

**Report to the Meeting of the
Oxford Health NHS Foundation Trust**

Board of Directors

BOD 56/2020

(Agenda item: 11)

30 September 2020

Experience and Involvement Quarterly Report

For: Information

Executive Summary

This report provides an overview on the feedback received from patients and carers and the work to improve people's experiences, as well as their involvement in service developments. The collection and use of patient, carer and family feedback continues to have decreased during the period April – August 2020 with over 1,441 survey responses from received during this time. The majority of feedback is positive, 91.51% of people would recommend the service, with the quality of care being rated 4.77 out of 5, however we are striving so that everyone receives a positive experience and patients are involved in every decision about their care and service changes.

The feedback received from patients and carers, formal complaints and serious incidents identify a common theme for improvement around communication and sharing information with patients and their families to enable joint decision making and involvement in care. We continue to strive to involve patients and their families in the quality improvement work we do and incorporate the patient voice into service design.

The report also details the work and progress changes to the national Friends and Family test question

Recommendation

The Board is asked to note the report.

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Lead Executive Director: Marie Croft, Chief Nurse

1. **Strategic Objectives** – this report relates to or provides assurance and evidence against the following Strategic Objective of the Trust:
Driving Quality Improvement

(Goals: patients will be safe from harm; patients will achieve the clinical outcomes they want; and patients and carers will have an excellent experience)

People who use our services are central to everything we do and every member of staff is responsible for ensuring each patient has a fulfilling; positive and inclusive experience.

We strive to provide the best possible care and outcomes for the people we work with and believe that involving people who use our services in co-design, co-develop and co-production is simply the right thing to do.

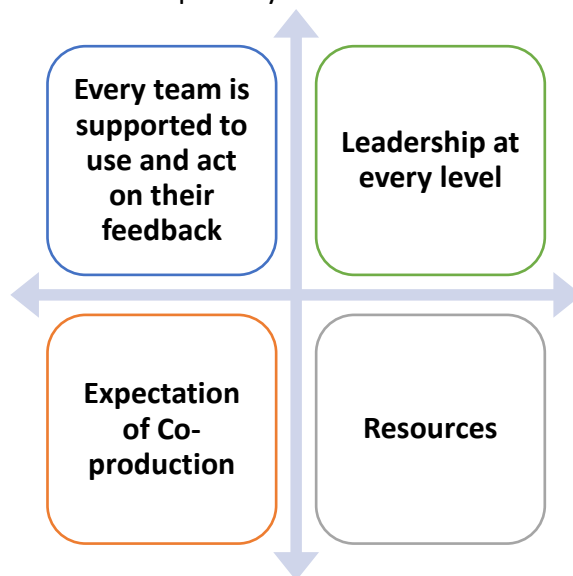
Patient experience & involvement (PEI) means including patients, carers and their families in making decisions about their care. This leads to better health outcomes and an overall improvement in patient experience. There are many different ways to achieve this but it is important we are able to evidence this work and evolve it from a tick-box exercise into a culture of listening to what our patients tell us and acting on this to improve our services. This quarterly report shows the work that has been undertaken by the Trust over the last year.

Experience and Involvement strategy: The Trusts experience & involvement strategy was launched in June 2019 for two years with one key aim:

The Trusts Strategy Aim-

“To ensure more people who use our services tell us that they have been given opportunities to be involved and empowered to make shared decisions about their care, treatment and support, as well as to work with staff in developments to services by April 2021.”

To achieve this aim we identified 4 primary drivers. These are:



Progress update on key areas of improvement identified for 2019/20

The COVID-19 outbreak has posed some challenges to delivering some of the objectives in the strategy in 2020 however this work will re-commence and during the pandemic, this also created many opportunities to be innovative in how we listen and involve patients/ service users. Some of the innovations are detailed in this report. The rest of this report shares some of the key work carried out under each of the four primary drivers of the strategy.

1. Leadership at every level

This objective covers a range of areas including:

- Staff behaviours (opportunities & challenges)
- Supporting staff to make changes (empower and equip)
- Resourcing for involvement in service changes (upskilling/information/ video capacity)

Council of Governors/ Membership: Members of the learning disability “Leading Together” co-production group have attended the Council of Governors meetings over the year and given feedback on potential developments to enable people with a learning disability to become Governors. Over the past few months the group has been developing work online including working on content to ensure becoming a member of Oxford Health is more meaningful for people with a learning disability. This has included creating easy read agendas, standardised easy read HR and Finance reports, easy read information about becoming a member and what being a Governor means. The group has also been involved in developing the membership matters email magazine being available in easy read 4 times per year.



Patient experience champions role: A role description and network has been set up to develop the work of patient experience champions across the Trust to help teams ‘put patients at the heart of any quality improvement projects’. This role should be the advocate of co-design and co-production. We will also move to encourage patients to become QI champions themselves to be able to ensure they are front and centre of quality improvement programmes going forward.

Staff of all banding are being encouraged to join the champion network and promote PEI work within their team. Our aim is that **Every** team should have their own PEI champion by April 2021.

Staff training: The experience & involvement team have begun to adapt their training tools so that they can continue to provide training sessions to a range of staff across the trust, including team level training around co-production, the use of experiences and how to involve patients/ carers – such as in recruitment, research and quality improvement. The team have

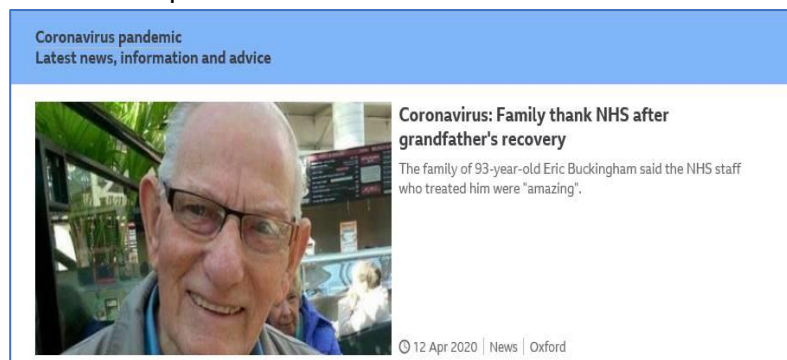
also been teaching on the management toolkit training, with 2 cohorts taught prior to COVID and the course being relaunched on-line with cohorts planned in Sept, Oct, Nov and Dec 2020. We have also continued to support a monthly session on patient/ carer experiences and involvement at trust induction for new starters.

LGBTQ+ Strategy: Four online working groups (2 for adults, 2 for young people) have been held to develop Trust-wide training materials and to review the Trust's guidance to better support LGBTQ+ patients. Themes for the training have been developed and participations are currently reviewing existing resources that are available and could be incorporated into the training. Work is being led by the experience and involvement team, participants are experts by experience and the work is being carried out in liaison with the Equality and Diversity Lead.



Patient and carer stories: are routinely used throughout the Trust both in person and via video and audio; to share at Trust Board meetings, for staff training or learning and for normalising experiences of care for those who might be utilising our services. Two examples of these are:

Trust news – a range of patient and carer experiences have been shared on social media during the COVID-19 pandemic, to highlight the care received by patients and offer thanks to teams who have been working hard to ensure patients have a positive experience of care.



Childrens integrated therapy (CIT) services review – stories were captured from a range of people who use services and shared with the CCG team at the monthly meetings to show the breadth of experiences and challenges of people who use the services.



District Nursing “Busy Blankets”: A Healthcare assistant in the Broadlands DN Team had a number of busy blankets made. This one was for a gentlemen with Lewy Body Dementia who became quite agitated towards the end of his life. The blanket was customized to him and became quite a help to him with his behaviors.

Recruitment: Patients and carers have played a vital role in the Trust’s recruitment processes this year. One example is for Specialist Community Public Health Nurses (SCPHN) for the school health nursing branch (SHN). Year 11 to 13 pupils were involved and at the end of the day of interviews, the educational panel review the scores of the candidates from their formal interview, activity with young people and their interview with the young people. The contributions of the young people are very much recognised: their comments, their scores and importantly whether they would want that candidate to be their SHN, absolutely inform our decision-making selection. The participation of young people in these annual interviews is hugely valued. Recent recruitment has successfully moved online such as for the OBSW Service Director interviews which had a digital patient panel.

Feedback from a participant in recruitment *“Thank you for making me feel so welcome. I enjoyed the experience and would be more than happy to do it again!”*

National staff survey results 2019: 81% of staff reported that the care of patients is my organisations top priority (above the national average) and 77% said my organisation acts on concerns raised by patients (above the national average). These are encouraging results but more work is needed. (2711 staff completed the survey)

2. Expectation of Co-production

This objective covers a range of areas including:

- Skills and training
- Buddying/ sharing good practice
- Diverse range of representatives

Co-production training session: Members of the experience and involvement team have been working with the Oxfordshire Recovery College to develop a new half day training session which will be available for all Oxford Health Staff to help develop skills and practical knowledge on how to involve and co-produce with people who use services. The session was piloted in early 2020 and it is hoped it will be made more widely available in autumn 2020 as part of a new online package. The session has been co-designed and co-developed and will be co-delivered in line with the colleges usual format.

Forensic Patient Zine: The first issue of the new patient Zine magazine was published in July 2020. A zine is a publication that is produced by amateur people who share something in common. Dubbed “The first Issue” the zine contains contributions of art, pottery, creative writing, opinion articles and poetry and a copy has been given to all patients and many members of staff. Feedback from patients has been very positive who were pleased to see their own and others work published. This issue and two further issues have been funded by the Oxford Health Charity.



Supporting co-production guidance: New guidance has been developed within the adult and older adult mental health settings for supporting co-production for strategy groups / meetings. This has been developed with a view to it being adopted for all working / strategy groups / meetings going forward and is currently being used in the development of the transformation/ recovery work and crisis pathway.

Integrated Locality Team south locality group: is attended every 6 weeks by community services, primary care, voluntary sector and social care has 2 highly valued service user representatives. These service users are equal partners of the group and are often referred to for them to provide balance and sense check what we are all reporting back as ‘progress’ towards joined up services.

Learning Disability awareness training: An expert by experience has co-produced and delivered a LD awareness session to GP’s and social care staff alongside the LD experience & involvement Lead. The sessions help staff to understand what can help people with lived experience to access services, possible adjustments and why its important to support people with LD in different settings.

Disability awareness films: Two new films have been co-produced by Oxford Health, My Life My Choice and their experts by experience, to raise awareness around learning disability and epilepsy. The proposed launch has been delayed from June 2020 but will aim to be rescheduled for later in the year.

Walking With You group (WWY): WWY for parent carers in Buckinghamshire CAMHS has successfully moved online to continue to provide information and support. Each themed group is supported by a number of the 7 Parent Volunteers, who co design and deliver sessions alongside Professionals from CAMHS.

Every member is sent information about the groups and the monthly newsletter which summarises the main topics covered in the presentation, top tips, resources and there are now 140 parents on the groups circulation list.

Themes covered include: Update on CAMHS, SPA and service developments, Anxiety / Anxiety and ASD, Positive Behaviour Support, medication and more.

Following discussions with Oxfordshire practitioners and the Parent Volunteers in Bucks a new Oxfordshire Group is being developed under the umbrella of Walking With You, sharing the format which is successfully running in Buckinghamshire.

Feedback from parents attending WWY online support group:

Thank you again - you were right that it was very helpful (and reassuring) to have a psychiatrist's input as you can feel rather uncertain about whether your family's issues are typical when you don't know anyone else with treatment plans etc.

I also wanted to say that it's (perhaps) strangely reassuring to hear from the parents of older children who have already been through so much. I understand what my child's prognosis is (statistically) likely to mean and the coming years can look very alarming, so parents who speak openly about addiction, hospital admissions and the other troubled and troubling behaviours provide so much emotional support. Thank you again.

Mental Health Services transformation Services have now formed a network of 25 experts by experience who attended an introduction meeting with key clinicians. Guidance for supporting co-production in service development has been co-produced and circulated to all clinicians leading in service development workstreams. A survey will be sent to all experts by experience to evaluate their experience of being involved and to allow us to learn how to support this more effectively. We have now completed introduction meetings for 7 of the pathway development working groups and 3 of the overarching working groups.

Uniform review Mental health services: informal feedback has been collected from service users and carers for a recent uniform review. 42 people gave their views at the earliest stage of the project and many are keen to be involved in the next stage of this review.



Forensic patients thank you: Specially designed and personally written thank you cards being sent to all patients in the service, along with an individual cake slice, to acknowledge the way they had cooperated and supported staff in dealing with the challenges of the COVID-19 pandemic restrictions.

Childrens Integrated Therapies: the service is currently being remodelled in a move led by the Oxfordshire Clinical Commissioning Group. We have involved the Oxfordshire parent carer forum in the process (parents of children with special needs). They have sent out a questionnaire to all their members about the current therapy service and the results of this questionnaire are being used to inform the future service model. A member of the parent carer forum is also a member of the remodelling board.

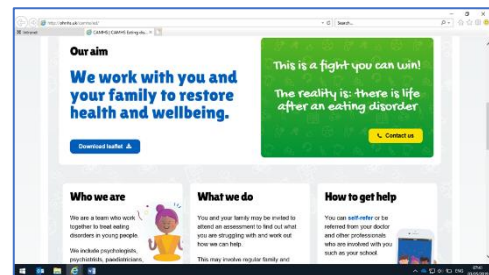
Buckingham Recovery College: have been working with the mental health experience lead to embed co-production into the newly established steering group. The student representatives on the steering committee are being supported to find effective and fair ways to elect student reps, communicate information from the steering committee to the student body and collate wider feedback to return to the steering group.

Regular involvement groups. Across the trust there are a range of involvement groups, which run regularly and work closely with services to promote the voice of people who use services, challenge services to continue to improve and engage in quality improvement work. Some of those groups include:

Bath & North East Somerset, Swindon and Wiltshire CAMHS Participation Group: A number of the participation team have been involved in a new film project with Boys in Mind called 'Getting through this together'. Each week children and young people across BaNES, Wiltshire and further afield have been sending in films they have made with messages of hope and support about coping with the challenges of COVID-19/lockdown. The films have had over 4000 views and the young people involved have found the opportunity to support one another rewarding and motivating. They are adding new films each week so if any other young people would like to get involved Boys in Mind can provide some simple instructions about making the them.

Buckinghamshire CAMHS Eating Disorder Service:

The Eating Disorder Service created a participation forum with the aim being to promote patient and family involvement in development of the service. The service invites young people and families to join the forum towards the end of treatment to provide a space where they can review their care and think about how to improve future care offered.



The forum participated in the service away day in January 2020, contributing the GP training and conference workshops, supporting the development of a mental health passport inspired treatment folder, developing motivational cards for new patients, and participating in designing and launching the new service website. The services away day was attended by two service users, a sibling and parent, to present the work of the forum and join us to consider how to develop our service in line with key QNCC standards. One of the young people and her mother recently wrote an article for the British Medical Journal published promoting understanding of the patient's perspective of anorexia: <http://www.bmj.com/content/359/bmj.j5378>

A further participation group is currently being developed with Oxfordshire, Buckinghamshire and BaNES, Swindon and Wiltshire for Adults with lived experiences of eating disorders to share their experiences and become involved in quality improvement work. This will be facilitated by a peer support work and member of the experience & involvement team.

South Oxfordshire CAMHS Participation Group: This online Participation Group now has six members. The group meets weekly for 40 minutes. The group have been working on

- Tops Tips for positive mental health and well-being. All group members contributed ideas of what they thought was a good way of helping positive mental health and well-

being and identified colours they wanted in the booklet which has been shared on the Trusts Twitter and Instagram accounts.

Feedback from the group has been really positive. Members find it fun and enjoy being part of something that is connecting with people.

3. Resources

This objective covers a range of areas including:

- Self-management and educational resources
- Quality and accessibility of information
- Funds to involve

Dentistry: Three films have been developed in joint work between CAMHS, learning disability services and dental services after feedback from the patient experience groups. These aim to reduce anxiety about going to the dentist for children, young people and adults with a learning disability and give information about having a general anaesthetic for dental treatment. A new dental passport has also been developed, based on the NHS dental passport. This has been trialled by an expert by experience before being implemented across dentistry services.



Urgent care: Minor injuries Unit in Abingdon have been working with The South Oxon Patient Experience Group (PEG) to increase the accessibility of their service. So far they have:

- Developed easy read versions of the forms people are asked to fill out on arrival at minor injuries/out of hours GP.
- Introduced accessible version of I Want Great Care feedback forms.
- Developed and delivered LD awareness training to volunteers from minor injuries which was co designed and delivered.
- A visit by the South PEG to visit Minor injuries in Abingdon to see what they thought of the environment and how it could be improved, identified the need to improve signage, reduce info on walls and increase accessibility of any info needing to be displayed and the need to translate the patient information leaflets they have to easy read.

- Developed a reasonable adjustment pack with communication aids, sunglasses, ear defenders etc which are being rolled out to the minor injuries units.

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Evenlode Voices; the Evenlode involvement group: This year the group have worked on a variety of projects including:

-An Easy read version of the “Evenlode Rules”, the gentlemen wanted them to be known as rules as they felt this was clearer for staff, agency staff and patients alike. These were almost complete and then needed to be updated with some changes due to COVID 19.

-An easy read unit leaflet has been created, for new patients and their coming to the unit . there is also a plain English version for anyone who may prefer this, which was also coproduced by a member of staff and a patient.

Easy read versions of the Hospital Kitchen menu were created to support the work within the unit for patients to cook some of their own meals. The patient experience and involvement team assisted with producing puzzles, colouring books and other activity resources for the ward, to support the gentlemen and staff. The PEI team supported the unit in producing easy read information about staff needing to wear masks etc.

Self Harm and Suicide Prevention Strategy: the carers workstream was tasked with improving the resources the Trust has available for family, friends and carers who are supporting someone who may be suicidal. Prior to COVID two focus groups were convened in Buckinghamshire and Oxfordshire to begin to look at safety planning and managing the risk of suicidality in the home environment.

Focus groups were well attended with three carers in Buckinghamshire and 5 carers in Oxfordshire and generated ideas to initiate development of a carers support plan and also identified the need for more education, training and support to specifically to meet the needs of carers in this area. It is anticipated that this involvement work will continue online during the autumn.

Easy read information: The creation of a web resource of easy read information to help all Trust staff, GP’s carers, support workers and families to support people with a learning disability.

Anxiety self-help: Young people from a CAMHS participation group have enjoyed the opportunity to support the development of a film and associated worksheets in relation to anxiety which has been uploaded to the Trust’s website. They reviewed the format and content of the parent/child film a clinician had produced and used that as a basis to produce a version suitable for young people. They appreciated the opportunity to advise not only on the format and content of the new film but also on the script. The group has also produced a set of associated worksheets and resources. Work has now started on resources in relation to low mood and depression.

Friends, family and carer webpages: New and improved carers webpages have launched on the main Trust website with the aim to provide carers with helpful information, guidance and support which they may need in their caring role. This has been co-developed with seven carers via MS Teams with the group giving feedback on what was needed and then reviewing the draft site to give further comments and ideas.

4. Every team is supported to use and act their feedback

This objective covers a range of areas including:

- Internal processes such as forms/ assessments/ service models
- Review internal systems to identify/challenge those that don't support.
- Develop the use of data to be 'proactive rather than reactive'

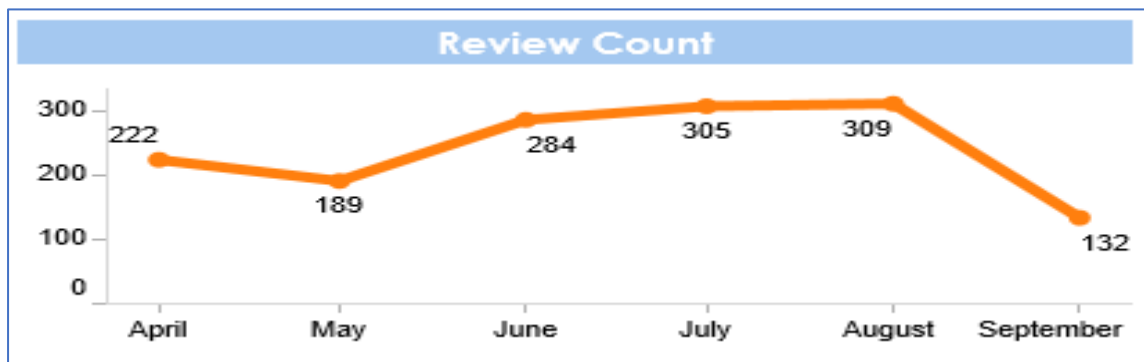
I Want Great Care is the standardised system the Trust uses to offer/ collect regular electronic and paper survey feedback from patients and carers. In addition to this method we use a range of other approaches i.e. focus groups, regular patient/ carer groups, telephone interviews, complaints, compliments, patient stories, national survey results. The Trust has received 1,441 responses through the software 'I Want Great Care' between 1st April 2020 – 31st August 2020 with an overall average score of 4.77 out of 5 across all the questions asked. The number of responses has decreased significantly from the previous financial year due to COVID. 91.51% said they would be likely to recommend (slight decrease from previous year <2.32%) with 2.69% being unlikely to recommend (slight increase from previous year >0.97%). (5.8% report neither or don't know to the question – slight increase from previous year by 1.4%)



Change to FFT question:

The single national FFT question is being changed from 1st December 2020, the question was 'Would you recommend.....' and is changing to 'Overall how was your experience'.. We have always incorporated the FFT question within our existing experience surveys provided by IWGC, alongside open text questions so that the feedback can be used to make changes. We have been working with IWGC and have just launched the new question and some changes to the gender question across all our children, adolescent, parent, adult, easy read and photo surveys in September 2020, giving us some time before we have to start externally reporting against the new question.

1,441 reviews received from 1st April 2020 – 31st August 2020 and the below graph shows the number of reviews per month over this time. The drop in numbers of surveys received during these months are due to the pressures of responding to the COVID-19 outbreak and the restrictions it brought so there were less face to face contacts with patients/ carers and the use of paper surveys was reduced. Prior to COVID we received at least 1,000 surveys a month via IWGC and our aim is to relaunch and get all teams routinely collecting and using feedback again.



A few examples of the feedback received via IWGC surveys are below:

The psychologist quickly recognised (my daughters) behaviour and knew when the session was getting stressful. The communication between us all has been really good, even with the complication of lockdown! I was concerned that video conferencing wouldn't work well due to (my daughters) visual impairment and concentration levels but it actually was fine. There isn't anything I would improve. The service was really good for us. Thank you. - **Bucks LD CAMHS**

The care experience was very good, It's just at times, we would have felt more reassured if the physio's could have come in person, as opposed to the telephone appointments. Please know that I understand it was because of COVID 19 and therefore beyond your control. – **West Oxfordshire community therapies service**

Best thing about having a Family Nurse is having one person who can provide support around so much that happens in pregnancy. That she is working with someone who is not judging her and her partner. That I will be there for her and baby.

Partner says he thinks it has been helpful for them both to have FNP and his girlfriend is always calmer when she has seen me, and sometimes picks problems apart in a way she didn't used to, because we have done that together. – **Family Nurse Partnership**

During COVID Evenlode Voices have given feedback every few weeks in the involvement meeting about the impact of the changes that have been necessary. Here is a small selection of comments

I am still not sure about the staff wearing their blue pyjamas, but we are getting used to it.

I struggle to hear some of the staff when they have a mask on

Our leave was very restricted. It still isn't back to how it was.

It is slowly getting back to normal

All the staff look the same, sometimes it is difficult to know who is who.....

IWGC survey feedback - A word cloud of 100 most commonly used words in positive reviews. The top 3 words used were care (246 times), good (238 times) and staff (196 times).



Free – text sentiment analysis:

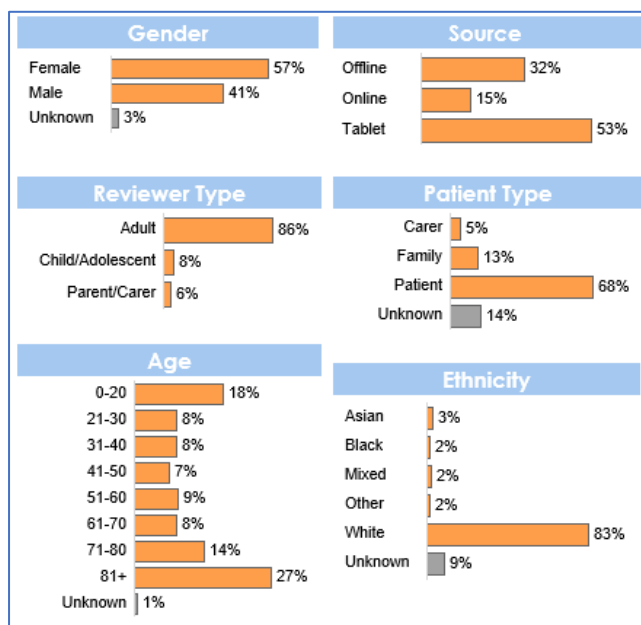
The free-text responses can be categorised into 6 key themes:

- Treatment
- Information & Involvement

- Staff
- Access
- Resources and availability
- Facilities

Nearly 60% of reviews mention Treatment in some way and it is the most positive theme with nearly twice as many mentions. Comments frequently referred to as “**Good**”, people feel **cared** for and comment that they are treated in a **friendly** manner. Some negative comments are due to people in early stages of treatment so don’t feel they can comment on **care and staff** and some reviews say staff treat them **rudely**.

This set of graphs show the demographic data of those reviewing services across the trust.



These graphs show the highest percentage of respondents are over 81 years (27%) followed by those under 20 years old (18%)

68% of respondents identify themselves as a patient and 18% as a family member/ carer.

83% identify themselves as white and 9% of respondents ethnicity is not known.

Sharing feedback: Sandford Ward display (left) is an example of how inpatient settings are working to ensure patients and staff are aware of feedback received and how it is being used. It includes feedback that is actioned and helps to raise staff morale with the positive and heartfelt feedback they often receive.



Although I Want Great Care (IWGC) is one of the ways in which we collect qualitative and quantitative feedback about peoples experiences of our services. We also use a range of

other methods, particularly in areas where patients are not able to access IWGC or the questions are not wholly appropriate, for any reason.

A few examples of other collection methods include:

Digital development: 74 people responded to the digital strategy development survey during July 2020. 53% patients (39 people) and 28% carers (21 people).

The respondents were from all geographical areas covered by the trust and from a wide range of services including adult mental health, Learning disability, dentistry, community hospitals, community therapies and forensic.

When asked how satisfied with current digital options the average score was 3.43 out of 5.

Digital developments that patients. Carers would like to see are :

- Online help/ support groups
- Online programmes aimed around managing your health/ specific conditions or diagnosis
- Social networking platforms tailored for patients/ carers
- Digital technology which is supplemented with physical resources (such as access to devices/ internet access/ loan laptops)
- Educational online material
- Virtual group clinics

This information will be used in the development of the Trust's digital strategy alongside information gained from a feedback form which is now available to every person who accesses a digital consultation.

Forensic services: A patient focus group was held in every forensic ward during February and March 2020 with information gathered from the 29 attendees being presented to senior leadership and the wider patient council.

Photo feedback forms: This year has seen the introduction of new photograph feedback forms developed with IWGC to enable accessibility as well as the launch of a project to further develop accessible feedback:

Accessible feedback: this project is working across the organisation with participation from clinicians from CAMHS, OSRU, children's therapy service and Learning disability.

The aim of the project is to develop a way of people with limited communication skills being able to express a view about their care. Initially we are exploring the idea of a communication board similar to a talking mat, but probably using different images for different services to ensure the images used help individuals understanding of what they are being asked.

Annual Adult and Older Adult Community Mental Health Patient Survey for 2020 is set to be published during November 2020. The Trust has received our preliminary results however this is not the final version. The fieldwork was completed from February-June 2020. We received 350 responses, slightly higher than last year. We are reviewing our internal results and analysing the open text responses as part of identifying future actions.

How we have been supporting people who use services during Covid-19



Letters to Loved Ones: Friends and family members are able to send emails / poems / pictures into a central inbox for loved ones who are in hospital. The experience and Involvement team have been printing the messages and delivering them to relevant wards. This initiative was launched in May 2020 and to date over 100 emails have been received from loved ones all over the world including Canada, Australia and Sri Lanka.

Feedback from family members using the scheme:

“Thank you so much for all your help and flexibility. It really means a lot.”

“Thank you for delivering my emails to my dad, it has been amazing to contact him in this way. “

Hello my name is...photo badge for PPE: A badge template and guidance has been designed to help make staff working within Oxford Health NHS Foundation Trust identifiable whilst donning PPE during the COVID-19 pandemic and



help improve our patients experience by reminding them there is still a friendly face under the PPE. Badges showing photos and names have been for staff working in areas where PPE is being worn and it is difficult for patients to see their faces. The experience and involvement team have supported the project and have helped to develop, produce and deliver the badges to relevant areas. So far over 1500 staff have received badges.

Carer befriending line: A phone line has been set up to offer support and information to people who have a caring role across the Trust. Carers are encouraged to leave their details on the answerphone to receive a call back between 11am-12pm any weekday from a carer volunteer or member of the experience & involvement team. To date, over 30 carers have contacted the line to receive support, information about carers services or have a friendly

chat to combat loneliness. The phone line will remain open into 2021 when it will be evaluated.

Easy read information: Weekly updates on web resources conducted into easy read information to help Oxford Health staff, GP's carers, support workers and families to support people with a learning disability during the pandemic have been created.

CAMHS Top tips for online appointments: The CAMHS Participation team has worked through the challenges of holding virtual participation meetings, discussing the difficulties this new way of meeting poses for young people working with CAMHS. This discussion turned to a project as to how online clinical meetings could be improved and examples of what had and hadn't worked for them. The group created a list of their top tips to share with clinicians and a Young Persons version of the Top tips list which provides information about what to expect, what options they have. It will also help them prepare for an initial appointment.