# Improving access to and experiences of healthcare for autistic patients: a partnership project between Ambitious about Autism and Whittington Health NHS Trust

2019/20

Lucy    Grace    Shane    Rosie    Jordan

Geoffrey    Raphaela    Mikey    Nicholas    Aqsa

## Purpose

- Create an evidence base of barriers faced when autistic people access healthcare.
- Support and maintain an autism confident healthcare workforce.
- Ensure that healthcare professionals are responsive to the needs of autistic patients.
- Ensure that patients and families are empowered to access entitlement to health care.
- **Overall, have an improved quality of care for autistic people.**

## Health Panel

- The project was led by **10 autistic young people** from across North London, all of whom have a connection with Whittington Health NHS Trust
- Some panel members were undertaking supported internships in the trust
- Other panel members had accessed Whittington services in both the hospital and the community
- **All had an interest in improving experiences** of healthcare for other young people like themselves

## Data and collection methods

- **Healthcare Professionals survey**
    - Quarter of staff unsure how to support autistic patients.
    - Staff were looking for additional training on autism awareness
- **Parent and carer case studies**
    - Practitioners are not confident when communication with their child or young person.
    - Parents shared that GP's had low autism awareness
- **Incidents and complaints data**
    - We found only 106 incidents reported in the system for 2019/20 under the 'Autism' tag.
    - Incidents were being under reported.
    - The categories used in the system gave no context to incidents.
- **Autistic young people**
    - The health panel had all had negative experiences accessing healthcare.
    - They felt that practitioners did not have enough autism awareness.
    - They wanted to know more about reasonable adjustments they are entitled to.

## Outcomes

- **Learning videos** for Healthcare professionals:
    - What is autism?
    - Experiences of healthcare and how to improve
    - Explaining the value of visual resources
- **Visual stories**:
    - Visiting hospital: Explaining current changes
    - What is PPE?
    - Visiting the pharmacy
- **Top tips** for healthcare professionals
- **Appointment checklist**
- **Hospital passport**

## Recommedations

- Improve **coding with incidents** and complaints
- Improve **accessibility of appointments** with pre-visit information, clear steps post-appointment and reasonable adjustments.
- Continue to **co-produce resources** with patients
- Improve **support during transition** between services.
- **Evaluate the exclusion criteria** for taking part in a specific service.

The Health Foundation

NHS Whittington Health NHS Trust

Ambitious about Autism