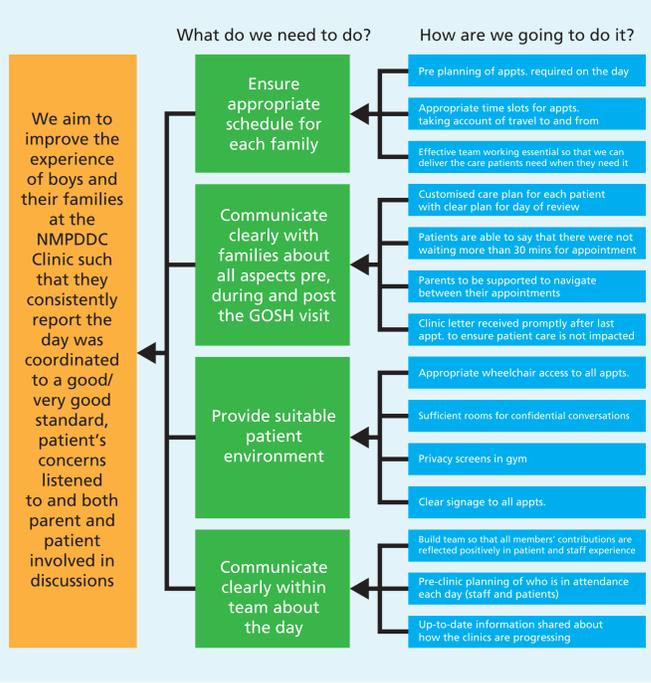


Multidisciplinary Outpatient Review Clinic for boys with Duchenne Muscular Dystrophy (DMD)

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Aims & Objectives



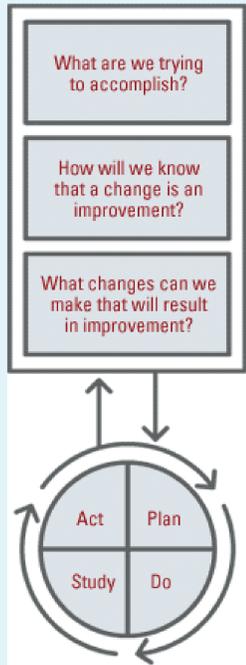
Background

DMD is a severe life limiting and deteriorating disease. The clinic selected is for many ambulant boys and lasts 3-4hrs with reviews by Physiotherapists, Dietitians, Clinical Nurse Specialists (CNS), Family Care Advisors, Consultants and Lung Physiologists. Patients also may undergo bone density and heart scanning and many also participate in clinical research trials.



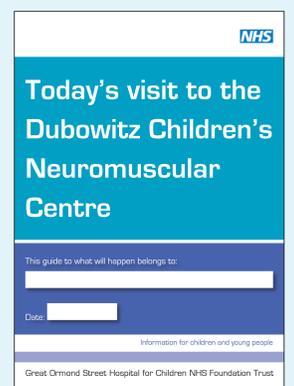
Methodology

The project used the Model for Improvement completing PDSA cycle(s) at each clinic alongside this Patient Family Centred Care (PFCC) methodology; patient shadowing, flow mapping, driver diagram, focus groups, surveys and interviews. Feedback was collected at each clinic from families and staff to support and evidence measures for improvement.



Interventions

- Clinic prep packs for clinicians' consultations
- Volunteer to support clinic
- Calling families pre appointment to confirm attendance
- Text alert system to remind families about appointments
- Vitamin D alert email to notify consultant when results are returned
- Revised weekly clinic schedule email for clinical team
- Neuromuscular in-tray in clinic waiting area
- Remote access for clinicians to Clinical Document Database
- New privacy screens in Physiotherapy gym
- Updated hard copy plan for patients
- More realistic appointment schedule
- New 9am consultant appointment
- New CNS review clinics

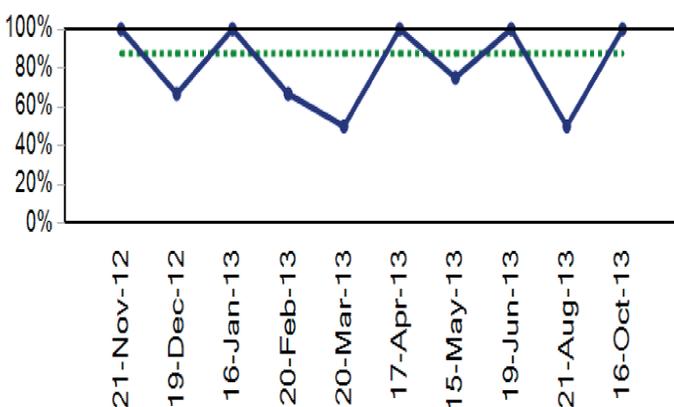


Outcomes

In September 2013...

Our families say...

Neuromuscular King's Fund – Family: Appt coordination good/very good?

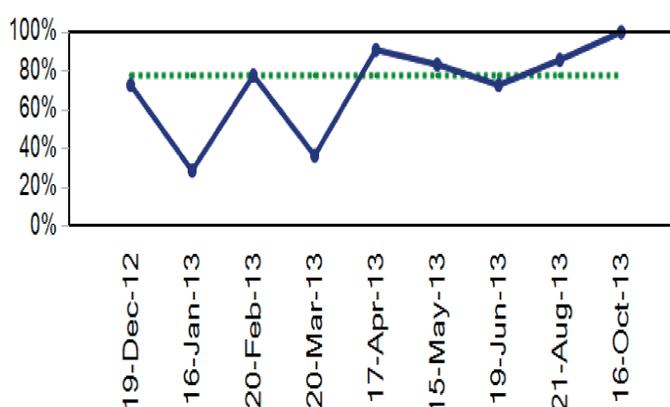


"better than ever"

"can't fault it"

Our staff say...

Neuromuscular King's Fund – Staff: Appt coordination good/very good?



Learning

- Involve families and advocacy groups from the start
- Request team commitment to test new ideas
- Ensure multidisciplinary engagement
- Sustain the momentum of change
- Be realistic

Next Steps

- Regular focus groups with families and support groups
- Introduce play volunteer for clinic
- Regular staff stress resilience workshops
- Implementation of family communication and information pack

