

Cancer Experience of Care Improvement Collaborative 2025

Reducing inequalities for people with a learning disability or autism that are referred on an urgent suspected cancer pathway in South East London

Understanding the issue - Background

- Feedback from staff (booking staff as well as clinical staff) at Guy's and St Thomas', King's College Hospital and Lewisham and Greenwich Trust highlighted that staff were often unaware of patient's additional needs and therefore unable to implement reasonable adjustments from the start of their pathway.
- Feedback from patients and carers: communication and admin processes not aligned
- Higher DNA rates reported for patients with a learning disability
- Suboptimal processes and communication requires patients and carers to be more proactive, we know that this is more challenging for patients with a learning disability and autism and put a great responsibility on cancers

Project aim

To improve the notification / communication of the reasonable adjustments needed to support patients with a learning disability and autism, from the point of referral into secondary care, through their urgent suspected cancer pathway by August 2025

Baseline Feedback – Patients and carers

Feedback from 2 patient and carers highlighted the below themes:

- Need for improved communication between primary and secondary care about reasonable adjustments needed for patients
- Need for improved co-ordination / administration of care, particularly around appointment bookings and diagnostic tests

Baseline Feedback – Booking staff survey (n=48)

- 43 / 48 (93%) of booking and admin staff report sometimes, rarely or never being aware a patient referred into their team has a learning disability
- 10 / 32 (31%) of staff say they were made aware by information included on the referral letter
- 10 / 47 (21%) say they are aware they should be making reasonable adjustments when scheduling patients with learning disabilities and autism but don't know what this means

Proposed Improvement and next steps

- The team have developed a proposed pathway for better supporting patients with learning disabilities, focused on main areas, each broken into project phases.
- Following a recent workshop, staff training, along with a standard operating procedure (SOP) has been developed to help booking staff with the steps required when supporting patients with a learning disability and autism.
- The following phases of the project will address the below areas

