp; depression team have undertaken specialist training in autism and the team have employed a number of clinical psychologists who have expertise in autism to help further develop interventions for this group of young people. The team have been working closely with the autism specialists in our Autism Assessment team to design and deliver joint training more widely across the service; members of the anxiety and depression pathway provide support to families via the autism teams’ Young SHaRON on-line network and the teams are developing joint workshops for families of young people with autism and anxiety.</p>
<p>There is a lack of early help when mental health problems arise. It feels as though we need to reach crisis point/hospitalisation before any action is taken.</p>	<p>We agree that more help needs to be available for children and young people as soon as mental health difficulties begin to emerge. This is an issue that does not only impact families in Berkshire – several national initiatives are currently being undertaken to address the need for earlier support, and the government have pledged funding to develop these strategies.</p> <p>Although Berkshire Healthcare CAMHS work primarily with children and young people with moderate/severe mental health difficulties, whose symptoms have often been occurring over several months, we have developed a number of resources that contribute to early help. Our on-line resource provides information and guidance for families and links to other self-help resources; the Young SHaRON on-line network provides immediate peer-moderated support to families of young people referred for an autism assessment and the anxiety and depression pathway run workshops for parents, carers and adolescents to provide early help following initial referral to the</p>

	<p>service. Information on early help services available in each of the Berkshire localities is available on our website and we work closely with our partners in the Clinical Commissioning Group and Local Authorities to support the development of more early help.</p>
<p>Parking is an issue. It's difficult to find a space.</p>	<p>Limited parking is a recognised problem across some Berkshire Healthcare sites. Initiatives have been put in place to improve parking for both service users and staff at Wokingham Hospital. The CAMH service in Reading has recently been moved to a new site with much better access to parking and further locality moves are currently being explored.</p>
<p>The attitude of (non-CAMHS) staff is sometimes a worry when we access A&amp;E services.</p>	<p>The issue of stigma around mental health, including from some health care professionals is something that has been highlighted as a concern nationally and there are a number of national initiatives that are seeking to address it. Young people who had been seen by the CAMHS rapid response team shared examples that related to their experiences of this locally while taking part in focus groups to explore their experiences of care. These examples have been shared with the relevant organisations, which have put in place actions to tackle this issue.</p>
<p>We would like to see changes in the way the 'was not brought' policy is communicated to young people/families when they do not arrive for appointments.</p>	<p>We have worked with our service user participation groups to review the letters that we send when families miss appointments. We are also working to include information on this and other important policies on our website and to ensure that information is clearly displayed in all of our service waiting areas.</p> <p>Missed appointments mean that time clinicians could be spending seeing young people is wasted, contributing to long waiting times for our services. Whilst in most of our teams the number of missed appointments is low, with around 16% of appointments to the ADHD team being missed.</p>

## School Nursing

The West Berkshire school nursing team have undertaken two focus groups in March:

One of these was with a small group of parents that were targeted by the Calcot children's hub. Parents were given the opportunity to identify what had been helpful and how the session could be improved when a 'school readiness' session is delivered.

A school nurse attended the localities 'school health champions' annual conference where a focus group had been held. The school nurse discussed the feedback received from last year as well as facilitating the students in the completion of a survey monkey, currently being circulated by Public health in the local authority, which will inform future commissioning of the service.

In Reading, the film to support the substance misuse resource has been completed; the team are now working with students on still images, including joint work with the local police force, for a social media project. A workshop is being planned immediately after Easter to prepare the team to deliver some pilot sessions using the film. Students will be given the opportunity for feedback in schools during the summer term.

Ten pilot sessions for a new Year 4 healthy lifestyle resource are currently underway in Reading schools; the resource was produced in partnership with a local primary school, Emmer Green primary, their year 4 teacher and class pupils. The teacher and class discussed and planned the content, the session which is quite interactive was then trialled by the class who gave feedback and then alterations were made accordingly.

Discussions at patient participation Champions workshop encouraged the service to openly acknowledge the service users concerns of issues relating to overall provision by BHFT, such as parking, and the service plans to circulate alternative travel information to support the use of public transport where this could be preferable to driving.

Amended feedback surveys, which include the Friends and family test questions, are in the process of being placed onto team iPhones and will be operational after the Easter break. The Friends and family test questions cards are being used to collect feedback from families who have received a care package but only had telephone contact with our service. These will complement school nursing surveys on iPhones which collect quantitative data at Nocturnal Enuresis clinics and 1:1 appointments. The feedback is explored and action is taken within team meetings leading to the production of 'you said, we did' actions. These are displayed in clinic settings and in schools using info graphics from Piktochart.

anger management, health issues which the student is finding hard to deal with, escalated behaviour during puberty, but to name a few.

information of how best to assist students with medical needs, which is incredibly valuable. XXX is always willing to go above and beyond and

Client experience  
See Table 2.

**Co-creation—service user involvement in development of the service**

Following the team's new service specifications requirements and new model of service delivery, significant service development has been required. The team have tried hard to involve service users and stakeholders in service development to ensure that our service is student, relevant and fit for purpose. Initiatives have included:

- An amended education session to be made by school nursing in partnership with the young people of Reading, while one school are producing the film, every student in Year 9 across the locality had the opportunity to feed into the project. The film will form the centrepiece of a new health promotion initiative to be rolled to all secondary provisions in the locality.
- Production of a Year 4 healthy lifestyle resource made in partnership with staff and students of a Year 4 class in one of our primary schools.
- Production of a new Year 4 presentation

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to support transition to secondary school and growing up developed in partnership with staff, students and parents of another primary school. Focus group held at a Pupil Referral unit to identify their views for their school nursing service.

**Resulting impact on service and process following the year-long pilot**

- A significant increase in face to face and telephone contacts with families has been evidenced.
- Health information is now available

**Wider team developments**

While the new model focused mainly on the practice of the qualified school nurses (QSPNs) in the team, a flexibility required flexibility and adaptation from all other team members to achieve the greatest impact. Other team members were affected in the following ways:

**School staff nurse**

School staff nurses worked with locality with the public health school nurses delivering targeted advice and support to children, young people and families to promote increased workforce methods are well established in their roles and are now in a period of consolidation. The next phase of development for the team will be how we can further develop the staff nurse role and contribution to the team's objectives and how the skills of the school health assistants (where primary role is to complete the National Child Measurement Programme and audiology screenings) can be harnessed to support team objectives further.

**Conclusions**

The academic year 2017-18 was a challenging one for Reading school



A recent article, written by Beverley Wheeler, School Nurse Manager, was published in the British Journal of School Nursing featuring a section on 'Co-creation: service user involvement in development of the service'.

YOU SAID....	WE DID.....
Feedback from young people in Reading: The health promotion resource should include, 'real people, telling real stories in real language'	Development continues on substance misuse resource following the 'you said' from service users.
Feedback from a previous quarter from young people in Reading requesting a 'male member of staff' in pupil referral unit	Male student nurse on placement with the team, targeted work to be planned that student can support with. Integrated working with other male colleagues from other services is happening as and when needed.
Feedback from service users in school nursing surveys re parking issues at nocturnal enuresis clinic.	Parking and travel information being produced which can support alternatives to driving to venues.  Feedback posters to acknowledge concerns regarding parking and state that Berkshire healthcare have a strategy to improve the issues.

## CYPIT

Given the structural changes within the service, the champions have found it challenging to allocate time to maintain progress on their feedback and participation mechanisms this quarter. Despite this, the service has put significant efforts into continuing the development of the questionnaire. The continued aim is to produce a standardised questionnaire for piloting with service users. As part of a SEND focus, the CYPIT team are considering the use of images, such as smiley faces, and colours to support the understanding of younger children with additional needs. The service is also planning to add diversity and inclusion questions within the CYPIT wide questionnaire.

The CYPIT feedback form, which captures service user involvement at various stages of the participation levels, continues to be used within support groups run by the service with the identified themes being explored and actions are taken. Quantitative information is also gathered from the early years speech and language therapy 'drop in' clinic. The staff team are currently working on displaying feedback to staff and service users.

Teams in the East of the county have developed a two week period, within each quarter, where the Friends and Family Test cards are given to each family. In the West of the County, the Newbury team are trialling an online, post-drop in, survey. This is sent out by email four times a year to families who have attended one of the drop-in clinics in the previous three months. This complements qualitative feedback gained through feedback slips at the drop-ins themselves. The operational lead is currently looking at the feedback that has been collected and will produce some



written information. This will be shared with service users on the portable drop in display boards alongside the current 'You said, we did' actions relating to the responses to the feedback slips. The feedback will be shared with the Early Years team at the next team meeting which is scheduled for early May.

YOU SAID....	WE DID.....
I do not see the same therapist each time	We allocated individual caseloads to the SLTs to increase consistency (Reading Early Years)
My child is not seen in the best environment	Increased home visits for children with ASD (Reading Early Years)
We have to wait a long time at drop in	Trialled a 'booking' service where families can to the local park if they wish then return for their appointment (Newbury Early Years)

### Immunisations team

The immunisations team is putting a lot of work into to responding the service user feedback that they would like more flexibility with regards to clinic availability and clinics outside of school hours.

- The team will be utilising the outreach vehicle in the summer term, and hopefully within the summer holidays, to capture as many unvaccinated children as possible and to be as flexible as possible to immunise children within the holidays and allow greater access. This will double up as a promotional exercise as again it will be advertised in a range of different sources. These sessions will be reviewed using FFT/PPI tablets to gain feedback at the sessions.
- Parental feedback within the East of the county has led to the service holding more catch up clinics on Saturdays and the service are currently exploring this within the West of the county.
- The team are investigating the option of holding evening clinics at Whitley Health and Social Services Centre and West Berkshire Community Hospital.

The service distributes and collects Friends and family test cards, for parents, carers and children to complete, although these are predominantly completed by parents/carers, at signing in desk at immunisation community clinics. Feedback tablets are used within all schools for children to complete. This feedback is shared with staff via Newsletters, emails, and discussed at team meetings. The service is looking to design A3 laminated posters to be displayed within immunisation community clinics. The Immunisation team also hope to display A3 laminated posters within schools and also to send a link to the school with the feedback so that they can incorporate this into their newsletters.

The distribution and collection of the surveys are regularly discussed at Immunisation team meetings and all feedback from the Friends and family monthly report is inserted into newsletters. The service routinely asks for staff feedback to obtain ideas. The feedback themes are taken back to a termly team meeting and then onto management in order for decisions to be made jointly. These actions are then placed onto 'You said, we did' posters which are displayed to service users within service waiting areas and will be uploaded onto the immunisations website page.

Upcoming plans: the immunisation team are currently....

- Exploring the possibility of having a promotional/immunisations stand/delivery of immunisations at Salt Hill Park venue in Slough on 7.8.19. To utilise PPI tablets/FFT cards. Playday is an annual event, over 40 stalls at the event ranging from Housing to Libraries to Healthwatch and Parks accommodating up to 3000 people, which is held all over England on the same day each year.
- Exploring the possibility of having a promotional/immunisations stand/delivery of immunisations at Southcote Community Fair in Reading on 11.5.19 alongside school nurses. To utilise PPI tablets/FFT cards.
- The team will involve parents and carers, and work alongside Reading Borough Council, to assist in designing an easy to read flu leaflet to be included in their health and well-being pack for home educated families.

YOU SAID....	WE DID....
We need more flexibility with regards to clinics outside of schools	We are investigating additional clinics on Saturdays, evening clinics and clinics in the holidays.

### Health Visiting

The health visiting team have been exploring options to meet the conversation and co-creation participation levels and they are in the process of planning focus groups across localities.

Regular attenders at the Early Years Panel and parents have expressed that they would like a group specifically for children with 'additional medical needs'. The Health Visiting team are the process of arranging this new group. The service has identified a venue and staff ahead of the group starting.

The service currently uses the friends and family test cards and bookmarked surveys on iPhones, with questionnaires are used at the beginning of the programme and at the end of programmes to evaluate the experience and measure the change in knowledge/skills/ confidence of families. The health visiting team are also currently designing questions to be used on Patient Experience tablets. They hope to have this working for all staff in the near future. The feedback will be explored and action will be taken at Children Centre meetings. The feedback and responses will be communicated to staff via email and displayed to service users within clinic settings and on the children's centre website.

YOU SAID....	WE DID.....
The video was too long in the post natal group presentation	We have used a smaller excerpt from the video and give out details of the link
Early Years Panel and parents have expressed that they would like a group specifically for children with 'additional medical needs'	We have set one up
You wanted more activities at the Arborfield Community Centre	<p>We are starting a post natal group there on a 4 week rolling programme which starts in April</p> <p>We are currently looking at capacity for holding 'Introduction to solids' and 'School Readiness' sessions at Arborfield</p> <p>We have increased our capacity to complete more development reviews and 6-8 week reviews at Arborfield to reduce travelling</p>

## Specialist children's services

The service currently uses the following methods to gain feedback from service users:

- Community Paediatrics – Electronic Questionnaire
- Children's Community Nursing – mobile electronic questionnaire
- Specialist School Nursing West – Paper questionnaires.

The service is currently working on developing feedback boards within the clinic areas.

The broad nature of the service, and a number of existing and unutilised feedback methods, has inhibited the focus of the service; however they have been working to focus on a core feedback offer to service users to engage both service users and staff within the process which can then be expanded over time.

The specialist children services team are currently being supported to develop specific feedback mechanisms to engage with children and young people with learning difficulties and disabilities. We are hopeful that this will allow the service to begin to collect further qualitative feedback, to complement the range of quantitative feedback measures that are already in place, and lead to the regular generation of 'You said, we did' outcomes. Again, the plan is for this feedback, and relating actions, to be showcased to service users and staff within clinical settings.

## BEDS – young people

The service utilises the Experience of Service Questionnaire (ESQ) alongside the Friends and Family Test. Experiences of Service Questionnaires are handed out as part of Routine Outcome Measures packs for young people and their parents to answer during reviews, at assessments, and at discharge. These are scored, uploaded, and collated. The service still needs to work on the

displaying of some feedback information and to proactively seek responses to the themes that are highlighted within the feedback.

The service’s participation group provides the opportunity for young people to contribute feedback and ideas to relevant matters within the service. For example the group have recently been involved in highlighting information that would be helpful to include in the service leaflet. The service users have also been involved in developing the presentation of the friends and family test in the waiting room as well as the decoration in the waiting room.

As the young people’s service merges with the adult service, we will work with the respective champions to ensure that a consistent and progressive feedback and participation systems are in place.

YOU SAID....	WE DID.....
You wanted better/more appropriate decoration in the waiting room and wanted your voices heard within this area.	We spent time listening to you and allowing your environment in an on-going project o decorating/changing the waiting room area to reflect your choices.
That it would be helpful for new parents starting out in the service and professionals helping support young people with eating disorders to understand some of the things that did or did not help during your recovery	We wrote down these ideas that you had in relation to what you did or did not find helpful and included it in the leaflet for the service that will be given out to parents when the leaflet is completed.
You wanted to present the you said/we did information in a different format	Discussion about how to present this.

## Adult BEDS

Adults BEDs currently uses the following methods for collecting feedback:

- FFT cards available in waiting rooms
- Suggestions box in waiting room
- Awaiting electronic feedback tablets

The results of satisfaction and rating measures are displayed on posters within the staff office, emailed to the staff team, and discussed within in monthly business meetings where all feedback and comments are again shared with staff. Posters are used to display the information to service users within waiting rooms and in corridors on units.

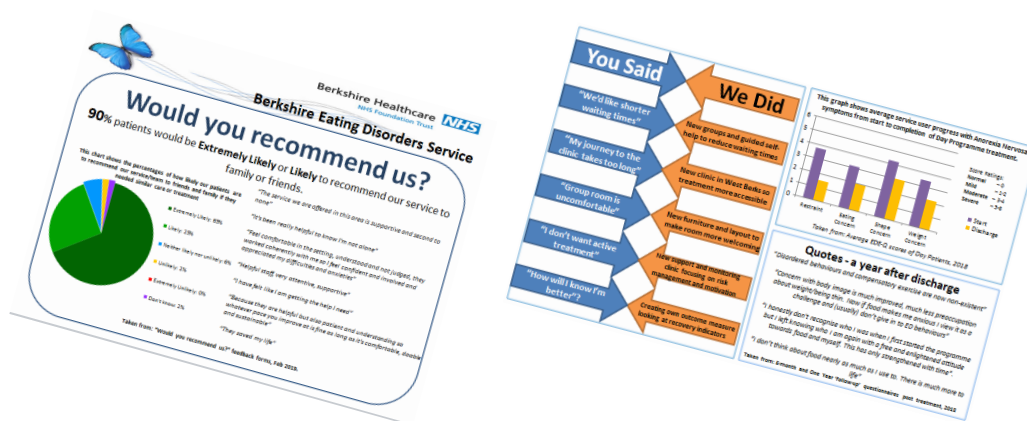
Qualitative feedback is collected using:

- FFT cards available in waiting rooms.
- Suggestions box in waiting room.

- Day Programme patients asked for feedback every block (12 weeks)
- Home Treatment and carer’s group given feedback forms every 6 months.

The feedback gathered through these means is discussed at a monthly team meeting and/or is used as part of the day programme planning day every 12 weeks. The Carer’s group feedback is discussed between staff responsible and the information is collated. The feedback is taken to monthly team business meetings and planning days for exploration and action. The response is communicated through “you said, we did” information in the waiting room and on the unit corridor, community meetings, and during the first day of the new day programme block with patients, with carer’s feedback being communicated in the carer’s group in the next month.

The day programme patients are given a space once a month with the team to raise any issues or concerns. Ex-patients are also able to give feedback to current group in day programme. Carer’s and relatives are given a questionnaire every 6 months which is then discussed in the carer’s group the next month.



YOU SAID....	WE DID.....
“We’d like shorter waiting times”	Introduced new outpatients groups and self-help programme which is getting people into treatment quicker
“We’d like a greater variety of food choice in the day programme”	Adapted the programme to give patients more of a say in meal options
“The patient group room is uncomfortable”	Redesigned the group room with new furniture and layout to make it more appealing for both relaxation and therapy
“We don’t want active treatment”	Introduced a support and monitoring clinic focussing on risk management and motivation

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