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24 DEVELOPING THE PHYSIOTHERAPY SERVICE DURING BONE MARROW TRANSPLANT (BMT) AT GOSH

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10.1136/bmjpo-2023-GOSH.11

Background GOSH is the largest Paediatric BMT centre in the UK, performing over 100 transplant procedures per year. Patient survival is increasing; complications associated with long term survival include functional difficulties and physical comorbidities. Evidence supports increasing activity and delivering physiotherapy through BMT to benefit functional and physical outcomes.

Historically, the Physiotherapy service responding to problems in patients undergoing BMT was reactive. Referrals at crisis point were associated with loss of function and delayed discharge in some cases. With a small increase in staffing, a proactive service was developed aiming to keep children active through BMT whilst maintaining responsiveness to changing presentations.

Method To ensure our service reflected evidence and clinical expertise, we systematically reviewed literature and experience across UK children's hospitals. Consensus was sought regarding best practice within the GOSH MDT and an expert national group of Physiotherapists was established. A new Physiotherapy BMT service pathway was proposed.

Results Every family and patient listed for BMT is invited to attend a virtual pre-BMT multi-professionals clinic. Each patient completes age-appropriate baseline standardised assessments on admission and discharge. Regular, timetabled physiotherapy sessions, at least twice a week, are offered throughout admission. Increased physical activity on and off the ward is encouraged by the MDT. A physiotherapy information pack is provided on discharge and onward referrals to community services made where indicated. Anecdotally these referrals have reduced following the change in service. Physiotherapy is now also part of a complex GVHD MDT clinic.

Conclusion Physiotherapists are ideally positioned to pre-empt deterioration in function and reduce risk of secondary complications in patients going through BMT. The pro-active approach to the service changes have been well received by the MDT, families and patients. Long term follow-up by the MDT is indicated. A formal service evaluation of outcomes and experience is in process.

34 INTERNATIONAL REGISTRY OF CHILDREN WITH EPILEPSY REFERRED FOR KETOGENIC DIET THERAPY

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10.1136/bmjpo-2023-GOSH.12

Objective Although effectiveness of ketogenic dietary therapy (KDT) as a treatment for drug-resistant epilepsy has been demonstrated in clinical trials, key research questions remain; many best addressed by a collaborative approach. We aim to establish an international registry of individuals with epilepsy referred for KDT to determine long-term clinical and safety outcomes and identify the most suitable candidates.

Methods To determine data items for inclusion in the registry, dietitians, neurologists, nurses, clinical psychologists, biochemists and other KDT healthcare professionals were invited to partake in a two-round Delphi survey. Participants indicated the degree to which they agreed/disagreed with inclusion of each item. Pre-defined thresholds of $\geq 75\%$ (strongly) agree and $< 15\%$ (strongly) disagree were adopted. Agreed data items were entered into an electronic registry platform using RED-Cap software. Three UK and two European KDT centres are currently piloting data entry using the registry platform and will report on its acceptability and feasibility of use via a questionnaire.

Results 153 participants across six continents responded to the Delphi, including all healthcare professions within KDT multi-disciplinary teams. 70 items reached agreement threshold, including sociodemographic, medical and dietetic data at baseline (referral), follow-up (routine appointments after starting diet) and post-diet.

Feedback so far from pilot centres indicates that data items are easy to understand and time taken for data entry is 'about right', although additional funding for dietetic and clinician hours would be needed for long-term implementation.

Conclusions With support of the international KDT community, we have determined data items for inclusion in an international registry. We await full feedback on acceptability and feasibility of use of the registry platform ahead of planning for wider roll-out. Patient and Public Involvement work will explore the possibility of a patient/parent registry section.

Acknowledgements for funding or support British Dietetic Association; Nutricia Advanced Medical Nutrition

38 REDUCING NOISE LEVELS IN THE NEONATAL INTENSIVE CARE UNIT: A QUALITY IMPROVEMENT PROJECT

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10.1136/bmjpo-2023-GOSH.13

Background Noise in the Neonatal Intensive Care Unit (NICU) can significantly impact on the neurodevelopment of both term and preterm infants. Excessive sound stimuli may cause abnormal brain and sensory development in preterm infants, as well as potential cochlear damage and hearing loss. To mitigate these risks, the American Academy of Paediatrics recommends noise not exceeding 45 decibels (dB) in NICUs. Additionally, continuous exposure to noise in the NICU can affect the well-being of parents and healthcare professionals.

Aim Our objective was to collect data and assess noise levels on NICU to understand the factors associated with high and low levels of noise. Our further aim was to use the data to promote education about the negative impact of noise for term and preterm infants and increase staff awareness on how to reduce noise levels.

Results In October 2022, we installed a ‘Sound Ear’ decibel (dB) monitor within the NICU, which continuously records and stores sound levels. This device acts as a traffic light system, lightening up green for safe noise levels (up to 50dB), amber as a warning (51db to 70db), and red for unsafe levels (above 70dB). Since its implementation, we have consistently monitored noise, identifying specific triggers for noise levels within the amber and red zones. We identified ward rounds, closing and opening of bin containers, monitors and syringe alarms as the most common source of noise.

Conclusion This project is ongoing, but it has already yielded valuable insights and promoted positive changes. Staff awareness of noise levels has increased, an educational video on the impact of noise on NICU has been shared with all hospital staff (available on the hospital intranet), and transitioning to quieter bin containers has been considered.

47 OPERATIONALISING A FRIENDS AND FAMILY TEST NATURAL LANGUAGE PROCESSING PIPELINE

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10.1136/bmjpo-2023-GOSH.14

Background To manage the workload of data entry, manual sentence splitting and redaction of patient feedback that comes in form of 2000 comments per month, the patient experience team have worked with multiple data teams at GOSH to automate the process through a pipeline that incorporates Artificial Intelligence techniques.

Methodology Part of this workflow involves a routine utilising artificial intelligence techniques, that handles sentence splitting, automatic data redaction and prediction. It was implemented in Python (Python Software Foundation. Python Language Reference, version 3.8. Available at www.python.org).

It runs as a scheduled task every midnight of each day, to process all feedback captured in the previous day. On our secure digital environment, patient feedback is pulled from a database and identifiable data are masked on doctor, nurse, patient names as well as phone numbers and email addresses.

Using natural language processing techniques, comments are split into grammatical sentences for further understanding of what sentiment is expressed in each sentence. This also enables the tool to assign topics from a predefined set of categories in the NHS Patient Experience Framework Themes 2022. Sentences from the same comment sharing the same sentiment and theme are joined by preserving the order of their occurrence.

We are working with the Patient Experience, Quality and Information Services teams to utilise this output for downstream operations like manual validation using an in-house built webapp and measuring and monitoring the overall patient experience performance through a dashboard across wards using the Qlik Sense platform.

Conclusion This pipeline demonstrates a use case of deploying an analytics project to be used near real time, it also shows collaboration amongst various departments with GOSH.

Acknowledgements for funding or support This work is supported by the Health Foundation.

50 CONVERTING QUALITATIVE DATA ON PSYCHOSOCIAL FACTORS INFLUENCING ACCESS TO PAEDIATRIC KIDNEY TRANSPLANTATION TO QUANTITATIVE OUTPUT WITH PATIENT AND PUBLIC INVOLVEMENT

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10.1136/bmjpo-2023-GOSH.15

Background Psychosocial factors are known to influence access to kidney transplantation in children with stage 5 Chronic Kidney Disease (CKD) but these factors are poorly understood. An exploratory Mixed Methods (MM) study was designed to prospectively investigate these psychosocial factors by interviewing and distributing questionnaires to participants. Here we describe the process of converting the qualitative interview data for utilisation in the quantitative questionnaire phase of the MM study, with patient and public involvement (PPI).

Methods Up to 37 semi-structured interviews took place with children with CKD, their carers and their renal multi-disciplinary team. The interviews were analysed by thematic analysis as per Braun and Clarke to generate preliminary themes. An initial list of existing and validated questionnaires compiled from a systematic literature review and expert recommendations, were mapped against the preliminary themes. The questionnaires were checked for internal consistency and test re-test reliability scores. Over email correspondences and video conference calls, the questionnaires were co-reviewed for their readability, relevance and acceptability with a steering group of patients and families with lived expertise of CKD, dialysis and transplantation.

Results An initial list of 18 questionnaires were mapped against them. After steering group reviews, 8 questionnaires were removed due to their unsuitable language, onerous length, limited validated age range and irrelevance to families with CKD. Cronbach’s alpha scores of all questionnaires picked for the final distribution list ranged up to or exceeded 0.8. The final list of questionnaires successfully received ethical approval and were distributed in the next phase of the MM study.

Conclusions Distributing questionnaires that are relevant and acceptable to families with CKD is important. It not only encourages retention but ensures that the research is meaningful to the families. We described the process of engaging the voices of families with lived expertise of CKD to meet this endeavour.

Acknowledgements for funding or support This work is funded by the NIHR Academy. The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health.

53 AORTOPEXY AND TRACHEOPEXY – A NOVEL TECHNIQUE FOR RESISTANT TRACHEOMALACIA

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10.1136/bmjpo-2023-GOSH.16

Background Tracheobronchomalacia can be quite resistant for treatment in children. They can be either isolated or as part of more extensive pathology, especially in those children with