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NATIONAL SURVEY OF PATIENT ADVICE AND LIAISON SERVICES (PALS) IN ENGLAND: CHILDREN, YOUNG PEOPLE AND PARENTS' ACCESS TO AND USE OF PALS

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EXECUTIVE SUMMARY

Since April 2002, all NHS Trusts and Primary Care Trusts (PCTs) in England have been expected to establish a Patient Advice and Liaison Service (PALS). PALS have been set up to enable patients and the public to access information and raise issues they are concerned about with their Trust. Together with the development of an Independent Complaints Advocacy Service (ICAS), PALS form part of a new system of user involvement in the NHS introduced by the NHS Plan (Department of Health, 2000).

PALS are intended to serve all, including 'vulnerable' and 'hard to reach sections of the community' (Department of Health, 2002). In this research we surveyed PALS in NHS Trusts and PCTs in England to examine whether and, if so, how, access to and use of the service was being promoted to children, young people and parents. The survey included some reference to other groups (such as older people and ethnic minorities) in order to explore whether PALS were more or less inclusive of different sections of the community.

A final sample of 243 PALS based in PCTs (n=122), NHS Trusts (n=101), pan-PCT and NHS Trusts (n=15), and Children's Hospitals (n=5) was obtained. The key findings were:

- PALS have so far been developed as a generic service, with some efforts to promote the service to specific sections of the community.
- Where PALS have focused on potentially hard-to-reach groups, they have tended to concentrate most of all on older people and least of all on children.
- Training for PALS staff was more likely to include a focus on people with communication difficulties, ethnic minorities and older people, and least likely to focus on children, young people and parents.
- Respondents felt more positive about the PALS ability to deal with the concerns of older people and parents than they did children and people with learning difficulties; they were generally confident of the service's ability to deal with the concerns of users in general.
- Respondents suggested ways in which the service could be promoted to children, young people and parents. However, some also expressed concern about the adequacy of existing resources to support additional promotional work, meet any increase in demand and deal with the specific needs of particular groups.

The results of the survey raises issues about how the PALS can be made more inclusive of children and young people as users in their own right, as well as their parents. This will be explored in the latter stages of this study where their perspectives will be sought and used to produce guidelines for Trusts on involving these users.

The survey also highlights the importance of recording parents' use of PALS on behalf of children and young people, and any indirect use of PALS by children, young people and parents via proxy-PALS staff in Trusts. Finally, the survey has identified concerns about whether existing resources are adequate to target and facilitate the involvement of specific groups such as children, young people and parents.

Background

The NHS Plan (Department of Health, 2000) set out a ten-year framework to modernise England's health service. One of the aims of the Plan was to enable patients and the public to have a greater say in the NHS. Patient Advice and Liaison Services (PALS) were set up for this purpose, to enable patients and the public to access information and raise issues they are concerned about with their Trust. Together with the development of an Independent Complaints Advocacy Service (ICAS), PALS forms part of a new system of user involvement in the NHS. Funding of £10m was made available for PALS from 2001, and implementation began with the establishment of over 100 Pathfinder PALS. From April 2002, this funding was added to NHS baseline allocations with the expectation that it would be used for PALS.

The aims of PALS are to:

- help to resolve patients' concerns quickly and efficiently, and improve the outcome of care in the process;
- provide information on services available, support choice and help make contact with the NHS as easy as possible;
- act as the visible contact point for patients and the public to enable them to access easily the new system of user involvement;
- gather valuable information for Trusts on the issues raised by patients and the public, enabling them to identify where improvements in the quality of services are required;
- support staff training and cultural change.

In view of the move to devolved decision-making under *Shifting the Balance of Power* (http://www.doh.gov.uk/shiftingthebalance/index.htm), Trusts were not compelled to establish a PALS. However, an active PALS is one of the key capacity assumptions underpinning the Local Development Plans (LDPs). Strategic Health Authorities (SHAs) are responsible for the performance of Trusts and in particular monitoring Local Delivery Plans. A PALS National Development Group has been set up and the Department of Health is working with this group, SHAs and the Modernisation Agency to aim towards all Trusts establishing a PALS.

Although PALS are intended to serve 'everyone', including 'vulnerable' and 'hard to reach sections of the community' (Department of Health, 2002), the NHS Plan does not draw

attention to the particular needs of children and young people. It is a concern that PALS may be developed in ways which are less inclusive of children and young people compared to adult patients. As the Kennedy report (Bristol Royal Infirmary Report, 2001) has highlighted, there is a need for children, young people and their parents to be involved in and informed about decisions regarding their healthcare. The importance of services that are accessible to children and obtain children's own views is indicated by research showing that children's and adults' views about the same situations differ and thus adults cannot act as proxies for children's views (Alderson, 1993; Beresford, 1997). However, ensuring that children are able to use a generic service such as PALS and express their views requires consideration of the differing abilities and needs of children and young people, and the design of child-friendly services.

It is therefore important to establish whether and, if so, how children, young people and parents acting on behalf of a child are being enabled to participate through PALS. This information is also required to ensure that the service is developed in ways which enhance the involvement of this group of users.

The PALS National Development Group (NDG) is looking at sharing learning and best practice in PALS and providing solutions to problems identified. Evaluation of the Pathfinder PALS informed minimum core service standards and guidance, issued by the Department of Health in January 2002, but since then the NDG has drawn up revised standards and developed an evaluation framework which PALS can use to assess their performance (http://www.doh.gov.uk/patientadviceandliaisonservices/standards.htm). The group is now developing communication systems and networks to share information and best practice, and the information from this research will feed into this process.

Methods

A national survey of PALS in NHS Trusts and Primary Care Trusts (PCTs) in England was carried out in March/April/May 2003. The aim of the survey was to examine to what extent, and how, PALS had promoted children's, young people's and parents' access to and use of the service. The survey was carried out as the first stage of a wider study exploring whether and, if so, how PALS could be more inclusive of this potentially hard-to-reach group. PALS Officers were asked to complete a questionnaire on the topic, comprised of mainly closed response questions (see the Appendix for a copy of the questionnaire). Some of the questions

included reference to other groups (such as older patients and ethnic minorities) in order to allow us to explore whether PALS were more or less inclusive of these groups compared to children, young people and parents.

For the purposes of the survey, 'children' were defined as 'all patients and members of the public aged 0-11 (inclusive)'; 'young people' were defined as 'all patients and members of the public aged 12-18 (inclusive)'; 'parents' were defined as 'all parents (or guardians/carers) of children or young people who may use PALS on behalf of their sons or daughters'; and 'other adults' were defined as 'patients and carers aged 19 and above who are potential users of PALS for themselves or on behalf of other adults'.

A draft of the questionnaire was piloted with five PALS Officers from children's hospitals, acute hospitals and PCTs. Two other PALS Officers and members of the project's Steering Group also commented on the same draft. The questionnaire was revised in line with their feedback. It was given ethical approval by an MREC in March 2003.

An up-to-date list of all NHS Trusts and PCTs was compiled and entered on a database in March 2003 using relevant directories and web-based information. Ambulance Trusts were excluded because of the specific nature of their work, which would have required a separate questionnaire to be designed. Specialist Trusts which were known not to provide services for children and young people were also excluded.

Five hundred and forty-six packs containing the questionnaire were sent out to 243 NHS Trusts and 303 PCTs on 27 and 28 March 2003, together with a covering letter, information sheet, and pre-paid return envelope. The packs were addressed to 'The Senior PALS Officer', in the absence of an up-to-date national list of PALS Officers at the relevant Trusts. PALS Officers were asked to complete and return the questionnaire, together with any supporting information and documents, by 18 April (3 weeks). All the questionnaires were given a unique code to facilitate identification of non-respondents, who were sent a reminder pack on 17 April 2003 with a final 3-week deadline of 13 May 2003. These were jointly addressed to 'The Senior PALS Officer/Patient and Public Involvement Lead' in the light of responses indicating some Trusts had not yet established PALS or were in the process of so doing.
At this point in the research, the results of a Department of Health (DH) mapping exercise (Department of Health, 2003) were made available to the researchers. The DH list of (named)

PALS Officers and offices was then used to send a third and final reminder to 37 Trusts who had not responded *and* had a different address to that previously used by the researchers. An additional seven Trusts on the DH list who were not included in the original survey (as they were not identified from the directories we used) were also sent a questionnaire. This meant that the total number of Trusts included in the survey was 553.

An Access database was created to facilitate data input from the closed-response questionnaires. These data were then imported into SPSS for analysis. Responses to open-ended questions and unsolicited comments were flagged on the database but processed and analysed separately.

Results

Sample characteristics

Of the 553 questionnaires sent out, 320 were returned, including 77 from Trusts that declined to take part. The responses included 290 from single Trusts and 30 from PALS operating across multiple Trusts (individually these PALS covered between two and six Trusts, and collectively 79 Trusts). An overall total of 369 Trusts were represented by the 320 questionnaires returned, a response rate of 67 per cent.

The respondents have been divided into the following groups: *PCTs* (covering all single and jointly-run PALS in PCTs only); *NHS Trusts* (covering all other single and jointly-run PALS by NHS Trusts including acute hospitals, mental health and learning disability Trusts but excluding children's hospitals); *children's hospitals*; and *pan- PCT & NHS Trusts* (covering a mix of the first two groups, for example, a PALS service operated jointly by a PCT and an acute hospital Trust). The number of responses for the various groups is shown in Table 1.

Table 1: Number of responses by different types of Trusts

Type of Trust(s) served	Positive - completed	Negative - declined	Total responses
PCT(s)	122	45	167
NHS Trust(s)	101	30	131
Children's hospitals	5	0	5
Pan- PCT & NHS Trusts	15	2	17
Total	243	77	320 responses (369 Trusts) 67% response rate

Table 1 shows that the questionnaire was completed by similar numbers of PALS in PCTs (n=122) and NHS Trusts (n=101), and smaller numbers of pan- PCT & NHS Trusts (n=15)

and children's hospitals (n=5). The PCT-based PALS include a larger number of joint PALS (n=11 covering a total of 25 Trusts) than the NHS Trusts group (n=1 joint PALS covering two Trusts). These 243 valid responses comprised the final sample of PALS upon which the analysis was based. Only 12 per cent (n=30) of these respondents indicated that they would be unwilling to help with the latter stages of the study.

Seventy-seven of the 320 respondents returned the questionnaire without completing it for the following reasons: the PALS was not yet established or there was no PALS officer in post (n=31); the PALS had only recently been set up (n=21); the Trust did not provide services, or only a limited range of services, for children and young people (n=16); and other reasons (n=10). Trusts that did not provide services for children and young people included those that provided services for adults and older people with mental health problems and learning difficulties. However, in a few cases the validity of this claim was questionable as respondents appeared to exclude children and young people treated in general practice or accident and emergency departments, for example. A breakdown by the type of Trusts served is shown in Table 2. Almost half (n=20, 44 per cent) of the PCTs that declined to take part did so because their PALS was not operational at the time of the survey, compared with nearly a third (n=9, 30 per cent) of the NHS Trusts that declined for this reason.

Table 2: Breakdown of reasons for PALS not completing the questionnaire

Type of Trust(s) served	No PALS/ PALS officer	Only recently established	Trust does not serve C or YP	Other reasons	Total
	n=	n=	n=	n=	n=
PCT(s)	20	17	1	7	45
NHS Trust(s)	9	4	13	4	30
Children's hospitals	0	0	0	0	0
Pan-PCT & NHS Trusts	2	0	0	0	2
Total PALS	31	21	14	11	77

The following analysis is of the responses to the structured questions. However, 50 per cent (n=121) of respondents made further qualitative comments at the end of the questionnaire which are dealt with later in the report.

Establishment and staffing of PALS

PALS were found to be at different stages of development. As Table 3 shows, most of the PALS had become operational in 2002 (n=151, 62 per cent). One in five had been running

since 2001 (n=48, 20%) and some PALS had been very recently established in 2003 (n=29, 12 per cent). Respondents frequently commented that their service was in its infancy and still in the process of being developed.

Table 3: Year PALS became operational

Type of Trust(s) served	2001	2002	2003	N responses (%)
PCT(s)	12	81	22	115 (94%)
NHS Trust(s)	33	56	7	96 (95%)
Children's hospitals	1	4	0	5 (100%)
Pan-PCT & NHS Trusts	2	10	0	12 (80%)
Total PALS (%)	48 (20%)	151 (62%)	29 (12%)	228 (94%)

PALS were staffed by a mix of full- and part-time staff who dealt directly with patients and the public and who provided administrative support. Almost half the PALS had a minimum of one full-time member of staff who dealt directly with patients and the public (n=114, 47 per cent); a fifth of the sample had two full-time staff in this role. A quarter of PALS (n=61, 25 per cent) employed one part-time member of staff instead of or in addition to the above. Some respondents commented that staff in general (or 'PALS link workers') were encouraged to provide the service to patients (n=10), or that staffing included unpaid voluntary staff (n=10). A few also noted that PALS staff had other responsibilities.

Over two-fifths of all respondents (n=103, 42 per cent) did not feel that the staffing complement was adequate to run the service well. This was particularly the case for PALS in children's hospitals (n=3, 60 per cent), pan-PCT & NHS Trusts (n=8, 53 per cent) and NHS Trusts (n=51, 50 per cent). However, relatively fewer respondents from PALS in PCTs felt that their staffing levels were inadequate (n=41, 17 per cent). In their comments, respondents from pan-PCT & NHS Trusts suggested more staff were required to cover the multiple sites in their area and to provide administrative support. In NHS Trusts, respondents commented that more staff and administrative support were needed to cope with demand, cover multiple sites, do outreach work, and to provide cover for staff attending meetings or who were off work. In PCTs, it was suggested that more staff were needed because of service expansion, staff having multiple roles within and outwith PALS, to facilitate outreach and out-of hours provision, to develop the service further, and to provide cover when staff were out of the office or off work.

In addition, a fifth of all respondents (n=51, 21 per cent) were unsure about whether or not staffing levels were adequate, mainly because the service was still new and in the process of

being developed. Some were concerned that existing levels would not be adequate if demand for the service increased. Others commented that while staffing was adequate, it limited the extent to which staff could be proactive, do outreach work and cover all locations. As one respondent from a PCT commented, they have two part-time staff and 240 'outlets' in primary care to cover.

Location of PALS offices and opening hours

The main PALS offices were based in various locations, depending on the type of Trust. Three-quarters of PALS in PCTs (n=92, 75 per cent) were based at Trust headquarters; the remainder were based in a range of settings, including health centres/clinics (n=7, six per cent) and town centre offices (n=4, three per cent). PALS in NHS Trusts were located in hospitals at the main reception (n=47, 47 per cent) and other areas of the hospital such as administration departments (n=34, 34 per cent) and in the community (n=11, 11 per cent). Only five (five per cent) of the NHS Trusts were based at Trust headquarters.

As Table 4 shows, half the respondents (n=132, 54 per cent) reported that their main PALS office was based in a location visited by patients and the public, including all the children's hospitals (n=5, 100 per cent). However, only a third of PALS in PCTs (n=37, 30 per cent) were in places visited by patients and the public.

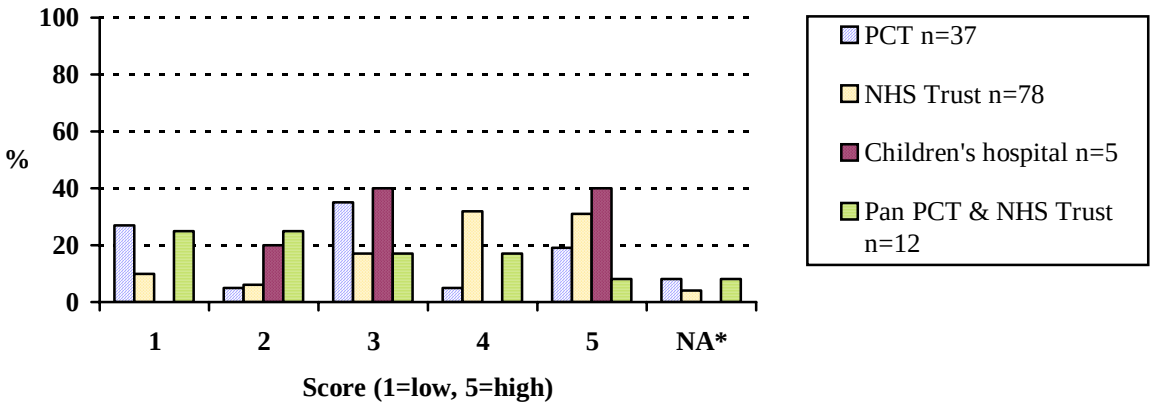
Table 4: Whether main PALS office is based in a location visited by patients and the public

Type of Trust(s) served	Yes (%)	No (%)	Total (%)
PCT(s)	37 (30%)	85 (70%)	122 (100%)
NHS Trust(s)	78 (77%)	23 (23%)	101 (100%)
Children's hospitals	5 (100%)	0	5 (100%)
Pan-PCT & NHS Trusts	12 (80%)	3 (20%)	15 (100%)
Total PALS	132 (54%)	111 (46%)	243 (100%)

If PALS were located in places visited by patients and the public, respondents were asked to rate on a five-point scale to what extent children, young people and parents were likely to observe the office during their visit (where 1= a very low likelihood and 5= a very high likelihood; NA = not answered). Figures 1-3 show that PALS were generally located in places that were more visible to parents than young people and children, although there was variation both within and across the four groups of Trusts. As Tables 5-7 show, on average, children's hospitals and NHS Trusts tended to outperform PCTs and pan-PCT & NHS Trusts.

It should be noted, however, that having a strong physical presence is one way of promoting access to the service – other methods include outreach work and advertisements.

Figure 1: Likelihood of parents observing the PALS office during their visit

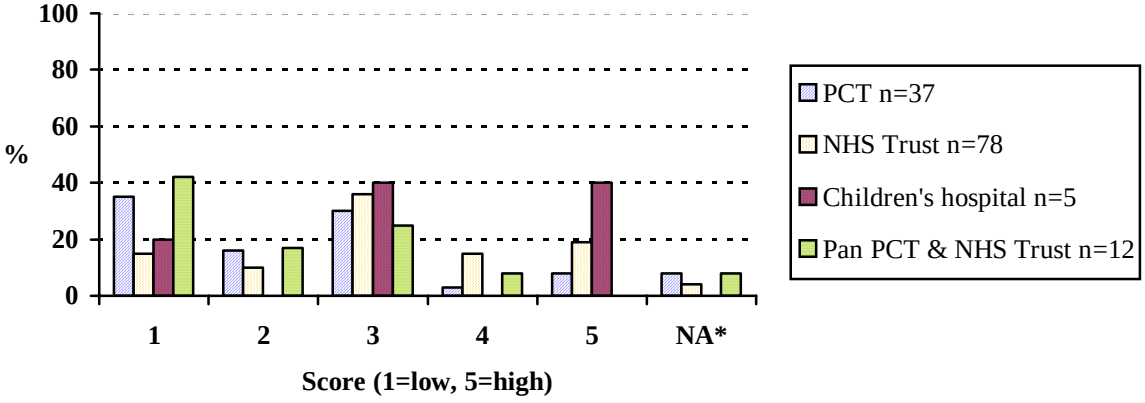


**NA = Not answered (included in n=)*

Table 5: Likelihood of parents observing the PALS office during their visit (mean scores)

Type of Trust(s) served	Mean score	N=
NHS Trust	3.69	75
Children's hospital	3.60	5
PCT	2.82	34
Pan-PCT & NHS Trusts	2.55	11
Overall	3.35	125

Figure 2: Likelihood of young people observing the PALS office during their visit

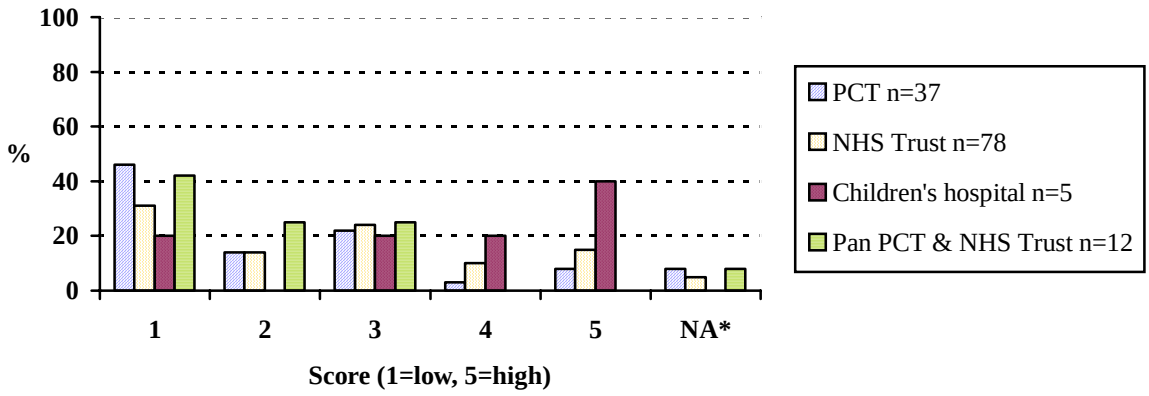


**NA = Not answered (included in n=)*

Table 6: Likelihood of young people observing the PALS office during their visit (mean scores)

Type of Trust(s) served	Mean score	N=
Children's hospital	3.40	5
NHS Trust	3.13	75
PCT	2.26	34
Pan-PCT & NHS Trusts	2.00	11
Overall	2.81	125

Figure 3: Likelihood of children observing the PALS office during their visit



**NA = Not answered (included in n=)*

Table 7: Likelihood of children observing the PALS office during their visit (mean scores)

Type of Trust(s) served	Mean score	N=
Children's hospital	3.60	5
NHS Trust	2.64	74
PCT	2.06	34
Pan-PCT & NHS Trusts	1.82	11
Overall	2.44	124

PALS were generally open to patients and the public in person during office hours on weekdays and by answer-phone at other times. Only seven PALS (three per cent) were open in person on a weekend. It was possible for patients to be seen outside of office hours at around half the PALS (n=137, 56 per cent). The majority of PALS would also visit patients on hospital wards (n=196, 81 per cent), at home (n=185, 76 per cent) and at school (n=149, 61 per cent), although this varied by type of Trust. For example, NHS Trusts were less inclined to visit schools than the other types of Trusts (n=47, 47 per cent compared with pan-PCT &

NHS Trusts n=11, 73 per cent; PCTs n=88, 72 per cent; and children's hospitals n= 3, 60 per cent). Many respondents indicated that PALS staff were also prepared to visit patients and the public in other locations such as general practices, health clinics, hospices, cafes, libraries, at work, CVS offices, CAB offices, and at any other safe and mutually convenient place.

Training

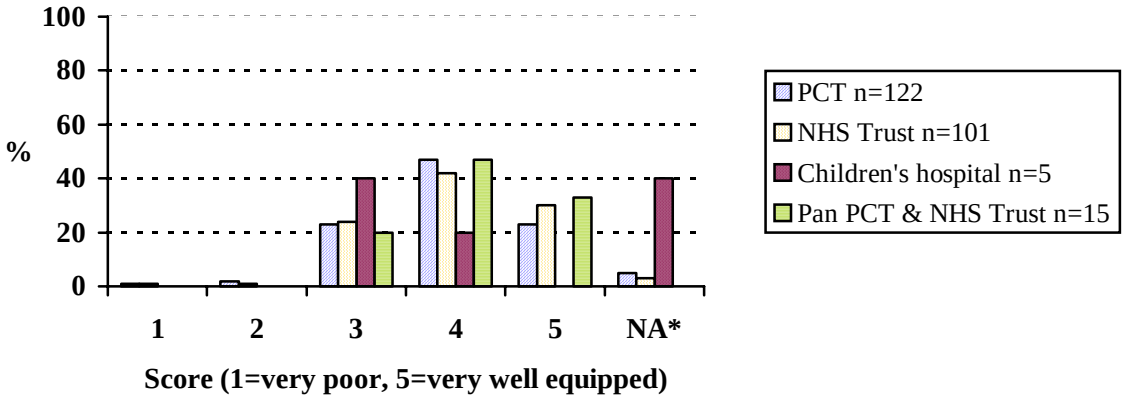
Nearly two-thirds of staff who dealt directly with patients and the public had been provided with training for this role (n=154, 63 per cent). However, this included only half the staff from PCTs (n=66, 54 per cent). Where training was provided, respondents were asked if it included a focus on children, young people, parents and other groups. Training was more likely to include a focus on people with communication difficulties, ethnic minorities and older people, and least likely to focus on children, young people and parents (see Table 8). Training of PALS staff at children's hospitals was the most likely to focus on children, young people and parents (n=3, 75 per cent for each group).

Table 8: Patient groups focussed on in staff training

Group	Number (%) of PALS providing training for group
People with communication difficulties	90 (58%)
Ethnic minorities	86 (56%)
Older people	84 (54%)
People with learning difficulties	68 (44%)
Parents	67 (43%)
Young people	45 (29%)
Children	38 (25%)

All respondents were asked to rate their subjective impression of how well equipped the PALS staff were for dealing with children, young people, parents and other groups. The results are shown in Figures 4-10 (where 1 = very poor and 5 = very well equipped). Tables 9-15 show related mean scores across the different types of Trusts and the mean scores for the overall sample are summarised in Table 16. The results indicate that respondents felt staff were relatively well equipped to deal with older people and parents, and least well equipped to deal with children and people with learning difficulties. Again, within the sample, children's hospitals had the best scores relating to children, young people and parents.

Figure 4: Extent to which PALS feel equipped to deal with older people

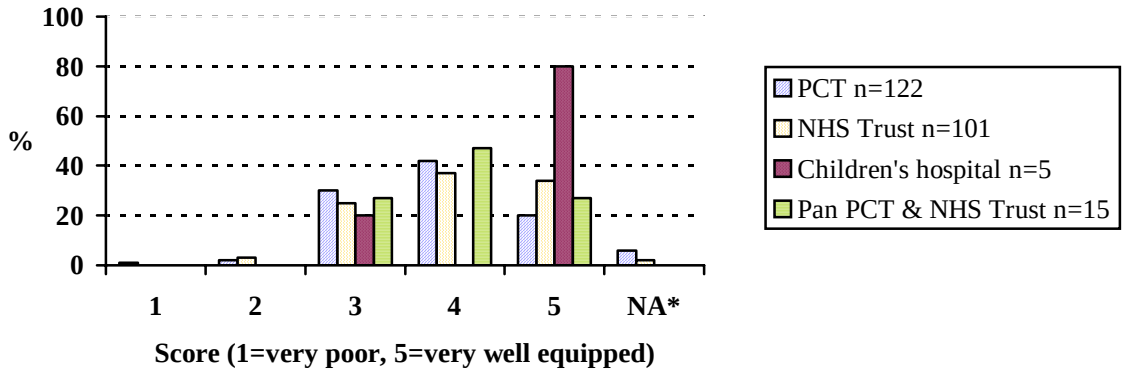


**NA = Not answered (included in n=)*

Table 9: Extent to which PALS feel equipped to deal with older people (mean scores)

Type of Trust(s) served	Mean score	N=
Pan-PCT & NHS Trusts	4.13	15
NHS Trust	4.01	98
PCT	3.94	116
Children's hospital	3.33	3
Overall	3.97	232

Figure 5: Extent to which PALS feel equipped to deal with parents

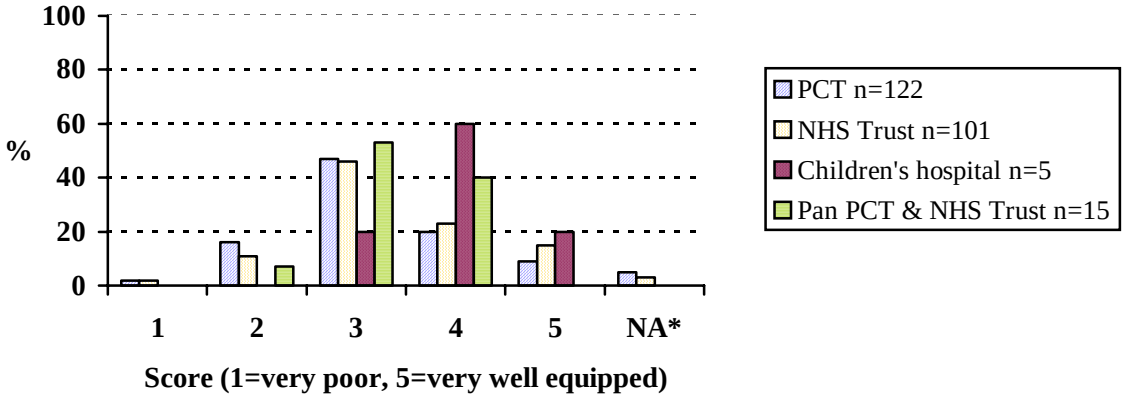


**NA = Not answered (included in n=)*

Table 10: Extent to which PALS feel equipped to deal with parents (mean scores)

Type of Trust(s) served	Mean score	N=
Children's hospital	4.60	5
NHS Trust	4.03	99
Pan-PCT & NHS Trusts	4.00	15
PCT	3.83	115
Overall	3.94	234

Figure 6: Extent to which PALS feel equipped to deal with young people

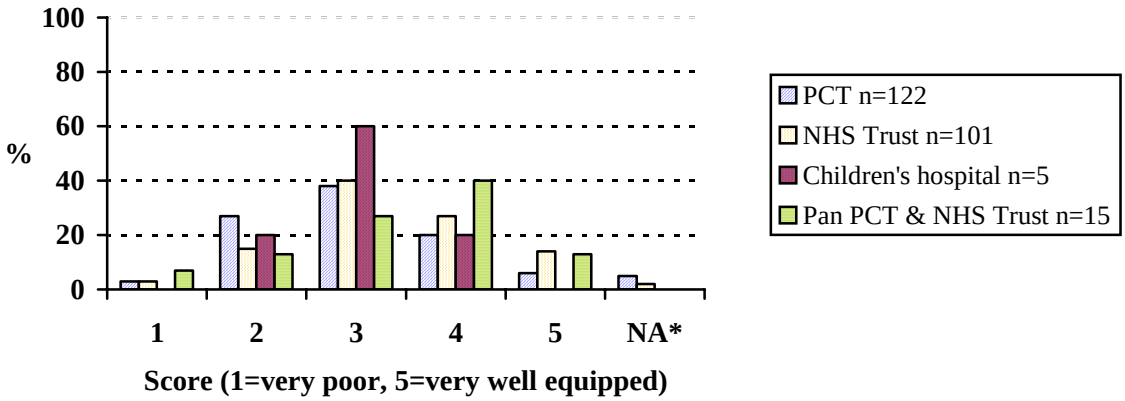


**NA = Not answered (included in n=)*

Table 11: Extent to which PALS feel equipped to deal with young people (mean scores)

Type of Trust(s) served	Mean score	N=
Children's hospital	4.00	5
NHS Trust	3.39	98
Pan-PCT & NHS Trusts	3.33	15
PCT	3.20	116
Overall	3.30	234

Figure 7: Extent to which PALS feel equipped to deal with people with communication difficulties

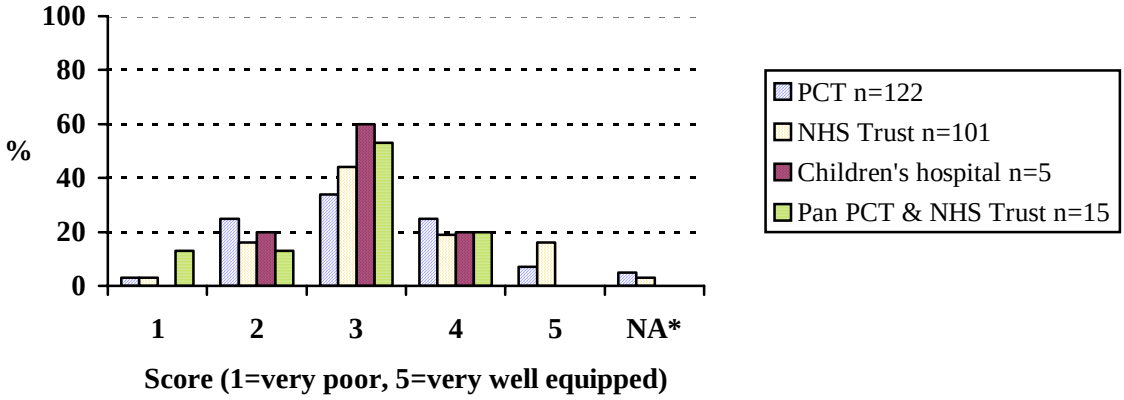


**NA = Not answered (included in n=)*

Table 12: Extent to which PALS feel equipped to deal with people with communication difficulties

Type of Trust(s) served	Mean score	N=
Pan-PCT & NHS Trusts	3.40	15
NHS Trust	3.34	99
PCT	3.00	116
Children's hospital	3.00	5
Overall	3.17	235

Figure 8: Extent to which PALS feel equipped to deal with ethnic minorities

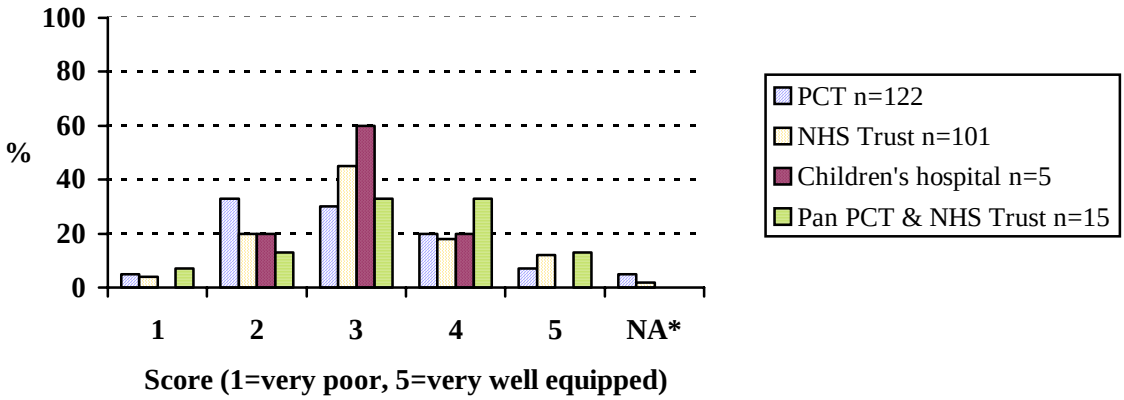


**NA = Not answered (included in n=)*

Table 13: Extent to which PALS feel equipped to deal with ethnic minorities (mean scores)

Type of Trust(s) served	Mean score	N=
NHS Trust	3.30	98
PCT	3.10	116
Children's hospital	3.00	5
Pan-PCT & NHS Trusts	2.80	15
Overall	3.16	234

Figure 9: Extent to which PALS feel equipped to deal with people with learning difficulties

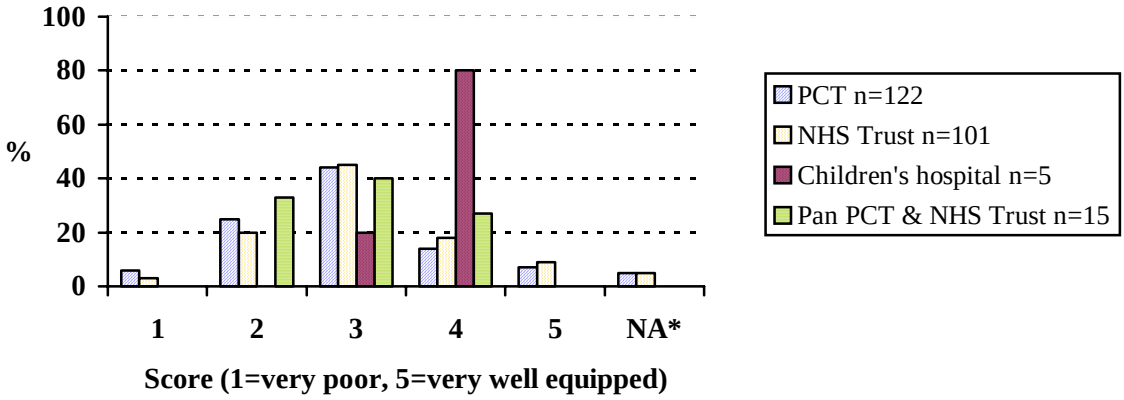


**NA = Not answered (included in n=)*

Table 14: Extent to which PALS feel equipped to deal with people with learning difficulties (mean scores)

Type of Trust(s) served	Mean score	N=
Pan-PCT & NHS Trusts	3.33	15
NHS Trust	3.14	99
Children's hospital	3.00	5
PCT	2.91	116
Overall	3.04	235

Figure 10: Extent to which PALS feel equipped to deal with children



**NA = Not answered (included in n=)*

Table 15: Extent to which PALS feel equipped to deal with children

Type of Trust(s) served	Mean score	N=
Children's hospital	3.80	5
NHS Trust	3.10	96
Pan-PCT & NHS Trusts	2.93	15
PCT	2.91	116
Overall	3.01	232

Table 16: Summary – extent to which PALS feel equipped to deal with various groups (mean score for all Trusts)

Rank	Group	Mean score (all Trusts)
1	Older people	3.97
2	Parents	3.94
3	Young people	3.30
4	People with communication difficulties	3.17
5	Ethnic minorities	3.16
6	People with learning difficulties	3.04
7	Children	3.01

Service specifications and monitoring

In general, policies and service specifications for PALS did not highlight the particular needs of children, young people, parents and other groups (or respondents were not sure if they did or not). However, as Table 17 shows, a quarter of PALS (n=57, 23 per cent) did have policies which highlighted the needs of ethnic minorities.

Table 17: PALS with policies and service specifications that highlight the needs of particular groups

Rank	Group	N= (%)
1	Ethnic minorities	57 (23%)
2	People with communication difficulties	52 (21%)
3	Older people	46 (19%)
4	People with learning difficulties	42 (17%)
5	Parents	29 (12%)
6	Young people	25 (10%)
7	Children	18 (7%)

Only nine per cent (n=23) of respondents submitted any documentation (leaflets, policy documents etc.) relating to their PALS.

Ninety-one per cent (n=222) of respondents indicated that their Trust did have a mechanism in place for reviewing the issues and concerns raised by patients and the public through PALS, and four per cent (n=10) did not. In most cases, the mechanisms consisted of monthly or quarterly reports to clinical governance, Trust boards and other groups, including service managers, complaints committees, patient and public involvement (PPI) steering groups, and risk management groups.

Links with PALS and other organisations

Eighty-seven per cent of respondents (n=211) indicated that there were between one and 41 other PALS in the geographical area covered by their Trust. In most cases up to four other PALS were in their area. Links with these groups were reported to be strong or very strong by 78 per cent of the sample (n=190). Almost all PALS (n=237, 98 per cent) also had links with PALS outside their geographical area, such as regional networks.

Respondents were asked if their PALS had links with organisations to which they could refer children, young people, parents and people from other groups. As Table 18 shows, PALS had relatively more links with organisations for the general public (for example, Citizens Advice Bureaus) and older people, and least with organisations for children, young people and parents. Children's hospitals generally had more links with organisations for the latter groups (children n=4, 80 per cent; young people n=4, 80 per cent; parents n=5, 100 per cent), although a similar proportion of pan-PCT & NHS Trusts reported having links with organisations for children (n=12, 80 per cent). In general, respondents indicated that PALS had moderate or low levels of referrals to the organisations with which they had links.

Table 18: Number of PALS with links with organisations for the groups concerned

Rank	Group	N= (%)
1	General public	217 (89%)
2	Older people	208 (86%)
3	People with learning difficulties	176 (72%)
4	People with communication difficulties	175 (72%)
5	Ethnic minorities	167 (69%)
6	Parents	151 (62%)
7	Young people	132 (54%)
8	Children	118 (49%)

Informing patients and the public about the role of PALS

Most PALS had used leaflets (n=225, 93 per cent), talks (n=225, 93 per cent) and posters (n=218, 90 per cent) to provide information to patients and the public on the service. Half the sample (n=131, 54 per cent) had also used a website for this purpose and more were planning to use this method too (n=80, 33 per cent). Other methods used included roadshows, public launches, newsletters, local press and radio, business cards, stands in shopping centres and digital displays.

Information leaflets were not generally designed and used to provide special (for example, age appropriate) information for different groups. However, as Table 19 shows, some groups were targeted more than others.

Table 19: Number (%) of PALS providing specialist information for groups

Rank	Talks	Leaflets	Posters
1	Older people 107 (44%)	Older people 68 (28%)	Older people 62 (26%)
2	Parents 73 (30%)	Parents 68 (28%)	Parents 60 (25%)
3	Ethnic minorities 69 (28%)	Ethnic minorities 60 (25%)	Ethnic minorities 48 (20%)
4	Communication difficulties 64 (26%)	Communication difficulties 43 (18%)	Young people 42 (17%)
5	Learning difficulties 52 (21%)	Learning difficulties 36 (15%)	Communication difficulties 31 (13%)
6	Young people 43 (18%)	Young people 36 (15%)	Learning difficulties 31 (13%)
7	Children 20 (8%)	Children 15 (6%)	Children 17 (7%)

Surprisingly, children's hospitals did not out-perform other types of Trusts in terms of providing leaflets designed for children and young people, as they did for parents (see Figures 11-13).

Figure 11: PALS providing leaflets designed for children

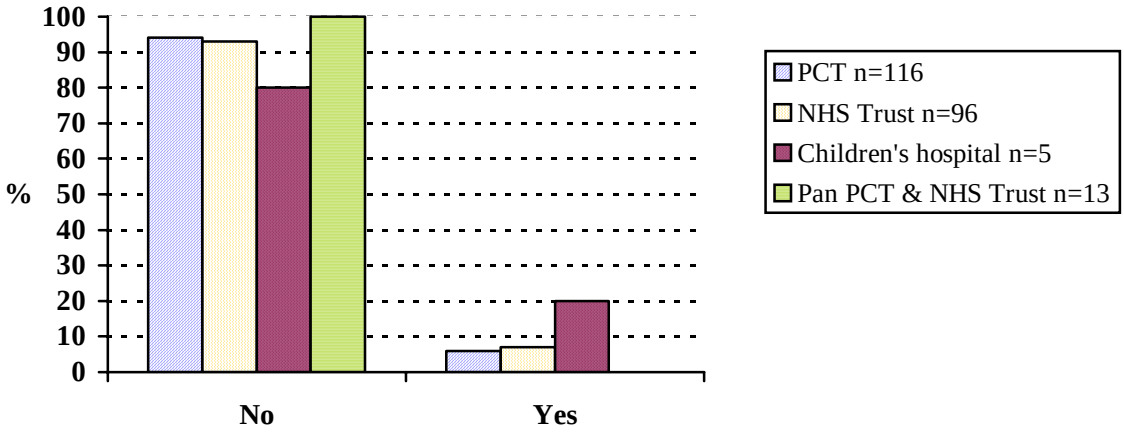


Figure 12: PALS providing leaflets designed for young people

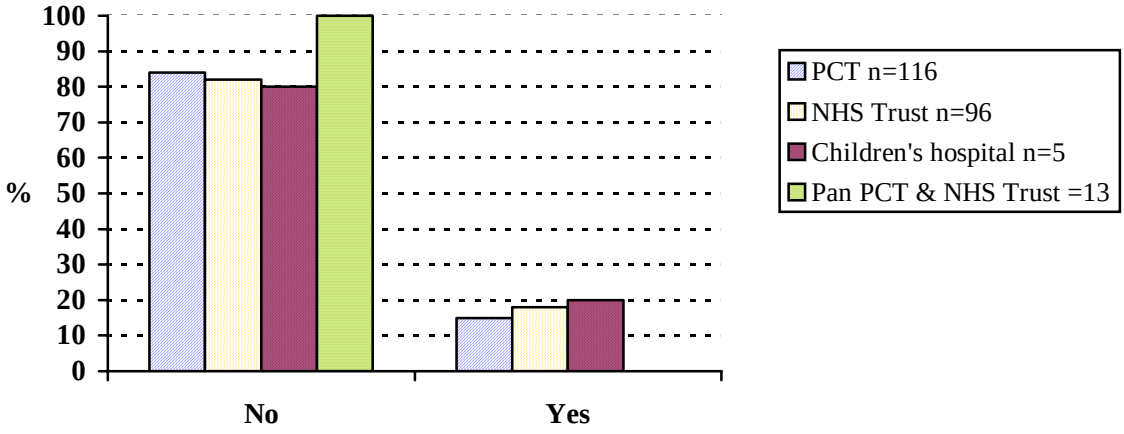
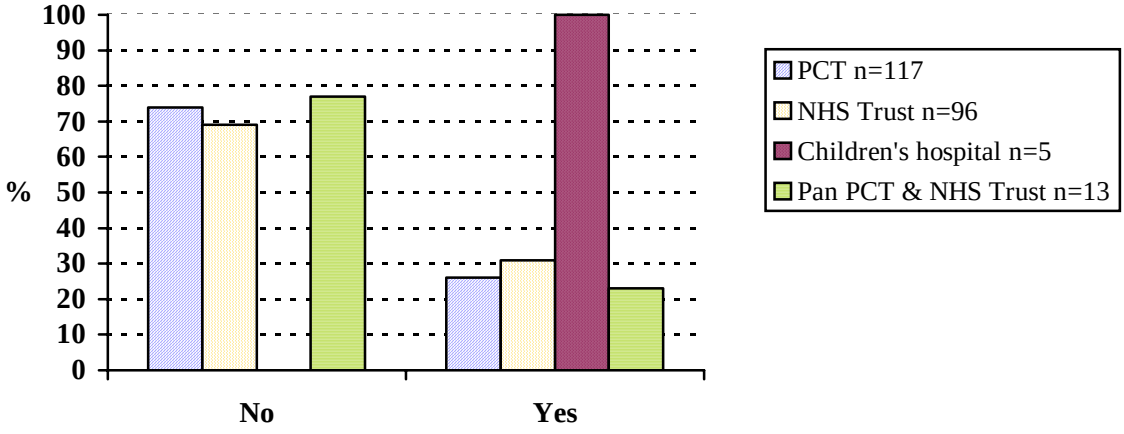


Figure 13: PALS providing leaflets designed for parents



Respondents were also asked which of the settings/groups in Table 20 had been given information to display or hand out to patients and the public on the role of PALS. As the table shows, settings specifically for young people and children were targeted least by PALS. Other settings/groups which PALS had targeted included: opticians, taxis, carer centres, supermarkets, midwives, Citizens Advice Bureaus (CAB), Community Health Councils (CHC), mosques, health fairs, social services, prison, neighbourhood watch, victim support, post offices, ICAS, social landlords, facilities for the homeless, MPs, drop-in-centres, housing departments, Sure Start, First Stop, Women's Institute (WI), library buses, breast screening bus, elderly day units, child development centres, colleges, leisure centres, and police stations.

Table 20: Settings/groups given information to display/hand out to patients and the public on the role of PALS

Rank	Group/setting	N= (%)
1	Voluntary organisation offices	183 (75%)
2	Hospitals – main reception	168 (69%)
3	General practices	156 (64%)
4	Community clinics	149 (61%)
5	Local press	141 (58%)
6	Hospitals – all departments	135 (56%)
7	Libraries	120 (49%)
8	Hospitals – selected departments	93 (38%)
9	Dental practices	91 (37%)
10	Chemists	78 (32%)
11	Family centres	65 (27%)
12	Schools	34 (14%)
13	Youth clubs and forums	23 (9%)
14	Nurseries/play groups	19 (8%)

Respondents were also asked if they had met with the professional groups listed in Table 21 to explain the role of the PALS. Again, professionals working with children and young people, particularly those who worked for agencies other than health, were among the least targeted of those listed. Other professionals with whom respondents had met included: podiatrists, adult mental health teams, general practice staff (including reception staff and practice managers), voluntary sector staff, medical secretaries, reception staff, ward managers, elderly day care centres, local refugee groups, prison/young offenders centre, psychologists, nursing staff, psychiatrists, dentists, Connexions, carers workers, chiropodists, child protection leads and estates/facilities staff.

Table 21: Number (%) of PALS who had met with professional groups to explain the role of the service

Rank	Professional group	N= (%)
1	Physiotherapists	168 (69%)
2	Occupational therapists	165 (68%)
3	Community nurses	147 (60%)
4	Speech therapists	139 (57%)
5	Social workers	128 (53%)
6	Health visitors	125 (51%)
7	General practitioners	122 (50%)
8	Dieticians	116 (48%)
9	Midwives	94 (39%)
10	Hospital paediatric staff	90 (37%)
11	School nurses	82 (34%)
12	Pharmacists	79 (33%)
13	Community paediatric staff	64 (26%)
14	Child mental health professionals	54 (22%)
15	Dentists	47 (19%)
16=	Play specialists	23 (9%)
16=	Youth workers	23 (9%)
18	Secondary school teachers	11 (5%)
19	Nursery/play group staff	11 (5%)
20	Primary school teachers	4 (2%)

In addition, respondents were asked to rate how good they thought PALS had been at informing various groups about its role. Around half the sample rated themselves as being relatively 'good' or 'very good' at informing NHS hospital and community staff and the general public. However, over 60 per cent rated themselves as being relatively 'poor' or 'very poor' at informing children, young people, and education and school staff.

Access to and use of PALS

Respondents were asked to indicate how many people from various groups had accessed the PALS over a three month period. Most respondents (n=206, 85 per cent) provided data on all users rather than specific groups. The maximum number of users any PALS reported seeing over three months was 921. Where actual or estimated data for children and young people were provided, the figures were very small (a maximum of 25 users was reported). In their comments, some respondents observed that it was usually parents who made enquiries on behalf of their children, with little direct contact from children and young people themselves.

Respondents were asked to state the three main reasons why children and young people accessed the service. In some cases the responses appeared to be particular to individual children and young people (possibly reflecting low numbers accessing the service) rather than

common reasons. The reasons children, young people and parents used PALS are summarised in Boxes 1-3:

Box 1: Why children used the PALS

- lack of information/communication
- care of parent or other relative
- lack of, or delays in, service provision
- arranging appointments
- obtaining age-appropriate provision
- GP allocation
- referrals to other services
- individual coping/support.

Box 2: Why young people used the PALS

- lack of information/communication
- confidentiality
- arranging appointments
- lack of, or delays in, service provision
- individual coping/support
- lack of age-appropriate facilities
- consultant/GP allocation
- access/referrals to other services
- staff attitude
- advice on health and practical matters (e.g. pregnancy, drugs, family planning, housing, benefits).

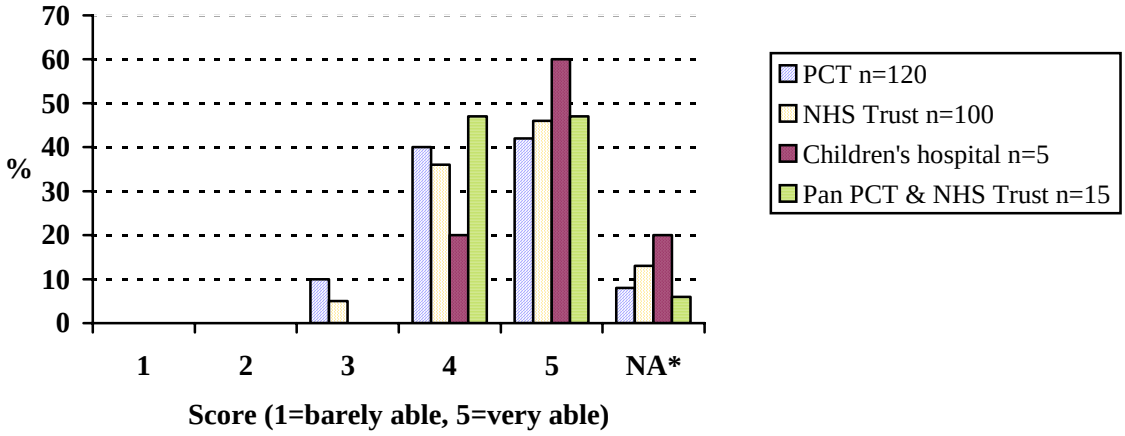
Box 3: Why parents used the PALS

- lack of information/communication
- confidentiality
- staff attitude
- facilities (e.g. parking, security)
- consultant allocation
- access/referrals to other services
- lack of, or delays in, service provision
- quality of care
- child protection issues.

Ability to deal with user concerns

Respondents were asked to rate how well they thought that PALS were able to deal with the concerns of children, young people, parents and other groups. Eighty-one per cent (n=198) of respondents felt positive about the PALS ability to deal with the concerns of 'all users' but, as Figures 14-21 show, views were more variable in relation to specific groups (1 = barely able, 5 = very able). Respondents were relatively positive about their ability to deal with the concerns of older people and parents, but felt least able to deal with those of people with learning difficulties, communication difficulties and children. Tables 22-29 show the related mean scores for different types of Trusts, and the overall scores are summarised in Table 30. It should be noted that it was not known to what extent these views were based on actual experience of dealing with the groups specified (see the section on 'access to and use of PALS' above).

Figure 14: Extent to which PALS felt able to deal with the concerns of all users

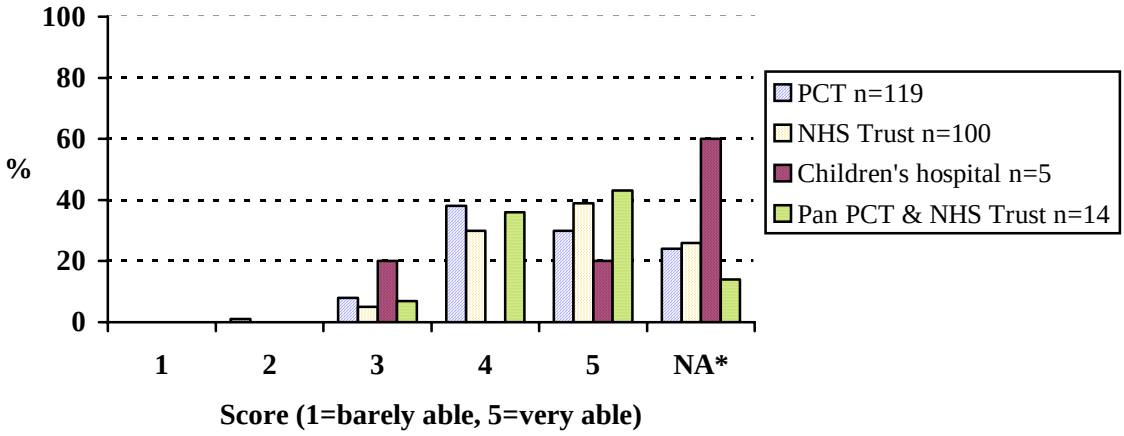


**NA = Not answered (included in n=)*

Table 22: Extent to which PALS felt able to deal with the concerns of all users (mean scores)

Type of Trust(s) served	Mean score	N=
Children's hospital	4.75	4
Pan-PCT & NHS Trusts	4.50	14
NHS Trust	4.47	87
PCT	4.35	110
Overall	4.41	215

Figure 15: Extent to which PALS felt able to deal with the concerns of older people

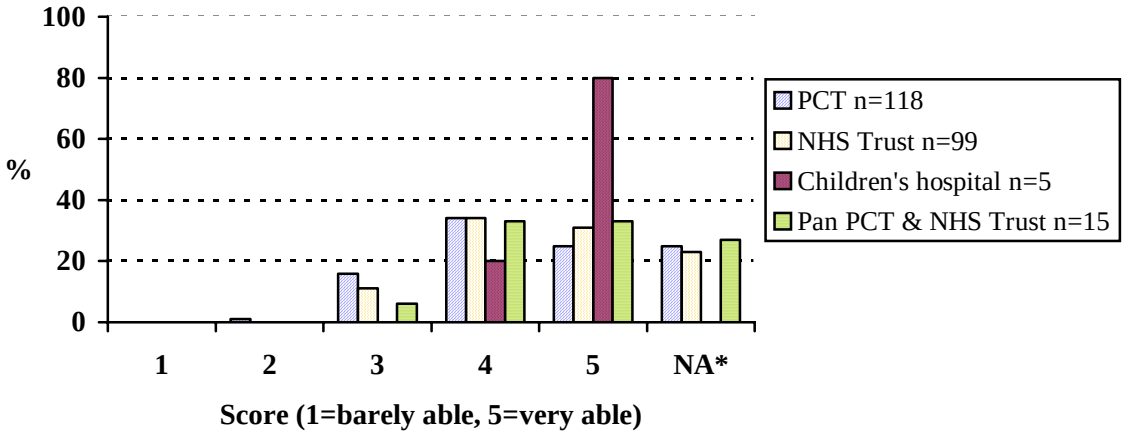


**NA = Not answered (included in n=)*

Table 23: Extent to which PALS felt able to deal with the concerns of older people (mean scores)

Type of Trust(s) served	Mean score	N=
NHS Trust	4.46	74
Pan-PCT & NHS Trusts	4.42	12
PCT	4.27	91
Children's hospital	4.00	2
Overall	4.36	179

Figure 16: Extent to which PALS felt able to deal with the concerns of parents

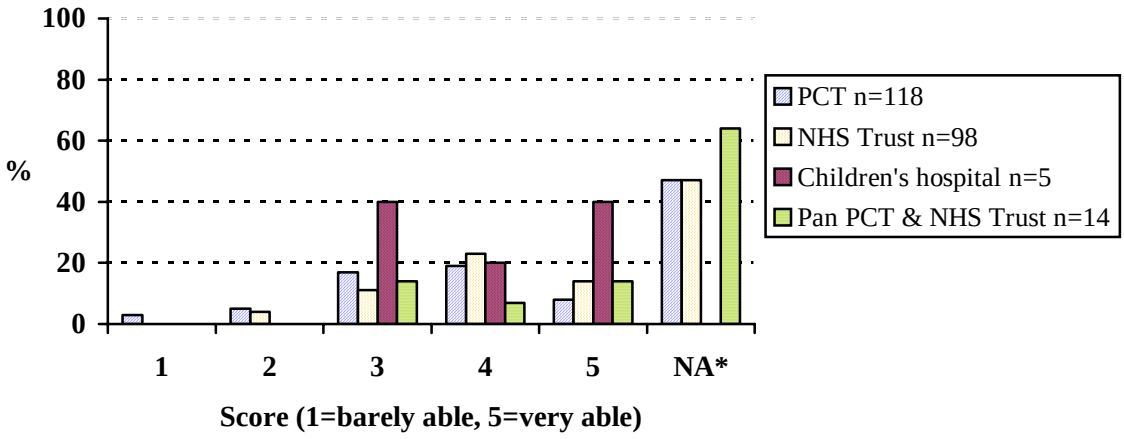


**NA = Not answered (included in n=)*

Table 24: Extent to which PALS felt able to deal with the concerns of parents (mean scores)

Type of Trust(s) served	Mean score	N=
Children's hospital	4.80	5
Pan-PCT & NHS Trusts	4.36	11
NHS Trust	4.26	76
PCT	4.09	89
Overall	4.20	181

Figure 17: Extent to which PALS felt able to deal with the concerns of young people

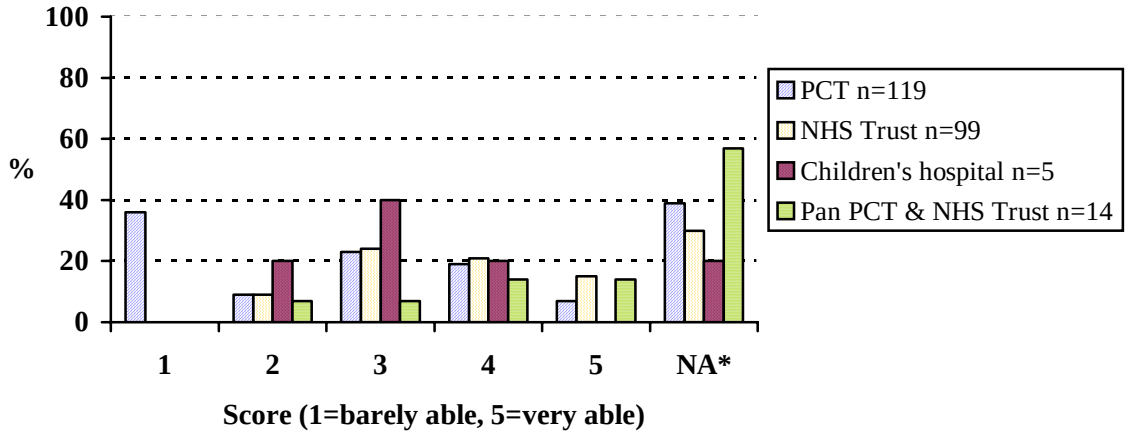


**NA = Not answered (included in n=)*

Table 25: Extent to which PALS felt able to deal with the concerns of young people (mean scores)

Type of Trust(s) served	Mean score	N=
Children's hospital	4.00	5
Pan-PCT & NHS Trusts	4.00	5
NHS Trust	3.90	52
PCT	3.46	63
Overall	3.69	125

Figure 18: Extent to which PALS felt able to deal with the concerns of ethnic minorities

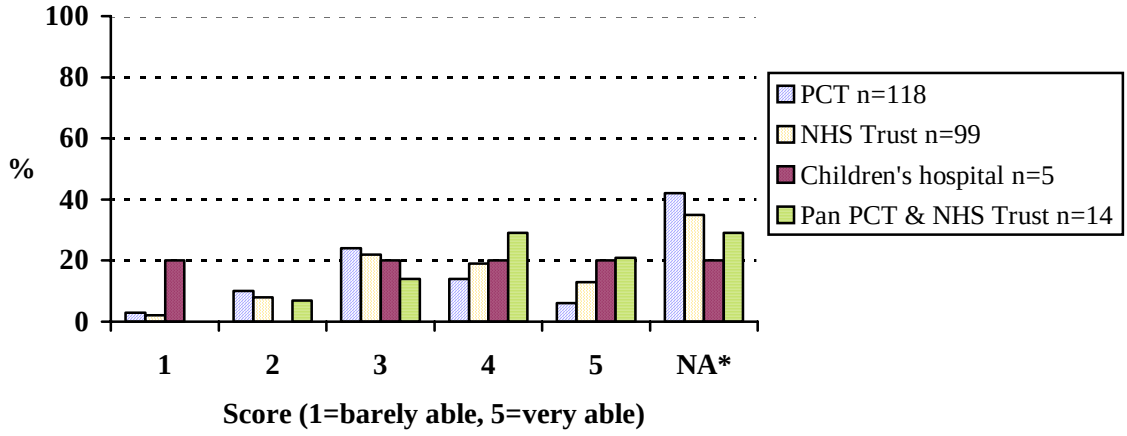


**NA = Not answered (included in n=)*

Table 26: Extent to which PALS felt able to deal with the concerns of ethnic minorities (mean scores)

Type of Trust(s) served	Mean score	N=
Pan-PCT & NHS Trusts	3.83	6
NHS Trust	3.61	69
PCT	3.27	73
Children's hospital	3.00	4
Overall	3.44	152

Figure 19: Extent to which PALS felt able to deal with the concerns of people with communication difficulties

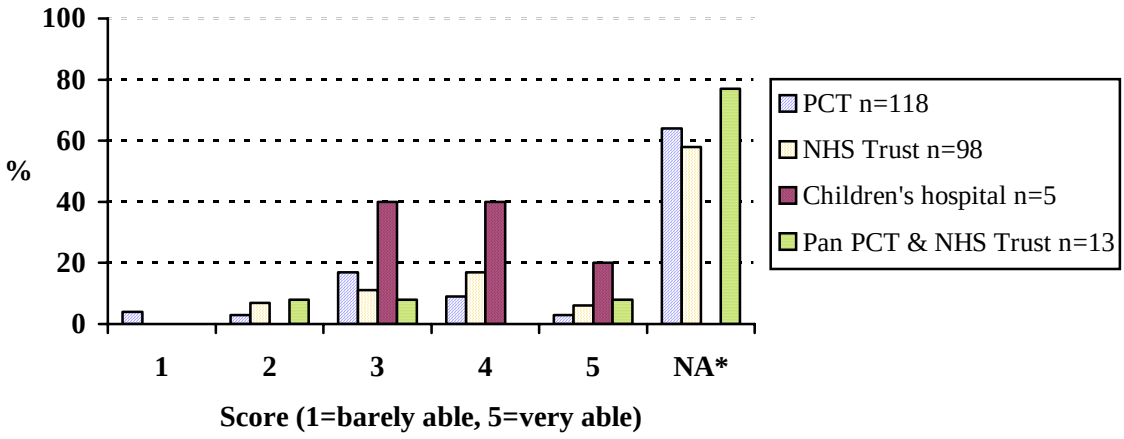


**NA = Not answered (included in n=)*

Table 27: Extent to which PALS felt able to deal with the concerns of people with communication difficulties (mean scores)

Type of Trust(s) served	Mean score	N=
Pan-PCT & NHS Trusts	3.90	10
NHS Trust	3.52	64
Children's hospital	3.25	4
PCT	3.16	68
Overall	3.37	146

Figure 20: Extent to which PALS felt able to deal with the concerns of children

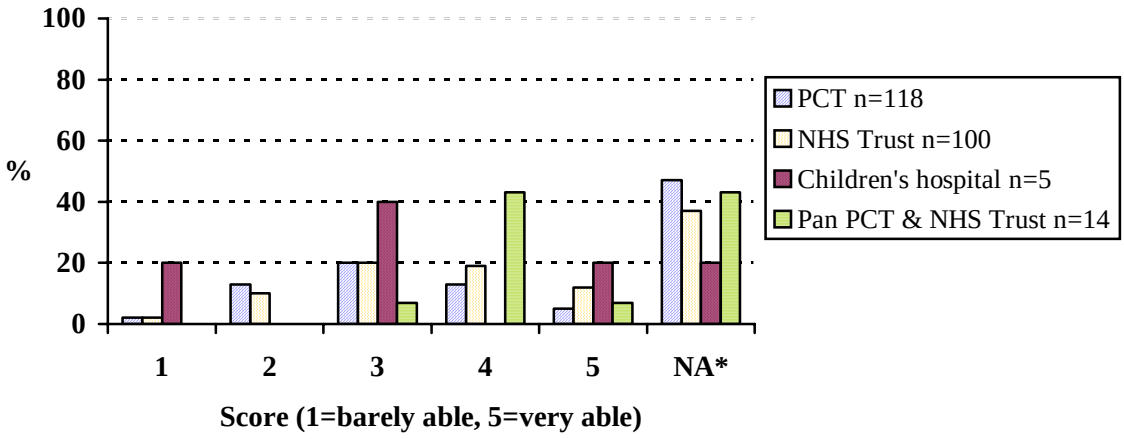


**NA = Not answered (included in n=)*

Table 28: Extent to which PALS were able to deal with the concerns of children (mean scores)

Type of Trust(s) served	Mean score	N=
Children's hospital	3.80	5
NHS Trust	3.54	41
Pan-PCT & NHS Trusts	3.33	3
PCT	3.07	43
Overall	3.33	92

Figure 21: Extent to which PALS felt able to deal with the concerns of people with learning difficulties



**NA = Not answered (included in n=)*

Table 29: Extent to which PALS felt able to deal with the concerns of people with learning difficulties (mean scores)

Type of Trust(s) served	Mean score	N=
Pan-PCT & NHS Trusts	4.00	8
NHS Trust	3.46	63
PCT	3.10	63
Children's hospital	3.00	4
Overall	3.31	138

Table 30: Summary – extent to which PALS felt able to deal with concerns of various groups (mean score for all Trusts)

Rank	Group	Mean score (all Trusts)
1	All users	4.41
2	Older people	4.36
3	Parents	4.20
4	Young people	3.69
5	Ethnic minorities	3.44
6	People with communication difficulties	3.37
7	Children	3.33
8	People with learning difficulties	3.31

Respondents were asked if various groups had raised any issues or concerns which the PALS had found difficult to deal with. A small proportion had experienced difficulties, mainly in relation to parents (n=42, 17 per cent) and older people (n=38, 16 per cent). The sorts of issues relating to parents included: out of area care/referrals; confidentiality; commissioning issues; child protection issues; lack of resources/service provision; cultural differences and conflict; sensitive topics; and information required on specific services (for example, child mental health services, dental services, private health care).

Promotion of PALS

Respondents suggested various ways in which access to and use of the service could be promoted for children, young people and parents (see Boxes 4-6).

Box 4: Suggested ways of promoting PALS to children

- adopt more suitable opening hours
- visit children's wards, nurseries and schools, youth clubs
- work with children's services
- employ specialist staff/advocates for children
- produce child-friendly information/publicity (e.g. involving children in its production)
- make links with relevant user groups
- develop specific service for this group (e.g. PALS in schools run by and for children)
- link with relevant clinical governance group
- develop strategy for user consultation for this group.

Box 5: Suggested ways of promoting PALS to young people

- adopt more suitable opening hours (e.g. accessible out-of-hours and at weekends)
- visit young people's wards, schools and colleges, youth clubs and youth forums, leisure facilities
- produce age-appropriate information/publicity and display in relevant settings (e.g. town centres, pubs and clubs)
- interactive websites
- work with groups such as Young Homeless, Connexions, and Young Carers
- employ specialist staff
- meet patients on admission to hospital to explain service
- involve young people on user groups
- develop strategy for user consultation for this group.

Box 6: Suggested ways of promoting PALS to parents

- visit playgroups, nurseries, schools, parents groups
- produce more targeted information/publicity
- work with midwives and health visitors
- link with organisations supporting parents
- develop specific service for this group.

Open-ended comments

Half the sample (n=121, 50 per cent) made additional comments at the end of the questionnaire. Several observed that the service was new and evolving and that they were planning to target the specific groups covered by the questionnaire in the future. However, the main theme to emerge concerned the resources that were needed to accomplish this. Some respondents pointed out that staff were already busy (because of levels of demand and/or other responsibilities) and that existing staffing and budgets were not sufficient to support additional promotional work and meet any increased demand. Some respondents suggested that there should be a national campaign advertising PALS and/or that leaflets in other languages should be produced centrally. In addition, some respondents indicated that the characteristics of their area – such as the size of the geographical area covered, the size of the population, the rural nature of the area, the number of sites covered, and the number of services covered (for example, general practices and dental surgeries) – presented difficulties in promoting and providing the service locally. Overall, respondents recognised the need to target particular groups such as children, young people and parents but were concerned that they did not have the time, resources and expertise to do so without diluting the existing service they had established.

Discussion

The overall response rate was considered to be good given that a number of PALS had not been established or had only been in operation for a short time. Comparison with the results of a recent mapping exercise by the Department of Health (Department of Health, 2003) suggest slightly more Trusts had yet to establish their PALS than had been officially reported through Strategic Health Authorities – although there are difficulties defining when exactly a PALS was 'established' and operational as this may or may not include the pre-launch

planning stages, the appointment and training of staff, and the gradual 'rolling out' of the service through the Trust.

Response rates for some questions were low. Over 35 per cent of the sample failed to answer questions on: which settings or groups had been given information on the role of PALS to display or hand out to patients (Questions 21b, f, g and h); which professional groups PALS staff had met with to explain the role of PALS (22b, f, h, i, j, k, l and r); and how well they thought the PALS were able to deal with the concerns of various groups (26 b, c, f, g and h) (see Appendix for a copy of the questionnaire). It is possible that a non-response was equivalent to answering 'No' in the cases of Questions 21 and 22. At the same time, some respondents may also have assumed that some of the items were not applicable to them in that they would be part of the remit of other types of PALS in their area (e.g. PCT PALS would be mainly targeting staff such as general practitioners, while NHS Trust PALS would be targeting hospital-based staff etc.). The low response rate to Question 26 may reflect low levels of contact of PALS staff with the patient groups concerned, giving respondents little experience upon which to base a response.

It is clear that many PALS are still in development and overall, the results suggest that many have so far been developed as a generic service, with some efforts to target specific groups of patients and sections of the public. Such efforts include outreach work, links with other organisations and professionals, and targeted publicity. Where such efforts have been made, they have tended to focus most of all on older people and least of all on children. While most respondents felt confident about their ability to deal with patients in general and older people, they were less confident about their ability to deal with children. This may relate to the lack of training focusing on children and young people. However, levels of confidence in their ability to deal with people with communication difficulties or learning disabilities and ethnic minorities was also relatively low, although training was more likely to focus on these groups. Overall, use of PALS directly by children and young people appears to be low at this stage. While some respondents identified ways in which access to the service could be promoted to children and young people, they also raised concerns about whether there were sufficient staff and resources available to enable them to target specific groups, increase outreach work, and meet increasing demand for the service.

Within the sample, the main variation across the PALS in the four types of Trusts was with regard to the location of the main PALS offices and whether or not these were in places visited by patients and the public. This also varied within PCTs where offices were variously located at Trust headquarters and/or in the community. There were no major differences in practices across the PALS although the small number of children's hospitals were generally more child and parent-oriented than the other types of Trusts.

Implications for policy, practice and future research

This survey has highlighted that PALS have been developed as a generic service, with some efforts being made to target potentially hard-to-reach groups, including children and young people. Limited promotion of the service to children and young people may reflect the adult-centric nature of PALS, demonstrated in the 'one size fits all' type information and publicity produced by most PALS. The survey has also highlighted the need for PALS to record and monitor use of the service by children and young people, and by parents acting on their behalf. This includes direct access to the service and any other contacts with Trust staff who act as proxy-PALS officers for children, young people and parents. Further research is required to establish how children, young people and parents would like to access and use the service (this will be explored in the latter stages of the study of which this survey is a part).

The survey has also identified concerns among respondents about the adequacy of existing resources (staffing, budgets and expertise) to support additional promotional work, meet any increased demand and deal with the specific needs of particular groups. Further consideration should be given to how PALS can be cost-effectively promoted, both nationally and locally, and across different types of Trusts (including PCTs, acute general hospitals and specialist Trusts). The funding of PALS may also need to be reviewed to ensure that it reflects the size and local characteristics of the Trusts covered.

Given that PALS are still in varying stages of development, the findings of the survey should be seen as a provisional 'snapshot' of the services. Considerable further development work is taking place at national, regional and local levels. Highlighting the specific needs of children and young people in this work can help to promote understanding of the need to further improve information about and access to PALS for this group.

Further note

The results of the survey were used to inform the selection of sites to be involved in the next stage of the research. A short-list of PALS which scored well on the following criteria was drawn up.

- Training included a focus on children, young people and parents (Q11).
- Feel well equipped to deal with children, young people and parents (Q12).
- Have links with relevant user groups (Q17).
- Feel good about informing children, young people and parents about role of PALS (Q23).
- Innovative practice indicated in qualitative comments and service documentation.
- Willing to help access children, young people and parents and host discussion groups.

Based on further review of these questionnaires, including the qualitative comments and any further documentation submitted, three sites were selected. The results of the rest of the study will be available in Autumn 2005.

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Appendix

The Questionnaire

CONFIDENTIAL

NATIONAL SURVEY OF PATIENT ADVICE AND LIAISON SERVICES (PALS) INVOLVEMENT OF CHILDREN, YOUNG PEOPLE AND PARENTS

Funded by the Community Fund and the Department of Health

Your name:	
Job title:	
Name of PALS and NHS Trust organisation(s) it serves:	
Address:	
Tel no:	
Email:	

Note: Please ONLY complete this questionnaire if your Trust provides services for children, young people and parents as defined above. If your Trust does not, then please complete this page only and return the questionnaire to us stating which patient group(s) your Trust does serve:

S | P | R | U

THE UNIVERSITY of York

CARNEGIE YOUNG PEOPLE INITIATIVE

VERY IMPORTANT ~ NOTES FOR COMPLETION

1. Throughout this questionnaire the terms 'children', 'young people', 'parents' and 'other adults' are defined as follows:

   'Children' = all patients and members of the public aged 0-11 (inclusive).

   'Young people' = all patients and members of the public aged 12-18 (inclusive).

   'Parents' = all parents (or guardians/carers) of children or young people who may use PALS on behalf of their sons or daughters.

   'Other adults' = patients and carers aged 19 and above who are potential users of PALS for themselves or on behalf of other adults.

2. If your PALS covers more than one Trust and you feel it would be more appropriate to fill in separate questionnaires, please contact Janet Heaton on 01904 433 608 for another form.

3. Please use the space provided at the end of the questionnaire if you wish to add comments on any of the questions, or supply further information.

4. If you would like any help when completing the form, please contact Janet Heaton on 01904 433 608.

PART 1: ESTABLISHMENT AND STAFFING OF THE PALS

Q1. When did your PALS become operational? *(Circle the month and year)*

Month	1	2	3	4	5	6	7	8	9	10	11	12
Year	2001	2002	2003									

Q2. Where are the PALS office(s) situated?

	Main office *(Tick only one)*	Other offices *(Tick all that apply)*
Hospital – main reception		
Hospital – other area(s)		
(*please describe*)		
Community Trust Headquarters		
Primary Care Trust Headquarters		
Other *(please describe)*		

Q3. Is the main PALS office in the location visited by patients and the public (e.g. a hospital)?

Tick

	Yes
	No - *please go to Q5*

Q4. If you answered 'Yes' to Q3, please rate whether each of the following groups are likely to observe the PALS office during their visit to the site? *(In each row, circle ONE number on scale, where 1 = very low likelihood and 5 = very high likelihood)*

	Very low				Very high
Children	1	2	3	4	5
Young people	1	2	3	4	5
Parents	1	2	3	4	5

Q5. When is the main PALS office open to patients and the public? *(Please state)*

	In person	By phone
Normal weekday hours:		
Normal weekend hours:		
Public holiday hours:		

Q6. Is the PALS available to see patients and the public outside of open office hours?

Tick

	Yes
	No

Q7. Will the PALS visit patients in any of the following locations? *(Tick all that apply)*

	Yes	No	Unsure
A hospital ward			
At home			
At school			
Other *(please describe)*			

Q8. In total, how many staff are involved in providing the PALS? *(Please state number)*

Total number of FULL-TIME staff who deal directly with patients and the public:	
Total number of PART-TIME staff who deal directly with patients and the public:	
Total number of other FULL-TIME staff:	
Total number of other PART-TIME staff:	

Q9. Is this staffing complement adequate to run the service well?

Tick

	Yes
	No – *please say why and how many staff are required:*
	Unsure – *please say why:*

Q10. Have those PALS staff who deal directly with patients and the public been provided with training for this role?

Tick

	Yes
	No – *please go to Q12*
	Unsure – *please go to Q12*

Q11. Did the training include a focus on dealing with the following groups? *(Place ONE tick in each row)*

	Yes	No	Unsure
Children			
Young people			
Parents			
Older people			
Ethnic minorities			
People with communication difficulties			
People with learning difficulties			

Q12. Please rate how well equipped the PALS staff are for dealing with the following groups? *(In each row, circle ONE number on the scale, where 1 = very poorly equipped and 5 = very well equipped)*

	Very poor				Very well equipped
Children	1	2	3	4	5
Young people	1	2	3	4	5
Parents	1	2	3	4	5
Older people	1	2	3	4	5
Ethnic minorities	1	2	3	4	5
People with communication difficulties	1	2	3	4	5
People with learning difficulties	1	2	3	4	5

PART 2: POLICIES, SERVICE SPECIFICATIONS AND LINKS

Q13. Do the policies and service specification for your PALS highlight the particular needs of any of the following groups? *(Place ONE tick in each row)*

	Yes*	No	Planning to
Children			
Young people			
Parents			
Older people			
Ethnic minorities			
People with communication difficulties			
People with learning difficulties			

** If you answered 'Yes' to any part of Q13, please attach a copy of the policy if possible.*

Q14. Are there any other PALS in the geographical area covered by your Trust (e.g. set up by other NHS Trusts or PCTs)?

Tick

	Yes – *please name the PALS(s) and the associated Trust organisation(s):*
	No – *please go to Q16*
	Unsure – *please go to Q16*

Q15. Please rate how strong the PALS links are with these other PALS? *(Circle ONE number on the scale, where 1 = very weak and 5 = very strong)*

	Very weak				Very strong
Links with others PALS	1	2	3	4	5

Q16. Does your PALS have links with any other PALS outside the geographical area covered by your Trust (e.g. in regional networks)?

Tick

	Yes – *please describe the links:*
	No
	Unsure

Q17. Does your PALS have links with any organisations, such as Advocacy Organisations, to which you can refer people from the following groups? *(Place ONE tick in each row)*

	Tick		
	Yes	No	Unsure
The general public (e.g. CAB)			
Children			
Young people			
Parents			
Older people			
Ethnic minorities			
People with communication difficulties			
People with learning difficulties			

Q18. If you answered 'Yes' to any part of Q17, please describe the organisation(s) and rate to what extent the PALS has referred patients and the public to them?
(Name the organisation(s) in the space provided and then, for each one, circle ONE number on the scale, where 1 = very rarely and 5 = very often)

Name of organisation	Very rarely				Very often
	1	2	3	4	5
	1	2	3	4	5
	1	2	3	4	5
	1	2	3	4	5
	1	2	3	4	5
	1	2	3	4	5

PART 3: INFORMING PATIENTS AND THE PUBLIC ABOUT THE ROLE OF THE PALS

Q19. Which of the following means have been used to provide information to patients and the public on the role of your PALS? *(Place ONE tick in each row)*

	Yes	No	Planning to
Leaflets			
Posters			
Video/audio tapes			
Talks to potential users			
PALS website			
Other means *(please describe)*			

Q20. Which, if any, of the aforementioned means were designed and used to provide special (e.g. age appropriate) information for the following groups? *(Tick all that apply for each of the following groups)*

	Children	Young people	Parents	Older people	Ethnic minorities	People with communication difficulties	People with learning difficulties
Leaflets*							
Posters							
Videos/audio tapes							
Talks to potential users							
PALS website							
Other *(please describe)*							

Q21. Which of the following settings or groups have been given information to display or hand out to patients and the public on the role of the PALS? *(Place ONE tick in each row)*

	Yes	No	Planning to
Hospital(s) – main reception			
Hospital(s) – selected departments			
Hospital(s) – all departments			
General practices			
Dental surgeries			
Schools			
Youth clubs and youth forums			
Nurseries/play groups			
Libraries			
Chemists			
Community Clinics			
Voluntary organisations' offices			
Family centres			
Local press			
Other places *(please describe)*			

Q22. Which of the following professional groups have the PALS staff met with to explain the role of PALS? *(Place ONE tick in each row)*

	Yes	No	Planning to
Hospital paediatric staff			
Community paediatric staff			
Health visitors			
General practitioners			
Community nurses			
Dentists			
School nurses			
Primary school teachers			
Secondary school teachers			
Play specialists			
Nursery/play group staff			
Youth workers			
Social workers			
Occupational therapists			
Physiotherapists			
Speech therapists			
Dieticians			
Child mental health professionals			
Midwives			
Pharmacists			
Other groups *(please describe)*			

Q23. Please rate how good you think the PALS has been at informing the following groups about its role? *(In each row, circle ONE number on the scale, where 1 = very poor and 5 = very good)*

	Very poor				Very good
The general public	1	2	3	4	5
Children	1	2	3	4	5
Young people	1	2	3	4	5
Parents	1	2	3	4	5
Older people	1	2	3	4	5
Ethnic minorities	1	2	3	4	5
People with communication difficulties	1	2	3	4	5
People with learning difficulties	1	2	3	4	5
NHS hospital staff	1	2	3	4	5
NHS community staff	1	2	3	4	5
Social services staff	1	2	3	4	5
Education and school staff	1	2	3	4	5

PART 4: ACCESS TO AND USAGE OF PALS

Q24. How many people from the following groups have accessed the PALS in the last THREE complete calendar months? *(Please state the months and provide exact figures from records where possible or, if not, an estimate)*

Usage of PALS over the **3** calendar months of:		to	
	Exact number	Estimate	Unsure
Children			
Young people			
Parents			
All users			

Q25. Please summarise the top three reasons why the following groups have used the PALS since it became operational? *(Please state)*

Children	1st reason	
	2nd reason	
	3rd reason	
Young people	1st reason	
	2nd reason	
	3rd reason	
Parents	1st reason	
	2nd reason	
	3rd reason	
All users	1st reason	
	2nd reason	
	3rd reason	

Q26. Please rate how well you think the PALS were able to deal with the concerns of the following groups? *(In each row, circle ONE number on the scale, where 1 = barely able and 5 = very able)*

	Barely able				Very able
All users	1	2	3	4	5
Children	1	2	3	4	5
Young people	1	2	3	4	5
Parents	1	2	3	4	5
Older people	1	2	3	4	5
Ethnic minorities	1	2	3	4	5
People with communication difficulties	1	2	3	4	5
People with learning difficulties	1	2	3	4	5

Q27. Have any of the following groups raised issues or concerns which the PALS have found difficult to deal with? *(Place ONE tick in each row)*

	Tick		
	Yes	No	Not applicable
Children			
Young people			
Parents			
Older people			
Ethnic minorities			
People with communication difficulties			
People with learning difficulties			

Q28. If you answered 'Yes' to the last question, please describe the nature of the concerns and which group(s) raised them?

Q29. Does the Trust have a mechanism in place for reviewing the issues and concerns raised by patients and the public generally through the PALS?

Tick

	Yes – *please describe:*
	No
	Unsure

Q30. What, in your opinion, could the PALS do to further promote access to and use of the service by the following groups?

Group	Comments
Children	
Young people	
Parents	

Q29. Do you have any other comments? (Please continue on a separate sheet if necessary)

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Thank you for completing this questionnaire.

Please return it in the pre-paid envelope provided as soon as possible (**and within the next 3 weeks**). If the envelope has become separated, please send the form to Janet Heaton at the address at the bottom of this page. If applicable, please remember to enclose examples of any leaflets, or any other information about your PALS, with the questionnaire (see Q18).

The results of the survey will be used as the basis for selecting Trusts to take part in the next stages of the research (see the information sheet). If you would **NOT** be willing to help with the next stages of the research (either by helping us to recruit some children, young people and parents to take part in discussion groups and interviews in your area, or by sending out questionnaires to children, young people and parents who have used the service) please tick here: ☐

A summary of the results of the survey will be published on the SPRU website: www.york.ac.uk/inst/spru/ later in 2003, together with periodic updates on the progress of the overall study, which began in January 2003 and will end in June 2005. When the study is completed, we will send you a summary of the findings.

If you would like any further information on the project, please contact either Janet Heaton or Tricia Sloper at SPRU. Our contact details are as follows:

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