Using the North of England Collaborative Cerebral Palsy Survey (NECCPS) to audit clinical care

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AIM:

- To establish whether there is variation in health care for children and young people with cerebral palsy across the north of England.

METHOD:

- Retrospective case note review:
  - 389 children & young people with cerebral palsy
  - Born 1995-2002, registered on the NECCPS

- Data collected on:
  - Cranial magnetic resonance imaging (MRI) as marker of aetiological assessment;
  - Status of hips & spine;
  - Pain, nutrition & growth.

- Subsequent data validation by paediatricians and physiotherapists.
Audit sample is not significantly different to whole birth cohort on the NECCPS register for:

- Type of CP
- Age at diagnosis
- Associated impairments
- Sex
- Plurality of pregnancy
- Birth weight
- Gestational age at delivery
- Socioeconomic circumstances

**RESULTS: MRI variation in practice**

- 13% had developmental brain anomaly.

**RESULTS: MRI trend over time**

- 18.5% had some degree of hip migration of whom 20.3% had full hip dislocation at least one hip.
- 62% had surgical intervention to prevent full dislocation.
RESULTS: Hips

- 33% monitored by orthopaedic surgeon overall.
- Among the 18.5% with hip migration:
  - 83% monitored by orthopaedic surgeon.
  - Significant difference between districts in access to monitoring of hips by an orthopaedic surgeon for those at GMFCS levels III-V.

RESULTS: Spine

- State of spine not recorded in 24.4%
  - Significant (p<0.01) variation between districts in recording state of spine.
- 23% had a spinal curvature.
- 47% had spine curvature monitored by a spinal surgeon; 10% had surgery.
  - Access to spinal surgeon varied by district on the borderline of significance (p=0.08)

RESULTS: Recorded discussions about PAIN

- 50% reported being in pain:
  - 43% among GMFCS I-II
  - 61% among GMFCS III-V
- 87% of those in pain had a written pain management plan in the case notes.
RESULTS: Recorded discussions about PAIN

- 9% had a gastrostomy (feeding tube)
  - 1% among GMFCS I-II
  - 26% among GMFCS III-V
- Average age at gastrostomy was 5.8 years.
- No difference in Body Mass Index between those with gastrostomy and those without.

RESULTS: Nutrition

- 95% had at least one weight measurement.
- Average time since last measurement 0.7 years.

RESULTS: Weight

- 95% had at least one weight measurement.
- Average time since last measurement 0.7 years.

- 26% within last year
- 14% 1 - 2 years ago
- 60% More than 2 years ago
CONCLUSION AND ACTION:
Variation across north England in aspects of health care for children and young people with CP confirmed.

Individualised reports sent to districts as catalysts for positive change.

Additional fields to be added to the NECCPS to continue to drive positive change and assist future audit cycles.

GOAL: more equitable health care with more equitable opportunities for the best health outcomes for all.

ANY QUESTIONS?

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