Benefits of Patient Feedback in Quality Improvement of a Local Cystic Fibrosis Service

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Aim: Evaluate the impact of patient and family feedback in quality improvement of a Local Cystic Fibrosis Service.

Background Cystic Fibrosis (CF) is a complex chronic disease which mandates patients and families to take on a heavy burden of treatment. Emphasis tends to be on a medical model of care which can mean parental or patient experience is not sufficiently considered in developing the service. In 2016 we started getting regular parental and parent feedback to help improve our service.

Methods: An anonymous questionnaire based on the CF Trust Standards of care was devised and then given to parents or patients in clinic or by post. In 2016 n= 23 responses [78%] and 2017 n= 22 responses [100%] out of 38 patients. Results: Main themes were around improving communication among CF team and option of local annual blood tests. Based on the responses in 2016 a series of recommendations & action plans were instituted to improve:

1] Accessibility of CF Team
2] Repetitive questioning in clinic
3] Staff hand hygiene
4] Cleanliness of ward
5] Food for inpatients
6] Inpatient physiotherapy
7] Communication between ward and community
8] Working with Tertiary Centre eg local bloods
9] Community support

This was reassessed in 2017 and showed improvements in Accessibility of CF Team [66% v 91%]; Written feedback in clinic [93% v 100%]; Overall organisation [87%v 93%]; Food on ward satisfaction [66%v 75%]; Infection control on ward [82%v 91%]; physiotherapy on ward [66% v 93%]. However staff hand washing before contact did not improve 89% v 87%.

Conclusion Parental and patient feedback is useful in both assessing a CF service but also looking for ways to develop and improve the patient experience. We have made and improvements to our service by engaging with families in a meaningful ongoing partnership.