

5th NH Patient-led World Café Report



Theme: Supporting Autistic Patients at Newham Hospital



Objectives (what we plan to do and achieve)

- To create a platform to discuss and explore the theme ‘Supporting Autistic patients at Newham Hospital.’
- To collaboratively generate and refine recommendations for enhancing the experience of autistic patients.
- To embed patient and community participation and involvement in Newham Hospital.



Introduction

This easy read report provides a summary of the discussion at the fifth NH Patient-led World Café:

THEME: Supporting Autistic patients at Newham Hospital

The discussion followed the world café format of three tables, three rounds of conversations, one question per round and twenty minutes per round, then groups moving to the next table.

Round 1:

What assumptions about autism have you come across in the hospital?

This question intends to focus the collective attention of the participants

Round 2:

What is missing or surprising about what you have heard today, and what else do we need to consider?

This question intends to connect Ideas for Deeper Insight

Round 3:

What are the practical changes or initiatives the hospital could implement to make the hospital more accommodating and inclusive for autistic patients?

This question intends to Create Forward Momentum and generate new ideas for improving the inpatient night experience at Newham Hospital



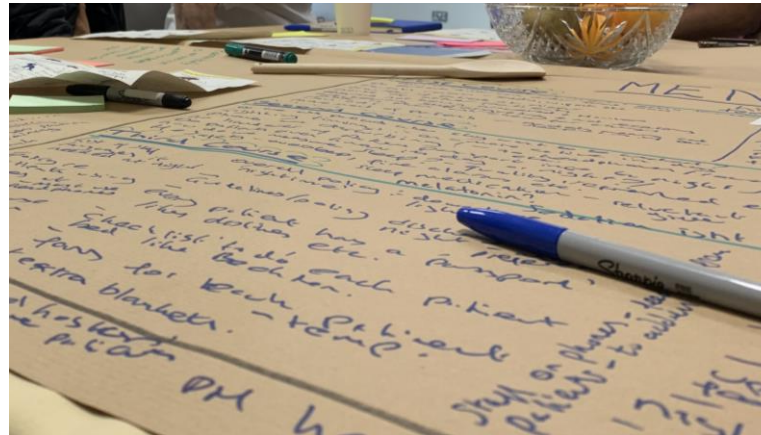
Round one main themes:

Experience in Hospital Setting: Autistic individuals often feel misunderstood and neglected in healthcare environments.

Assumptions and Misconceptions: Widespread beliefs about autistic individuals' capabilities and behaviours are often negative and inaccurate.

Stigmatisation and Labeling: Fear of being labeled leads to stigma and affects self-perception and treatment.

Need for Awareness and Education: A lack of understanding among healthcare staff necessitates better training and awareness of autism.



Communication Barriers: Misunderstandings arise from ineffective communication between autistic individuals and caregivers or staff.

Mental Health and Well-Being: Anxiety and mental health issues are often dismissed, neglecting the emotional experiences of autistic individuals.

Cultural Influences: Cultural stigma shapes negative perceptions and treatment of autistic individuals.

Independence and Autonomy: Concerns about losing independence are prevalent, along with hospital staff misconceptions about needing constant support.

- There is an assumption that there is no in-between; autistic people either have ability or they do not have ability.
- Staff are often unsure how to approach or engage autistic people.
- Some autistic patients struggle to communicate, and it's worth remembering that some autistic individuals may suffer from selective mutism in an unfamiliar environment due to anxiety.
- Autistic people need clarity, and they want to know their care plan as soon as possible.
- Building relationships with service users is vital for effective care.
- Therefore, more understanding of autism is needed within the hospital setting.
- A nurse stated, "I have never seen an autistic passport in my 19 years as a nurse."

Round two Missing or surprises / need to consider

Round two, main themes (Deeper Insight)



- Nine out of ten staff members do not look at the hospital passport when caring for autistic patients.
- The role of non-clinical staff is critical in improving the experience of autistic individuals in healthcare settings.
- There is currently no flagging system in the electronic patient records for identifying autistic individuals
- Many autistic people mask their behaviour, which can complicate understanding their needs.
- There is a significant variance in the quality of care provided between paediatric and adult services.
- There is not enough time and resources to adequately support frontline staff in their care of autistic patients

Recommendations / Change Ideas

Accessible Appointment Scheduling: Offer extended and quieter appointment times to accommodate the specific needs of autistic patients, ensuring a more comfortable healthcare experience.

Autism Identification and Support: Implement an autism flag and lanyard system to identify and communicate the support needs of autistic patients effectively within the hospital.

Community and Volunteer Engagement: Educate community groups on autism support practices and utilize volunteers to assist patients in navigating hospital procedures.

Patient-Centric Communication: Implement non-verbal communication aids and regular check-ins to actively inquire about the support needs of autistic patients.

Improved Documentation and Accessibility: Enhance health records to flag autism needs and streamline the transfer of autism passports across wards for better care continuity.



Sensory-Friendly Environments: Establish sensory and quiet rooms with features like dimmable lighting and sensory packs to create calming spaces for autistic individuals.

Comprehensive Staff Training: Provide ongoing training for staff on autism awareness and best practices, incorporating patient experiences to enhance understanding and responsiveness.

Specialised Staffing: Appoint autism champions in each ward and submit a bid for a specialist autism nurse to provide focused support and advocacy for autistic patients.

Thematic analysis

Introduction:

This analysis summarises key insights from the World Café discussions on enhancing support for autistic patients at Newham Hospital. Participants addressed misconceptions about autism, including it often being wrapped up as a learning disability, and highlighted dismissive attitudes and inadequate environmental considerations.

Surprisingly gaps included limited use of hospital passports, absence of autism-specific flagging systems, and differences in care between paediatric and adult services.

Practical recommendations focused on structural improvements, staff training, sensory-friendly resources, and volunteer integration. These discussions underscore the importance of tailored, inclusive approaches to improve healthcare experiences for autistic patients at Newham Hospital.

Thematic analysis

Assumptions and Misunderstandings about Autism:

1. The discussions reveal widespread misconceptions regarding autism. These include beliefs that autistic individuals are inherently “challenging,” incapable of self-advocacy, or that their needs can be generalised based on limited observations or stereotypes or assumptions that autistic individuals are either “sub-human” or “superhuman.”

Such assumptions often stem from a lack of awareness about the diversity within the autism spectrum. For example, the belief that non-verbal or situationally mute autistic individuals cannot make decisions reflects a misunderstanding of autonomy and capacity.

2. Barriers to Effective Communication:

There are significant barriers related to communication between healthcare staff and autistic patients. Communication challenges are exacerbated by anxiety and unfamiliar environments, making it difficult for autistic individuals to express their needs effectively. Additionally, there is a noted lack of training among staff on how to engage with autistic patients, which can lead to neglecting the patient's individual care requirements.

3. Overlooked Individual Needs:

Autistic individuals often feel their specific needs are overlooked, both due to a lack of understanding among staff and a failure to actively inquire about those needs. The assumption that an individual's appearance (which could be an individual masking) indicates their internal state can lead to unmet care requirements and dismissals of valid experiences, such as anxiety or sensory sensitivities.

Thematic analysis

4. Need for Structural Changes:

Participants emphasised the need for practical changes within hospital systems to create a more accommodating environment. Key suggestions include introducing autism awareness training for all staff, developing communication aids for non-verbal individuals and those who may experience selective mutism, and implementing an autism flagging system within electronic health records to help staff recognise and cater to autistic patients' needs. Discussions also focussed on the need for quiet rooms to help people regulate and the provision of other self-regulation tools such as stress balls.

5. Importance of Relationships and Trust:

Establishing strong relationships between staff and autistic patients is vital for quality care. Autistic individuals expressed a desire for clarity regarding their treatment plans and personalised interaction from healthcare providers. Building trust occurs when staff try to better understand and engage with autistic patients, reducing feelings of anxiety and isolation.

6. Cultural Stigmas and Their Impact:

Cultural perceptions of autism can significantly influence how autistic patients experience healthcare. Stigmas surrounding both autism and mental health can lead to further alienation of individuals who already face systemic barriers in receiving appropriate care.

7. Lack of Systematic Support and Resources:

The discussions revealed widespread criticism of the support structures and resources available for both frontline staff and autistic patients. Many staff members felt underprepared to address the unique challenges posed by autistic individuals due to insufficient training or time constraints.

Conclusion and recommendations

The findings from the discussions highlight a robust need for change in how the system interact with autistic individuals. While assumptions and misunderstandings about autism form significant barriers to effective healthcare, practical initiatives can be implemented to promote inclusivity.

- 1. Staff Training and Support:** Implement regular training programs for all hospital staff, emphasising the diversity of the autism spectrum and outlining effective strategies to engage autistic patients. Nominate compassionate engagement champions in wards and clinics. Utilise volunteers to guide autistic patients and other vulnerable patients in navigating hospital services effectively.
- 2. Autism Flagging System:** Introduce an autism flag in patient records to ensure all staff are aware of a patient's autism status and can take appropriate steps to accommodate their needs.
- 3. Enhanced Communication Tools:** Develop tools and aids to facilitate communication, especially for non-verbal patients and those who suffer from selective mutism, such as picture communication cards and sensory kits.

Conclusions and recommendations

4. Patient-Centred Approaches: Incorporate patient feedback into the design and implementation of autism-related services. Build relationships through clearer care plans and communication pathways. Engaging autistic individuals in discussions about their care could improve trust and communication. Foster patient-centred communication by asking autistic individuals about their support needs.

5. Cultural Competency: Address cultural stigma through community education programs that raise awareness and promote understanding of autism within the broader healthcare landscape.

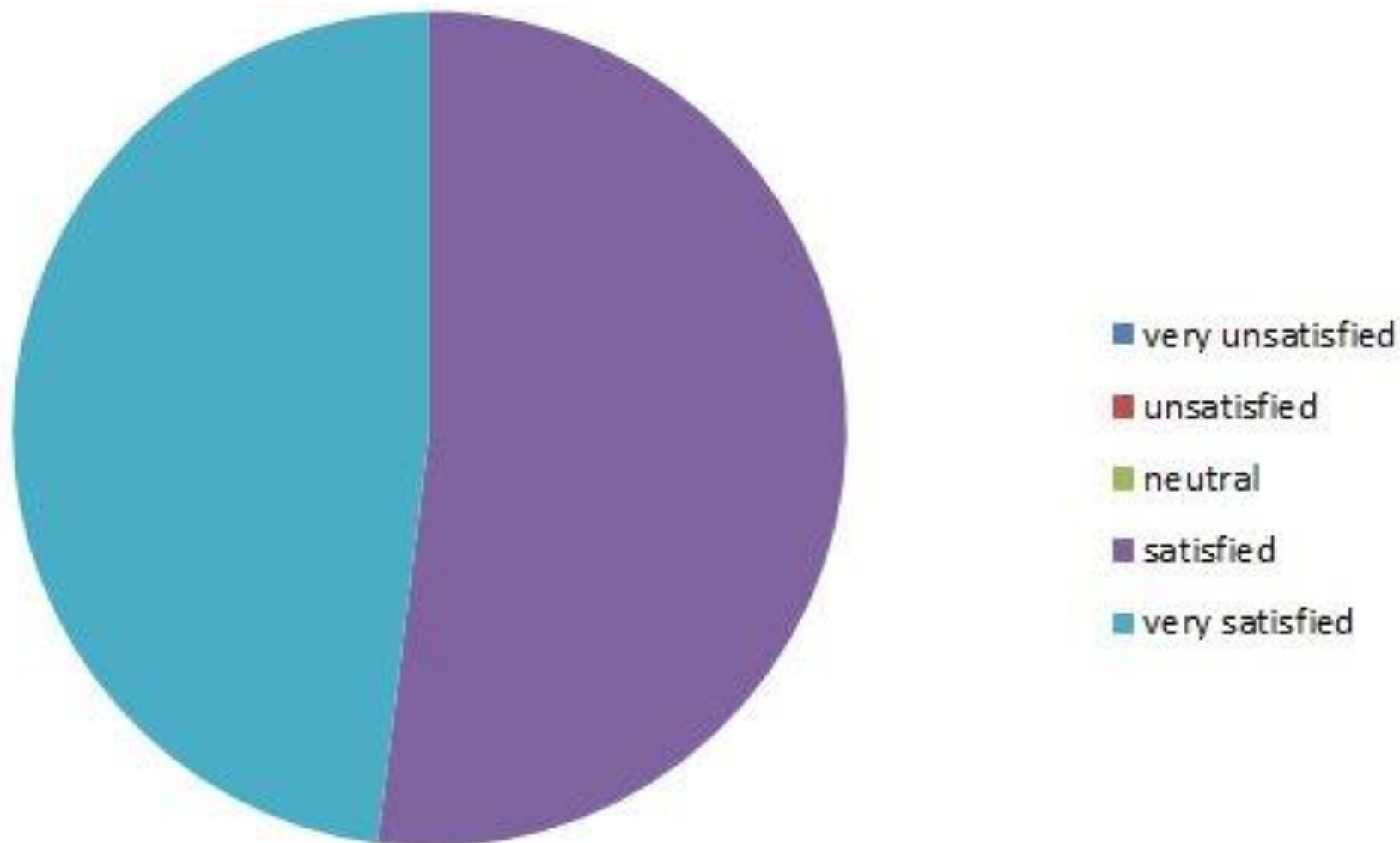
6. Embrace Flexibility: Adapt hospital environments by creating sensory-friendly spaces and allowing for extended appointment times to reduce anxiety among autistic patients.

Through these recommendations, the hospital can begin to dismantle the barriers faced by autistic individuals, fostering a healthcare environment that respects and responds to their unique needs. Transforming service delivery in this way not only benefits autistic patients but enhances overall patient care, accessibility, and satisfaction for all individuals seeking medical support.

Feedback from Participants

- “Good format, particularly enjoyed the fact that you didn’t have to verbalise your ideas and could write them down”.
- “Interactive, involving and engaging – patient involvement It was well structured, it was excellent”.
- “Great! Especially staff having staff from different departments and patients together”.
- “It was well structured, and I liked the idea of the talking spoon as it enabled everyone to speak in an organised way”.
- “Really good – maybe keep all three questions visible during discussions to avoid overlap”.
- “Was nice to have Newham Autism commissioner there”.
- “I loved hearing from experts by experience”.
- “I really enjoyed it, people were energised from start to finish”.
- “The part I enjoyed most was meeting staff who care and want to change and improve the hospital”.
- “I learnt many things about autism”.
- “Really liked the presentation by Ben at the end, it was refreshing to see a medical staff member be very knowledgeable about autism”.

Satisfaction with World Café event



Appendix

The full Transcript of the 6TH Patient-led World Cafe

Round 1: What assumptions about autism have you come across in the hospital?

- Autistic individuals are challenging to deal with.
- The assumption that a person may have difficulty retaining information.
- There should be someone who 'informs' the community.
- Staff make assumptions based on previous experiences.
- Myths and assumptions about children's behaviour may follow them into adulthood.
- I assumed my autistic passport would be shared when I moved wards.
- The belief that non-verbal autistic individuals can't make decisions for themselves.
- The notion that autistic individuals are fixated on one thing—films may contribute to this perception.
- The fear of being labelled.
- It's often assumed that the adult with a child doesn't have autism; both may be autistic.
- It's often assumed that children with autism are experiencing a mental health crisis when they are not.
- I worry that my independence will be compromised when I go to the hospital, and this can be scary.
- Often, people assume everything is okay because I appear 'fine' on the exterior, while inside I may feel scared and anxious in unfamiliar surroundings with unfamiliar people.

Round 1: What assumptions about autism have you come across in the hospital?

- Autistic staff may feel hesitant to open up, fearing they will be labelled.
- People may assume that the hospital experience is the same for everyone.
- Often, hospital staff may assume I am more capable than I am because I mask my difficulties.
- People may assume that if someone is with a carer, that's who you should approach; the patient's needs can become overlooked.
- Cultural stigma can significantly influence assumptions and perceptions about autistic individuals.
- There may be a lack of consideration for reasonable adjustments.
- Autistic service users/patients may be unfairly labelled as challenging.
- There is often no validation of my anxiety.
- The belief that I cannot care for myself (no autonomy) and require support from another individual.
- The belief that I cannot care for myself (no autonomy) and require an escort.
- The perception that I am unable to navigate the care system.
- "They are not my problem," suggesting that it is the responsibility of the Learning Disability Nursing Team.

Round 1: What assumptions about autism have you come across in the hospital?

- The misconception that the autism spectrum is linear.
- People may behave differently when they know I am autistic.
- The belief that autistic individuals are either sub-human or superhuman.
- "Too smart to be autistic."
- Limited understanding of autistic individuals.
- Autism should not be equated with a learning disability (LD).
- The assumption that autistic individuals do not require human interaction.
- The notion that the hospital environment is accommodating for everyone.
- Dismissal of our experiences as autistic individuals.
- Safeguarding issues may not always be taken seriously.

Round 2: What is missing or surprising about what you have heard today, and what else do we need to consider?

- There is an assumption that there is no in-between; individuals either have ability or they do not have ability.
- Staff are often unsure how to approach or engage autistic people.
- Some autistic patients struggle to communicate, especially non-verbal autistic individuals, in an unfamiliar environment due to anxiety.
- Autistic people need clarity, and they want to know their care plan as soon as possible.
- Building relationships with service users is vital for effective care.
- Therefore, more understanding of autism is needed within the hospital setting.
- A nurse stated, “I have never seen an autistic passport in my 19 years as a nurse.”
- Nine out of ten staff members do not look at the hospital passport when caring for autistic patients.
- The role of non-clinical staff is critical in improving the experience of autistic individuals in healthcare settings.
- There is currently no flagging system in the electronic patient records for identifying autistic individuals.
- Many autistic people mask their behaviour, which can complicate understanding their needs.
- There is a significant variance in the quality of care provided between paediatric and adult services.
- There is not enough time and resources to adequately support frontline staff in their care of autistic patients.

Round three: What are the practical changes or initiatives the hospital could implement to make the hospital more accommodating and inclusive for autistic patients

CHANGE IDEAS

- Implement an Autism Flag:** Introduce an autistic 'flag' in the hospital systems, similar to what we have for learning disabilities.
- Sensory and Quiet Rooms:** Provide sensory and quiet rooms across the hospital that can be accessed by autistic individuals.
- Autism Champions:** Appoint an autism champion on every ward to advocate for the needs of autistic patients.
- Welcome Pack:** Create a welcome pack specifically for autistic patients.
- Autism Strategy/Policy Awareness:** Review the existing autism strategy or policy. Ensure staff are aware of it.
- Staff Training:** Provide regular training for staff that incorporates service user stories and experiences, such as during Egad Day.
- Specialist Autism Nurses:** Advocate for the hiring of autism specialist nurses, particularly in Newham, where there is a high population of autistic individuals.
- Ongoing Training:** Ensure training and information on autism are regularly updated to accommodate new staff.
- Staff Autism Forum:** Establish a forum for staff to discuss and address autism-related issues.
- Autism Lanyard:** Introduce an autism lanyard (e.g., sunflower lanyard) for patients to carry, indicating their support needs.
- Community Education:** Educate community groups about autism and best practices in support.

Round three: What are the practical changes or initiatives the hospital could implement to make the hospital more accommodating and inclusive for autistic patients

CHANGE IDEAS

Non-Verbal Adjustments: Offer non-verbal communication aids on wards, such as picture menus.

Dimmable Lighting: Install dimmable lights in hospital areas to accommodate sensory sensitivities.

Training Questionnaire: Develop a training questionnaire to identify knowledge gaps regarding autism among staff.

Autism Passport Transfer: Explore ways to transfer the autism passport between wards without requiring the carer to bring it each time.

Extended Appointment Times: Allocate additional time for appointments when requested by patients.

Business Case for Specialist Nurse: Prepare a business case to justify the need for a specialist autism nurse.

Improved Health Records: Enhance the recording of autism in health records and introduce a flagging system so frontline staff can provide reasonable adjustments for patients.

Support Needs Documentation: Include the support needs of autistic patients in their health records.

Combining Passports: Explore the possibility of combining the learning disability and autism passports.

Compassionate Engagement Champions: Nominate compassionate engagement champions in wards and clinics to improve engagement with autistic patients.



Newham Hospital:

- The report will be presented at the Patient Experience and Engagement committee
- There will be a dedicated workshop at the Patient Experience and Engagement Committee meeting to map out an action plan for the implementation of the recommendations.
- The report will be circulated hospital-wide and shared on The Trust Wide 'We Share' page.

The report will be sent to Newham Autistic Residents Advisory Group, the Commissioner for Autism in Newham and Newham Healthwatch



