

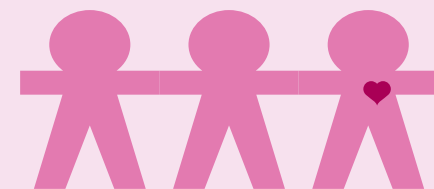
Claire Stevens



*“now you’re out!”*

The Summary Report of the Survey  
of the Current Perceptions of Families on  
Services After Leaving the Paediatric Cardiac Unit.

August 2003



**children's heart**  
FEDERATION

## Now You're Out

Taking your new family member home at last.....if your new baby was rushed into hospital with a heart problem, this is the occasion you have been awaiting for several months.

Or maybe your older child had been on the list for surgery - weeks, months or even years of waiting, followed by arrangements for while you are in, tests, surgery, intensive care, and recovery.

So the moment has come. You are being discharged.

Packing clothes, cards and presents into a bag only big enough for the clothes, you just have to wait to speak to the nurse to get the medication, and then you are off. You wait patiently (or not) and finally nurse with paper bag and other pieces of paper arrives.

You are given the medicines, told what to do with them, follow-up appointment date for outpatients perhaps at your local hospital, to look out for inflammation on your child's scar, a telephone number to contact, a letter that has been sent to your GP, maybe feeding instructions. You may have a few questions - can he sleep on his front, can she go on holiday to France, where is a staff member you want to thank or to say goodbye to.

So now you are home - the medicines go into the fridge - or not. Are you sure where they should be kept? Someone has helpfully run a bath for child to play with new water-toy - should you keep the chest dry, or was it just clean? Your child won't eat and won't settle, a slight fever maybe? Should you speak to the hospital, your GP, health visitor, community nurse or just go straight to A&E?

While the heart services for children were being reviewed, many parents told the Children's Heart Federation (CHF) that they felt lost and alone after their children came out of hospital. They reported difficulty with feeding, getting medication, unhelpful community health services, lack of knowledge and understanding at their local hospitals. They feared that they had insufficient information to be responsible for their child's care.

To see what kind of problems parents have, and to suggest ways in which they should be remedied, we have carried out a survey of parents whose child had recently come out of the Paediatric Cardiac Unit (PCU) after treatment for a heart condition.



What we found broadly is that practice is different depending on which children's heart hospital you attend, and that the hospitals are often seen to be good at one thing, and really inadequate at another.

This paper shows our findings - first the question that we asked, then some quotes from parents about their experiences, and then the performance of the best and worst hospitals.

Following the review of the services (PCCS - Paediatric and Congenital Cardiac Standards), PCUs have been asked to co-ordinate services as a region:

London:           Great Ormond Street Hospital (GOSH)  
                      Guy's  
                      Royal Brompton and Harefield (RBH)

Midlands:        Birmingham  
                      Glenfield (Leicester)

South:            Bristol  
                      John Radcliffe (Oxford)  
                      Southampton

The PCUs will need to make sure that there are services in the local community for our heart children and that the way in which your child receives medical care is understood by all those involved.

### **Recommendations**

The two broad recommendations of this report are:

- Full information tailored to the family's needs, (written and verbal) is provided on caring for each child before discharge from the PCU.
- Specialised support is made available at community level.

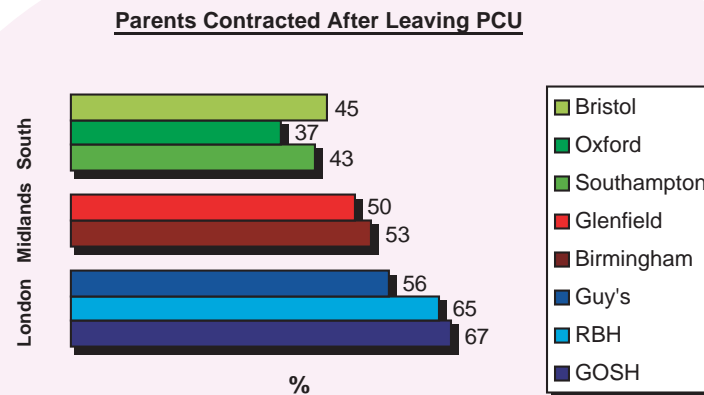
If you would like to read the full report it is available from our office or can be accessed from our website:

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**SE11 5SW**  
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**www.childrens-heart-fed.org.uk**



## Were you contacted by a healthcare professional post discharge? (Q6.)

This is in line with PCCS 7.3 “Following discharge, there should be a follow-up telephone call by the liaison service to the patient/parents within 2 working days and ongoing contact at agreed intervals, as noted in the patient held record.”



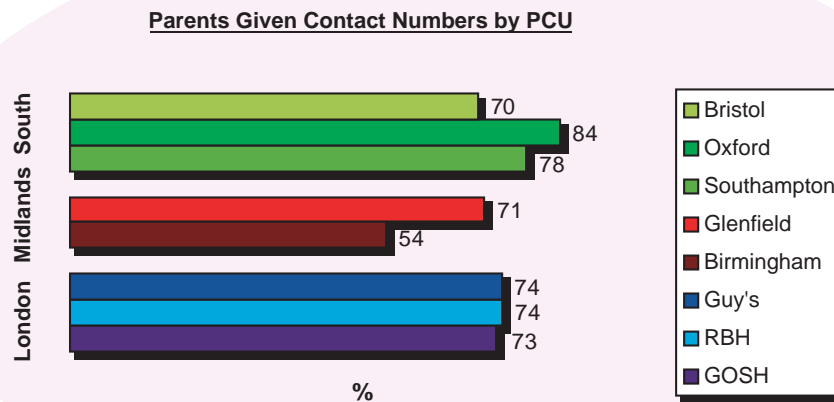
*“It was such a relief to hear from the cardiac liaison nurse, we didn’t feel so alone and could ask questions.”*

### CHF Recommendations:

1. Cardiac liaison service to telephone family within 2 working days.

## What contact numbers were you given by the hospital? (Q7.)

This is in line with PCCS 7.1 “An appropriate, integrated and needs-led discharge plan and shared care programme should be agreed with the patient/parents and the community team before discharge. Copies of the plan including 24 hour contact numbers should be given to the community team (including, where relevant, the palliative care team) and the patients/parents.”



*“If only I had known about the support group ..... it would have made all the difference talking to someone who had been through it all.”*

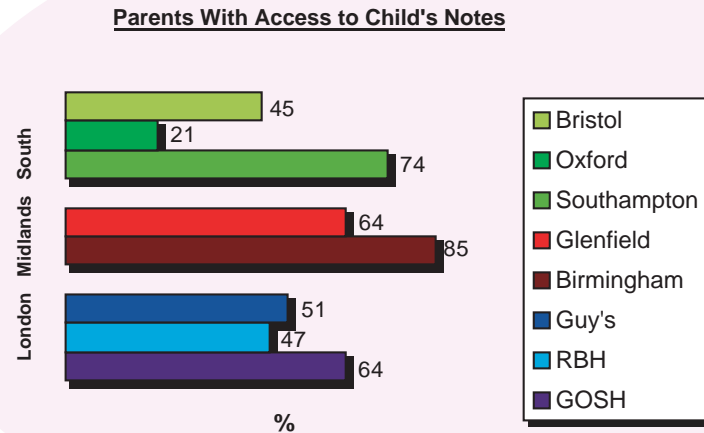
### CHF Recommendations:

2. Parents are given a named contact and a telephone number of the ward where child was treated.
3. Parents are given a named contact and a telephone number of cardiac liaison nurse (CLN), social worker/social services and are told in what circumstances contacts are available and at what time they can be contacted.
4. At least one contact number is covered 24 hours a day, seven days a week.
5. Parents are given contact details of CHF and any other relevant support group.
6. The role of the hospital social worker is explained to parents.
7. Parents to be directed to support group literature.
8. Support group literature to be displayed prominently.
9. Support group literature to be updated and replaced regularly.



## Were you given your child's records? (Q8.)

This is in line with PCCS 7.4 "Patients/parents should hold their own records in order to ensure that adequate information is available at each stage of the clinical network. These records should be updated at each stage of the process and taken away by the parent/patient."



### CHF Recommendations:

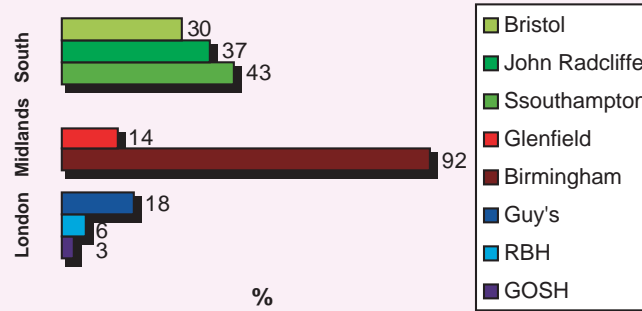
10. Parents have access to child's records.
11. Records updated regularly by healthcare professional.
12. Records written in accessible language.
13. Where appropriate, parents have information contained in records explained to them.

## What written information on the care of your child at home? (Q9.)

This is in line with PCCS 4.1 “Information in accessible and appropriate formats, always orally and backed-up by written information, and with the option of accessing further information if required.”

*“I had to rely on the web for all my information.”*

**Received Written Information on Care of Child at Home from PCU**



*“When we got home we were tired and emotional and busy caring for our daughter, we just couldn't remember what the hospital told us.”*

### CHF Recommendations:

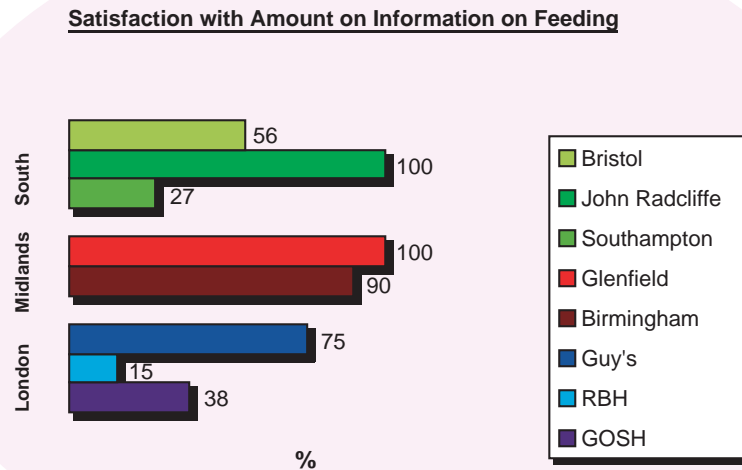
14. Parents are told information as well as given it in writing. It will follow that:
15. Parents are given guidance on sources of information.
16. Patient/parent information is reviewed and updated regularly.
17. Patients/parents are involved in the writing and reviewing of patient literature.
18. Patients have access to evidence based information which is balanced and unbiased.
19. Written material is checked for plain English.
20. Parents have access to a translator and a translation in their first language.
21. Parents have access to information, which is specific to their needs.
22. Parents are aware of what signs to look for which indicate problems with wound healing e.g. inflammation.
23. Parents are made aware of possibility of emotional change in children/babies after a hospital stay.
24. Parents are informed when child can resume “normal” activities (including bathing) and possible limitations.
25. Where a child has other health problems parents need to know which symptoms may be cardiac related.



## How satisfied were you with the information you received on feeding? (Q10.)

### CHF Recommendations:

26. Parents have access to a specialist health visitor, a feeding specialist or a nutritionist.
27. Parents are given training, support and information on feeding.
28. Parents are given contact name and telephone number of feeding specialist.
29. Where feeding is an issue, a follow-up appointment is made for family to see community feeding specialist.
30. Parents have access to information on all types of feeding including tube feeding and breast feeding.
31. Parents are involved in writing information on feeding.
32. Parents are given emotional support on feeding.



*"I was so worried as the other babies were so much bigger, but nobody told me how to help her feed better."*



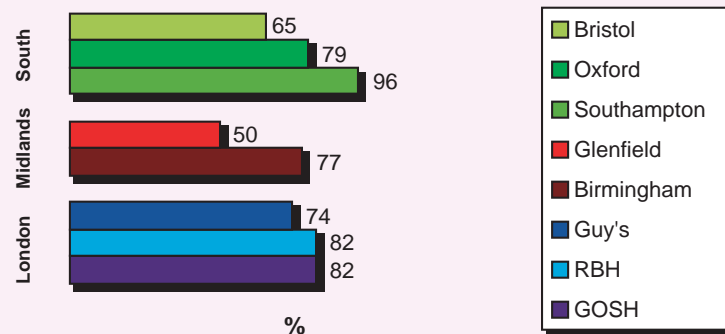
## Did you receive a dental card? (Q11.)

### CHF Recommendations:

33. Children at risk of bacterial endocarditis (BE) are given a card explaining the risks of BE.
34. Parents have access to written and verbal information explaining the importance of dental hygiene and the need for antibiotics prior to dental work and other forms of skin penetration.
35. It follows that cards are for the prevention of bacterial endocarditis and should be renamed accordingly.

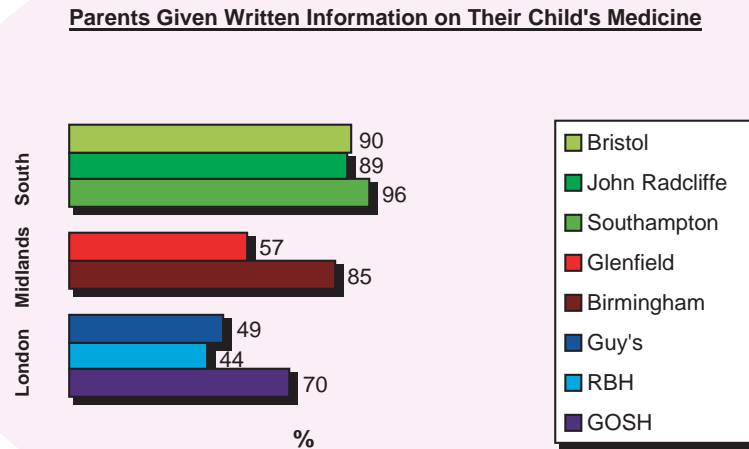


Parents who received a dental card



## What information on your child's medicine did you receive? (Q12.)

This is in line with PCCS Annex F - The Role of the Cardiac Liaison Service: "Parents should have a copy of the discharge plan, information about prescribed medication and be aware of how to contact the unit."



*"Our GP would not give us any more medicine, we ended up having to go back to our cardiologist and after many phone calls finally got it."*

*"I was so nervous, I had a bag full of drugs and didn't really know where to start. Being a single parent I felt so alone. I just needed someone to reassure me I was giving her the medicine correctly."*



## CHF Recommendations:

36. Patients/parents are given at least 14 days supply of medication (where appropriate).
37. Parents are given the contact details of a medicines helpline (where this exists) or contact details of the hospital pharmacist.
38. Every medication pack includes a PIL (patient information leaflet) relating to children.
39. Child's GP has an updated copy of the child's medication plan electronically on the day of discharge.
40. Hospital Pharmacist to ensure patient's medication is available at time of discharge by planning discharge from time of admission.
41. Community Pharmacist Care Plan, detailing all discharge medication is sent on the day of discharge.
42. Information on medication is available to all care teams.
43. Each care team is informed of changes to medication.
44. GP practice liaises with community pharmacy to ensure adequate stock levels and are familiar with use of drug in children.
45. Hospital pharmacist exercises responsibility for children with complex medication needs by speaking to parents at discharge and to family's community pharmacist.
46. Parents and children (where possible) are involved in the medication process from admission.
47. Parents are trained how to administer medication by nurse/pharmacist/pharmacy technician.
48. Parents are given a dosage chart to record when and how much medication child has been given.
49. When brand names or formulations of medication are changed it is explained to children (where appropriate) and parents that the medication itself remains the same only that it is produced by another manufacturer.
50. Patients and parents are made aware of effects of medication on behaviour and physical state e.g. diuretics can cause bed wetting.

*"We never realised what the medicine would do to him, if only we knew we wouldn't have worried so much."*

*"The chemist had never come across a child having this medicine and asked a lot of questions."*



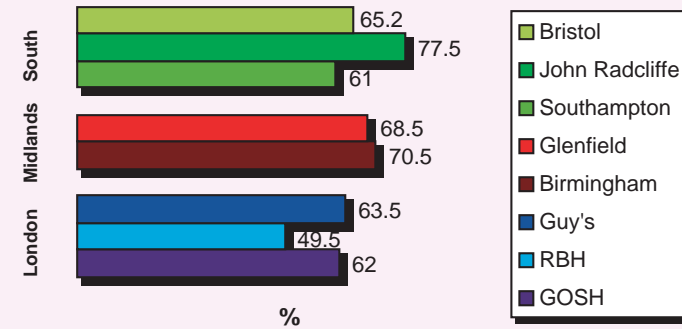
## Parents Said:

They were not given enough written information on:

- Feeding
  - Medication
  - Care of child at home
- 
- ✓ They do not have enough support from GP/health visitor.
  - ✓ They were not told about support groups, social services.
  - ✓ They had difficulties obtaining prescriptions (25%).
  - ✓ They did not have their child's notes (53%).
  - ✓ Communication between PCU and primary and secondary services was inadequate.
  - ✓ They feel isolated and alone after leaving the PCU.

*"We were left to fend for ourselves with a baby just out of surgery."*

### Average Scores By PCU



### Average Scores By Region

