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# Protocol for PALS & Independent Advocacy Joint Working

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*advocacy across london*



King's College Hospital **NHS**  
NHS Trust

**NHS**  
London Regional Office

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## **Acknowledgements**

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## **1. Introduction**

This document constitutes a first attempt at defining a set of relationships between the newly established Patients Advice and Liaison Services (PALS) and local, independent advocacy agencies. In particular, the protocol focuses on the criteria for and nature of referrals between the two types of agency. We believe that a constructive working relationship between agencies will help to secure the best possible outcomes for service users and ensure that NHS Trusts are better equipped to deal with patients' concerns and grievances in an effective and sensitive way.

## **2. The Pilot Project**

Following discussions between the Patient and Public Involvement Unit, NHS London Regional Office and Advocacy Across London, a resource and support agency for advocacy groups in London, it was decided that the London Regional Office would commission a pilot project to develop a protocol for partnership working between PALS and independent advocacy schemes. The chosen pilot site for the protocol development was King's College Hospital, based in Camberwell, South East London. A joint working group was convened to take the work forward, with a view to producing a draft protocol by the end of 2001.

The protocol is designed to support the provision of an effective service for the public. It is the group's intention that the protocol may be used not only by PALS staff and the advocacy schemes, but also to be useful to a wider audience, including clinicians. It is hoped that a clearer understanding of the roles will help to foster good working relationships between PALS, advocacy schemes and clinicians.

The protocol aims to address the following:

- Definitions of the different types and levels of advocacy available.
- The interface between PALS services and advocacy services.
- Information on when and how to refer.
- Good practice for PALS staff to follow.
- When advocacy services should refer to PALS.

### **2.1 Introduction from King's College Hospital NHS Trust**

King's development of a PALS Pathfinder site provided the opportunity to develop existing links and forge new relationships with advocacy services locally. The Trust recognises the benefits to patients in having the option of accessing external, independent advocacy services. The new service may result in an

increase in the numbers of cross referrals between both PALS and advocacy services, once responsibilities and modes of referral had been agreed.

In attempting to define a protocol a number of key issues were identified. These were:

1. Accreditation. PALS staff may offer patients the option of a referral to an existing advocacy organisation either local to the hospital or further afield according to the requirements of the patient. At present there is no formal accreditation, standards for practice or performance monitoring. Working with local organisations has helped us to build an understanding around responsibilities and modes of referral but further work is required to achieve a standards framework for advocacy organisations so that the referral process can be formalised.
2. A practical difficulty in making referrals to advocacy services has been identified by PALS staff when the patient does not fit into an organisation's target client group, the subject is not one they specialise in or the patient does not live in their catchment area. This has all served to highlight the need for the improved provision of general health care advocacy to support patients making complaints. Hopefully this problem will be addressed by the proposed Independent Complaints Advocacy Service.
3. When developing the protocol it became apparent that it would be severely tested by the diversity of cases presenting themselves to PALS and advocates and that success could only be measured over time through the review of a number of closed cases.

Despite these concerns it is felt that the work undertaken by King's has been extremely valuable. It has led to an improved understanding of the role of advocates, particularly in supporting clients with mental health problems or learning difficulties. Furthermore, staff are also much more aware of the range of advocacy services available locally, how to access these services and how the patient may benefit from this contact.

In establishing a PALS service it would seem apparent that meeting with local advocacy organisations to discuss methods of referral will prove to be of great benefit to the development and operation of the service.

## **2.2 Introduction from Advocacy Across London**

Our initial aim with the pilot project was to demonstrate that it was possible to define a positive and constructive working relationship between PALS and independent advocacy services. There will be occasions when an advocacy scheme will be better placed to respond to users' needs than PALS, and vice versa. Not only does the protocol specify the conditions under which a cross-

agency referral may be appropriate, but also the areas where future joint working is possible.

We would like to express thanks to all who participated in the pilot project and hope that the document proves useful both to PALS and advocacy schemes, and as a basis for negotiation around the development of local protocols.

### **3. *Legislative background to the introduction of PALS***

With the advent of the NHS Plan in August 2000, the government unveiled its plans for more patient representation in the NHS. While it had suggested the importance of user involvement in services in various policy initiatives since 1992, the NHS Plan made such involvement mandatory. New structures were proposed to increase patient representation, among them a new service – the Patient Advice & Liaison Service or PALS.

Like the other structures proposed in the NHS Plan, such as Patients' Forums and Local Authority Overview & Scrutiny Committees – the PALS service aims to enable patients to influence NHS services. By providing information about the trust's services, liaising with patients, carers and their families to resolve issues and guiding people on to the complaints procedure and/or external independent advocacy services, the PALS will provide a direct and highly visible service. It will also feed information back into the trust, by recording and noting trends in areas of patient concern, in order to influence services.

### **4. *The King's PALS Scheme***

King's College Hospital is a pilot pathfinder site for the Patient Advice and Liaison (PALS) Service. The service opened in July 2001 and is staffed by two full-time PALS Co-ordinators. The service is located close to the main entrance on Bessemer Road on the Denmark Hill site although staff will visit patients on other sites if required. The service has proved a valuable resource for the Trust and is accessed by staff members as well as patients, their friends and relatives.

One of the key aims of the service is to improve the service offered to patients through the provision of information about the Trust's services and other health related issues. The team also act as facilitators and problem solvers with an emphasis on the swift resolution of concerns and attempt to capture the views of users of the service to act as a catalyst for change through regular reporting to Care Groups and the Trust Board.

In attempting to resolve patients' concerns, the PALS staff do not attempt to deflect them away from entering the formal complaints procedure or from obtaining independent advice or representation. Instead it is hoped that the service will make it clear to patients the options available to them to resolve their concerns.

## **5. What is Advocacy?**

Advocacy means speaking up for people or supporting them in speaking up for themselves. Often, people lack the confidence or ability to make their views and wishes known, or find it difficult to get heard within a particular service or situation. Advocates can support people to obtain their rights, access services and seek redress for particular grievances or complaints. Usually, advocates are independent from service provider agencies, and as such are free from any conflict of interest, enabling them to properly support their client and take instruction only from them.

Over the past 15 years the number and type of independent advocacy schemes in the UK has risen dramatically. There are now advocacy schemes in most local areas, although most are specific to a particular client group (for example mental health, older people) or to a particular form of advocacy (citizen advocacy, peer advocacy and so on).

It is important to note that many groups provide advocacy support to clients but that advocacy work may not be their primary role. These groups may be important for PALS services as they may support, advise or provide information to client groups not supported by other advocacy organisations.

NHS Trusts wishing to find out about advocacy schemes and other community groups in their area are advised to contact their local Council for Voluntary Service (CVS) or refer to the 'useful contacts' section at the back of this document.

### **5.1. Different Types of Advocacy**

Independent advocacy comes in many forms, depending on the client group and area served. The main forms of advocacy operating in London are as follows:

**Citizen Advocacy** – one-to-one, volunteer advocacy, usually long-term. Citizen advocates are 'ordinary' members of the community who are matched with a person in need of advocacy support and are able to represent their particular views and concerns. CA schemes work with a wide range of client groups, including people with learning disabilities, mental health and older people.

**Professional Advocacy** – advocacy provided by paid staff, usually on a casework basis. Professional advocacy may encompass a range of service areas, including health, social care, housing and welfare rights. Most schemes work with clients on a short to medium term basis.

**Peer Advocacy** – peer advocates are people who have themselves used services and are able to use their experiences to support others in a similar situation. Most peer advocates give their time voluntarily although some may be paid.

## **6. Issues for Consideration when Referring**

There are a range of circumstances whereby a referral from PALS to an independent advocacy scheme will be appropriate. These centre primarily on user choice, and differing levels of skills or knowledge in a particular area. It should also be made clear that the approach taken by PALS staff does not conform to any of the existing advocacy models described above, although many of the skills are transferable: their role is in facilitating a means of local resolution and redress for patients' concerns. Individuals requiring long term, one to one support across a range of service areas may still be best served by independent advocacy agencies.

Some of the factors to consider when making a referral are explored on the following pages:

### **6.1. Choice**

Patients have a right to ask for support from friends, relatives or independent advocates in their contact with the hospital. Whether they decide to enlist this type of help is the patient's choice but it is important that they are aware of this option, particularly if they raise concerns or have difficulty in communicating their wishes to the hospital. If a patient does appoint their own advocate, this should be respected by Trust staff, although the fact of having an advocate should not preclude them from accessing the PALS service in addition.

There might also be circumstances under which an advocacy agency or individual advocate cannot adequately support the patient. This may be because the case is outside of their remit or they do not have the capacity. In some instances, the advocate may lack particular expertise (eg in maternity care) or have a moral or ethical objection (eg pregnancy termination) which compromises their ability to provide objective, independent support to an individual. Most advocacy schemes will have written policies and procedures to deal with such situations.

### **6.2. Core Skills and Knowledge**

Depending on the nature of the enquiry, it is essential that whoever supports the patient has the necessary skills, knowledge and expertise to manage their case. Hence, a deciding factor in which agency supports a particular patient will be the agencies' track record in dealing with similar issues. In situations where an

agency or individual advocate does not have the required expertise they should make the patient aware of this and inform them of the option to refer on to someone who does.

Given that the concept of advocacy is still relatively poorly understood by the general public, it is important that all agencies involved make available to patients accessible and clear publicity materials to help people to make informed choices. In particular, agencies need to be explicit about what they can and cannot provide, and any areas of specialist knowledge or expertise (eg mental health, bilingual advocacy). Ultimately, it should be the patient's choice who supports them through the process.

### **6.3. Complexity**

One of the core strengths of PALS is its ability to develop high levels of knowledge and skills within a particular Trust. This should mean that in most cases, the PALS scheme will be able to negotiate a satisfactory resolution to patients' issues and concerns. However, many individuals will present to PALS schemes with a multitude of issues which go beyond a broad definition of health. These may include (but not be limited to) problems with housing; welfare benefits; social services; racism or domestic violence. PALS staff may be able to provide information on how to access support from elsewhere. Independent, community based advocacy agencies may be better placed to handle cases of this nature although some of these agencies may also be limited in their ability to work across a wide range of service systems.

### **6.4. Conflict of Interest**

There will be occasions where a conflict of interest arises between a patient and the PALS service, or where the ability of PALS staff to support an individual is limited by the fact that they are within the NHS Trust system. This may be as much an issue of perception as of reality. Again, it may be that independent, specialist advocacy schemes are best placed to receive and handle such cases.

Where appropriate, PALS workers should make it clear to patients that they are not independent within the Trust system, and support patients to contact independent, specialist advocacy agencies. In this sense, PALS will act as a gateway to independent agencies, not a gatekeeper. However, it is likely that a significant proportion of cases will be resolved satisfactorily by the PALS service.

### **6.5. Cultural Sensitivity**

In a diverse, multicultural society it is essential that all health and social care services are designed to be responsive and sensitive to peoples religious, cultural and language needs. PALS staff and independent advocates will need

the skills to approach cultural issues appropriately and avoid making assumptions about what individuals might need or they may cause offence to the patient.

When dealing with cases where English is not the complainant's first language, or where there is a cultural dimension to the complaint itself, it may be advisable to seek specialist, independent support. This can be obtained via an interpretation and translation agency or from a local minority ethnic community association. Wherever possible, a bilingual advocate should be sought who understands both the language and culture of their client. Most NHS Trusts will already have arrangements in place for interpretation and translation services to be made available to patients, including sign language for deaf people.

## **6.6. Access to PALS**

There may be individuals who are unable to access the PALS service as they are unable to make their views known. This could be due to language or other communication difficulties, learning disability, dementia or lack of confidence or knowledge of the system. It may be that an independent advocate has a role to play in supporting people to access the PALS service, or to act as the primary advocate in cases where capacity is an issue. In either case, staff will need to allocate sufficient time to get to know the person and develop a trusting relationship with them.

## **7. Making Referrals**

Where PALS staff have identified with a patient that a referral to independent advocacy is the preferred course of action, they should discuss whether they would like the PALS team to contact the advocates on their behalf. Alternatively the patient may prefer to self-refer.

If the referral is to be made by PALS the team should make preliminary contact with the advocacy organisation to ascertain whether the referral is appropriate and the organisation is able to accept the case.

If an individual approaches an advocacy organisation with concerns about King's, they may feel that the issue could be resolved through PALS. In such cases they may either contact PALS on the patient's behalf, refer the patient to PALS or contact PALS and provide the patient's details so that contact can be made.

## **8. Monitoring and Feedback**

Where an individual is referred to an independent agency by PALS staff, it is important to clarify where responsibility for monitoring progress lies. This is

important for two reasons; firstly, to ensure a satisfactory outcome for the patient and ensure that the complaint does not get 'lost' in the system and secondly, in order that data about the nature and number of complaints is fed back to the Trust Board via Patients Forums.

Locally, it will be advisable to develop joint protocols for the sharing of information between PALS and independent advocacy agencies. Given the constraints of confidentiality, such information will necessarily be shared in an anonymous format, highlighting key process and outcome issues and identifying any implications for organisational learning and change.

## **9. Referral checklist**

It may be useful for PALS staff to consider the following points in relation to new referrals:

- \* Can the complaint/concern be resolved locally by the PALS scheme?  
What outcome is the client seeking?
- \* Has the client been made aware of their right to independent representation?
- \* What information has the client got about local independent advocacy/support/advice services?
- \* Has the client expressed a preference about whom they wish to support them?
- \* What is the nature of the complaint/concern? Does it relate specifically to services provided by the Trust or are other agencies involved? Would it be better handled by an independent person?
- \* Is there a need for specialist legal advice or representation?
- \* Does the client have particular communication difficulties or cultural/language/religious needs? How will these be addressed?
- \* How will the client be kept informed of progress with their complaint/concern? Which agency will monitor progress?
- \* Does the client appear to understand the process?

## **10. Issues for Further Consideration**

The working group identified a number of issues which, whilst outside of the remit for this project, we believe require further consideration by those involved with both PALS and independent advocacy agencies. These are as follows:

**Training for PALS Staff.** It is apparent that there is a deficit of training courses on offer that will meet the specific needs of PALS staff. Training currently offered for advocates does not reflect the fact that PALS will be often acting as an intermediary and cannot be seen to be independent of the Trust where they work.

Furthermore, the training given needs to provide PALS staff with some of the skills of advocates to help them ascertain from clients why they have accessed the service and their expectations. They must also be able to negotiate with staff at all levels within the organisation to resolve any problems as quickly and amicably as possible.

**Standards for Independent Advocacy.** PALS staff need to know that the independent organisations they refer people to are reputable and accountable. One way of facilitating this would be to develop some form of standards or accreditation for advocacy agencies. The proposed Commission for Patient and Public Involvement in Health will be charged with developing and implementing standards for 'independent complaints advocacy' - will these standards be applicable more broadly?

**Responsibility for Casework Monitoring/ Communication between Agencies.** Once a patient has been referred to an independent agency, where does responsibility for casework monitoring lie? How can we ensure that feedback from casework is passed up the Patients Forums? How can we reconcile the need for feedback with the need to safeguard confidentiality?

## **Appendix 1**

### **Useful sources of information:**

Advocacy Across London  
PO Box No 31856  
Lorrimore Square  
London SE17 3XR  
Tel (020) 7820 7868  
[www.advocacyacrosslondon.co.uk](http://www.advocacyacrosslondon.co.uk)

Citizen Advocacy Information and Training  
Unit 162 Lee Valley Technopark  
Ashley Road  
Tottenham Hale  
London N17 9LN  
Tel (020) 8880 4545  
[www.citizenadvocacy.org.uk](http://www.citizenadvocacy.org.uk)

Greater London Mental Health Advocacy Network  
C/o IAS, Cambridge House and Talbot  
131 Camberwell Road  
London SE5 0HF  
Tel (020) 7703 0261  
[www.capitaladvocacy.org.uk](http://www.capitaladvocacy.org.uk)

Council of Ethnic Minority Voluntary Sector Organisations (CEMVO)  
London Regional Office  
Boardman House  
64 Broadway  
Stratford  
London E15 1NG  
Tel (020) 8432 0300

London Voluntary Service Council  
356 Holloway Road  
London N7 6PA  
Tel (020) 7700 8107  
[www.lvsc.org.uk](http://www.lvsc.org.uk)