

WHAT MATTERS TO ME?

A REGIONAL, ODN LED, PATIENT AND FAMILY ENGAGEMENT PROJECT

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Introduction

In April 2023, the Programme Manager and QI (Quality Improvement) Lead Nurse of the North West Children's Cancer Operational Delivery Network (NWCCODN) facilitated a patient and family engagement project called What Matters to Me? The ODN staff worked with professionals within RMCH and AHCH (the 2 PTCs) to listen to patients and families' experiences and learn what is important to them from a service user perspective regarding their cancer care. Feedback was collated and used to inform service development within the specific providers, in addition to influencing the strategic direction of the NWCCODN.

Method

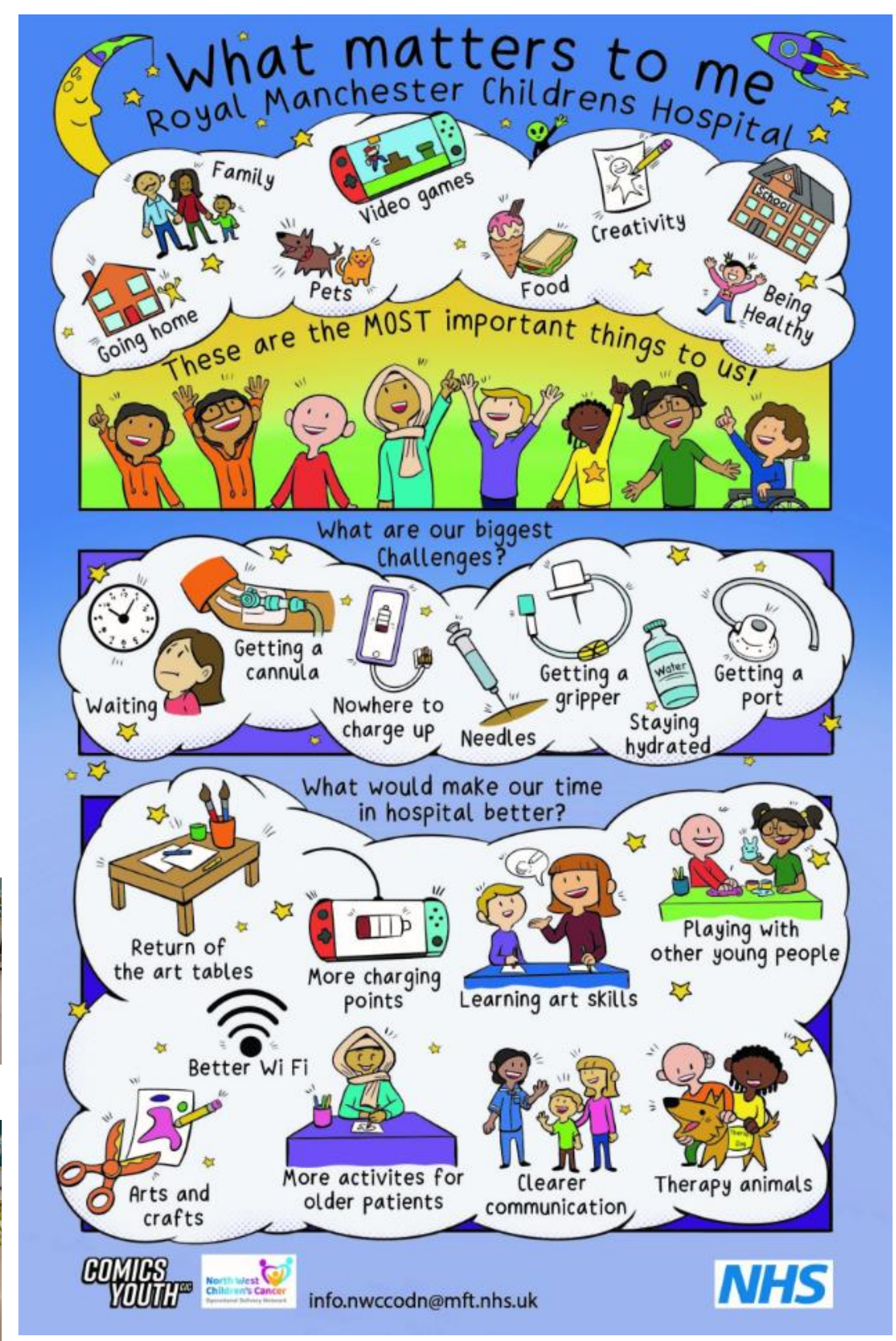
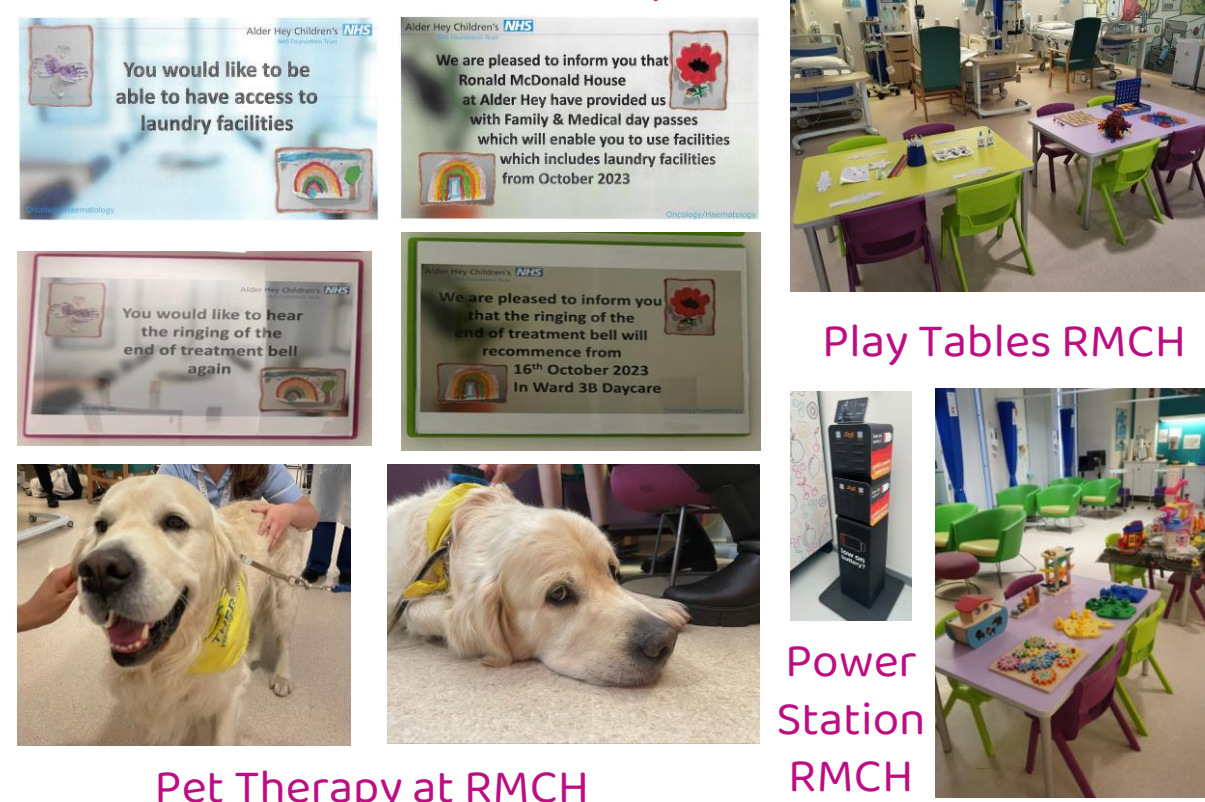
2 half days were allocated at the 2 PTCs. Families who were on the unit on the allocated days were approached. The team engaged with 42 families. Information was collected through staff delivered questionnaires, or through an art based interaction with Comics Youth artists.



Results

Out of the 42 families who were involved in this project; 15 completed the worksheets with the artist, 27 completed the questionnaire. The results were analysed, and thematic analysis was completed. The information was presented in an anonymous and easy read format to the provider teams, the National PPI Group and the regional Network Oversight Group.

You Said, We Did at Alder Hey



Discussion

Understanding and utilising the feedback and suggestions from patients and families is a vital part of service development. Obtaining this feedback can however be challenging due to resource issues. The NWCCODN programme manager and quality improvement nurse designed and delivered this experience survey. As well as standard questionnaires the staff were able to facilitate a more novel approach using an art-based interaction with children and young people. The information collected to date has been invaluable in informing the maturing network and work planning around service provision. Providers are internally responding to the suggestions from service users to improve experience within the PTC's. A 'You Said, We Listened' approach has been adopted and progress is displayed visually on the units. Identified 'Quick Wins' such as increased arts and crafts and pet therapy have already been actioned. A review of Wi-Fi and additional charging points is currently underway. This is evidence of the value of the NWCCODN staffing resource in ability to design and deliver regional projects with implication for patient benefit. Further work will be carried out to capture a wider population to ensure representation across the large geographical area.