

## 97 PICTURE-RISK – A METHOD FOR PATIENT RISK SCORING USING ELECTRONIC HEALTH RECORD DATA

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**Background** Risk scores are widely used tools that help clinicians assess risk for a patient. Benefits of such tools range from disease prevention and management to more efficient clinical resource utilisation. Developing and using a risk score tool often involves many steps from data extraction to rigorous testing and validation of its clinical usefulness and safety.

**Methods** We have worked with clinicians to create a tool that simplifies the development, validation and deployment of risk scores and supports their use in clinical settings. We present PICTURE-Risk, a generalisable component of PICTURE, a clinical informatics platform developed at Great Ormond Street Hospital (GOSH).

As a PICTURE component, PICTURE-Risk benefits from the standard electronic health record (EHR) extraction processes developed by the GOSH Digital Research Environment (DRE) and PICTURE's cohort builder and analytics functionality. A new risk score can be configured by specifying a set of items (risk factors) and their contribution to the total score. PICTURE-Risk will then calculate and present on demand the total risk for a given patient or cohort in an interactive user interface.

**Results** We have developed proof-of-concept (POC) risk scores for diabetes and sudden cardiac death in collaboration with clinicians. The total risk, a breakdown of the risk factors' contribution and various analyses of the cohort risk scores were generated on demand for a patient or cohort using EHR data. The POC version has been developed in R and Shiny and most of the user interface was built using TypeScript and React.

**Conclusion** The POC application of PICTURE-Risk has demonstrated that it is feasible to make a wide range of risk scores available for research and clinical use with a high-level specification of the risk score being the only required input. We envisage this component will accelerate the development and use of risk scores at GOSH.

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## 99 CURRICULUM CO-DESIGN: USING THE VOICE OF YOUNG PEOPLE

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**Background** Patient engagement in the design, planning and delivery of education can lead to improved outcomes, patient experience, and better use of resources. We aimed to co-

design the key elements of two new academic programmes in partnership with the Young People's Forum.

**Methods** A focus group involving 20 young persons was held using workshop activities to explore the feelings, attitudes, and opinions of young people in relation to the design of postgraduate education and their participation in aspects of work-based learning and assessment.

**Results** The key emergent themes were: The young people reported an understanding of their necessity to be involved in the training of healthcare professionals but suggested they could have more involvement in agreeing to when and how this happens.

They felt our programmes should include strong elements of general paediatrics, as well as a focus on specialist training. Young persons reported this to be important in ensuring the delivery of safe, effective, and holistic care.

Suggested teaching topics related largely to communication, particularly communicating with adolescents, and how this needs to differ to children. They also conveyed the benefits of having a greater understanding of shared decision making and respecting their individuality as part of their overall care.

Importantly, some lived experiences indicated that staff were not always aware of legal issues such as consent and capacity, and therefore identified a need for this to be included in our training.

They held no fixed views about which base professionals should be trained as an advanced clinical practitioner.

They suggested using young people as 'associate examiners' as a possible assessment method.

**Conclusion** All emergent themes above have been considered in programme learning design. Using young people as 'associate examiners' is being explored for the first student intake, ensuring the patient voice continues to be represented throughout practitioner training.

## Poster Presentations

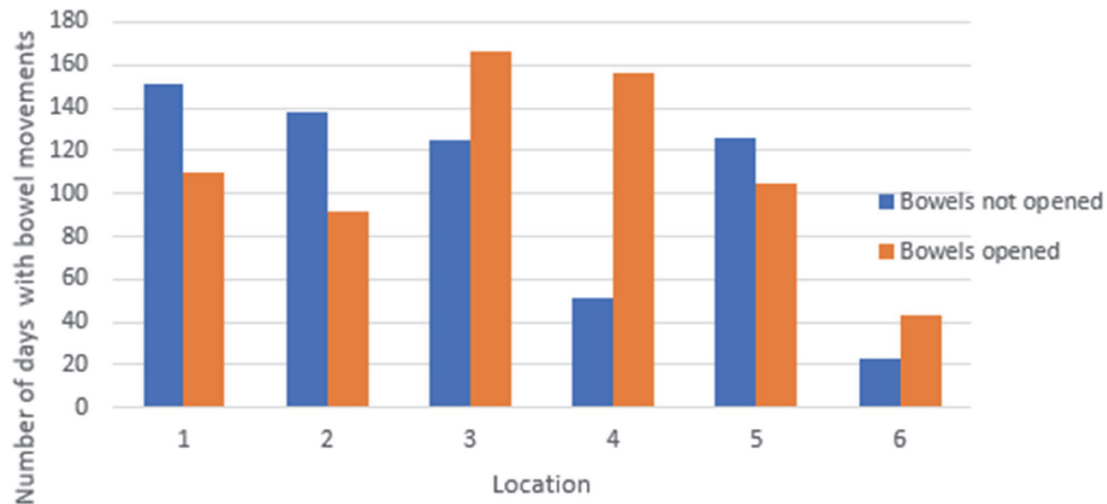
### 11 A MULTICENTRED EXPLORATION OF THE INCIDENCE AND FACTORS ASSOCIATED WITH CONSTIPATION IN CRITICALLY ILL CHILDREN

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**Objective** To characterise the incidence and factors associated with constipation in critically ill children.

**Study Design** A multicentre prospective service evaluation of children admitted to Paediatric Intensive Care Unit (PICU). Constipation was defined as i) three days without bowel movements from the start of admission or at any timepoint during admission or ii) stool consistency types 1 or 2 from the Bristol Stool Chart. Data collection was completed by PICU dietitians using an anonymised online data collection tool and included; diagnosis, records of pharmacopeia, nutrition support and defecation up to day 10 of admission. Inclusion criteria: PICU length of stay (LOS) of more than 48



Abstract 11 Figure 1

hours. Exclusion criteria: children with a known condition affecting intestinal transit, exclusive parenteral nutrition, and multiple admissions.

**Results** 216 children, across 5 NHS trusts and 6 intensive care units (1 cardiac ICU, 5 mixed PICU). Participants were 61.1% male, 21.1% born preterm, mean age  $35.4 \pm 55.0$  months, weight  $12.6 \pm 13.6$  kg and PICU-LOS mean  $6.0 \pm 2.7$  days. Admissions were post cardiac surgery 39.4% ( $n=85/216$ ), respiratory disease 30.6% ( $n=66/216$ ), other cardiac 15.7% ( $n=34/216$ ), neurology 6.5% ( $n=14/216$ ), other 7.9% ( $n=17/216$ ). Constipation on admission was 45.9% ( $n=96/216$ ) patients, Bristol stool type  $5.6 \pm 1.1$  and 18% ( $n=39/216$ ) patients did not open their bowels during admission. Of those who did, mean time to passage of first stool was  $1.8 \pm 1.8$  days. Two centres had bowel management protocols. Stool type in units with a bowel management protocol were significantly different  $5.8 \pm 0.8$  compared to those with no protocol  $5.5 \pm 1.2$  ( $p < 0.05$ ). There was no difference in stool types between children requiring inotropic support  $5.6 \pm 1.0$  compared to requiring no support  $5.5 \pm 1.2$  ( $p > 0.05$ ).

**Conclusion** Constipation in critically ill children is common, although centres with a bowel management protocol may have reduced incidence. Further data analysis is required to elucidate any correlation between constipation on achieving nutrition support goals.

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#### FETAL CLOSURE OF MYELOMENINGOCELE – EXPERIENCE OF THE SPINA BIFIDA MDT CLINIC AT GOSH AT 5 YEARS

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**Background** Since 2018 NHS England has supported fetal surgery for spina bifida (SB) through a GOSH, UCLH and Leuven, Belgium partnership. Children across the UK, have centralised follow-up at GOSH specialist multidisciplinary

team (MDT) clinic, providing assessment at specified time points and responsive management to acute needs.

**Aims** To describe the outcome of children with fetal closure of SB and identify needs of service users within a collaborative NHS partnership.

**Methods** Retrospective Service evaluation (Registration no: 3118) of patients who underwent fetal surgery (~24wks GA) as per MOMs trial,<sup>1</sup> between Jan 2018-Aug 2023. Outcomes were extracted from Electronic Patient Record (EPR) and comprised GA at delivery, shunt placement rate and urological status Myelomeningocele Motor Functional Classification (MMFC)<sup>2</sup> was completed for the pre-school cohort.

**Results** 32 children were delivered at UCLH or local maternity unit between August 2018- October 2022 following fetal surgery for SB. 50% GA  $\geq 36$  weeks; 44% GA 32- <36wks; 2 children were delivered <32wks GA. 19 under GOSH exclusively, whilst 13 followed up in partnership with other UK centres. GOSH catchment children were seen as prescribed +/- 2 months (newborn, 6m, 12m, 24m, 36m, <60m) with shared care cohort seen at 12m, 24m and < 60m – virtually or face-to-face.

**Outcomes** 2/3 shunt free; > 3yrs 2 have successfully toilet trained whilst 10 use CIC to support bladder emptying; pre-schoolers: 2 wheelchair uses (MMFC1), 5 walking independently or stepping with support (MMFC2-4). EPR and MyGOSH enabled timely response to queries from across team.

**Conclusion** GOSH specialist clinic supports SB children following fetal surgery. Hybrid visits enabled planned and acute follow-up to continue through the pandemic. A reduced need for shunts and further invasive surgery, and improved mobility was observed in keeping with best international results.

#### REFERENCES

1. Adzick, et al. *N Engl J Med* 2011;**364**(11):993–1004
2. Dias. *J Child Orthop* 2021;**15**(1):1–5

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