

Access to and use of NHS Patient Advice and Liaison Services (PALS) by children, young people and parents – user and staff perspectives

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The NHS Patient Advice and Liaison Service (PALS) was set up to help patients and the public obtain 'on the spot' information and advice, and deal with any issues or concerns about their health care. Our study examined to what extent PALS were inclusive of children, young people and parents. We describe the views of these users, and PALS staff, on what has been done to help them to access and use the service, and how this could be improved. The main findings were:

- Young people and parents felt that existing promotional materials should be improved and made more attractive, informative and age-appropriate, and awareness of PALS could be raised through wider advertising of the service.
- They wanted PALS to be open outside school hours and located in places that are used by young people, such as drop-in centres.
- PALS staff suggested that the service could be better promoted to children, young people and parents by developing links with existing organisations that work with these groups, and access facilitated by adopting a more proactive approach to involving children and young people.
- PALS staff would welcome training in dealing with direct enquiries from young people and, to a lesser extent, parents.
- Parents and especially young people are low users of PALS. Parents who had used PALS and responded to our survey were generally satisfied with the service they received.

Background

PALS have been established in all NHS trusts in England as part of a wider strategy designed to promote user involvement in health care decision-making. The service is intended to help all people, including children and young people (for brevity we will hereafter refer to 'children and young people' as 'young people'). This study was carried out to examine to what extent the service was accessible to young people and their parents, and to find out how this could be improved. In a previous Research Works (no. 2003-04) we reported the results from a national survey of PALS. This showed that PALS had been developed as a generic service. While efforts were being made to target some potentially 'hard-to-reach' groups, least was being done to include young people. Here we report the results from the next stage of the research, in which user and staff views on young people's and parents' access to and use of the service were examined.

Findings

The following findings are based on information collected through discussion groups and interviews with 30 young people and 16 parents; a postal survey, to which 171 parents who had used PALS on behalf of a child responded; and interviews with 14 PALS staff.

Views of children, young people and parents

In the discussion groups and interviews with young people and parents, they identified ways in which PALS could be better designed with their needs and preferences in mind (see Box 1).

Publicity: young people and parents thought that existing methods of promoting PALS could be improved. For example, leaflets and posters could be made more attractive to and appropriate for different age groups, including teenagers aged 16-18 who were the most dissatisfied with existing promotional material. The inclusion of photographs of young people, text saying that the service was for young people as well as adults, and examples of how PALS has helped or could help young people, was recommended. Young people and parents also thought that PALS should be more widely advertised, for instance through advertisements on national and local television and websites.

Access/location: young people and parents thought PALS should be open outside school hours and located in convenient places, such as venues they used for other services (eg drop-in centres, Connexions). Being able to access the service discretely was important to teenagers aged 16-18. Most thought that young people should have the option of seeing an adviser alone or with someone else present for support. Most young people and parents would prefer to speak to a PALS adviser in person, although some preferred to make contact by telephone or email.

PALS advisers: young people and parents thought that PALS staff should be able to relate to young people and their issues.

Environment: young people thought it important that they could talk to PALS staff in a room that was informal, friendly, private and comfortable.

Box 1:

Children's, young people's and parents' suggestions for improving access

- Re-design leaflets and posters with different age groups of children and young people in mind.
- Use other methods of advertising PALS more widely (eg advertisements and websites).
- Ensure PALS are open outside school hours and situated in a convenient location, with discrete and independent access if required.
- Provide a room that is child-friendly (eg informal, friendly, private and comfortable).
- PALS staff should be able to relate to young people and their issues.

In the survey of parents who had used PALS on behalf of a child, respondents provided feedback on their experience of accessing and using the service. The majority of parents had found out about PALS via other NHS staff (48%) or a leaflet/poster (22%). They first contacted the service by telephone (58%) or in person (34%). In only 9% of cases did parents say that their child had been given the option of talking to a PALS adviser; the majority (63%) claimed that this was not relevant because the child was too young or too sick. Almost half the parents who responded (45%) were enquiring on behalf of a child aged five or less; 25% for children aged 6-12; and 30% for young people aged 13 or older. The most common reasons parents contacted PALS were to enquire about delays or problems with appointments; issues with treatment or care; and to seek advice, information and support.

There were high levels of satisfaction with the service among parents who responded to the survey: 89% found it easy to contact PALS; 96% thought that PALS staff were easy to talk to; 70% thought that PALS had helped them with their enquiry and 16% had partly helped; 85% said they would use PALS again; 90% said they would recommend PALS to other parents; and 82% rated PALS as either 'excellent' or 'good' overall.

While parents were generally satisfied with PALS, around half the respondents suggested one or more ways in which the service was limited and/or could be improved. Their suggestions included: raising the profile of PALS so that more people are aware of their existence; ensuring the PALS office is in a visible location; improving follow-up and feedback in response to users' enquiries; increasing staffing and opening hours; enabling people to raise issues without jeopardising confidentiality or their children's future treatment; ensuring PALS have the necessary authority to resolve issues; and ensuring that PALS are independent, acting on behalf of parents and not just the hospital/trust.

Views of PALS staff

Most staff reported that parents were relatively low users of PALS in their trusts (except in children's hospitals), and all described young people as low users. They did not know why this was the case, but did suggest ways in which parents and young people might be better helped to use the service (see Box 2).

All staff thought PALS advisers would benefit from training in dealing with young people. This included training in communication, legislation relating to young people, child protection, staff safety/boundaries in working with young people, and services for young people. Half the staff also thought that it would be useful to have training in dealing with parents too, such as in counselling skills, child protection, understanding parents' perspectives, and specialist services for families.

PALS staff who were interviewed had mainly dealt with enquiries from parents. While they were willing in principle to talk to a young person with a parent present, some had concerns about talking to a young person alone, especially if s/he was aged under 16. This was thought to be a matter of judgement in each case. A few also added it was difficult to involve young people when contact was made by a parent over the phone.

Box 2:

Staff suggestions for improving access by children, young people and parents

- More and better targeted publicity for children, young people and parents.
- Develop outreach work with organisations working with children, young people and parents (eg schools, youth councils).
- Adopt a more proactive approach to involving young people (eg going to see them on the wards).
- Make use of technologies for accessing PALS that might better suit young people (eg text messaging).
- Make PALS offices more child-friendly.

Recommendations

Awareness of PALS: more could be done to raise children's, young people's and parents' awareness of PALS by developing promotional materials that are age appropriate. Leaflets and posters could be improved by adding photographs of young people; examples of how PALS can help young people; and text saying the service is for young people and adults. PALS could also be advertised more widely.

Access to and use of PALS: young people and parents would prefer if PALS were open outside school hours, in convenient locations, and could be accessed discretely if necessary. Young people should have the choice of seeing a PALS adviser alone or with a parent or someone else present for support. They would like to meet in a child-friendly room. PALS staff could develop a more proactive approach to involving children and young people (eg visiting them on the ward, at school).

Training: Young people want to talk to a PALS adviser who is able to relate to people of their age. PALS staff would welcome training in dealing with direct enquiries from young people and, to a lesser extent, parents too.

Links with other services: both public awareness of PALS, and staff ability to deal with (or refer on) enquiries from young people and parents, could potentially be improved by PALS developing links with existing organisations that work with these groups, such as schools and youth councils.

Methods

User perspectives

Thirty young people and 16 parents took part in discussion groups or individual interviews about accessing and using PALS in acute trusts, children's hospital trusts, and primary care trusts (PCTs). Separate groups were held for young people aged 10-12, 13-15, 16-18 and parents. Participants were required to have experience of using hospital or primary health services, but not PALS. Information on PALS was provided. The topics discussed used examples of how PALS had been promoted in different types of trusts, and situations in which young people and parents might want information and advice about local services.

A postal survey of 804 parents/carers who had used 26 PALS on behalf of a child was carried out, to find out how they had accessed the service and whether or not they found it useful. Replies were received from 171 (22% response rate) parents who had used PALS in children's hospitals (58%, n=99), acute trusts (22%, n=38), PCTs (16%, n=27), and PALS covering multiple types of trusts (4%, n=7). Because of the low response rate, the results must not be taken to represent the views of parents as a whole, only those who responded. Thirty five young people were also surveyed, but only 9 (26%) responded, which is too few to report. Parents and young people were involved in the design and piloting of questionnaires.

Staff perspectives

Fourteen PALS managers and advisers from four acute trusts, two children's hospital trusts and eight PCTs were interviewed by telephone. The interviews included questions on what had helped and hindered parents' and young people's access to and use of PALS, and how this could be improved.

Further information

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