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# *National Specialised Commissioning Team (NSCT)*

Testing assumptions for future  
patient flows and manageable clinical  
networks

*Executive Summary – Workstreams 2, 3 & 4*

*Final report  
October 2011*

*Workstreams  
2, 3, & 4: Clinical,  
Parent & General  
Public*

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# *Executive summary:* Clinical, Parent and General Public

## ***Evidence base:***

- *Workstream 2:* Interviews with two nominated clinicians from each of the 11 surgical centres that were the focus of Safe & Sustainable (S&S). 153 responses to a postal survey (37% - 40+% response rate range) of referring paediatricians. Three clinician focus groups (42 clinicians) to 'sense check' Workstream 2 findings and agree issues.
- *Workstream 3:* 172 responses to a postal survey (25% response rate) by parents from the 22\* postcode areas identified by the NSCT for testing and 21 telephone interviews with parents.
- *Workstream 4:* Focus groups with 102 members of the general public recruited from across the 22 postcodes identified for further exploration by NSCT.

*\*22 postcode areas:*

*Bradford, Brighton, Coventry, Doncaster, Dorchester, Guildford, Hemel Hempstead, Hereford, Huddersfield, Halifax, Hull, Leeds, Lincoln, Nottingham, Oxford, Peterborough, Reading, Redhill, Sheffield, Slough, Wakefield and Worcester*

## ***Clinical, parent & public feedback***

### **Referrals/patient flows**

- Although clinician interviews on the whole identified the view that patient volumes would increase under *Safe & Sustainable* (S&S) options, they considered a degree of patient flows may not be as assumed on the basis of a number of specific postcode areas.
- In particular there were some postcode areas identified by clinicians and also the majority of parents and the public, where the indication would be that the S&S assumed surgical centre would not be the preferred choice.
- If patient flows for these postcode areas were factored into assumptions and projected levels of activity, they may have implications in particular for the Newcastle centre under Options A, B and C – ***see table overleaf***.
- That said, the majority of parents and the public also indicated if told/advised to go to an alternative centre compared to their preferred centre, they would consider the alternative. However there was more reluctance amongst members of the public to consider travelling to Newcastle as a centre.
- As per the table overleaf, there are also implications for the Leicester centre under Option A, the Bristol and Southampton centres under Option B and Leeds under Option D. *For note: in discussing options with parents and the public, the surgical centres referred to were as per those specific centres named for Options A – D in S&S (see Appendix).*
- Centres all indicated having plans to accommodate the increased patient flows under S&S options. However, clinicians expressed concern that the projected flows were worked out on children's procedures only, but practically grown up children's (GUCH) services would also be undertaken and these could stretch units beyond their capacity.
- When a number of referring paediatricians were surveyed about their referral patterns under the four options identified by S&S, they indicated that on the whole they would refer to the cardiac surgical centres assumed, even where this required a change in current referral behaviour – ***see table overleaf***.
- For example, 94% of referrers indicated complying with S&S assumptions under Option A and 44% suggested this would require a change in their referral pattern, while 97% of referrer under Option C would refer to the assumed centres and 59% of them would require a change in their referral pattern to do so for this option.
- The key factors identified by referring clinicians as determining their referral preference were: *Existing joint working relationships; Proximity of surgical cardiac centre; and Clinical outcomes*.
- When parents were asked to prioritise factors influencing choice of cardiac surgical centre, travel time was prioritised below factors such as: *Reputation of the centre; Recommendation from a GP or other healthcare professional; Availability of the surgical team and Previous experience of using the centre.*

# Overview of clinician, parent & general public feedback

## Referral behaviours and patient flows

✓ = majority parents/public agree with S&S assumptions	Postcode areas highlighted where parents & public prefer not to flow to S&S assumed centres					% of Referring clinicians who would refer to surgical centre assumed by S&S	% of Referring clinicians who will need to change referral patterns to align with options	Key factors identified by the referring clinicians as determining their referral preference	
	Option A	Option B	Option C	Option D					
Freeman, Newcastle	Leeds, Wakefield	Leeds, Wakefield, Doncaster & Sheffield	Leeds, Wakefield, Doncaster & Sheffield	N/A				<ul style="list-style-type: none"> <li>Existing joint working relationships (34%)</li> <li>Proximity of centre (28%)</li> <li>Clinical outcomes (15%)</li> <li>Personal professional relationship with the centre (14%)</li> <li>Historical (7%)</li> <li>Patient choice (1%)</li> </ul>	
Alder Hey, Liverpool	✓	✓	✓	✓	Option A	118 (94%)	Yes (44%)		
Glenfield, Leicester	Coventry	N/A	N/A	N/A	Option B	114 (96%)	Yes (50%)		
Birmingham	✓	✓	✓	✓	Option C	114 (97%)	Yes (59%)		
Bristol	✓	Reading	✓	✓	Option D	112 (93%)	Yes (49%)		
London x 2	✓	✓	✓	✓					
S/hampton	N/A	Brighton	N/A	N/A					
Leeds	N/A	N/A	N/A	Nottingham	Less disruptive				More disruptive

### Key factors identified by parents influencing choice of cardiac surgical centre

1. Reputation of centre
2. Recommendation from a GP or other healthcare professional
3. The surgical team available
4. Previous experience of using centre

*These factors were the ones most commonly identified as influencing their current centre and preferred centre under the different S&S options.*

### Key factors identified by the general public as influencing choice of cardiac surgical centre

1. Ability to see the same team of doctors and nurses each time
2. The hospital has a good reputation
3. Availability and price of car parking facilities
4. Ability to spend enough time with doctors and nurses
5. The hospital has good facilities
6. Part of a network, where you could go to a local hospital for outpatient appointments and a specialist centre for surgery

- 153 referring clinicians responded to a survey; of these 105 out of 122 (86%) who reported their role identified that they were not a paediatrician with expertise in cardiology.
- 46% of respondents (70) indicated that their average number of referrals per annum to paediatric cardiac surgical services was in the range of 0 – 5.
- In terms of mode of travel, 142 parents (83%) indicated that they had access to their own car for either all or part of their journey.
- Most general public focus group participants indicated that they would travel by car; with less than 10% indicated that they would use public transport to access one of the current centres if travelling for surgery.

## ***Clinical, parent & public feedback***

### **Referrals/patient flows cont'd**

- The general public highlighted: *Ability to see the same team of doctors and nurses; Hospital having a good reputation and Availability and price of car parking facilities*, as the factors that mattered to them.
- When a number of these findings were discussed at the three clinician focus groups that were held to 'sense check' primarily the clinical workstream findings, but also feedback from parents and the public, there were helpful comments from participants. In particular there were some views around the referrer survey results and factors to consider in interpreting the findings (table opposite).
- Overall the findings on referrals/patient flows generated good discussion in the clinical focus groups and led onto specific dialogue around issues identified by participants as important for debate, such as: managed clinical networks, the role of outreach clinics, cardiology centres (learning from the experiences of Manchester and Cardiff), retrieval and impact of S&S options on other services.

### **Clinical focus group questions/comments to consider in interpreting findings:**

- The response rate for the referrer survey was queried and that too much reliance may be placed upon it. The response rate was in the range of 37% to 40%. In our experience this is positive for a postal survey where no reminders have been sent and it provides a good 'snap shot' of referral behaviours.
- The focus on referring paediatricians for this survey was also discussed; and whilst it was understood, there was a view that input from referring obstetricians would have been helpful, as increasingly cardiac problems are being detected at the antenatal stage.
- It was indicated that referral behaviours may vary dependent on the type of referrer and the nature of case presenting e.g. co-morbidities. Also the impact of patient choice and clinical outcomes on referral behaviour and commissioning behaviours was highlighted.
- It was highlighted that experiences/feedback can vary by what stage of the patient journey individuals/families are at.
- There was some surprise that travel did not feature as more of an issue with parents. The majority of parents surveyed indicated that they travelled to centres by their own private transport. Most members of the public (representing a range of socio economic backgrounds) who participated in focus groups also indicated that they would plan to travel to centres by car. Feedback suggested that when travelling with a child or children for a hospital appointment it was preferable (where possible) to use private transport.

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## ***Clinical, parent & public feedback***

### **Travel times**

- Given the smaller number of centres proposed under the four S&S options, as expected a lower proportion of parents estimated that they would be within one hour of a paediatric cardiac surgical centre under Options A – D when compared to current travel arrangements.
- The majority of parents indicated travelling to centres by their own private transport. Most members of the public who participated in focus groups also indicated that ideally they would travel to centres by car.
- Less than 10% of focus group participants indicated that they would use public transport if accessing surgery, although nearly 20% stated that they might use public transport when travelling for an outpatient appointment – ***see table on slide 5.***
- In addition, members of the general public identified some ideas on how S&S options could be made more amenable and accessible, and these are summarised in the table opposite.

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### **Members of the general public identified how S&S options could be made more amenable and accessible under two themes of travel and information issues:**

#### *Travel Issues:*

- Financial assistance with additional travel costs over and above distance to nearest hospital and help with car parking (e.g. no charge, reduced rates or vouchers).
- Affordable overnight accommodation; and an ambulance or personal transport for those in very remote areas.

#### *Information Issues:*

- More information on travel times, distances and routes to centres; as well as in terms of specialists available, waiting times and facilities to enable decision making.
  - Flexible visiting times, ideally to fit with off-peak public transport; and accessible information and better co-ordination of public transport options.
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## ***Clinical, parent & public feedback***

### **Managed clinical networks**

- Clinicians at the centres mainly stated that currently ‘informal’ networks were in existence or elements of networks as envisaged by S&S.
- Referrers, as well as clinicians at the cardiac centres were supportive of the concept of clinical networks. They however identified varying levels of existing network development and suggested that the most well developed current networks were those related to centres that were more likely not to continue to be cardiac surgical units under S&S options - ***see table overleaf.***
- Clinical discussions did identify challenges with networks but also helpfully a range of enabling actions such as alignment with other networks, protocols being in place and communication channels being supported - ***see table overleaf.***
- In terms of managed clinical networks, while both parents and the general public were positive about the concept of these, there was more of a preference from parents to access all care at a specialist centre. This was somewhat in contrast to members of the general public who indicated it was more desirable to have care managed locally rather than travelling to a specialist centre all the time for all aspects of care.

### **Managed clinical networks - *see table overleaf***

#### **Views from parents**

- Parents were asked whether they would prefer to have outpatient appointments and ongoing management of care at their preferred centre under each of the options or at a more local centre. A slightly higher proportion wished to access all care at a specialist centre.
- 48 – 53% of parents across the four options indicated they would prefer to have all care at a specialist centre whereas 39 – 46% stated they would prefer to have outpatient appointments and ongoing management of care at a local hospital.

*“It would depend if you would be seeing the same surgeon, if you could see the same surgeon or cardiologist as at the specialist centre then I would go to a local hospital, otherwise I would probably just travel.” (Quote from parent)*

*“I would worry a lot about continuity of care and transfer of patient notes.” (Quote from parent)*

#### **Views from members of the general public**

- Overall networks were considered a good idea and members of the public felt that it was more desirable to have care managed locally rather than travelling to a specialist centre on several occasions.

#### **Factors to consider to help support networks**

- Members of the general public identified three key themes to help support the successful functioning of clinical networks, as follows:
  1. Continuity of care within the team of health professionals.
  2. Continuous and strong communication between the specialist centre and local care provider, supported by technology (e.g. email, video-conferencing).
  3. Ability to meet the surgeon prior to an inpatient admission and ideally for one follow-up.



# Overview of clinician, parent & general public feedback

## Managed clinical networks

Under each of Options A - D, referring paediatricians indicated the most well developed network feature and the least well developed feature					Option A	Option B	Option C	Option D
	Option A	Option B	Option C	Option D	Parents indicating preferring to have outpatient appointments &/or ongoing management of care at a local hospital by Options A – D:			
<i>Most developed network feature</i>	Development of the role of PECs (60%)	Development of the role of PECs (61%)	The delivery of non-interventional care in local care settings (51%)	The delivery of non-interventional care in local care settings (67%)	56 (44%)	51 (43%)	52 (46%)	52 (39%)
<i>Least developed network feature</i>	Formal protocols agreed by the surgical centre and local services (39%)	Formal protocols agreed by the surgical centre and local services (40%)	Formal protocols agreed by the surgical centre and local services (32%) and strengthened cardiac liaison teams (32%)	Strengthened cardiac liaison teams (39%)	Parents indicating preferring to have all care at the specialist centre by Options A – D:			
					67 (53%)	59 (50%)	54 (48%)	70 (53%)

• Respondents to the referrer survey, indicated that of the existing 11 centres which S&S identified, Leicester, Southampton, Bristol and Leeds appeared to have the most well developed network features, as envisaged by S&S.

Key challenges	Enabling factors - referrer survey/ focus groups	Key challenges	Enabling factors - referrer survey/ focus groups
Links/alignment to other services	<ul style="list-style-type: none"> <li>• Closer links between ante-natal, neonatal and adult cardiac services.</li> <li>• Improve transport arrangements through development/use of a critical care transport service.</li> </ul>	Shared protocols and pathways	<ul style="list-style-type: none"> <li>• Shared cardiac protocols.</li> <li>• Cross-network protocols/working arrangements.</li> </ul>
Capacity for increased workload	<ul style="list-style-type: none"> <li>• Increased capacity and space at future centres under selected option for medical and surgical cases and critical care.</li> <li>• Formal service level agreements in place.</li> </ul>	Role of local paediatricians	<ul style="list-style-type: none"> <li>• Increasing the number of PECs in local hospitals and appropriate support for nursing staff, with training and funding in place.</li> </ul>
Level of outreach clinics	<ul style="list-style-type: none"> <li>• Increased capacity at outreach clinics and greater number of clinics.</li> <li>• Greater consistency in equipment and staff availability at clinics.</li> </ul>	Commissioning and funding	<ul style="list-style-type: none"> <li>• Robust commissioning arrangements in place and funding to support effective networks.</li> </ul>
		Communications	<ul style="list-style-type: none"> <li>• Telemedicine with real time video imaging</li> <li>• Systems to support confidential sharing of patient notes across networks, as required.</li> </ul>
		Transition planning	<ul style="list-style-type: none"> <li>• To support effective network operation and give all key stakeholders confidence that their views were being considered, a desire for transition planning was highlighted and sooner than later.</li> </ul>

Source: PwC survey of referrers & parents, clinician interviews and focus groups with clinicians & general public

## ***Clinical, parent & public feedback***

### **Managed clinical networks cont'd**

- Discussion of these findings in the clinician focus groups flagged that parents view's on networks were likely influenced by the fact that a number of children requiring cardiac surgery have several co-morbidities requiring specialist input and so the preference for parents would be to visit a centre that could address all their children's needs.
- Participants at the focus groups suggested that clarity was needed on how networks would be set up, and how they would function. Specifically they discussed the following, which overlaps with some of the feedback from the clinician interviews:
  - The need for transition plans to be developed and quickly operationalised once a preferred S&S option has been chosen. It was also highlighted that these should cover a range of factors including training at paediatrician and nursing level as well as 'step down' care.
  - Aligning the cardiac networks to other existing networks, such as those for foetal/obstetric services, neonatal services and grown up children in order that a holistic, child centred approach is taken to ensure that children with co-morbidities receive all services in a single centre or a small number of hospitals working together.
  - Clarity on how the network models would deal with cross-over between, for example London and the Midlands and specific postcode areas where clinicians indicated that there were issues or uncertainties.
  - The need for IT systems to support network functioning, particularly to promote good communication within and between centres and also to allow the confidential sharing of patient notes by professionals working across each network.
  - Clear guidance for referrers on how the system should operate in their area, supported by robust commissioning arrangements. Also clinical protocols developed by networks to reduce variation.
  - Funding arrangements for patient care to incentivise network functioning by being attractive to both the centres and peripheral units.
- Other themes that were highlighted by clinicians as needing further consideration in the spirit of supporting the principles of S&S were: *The role of the cardiology centre; Retrieval; Promoting positive clinical outcomes; Impact of S&S options on other services and Consistency in outreach clinics as well as support for community paediatricians and nursing staff.*

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## ***Clinical, parent & public feedback***

### **Summary**

- Overall, the clinical, parent and public workstreams brought together a range of viewpoints but all were united in wanting to promote high quality services for children's heart surgery as well as providing constructive feedback on patients flows/referrals and managed clinical networks.
- On the whole the feedback was provided in the spirit of wanting the decision making process on S&S options to be appropriately informed of key facts and issues; and also for thought and consideration to be given to any associated transition and implementation plans.

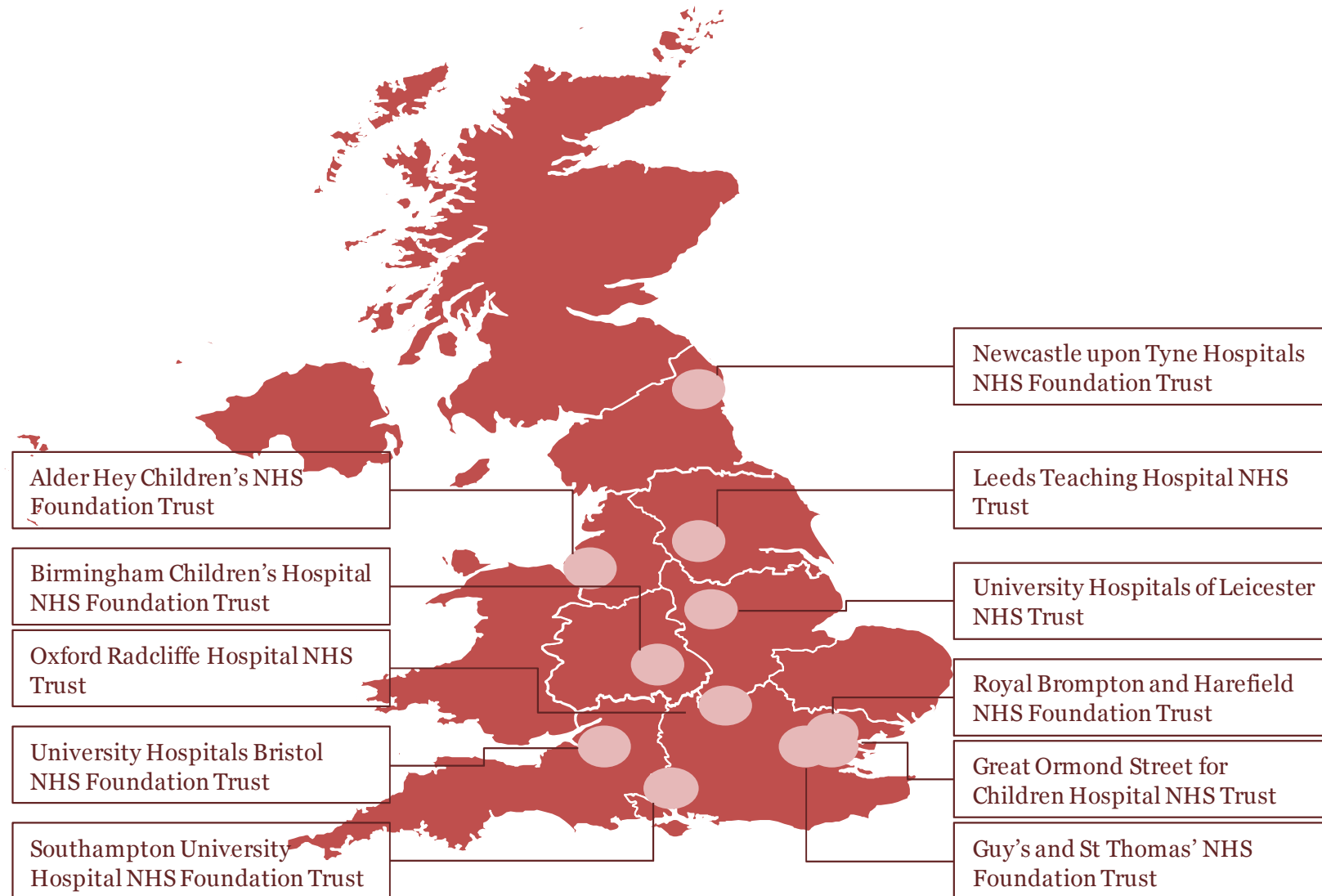
### ***Acknowledgements***

- The PwC team is grateful to all those who have contributed to this project. In particular, we appreciate the contributions from parents of service users of paediatric cardiac surgical services, the general public and clinicians who have given up their valuable time in order to participate in surveys, interviews and focus groups.

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# *Appendix*

## ***Safe and Sustainable Review - 11 centres focused upon...***



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## ***Safe and Sustainable Review - Options A, B, C & D and associated centres...***

### **Option A:**

#### ***Seven surgical centres at:***

1. Freeman Hospital, Newcastle (NUTH)
2. Alder Hey Children's Hospital, Liverpool (AH)
3. Glenfield Hospital, Leicester (UHL)
4. Birmingham Children's Hospital (BCH)
5. Bristol Royal Hospital for Children (UHB)
6. Evelina Children's Hospital, London (GSTT)
7. Great Ormond Street Hospital for Children, London (GOSH)

### **Option C:**

#### ***Six surgical centres at:***

1. Freeman Hospital, Newcastle (NUTH)
2. Alder Hey Children's Hospital, Liverpool (AH)
3. Birmingham Children's Hospital (BCH)
4. Bristol Royal Hospital for Children (UHB)
5. Evelina Children's Hospital, London (GSTT)
6. Great Ormond Street Hospital for Children, London (GOSH)

### **Option B:**

#### ***Seven surgical centres at:***

1. Freeman Hospital, Newcastle (NUTH)
2. Alder Hey Children's Hospital, Liverpool (AH)
3. Birmingham Children's Hospital (BCH)
4. Bristol Royal Hospital for Children (UHB)
5. Southampton General Hospital (SUH)
6. Evelina Children's Hospital, London (GSTT)
7. Great Ormond Street Hospital for Children, London (GOSH)

### **Option D:**

#### ***Six surgical centres at:***

1. Leeds General Infirmary (LTH)
  2. Alder Hey Children's Hospital, Liverpool (AH)
  3. Birmingham Children's Hospital (BCH)
  4. Bristol Royal Hospital for Children (UHB)
  5. Evelina Children's Hospital, London (GSTT)
  6. Great Ormond Street Hospital for Children, London (GOSH)
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