Symposium 2
British Intestinal Failure Alliance Symposium
David Wilson
Progress towards a paediatric IF network

Dr Sue Beath  29th November 2011
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On behalf of the BSPGHAN Nutrition Committee and Intestinal Failure working group
Introduction – rationale for networks

- Increased prevalence of multi-faceted conditions; greater complexity
- Emergence of new technologies
- More specialisation & more children surviving illnesses which were once fatal eg gastroschisis, NEC
- Prognosis chronic IF in children is good - 75% come off PN within 2 yrs
- Concept of networks gaining acceptance but still underdeveloped in many areas
NCEPOD report Oct 2011 – review of children’s surgery

373 hospitals identified – 290 questionnaires returned

<table>
<thead>
<tr>
<th>Hospital category</th>
<th>Total</th>
<th>%</th>
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<tbody>
<tr>
<td>DGH &lt;500 beds</td>
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<tr>
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<tr>
<td>SSH</td>
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<tr>
<td>Single Specialty Hosp</td>
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<tr>
<td>Total</td>
<td>290</td>
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NCEPOD report Oct 2011 – hospitals carrying out children’s surgery who also have MDT meetings

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<th>Hospital type</th>
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<td>20</td>
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What does a good clinical network look like?

Requirements for a network to function

• Common aim eg IF rehabilitation
• Clarity about timing of referral and what constitutes “trigger points”
• Ease of communication
• Ease of patient transfer
• Useful feedback between members of network ie forum for communication & education
• Opportunities for patients and families to influence
• Auditable outcomes  
  
  NB NCEPOD of paediatric surgery concluded that care was good in 71% of cases
<table>
<thead>
<tr>
<th>Case type</th>
<th>n</th>
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<tr>
<td>Congenital paediatric general surgery</td>
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<td>7.1</td>
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<tr>
<td>Ear, nose and throat</td>
<td>10</td>
<td>3.2</td>
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<tr>
<td>General paediatric (not congenital) surgery</td>
<td>22</td>
<td>7.1</td>
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<tr>
<td>Trauma- including head injury</td>
<td>25</td>
<td>8.0</td>
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<tr>
<td>Neurosurgical - non trauma</td>
<td>36</td>
<td>11.6</td>
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<tr>
<td>Necrotising enterocolitis (NEC)</td>
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<td>33.1</td>
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<td>Congenital cardiac surgery</td>
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<td>Other</td>
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<td><strong>Subtotal</strong></td>
<td>311</td>
<td></td>
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<tr>
<td><strong>Not answered</strong></td>
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<tr>
<td><strong>Total</strong></td>
<td>378</td>
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If NCEPOD reviewed Children’s IF network – what would they find?

• Regional IF paediatric services well established

• Quadrupling of home PN cases in 20 yrs

• Increased treatment options: Bowel Tx, novel approaches venous access, bowel lengthening surgery

• Improvements in delivery/supervision of EN reducing time spent on parenteral nutrition (PN)

• See BSPGHAN reports e.g. Trends in paediatric HPN. Clin Nutr. 2011; 30:499-502

• Education & teaching days accessed via www.bspghan.org.uk www.spghang.org.uk www.bapen.org.uk

• British Intestinal Failure Survey – registered 538 patients to date
### Data provided by BIFS – 2 yr outcome audit

<table>
<thead>
<tr>
<th>Outcome Category</th>
<th>Short gut (n=153)</th>
<th>Enteropathy (n=29)</th>
<th>Dysmotility (n=31)</th>
<th>Other (n=30)</th>
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<tbody>
<tr>
<td>Weaned off PN (n=154)</td>
<td>66%</td>
<td>48%</td>
<td>55%</td>
<td>77%</td>
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<tr>
<td>Non-transplant Surgery (n=89)</td>
<td>44%</td>
<td>7%</td>
<td>55%</td>
<td>7%</td>
</tr>
<tr>
<td>Sepsis (n=125)</td>
<td>52%</td>
<td>34%</td>
<td>61%</td>
<td>53%</td>
</tr>
<tr>
<td>Jaundice (n=55) bili &gt;50mmol/L</td>
<td>27%</td>
<td>28%</td>
<td>6%</td>
<td>13%</td>
</tr>
<tr>
<td>Referred for ITx assessment (n=45)</td>
<td>21%</td>
<td>17%</td>
<td>16%</td>
<td>0%</td>
</tr>
<tr>
<td>Died (n=27)</td>
<td>10%</td>
<td>14%</td>
<td>13%</td>
<td>13%</td>
</tr>
</tbody>
</table>
BIFS audit 2010*

33 reporting centres

22 currently supporting 139 children on Home PN

13 currently training carers to perform Home PN

Point prevalence HPN 13.7 per million

- Children with massive small bowel resection
- All children with congenital enteropathies who are destined for life-long PN dependence
- Diagnostic / prognostic uncertainty (e.g., uncharacterised protracted diarrhoea)
- All children requiring PN for more than 28 days
- Hyperbilirubinaemia (conjugated plasma bilirubin more than 50 micromol/L)
- Vascular access problems in patients on long term PN
- Thrombosis of two out four upper body veins
- The request of the family
Children’s IF network – recommendations

- Maintain specialized regional services
- Promote recognized standards for management of IF and provision of PN with the aim of rehabilitation and eventual autonomy from PN
- Recognize interdependencies between medical and surgical training in paediatric gastroenterology
- Promote staffing structures and access to new treatments and new modes of service delivery, e.g., venous access teams
Children’s IF network – recommendations 2

• promote and facilitate networking between regional centres by supporting regular clinical meetings which produce auditable reports

• recognize the important role of the supra-regional SBTx centres in supporting regional networks of care and contributing to audit at national and regional level

• Recognise children’s developmental needs and transition services
Summary

• IF network in children is still largely geographically based

• BSPGHAN & BAPS are leading on common standards of service/staffing, joint policies on referrals, shared care & audit

• Some centres interact with Tx services, which, being nationally commissioned, cuts across organizational boundaries
Conclusion

Compelling case for planning paediatric IF services strategically with:

• a user focus following the patient journey, cutting through barriers to referral & multi-professional care

• commissioning of designated regional centres for Mx of complex cases and well supported networks for shared care, is highly desirable

• goal of accessible, high quality care provided as near as possible to home for all patients has not yet been realised
Acknowledgement and contacts

• Mr Henry Gowen  BIFS registry manager
  henry.gowen@bch.nhs.uk
• Dr Mark Beattie President of BSPGHAN
• Dr Sue Protheroe Secretary of BSPGHAN
• Mr Ian Sugarman Secretary of BAPS
• Prof David Wilson chair of BSPGHAN Nutrition Committee and IF working group
• Dr John Puntis  (Chief investigator BIFS)
• Members of the Nutrition Working Group of the BSPGHAN – contact via Henry Gowen or David Wilson
Patients on HPN

Lynn McCready, Calea UK
Patients on HPN

Lynn McCready, Calea UK
Integrated Management of IF
– A Dietetic Perspective

Barbara Davidson
Newcastle upon Tyne
In the beginning........

Hope Hospital

Freeman Hospital

St Mark’s
Development of a service

- 2000 Nutrition team established at Freeman Hospital including surgeon with interest in Intestinal failure
- 3 or 4 local patients managed on HPN – mostly crohn’s or post traumatic short bowel
- Links established at consultant and dietetic level with St Mark’s and Hope to facilitate joint management of patients
Current Situation

- 46 patients managed on HPN at Freeman Hospital
- Strong nutrition team with 2 surgeons carrying out IF surgery
- Referrals from the Northern region and Cumbria
- Service had grown steadily without any extra funding until 2009
- Links made with Oxford and Cambridge Small bowel and multi visceral transplant units with 4 patients referred and 3 transplanted over the last 2 years.
Northern nutrition network

- Instituted 2003
- All clinicians, dietitians, pharmacists, biochemists, nurses, with an interest in nutrition invited
- 17 trusts across Northern England
- Over 40 attended
Medical lead but strong multidisciplinary membership
Twice yearly meetings in Durham
Forum for; dissemination of BAPEN information, case study discussion, audit, response to national alerts.
Invited guest speakers eg commissioners, NSPA
Putting faces to names and making connections has been crucial
The network has strengthened links between dietitians and clinicians across the region.

- Referral process often starts with a dietetic contact.
- Patents often referred for HPN training in the first instance – surgical intervention often follows.
HPN service provision

- The centralisation of the HPN service at Freeman has enabled a regional HPN contract to be tendered for and awarded.
- Substantial cost saving to the trust.
- Consistency for patients – only 1 company to deal with.
- Patient management for Nursing, Dietetic and pharmacy staff more streamlined.
- Nursing and dietetic posts created as part of the contract.
SWOT Analysis
Strengths
Audit– to date;
- TPN audit
- Feeding on ITU
- PEG audit
- Nutrition Team audit
- BAPEN approved study days

NCEPOD response → new TPN documentation
NSPA response → new documentation

Joined up regional PEG documentation and policies
Regional refeeding policies
N.N.N Publications

- Nutrition Provision for Patients on Intensive Care units in the Northern Region of England. Dipper, C. R.; Rollo, M.; Rutter, M.; Davidson, B.; Thompson, N. P. CLINICAL NUTRITION SUPPLEMENTS - 2008 ; VOL 3; SUPP/1 ; Pages: 46

- Northern Nutrition Network regional PEG audit: third cycle S White, A Torrance, K Matthewson
  Gut 59:A146 doi:10.1136/gut.2009.209049r

Weaknesses
Getting ‘bums on seats’ always a challenge – consider day, venue, time get agreement then change them again!

Communication can break down when data gathering

Can become a bit dietetic – heavy (clearly because we are so enthusiastic! and not necessarily a weakness!!)
Opportunities
- Discuss difficult cases and get MDT view
- Patients passing between centres get joined up care
- Surgeons can engage with the rest of the team and become demystified!
- Excellent resource for research and audit
- Ready made regional BAPEN branch!
Threats
Territorial surgeons

Distrustful dietitians

Anxious patients

FINANCE – or lack of it!
IF management – dietetic challenges

Patient assessment and monitoring

Liver dysfunction

Stoma / fistula management

Unknown bowel anatomy

Conflicting advice
The future

- Proper, targeted funding and tariffs which reflect the work involved in managing these complex patients
- Continued dialogue between all members of the IF management team
- Patient centred consistent care with the centres providing expert surgical and medical interventions and training and the region providing support.
In the future....

Diagram:
- PATIENT
- Regional IF Centre
- Transplant Centres
- Homecare companies
- National IF Centres
- GP
- Local Hospital
Thank You
Christopher Chan
HIFNET progress

- Currency and costing review group
- ASGBI involvement and IF guidelines
- ASGBI symposium
- Specialised Intestinal Failure Services: Service Description and definition of Specialised IF Surgery.
- BANS
- NHS Commercial medicines Unit: national procurement HPN
- Preparation for Designation: SCG Directors.
Specialised Intestinal Failure Services: Service Description

- Clinical definition of IF.
- The Who: Characteristics of the patient requiring treatment and their specific healthcare needs
- The What: Description of the intervention(s) required to meet that healthcare need
- The Where: Standards and infrastructure required for safe and effective provision of healthcare interventions to meet that need.
- Definition of specialised intestinal failure surgery
HIFNET setbacks

- Liberating the NHS: The white paper
- Specialised Commissioning through the NHS Commissioning Board
- Health and Social Care Bill – the pause
- NHSCB now to be fully operational April 2013
- Transition Oversight Group Sir Neil McKay - some Services to be commissioned next year:
  - Clear consensus that the service meets the four factors on the face of the Health Bill – YES
  - Activity can be identified and separately commissioned – NOT YET
  - Successful commissioning of the service is already in place within at least some SCGs. – NO
HIFNET 2012

- Designation process going to SCG Directors for endorsement on 28 November – will start in December (assuming sign-off)
  - Peer review
  - Commissioners designation
- National Procurement HPN
- BANS
- Audit and repeat stocktake (Surgery)
Zones for the procurement and provision of HPN
HIFNET:
Keeping up the Clinical Pressure

- Three postponements
- But National Procurement HPN, BANS, Designation
- Regional activity/inactivity
- But NHSCB starts April 2013: reassuring?
- RCP, RCS, NSCG
- Currency and costing: surgery
- No room for complacency