PIER - Innovation and Improvement Report

Title
Nutrition in children with kidney disease: using electronic records to obtain growth data.
Why this project (e.g. what was the problem, why was it a priority)
Kidney disease is a rare disease with no cure that costs the NHS billions. Good nutrition can delay the progression of disease, but malnutrition has long been recognised, with poor growth increasing morbidity, mortality and hospitalization, decreasing school attendance and causing many psychological issues. This is further complicated by the recent rise in obesity in CKD, the multifactorial cause of growth failure and the nausea, vomiting and taste changes that can occur. There are no large growth datasets to characterise growth patterns in CKD outside end stage disease, and small cross-section studies have shown that growth changes can start early in disease. Establishing when changes start and the prevalence of malnutrition and obesity can help optimise clinical management to improve outcomes. However, obtaining growth data manually takes time and until recently there was no electronic way to access large data sets across the ages and stages of disease. This project was a feasibility project to set up the process to access data electronically to obtain growth data and provide a baseline from which to evaluate service provision, monitor growth response to treatment and improve clinical outcomes.
Brief description including setting (e.g. ward based, community etc)
Children under the care of the regional paediatric nephrology service were used to obtain growth data taking their first measurements from out-patients at a set time point.
Improvement methodologies (e.g. PDSA cycles)
This was a baseline assessment to understand the problem and identify clinical areas that require a more focused approach to improve clinical outcomes for growth. PDSA cycles were used with the renal project team to plan the project and process, access the electronic data, review the quality of data obtained and repeat the process with amendments to enable sufficient quality data to be obtained.
Patient involvement (yes/no, if yes please describe)
The baseline assessment did not involve children or their families in the design, however the value of obtaining the information to understand the problem was been discussed with them and the results have been shared. As a result a young person and parent group is being step to help undertake a service review and understand what matters to those using and providing the service and how we can make it better to improve growth outcomes.
Measures used (e.g. process , outcome and balancing measure, what data did you collect, how did you record it)
Outcome measures: Quality of care: Pathway design of the process to obtain growth data; Service measures: Documentation of the problem – prevalence of under and over nutrition. Process measures: Baseline performance measure to characterise the problem. Balancing measures: Competing clinical needs and priorities once under and over nutrition have been explored; increased work load for those required to treat under and over nutrition; lack of

infrastructure to effect improvement in under and over nutrition.
Data collection and recording:
Children were identified using clinic codes for paediatric nephrology. The first appointment that recorded weight, height, and creatinine level on the system was taken. Data was electronically transferred onto a specifically designed database and used to generate z scores for weight, height and BMI; and estimated glomerular filtration rate. SPSS was then sued to statistically analyse the prevalence of under- and over-nutrition and explore the relationship with kidney function.

Outcome
(e.g. what were the key findings/learning points, did these result in a change in practice for patient benefit, was this sustainable)

Key Findings
This is the first and largest weight, height, and data set for children with CKD looking at all ages and stages of disease. The worst disease had the lowest weight, height and BMI; obesity in those with mild disease had a similar prevalence to that of the Hampshire general population; however transplanted children on the one hand had a much higher level of obesity but on other had a higher level stunting. In addition, the younger children had lower weight and height sds.
Learning points
Accessing the systems took a lot of time, and whilst a large data set was obtained it lacked the sensitivity and specificity as it was not possible to link electronically to co-morbidities.
A structured approach to care using an electronic system fit for purpose needs to be developed to enable the changes to clinical practice and improvements in clinical outcome to be monitored and reviewed. This then needs to be embedded in to clinical case reviews and service development.
Changes in practice
An algorithm using Height and BMI z score grid is being developed to help assess case reviews and evaluate service effectiveness.
The development of an electronic annual report is being explored to monitor and review changes in practice.

Details of where published/presented

This has been presented at the 3rd International Paediatric Renal Dietitians meeting 2015 and PIER 2016.

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Key search words

Paediatric kidney disease, growth, weight, height, BMI, z scores