Access to and use of Patient Advice and Liaison Services (PALS) by children, young people and parents – a national survey

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Patient Advice and Liaison Services (PALS) are a key part of the new system of user involvement in the NHS in England. In this study, we examined to what extent PALS have been developed in ways that are inclusive of children, young people and parents. A national survey of PALS officers in England was carried out. The key findings were:

- PALS have so far been developed as generic services, 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 on older people and least 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 about children. 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.

Background

Since 2002, all NHS Trusts and Primary Care Trusts (PCTs) in England have been required to establish a Patient Advice and Liaison Service. PALS have been set up to enable patients and the public to access information and raise issues of concern with their Trust. The service provides 'on the spot' help and may be accessed in person or via the telephone or email.

PALS are intended to serve all, including vulnerable and hard-to-reach sections of the community. 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 their parents. The survey was carried out as part of a wider study exploring what PALS have done and can do to involve these potential users.

Table 1:
Number of PALS focusing on specified patient groups in staff training

Group	N (% of respondents provided with training)
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%)

Findings

Respondents from 243 PALS provided information for the survey: 122 in PCTs, 101 in NHS Trusts, 15 serving both PCTs and NHS Trusts, and 5 in Children's Hospitals.

Establishment and staffing

PALS were at different stages of development. Most had become operational in 2002 (62%, n=151); 20% (n=48) had been running since 2001 and 12% (n=29) had been established in 2003.

PALS were staffed by a mix of full- and part-time staff who dealt directly with patients and the public or who provided administrative support. Volunteers were also used by some PALS and a few Trusts encouraged all their staff to act on behalf of the PALS.

Over two-fifths of respondents (42%, n=103) did not feel that the staffing complement was adequate to run the service well. A fifth (21%, n=51) were unsure about whether staffing levels were adequate, mainly because the service was still 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 staffing levels limited the extent to which staff could be proactive, do outreach work and cover all locations.

Location of PALS offices and opening hours

Half of all respondents (54%, n=132), but only 30% (n=37) of PCTs, reported that their main PALS office was based in a location visited by patients and the public.

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 (3%) were open in person at weekends. It was possible for patients to be seen outside office hours at around half the PALS (56%, n=137). The majority of PALS would also visit patients on hospital wards (81%, n=196), at home (76%, n=185) and at school (61%, n=149), although this varied by type of Trust. Many respondents indicated that the PALS staff were also prepared to visit patients and the public in other safe and mutually convenient places.

Training

Nearly two-thirds of PALS staff who dealt directly with patients and the public had been provided with training for this role (63%, n=154). In general, 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 (Table 1). Training of PALS staff at Children's Hospitals was the most likely to focus on children, young people and parents (75% for each group).

In rating how well equipped the PALS staff were for dealing with different groups (using a five-point

Table 2: Number of PALS with policies and service specifications that highlight the needs of particular groups

Group	N	(% all respondents)
Ethnic minorities	**57**	(23%)
People with communication difficulties	**52**	(21%)
Older people	**46**	(19%)
People with learning difficulties	**42**	(17%)
Parents	**29**	(12%)
Young people	**25**	(10%)
Children	**18**	(7%)

Table 3: Number of PALS with links with organisations for the groups specified

Group	N	(% all respondents)
General public	**217**	(89%)
Older people	**208**	(86%)
People with learning difficulties	**176**	(72%)
People with communication difficulties	**175**	(72%)
Ethnic minorities	**167**	(69%)
Parents	**151**	(62%)
Young people	**132**	(54%)
Children	**118**	(49%)

scale where 1= very poorly and 5= very well equipped), respondents felt that staff were relatively well equipped to deal with older people (mean score 3.97) and parents (3.94), and least well equipped to deal with people with learning difficulties (3.04) and children (3.01). Children's Hospitals had the best scores relating to children, young people and parents.

Service specifications and monitoring

In general, policies and service specifications for PALS did not highlight the needs of particular groups, and least of all children, young people and parents (Table 2).

Informing patients and the public about the role of PALS

Most PALS used leaflets (93%, n=225), talks (93%, n=225) and posters (90%, n=218) to provide information to patients and the public on the service. Half the sample (54%, n=131) also used a website for this purpose and more were planning to use this method (33%, n=80).

Information leaflets were not generally designed and used to provide special (e.g. age appropriate) information for different groups. Children and young people were least likely to have information designed for them.

Various organisations had been given information to display or hand out to patients and the public on the role of PALS. However, only a quarter of PALS had targeted family centres and fewer had targeted other organisations for young people and children (such as schools, youth clubs, and nurseries/play groups).

PALS staff had also met with various professional groups to explain the role of the service. 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.

Around half the sample rated themselves as being 'good' or 'very good' at informing NHS hospital and community staff and the general public about the role of PALS. However, over 60% rated themselves as being 'poor' or 'very poor' at informing children, young people, and education and school staff. Some respondents suggested ways in which the service could be better promoted to these groups, for example, through age-appropriate publicity and targeted outreach work.

Use of PALS

Respondents were asked to report how many children, young people and parents had used the PALS over a three month period but these data were seldom provided. Some respondents commented that it was usually parents who made enquiries on behalf of their children, with little direct contact from children and young people themselves.

Links with other organisations

Many PALS had developed links with organisations to which they could refer users. As Table 3 shows, PALS had relatively more links with organisations for the general public (e.g. Citizens Advice Bureau) and older people than those for children, young people and parents. Children's Hospitals generally had more links with organisations for the latter groups.

Ability to deal with user concerns

Overall, 81% (n=198) of respondents felt positive about PALS ability to deal with 'all users' but views were more variable in relation to specific groups. Respondents rated PALS ability to deal with the concerns of different groups on a five-point scale (where 1= barely able and 5= very able to deal with concerns). Respondents were most positive about PALS ability to deal with the concerns of older people (mean score 4.36), parents (4.20) and young people (3.69), but were less positive about its ability to deal with those of people with learning difficulties (3.31), children (3.33), and people with communication difficulties (3.37). However, it was not known to what extent these views were based on actual experience of dealing with the groups specified.

Implications

The results of the survey suggest that PALS have been developed as a generic service to date. Most PALS have developed links with outside organisations, and some efforts were being made to target potentially hard-to-reach groups. Children and young people seem least likely to be targeted. This raises issues about how PALS can be made more inclusive of parents and, especially, children and young people as users in their own right. These issues will be explored in the later stages of this study where the perspectives of young people and parents 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 of some respondents about whether existing resources are adequate to target and facilitate the involvement of specific groups such as children, young people and parents.

Methods

The survey was carried out between March and May 2003. Questionnaires were sent to Senior PALS Officers/Patient and Public Involvement (PPI) leads in 553 NHS Trusts and PCTs. Ambulance Trusts, and Specialist Trusts that were known not to provide services for children and young people, were excluded.

For the purposes of the survey, 'children' were defined as 'all patients and members of the public aged 0–11'; 'young people' as 'all patients and members of the public aged 12–18'; 'parents' as 'all parents (or guardians/carers) of children or young people who may use PALS on behalf of their sons or daughters'.

Questionnaires were returned by 320 respondents, including 290 PALS in single Trusts and 30 PALS covering two or more Trusts. A total of 369 Trusts were represented, a response rate of 67%. The 320 respondents included 77 Trusts that declined to take part, mainly because they did not have a PALS in operation (n=31) or had only recently set up the service (n=21). The final achieved sample therefore comprised 243 PALS.

Further information

This research was funded by the Community Fund and the Department of Health. It is being carried out in collaboration with Carnegie Young People's Initiative. The full study is due to be completed in 2005.

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