

**Patient Partnerships**

Toolkit for staff for setting up a user group

How to effectively involve Patient Partners

### March 2018

### Next review: March 2019



1. **Introduction**

This toolkit has been designed to enable members of staff to involve patients for involvement opportunities such as patient user groups, transformation, measurement, service development and feedback. It can be used as a reference document to ensure that the needs of those attending have been considered and that people's time is used effectively and objectives achieved.

The successful involvement and engagement of patients, their family/ carers and the public correlates closely with how well St Georges University Hospitals NHS Foundation Trust (the Trust) has put in place practical support structures.

Patient and Public Engagement and Experience (PPEE) should be welcomed, valued and recognised as part of the changing culture of the NHS. PPEE continues to develop at the Trust, and already there is growing evidence that involving patients, their family carers and the public has brought about improvements to services and the overall patient experience.

1. **Patient Partnership**

There are both national and local strategies and legislation, which require professionals to engage actual and potential users of local services in making decisions at both an individual and collective level. For details please contact [patient.partners@stgeorges.nhs.uk](mailto:patient.partners@stgeorges.nhs.uk) or contact Patient Partnership Coordinator on ext 5947.

Successful patient and public involvement is not always easy to achieve. It requires time, commitment and cultural change to overcome the barriers that often exist. However, evidence confirms that there are benefits for both the people who use health and social care services and other related services and for those who provide them, such as:

* Better quality and more responsive services
* Better outcomes of health and better health for the population
* Reductions in health inequalities
* Greater local ownership of health and social care services
* A better understanding of why and how local services need to change and develop
* Involvement can range from being consulted about treatment and care or local issues; being informed about a service; taking part in a survey or interview; joining a user, focus, support or specific project group to being consulted about a major plan or development.

1. **The St George’s University Hospitals NHS Foundation Trust Hospital User Consultative Framework**

The Trust has, over the last few years, built up a successful number of Patient user groups involving patients, their carers, local voluntary/ statutory organisations and community groups.

Patient user groups that are now established at St George's University Hospitals NHS Foundation Trust include:

* Cancer Services
* Learning Disability Expert Patient Group
* Maternity Voices
* VOICE Macmillan
* End of Life Care
* Sepsis
* Patient Partnership and Experience Group

1. **What is a Patient User Group?**

Patient User groups:

* Provide a platform for people to reflect on or represent the views of the wider community in co-producing services
* Involve patients and the public in shaping NHS services to meet the needs of individuals and the local community
* Ensure that the services the Trust provides reflect the needs and views of the people who use them
* Enable people to share good practice and raise areas of concern
* Help to build better working relationships and networks with local communities, the voluntary/ statutory sectors and with individuals
* Positively influence change and actively engage people in helping to develop services, meet standards and provide information

These groups can consider a wide range of issues including:

* Specific issues of interest/ concern to their patient group
* Operational issues
* Issues raised through patient surveys/ questionnaires
* Local/ National frameworks or standards
* Research and development

1. **Who can be Involved in a Patient User Group?**

* Individual patients and service users
* Relatives and carers
* Members of the public with relevant expertise or interest
* Members of relevant patient groups, self-help groups and voluntary organisations
* Members of local community groups or organisations
* Members of St Georges University Hospitals NHS Foundation Trust
* Existing St Georges University Hospitals NHS Foundation Trust representatives
* Clinical Commissioning Group representatives
* Social Care Services representatives

Patients offer their time to:

* Share their experiences of the services they have used
* Give ideas and suggestions on how services could be improved
* Share ‘good practice’ and what the organisation does well
* Help the Trust to plan and make decisions about the services it provides
* Bring an independent user perspective to the design, improvement and delivery of services and service plans.

Patients can bring many different perspectives to a Patient User group, in terms of experience, interests, knowledge and expertise.

As a patient or carer they will have expert knowledge of living with or caring for someone who has a particular disease or condition. They will know how it affects their everyday life, will be able to share the bigger picture and have the experience of a variety of services and/ or organisations.

As a member of a local community group or voluntary organisation, they will have specific insights into the needs of, or quality of service provided to, a particular group such as, people with a disability, older people or people from black and minority ethnic communities.

1. **Patient User Groups are not:**

* The place to raise individual complaints about staff, services, treatment etc. Individuals should be informed of the NHS Complaints Procedure and given contact details for the Patient Advice and Liaison Service (PALS)
* Required to fundraise but there is no objection to an individual member using his or her own contacts to raise funds for a group project. The Trust would expect a more general request for project funding to be handled by the Trust lead for the group. Monies raised would be held within St George’s Hospital Charitable funds and disbursed in accordance with fund rules
* The place to raise issues about services, departments etc outside the remit of the group. Any issues, concerns should be raised with the appropriate Trust lead
* Just information-passing groups. They should have agreed terms of reference and achievable action plans to develop services at the hospital
* A token gesture, or a critical friend.

1. **The Patient Partner Consultative Framework Terms of Reference – Patient User Groups**

(See Appendix 2 – Example of Terms of Reference for Patient Partner Groups)

The Patient Partner Consultative Framework Terms of Reference were agreed by the Trust to give guidance in the development of the framework and setting up new Patient User Groups at the Trust.

It is important that each group has its own individual and agreed Terms of Reference, so that all the members of the group understand and are clear about the purpose and aims of that particular group.

The Terms of Reference can also include relevant directives and standards such as, National Service Frameworks, NHS initiatives and national and local development plans and policies.

Terms of Reference should be reviewed on a regular basis and changed as the group develops.

1. **How do I set up a Patient Partner Group?**

The division/ department will need to agree who is going to be the lead staff member for the group and allocate time for that person to undertake the role and responsibilities of the Patient Partnership Group Trust lead. This person will need to be able to support, facilitate and take issues forward on behalf of user group members (see Appendix 3 – Guidance on Roles and Responsibilities).

The Trust lead should contact the Patient Partnership Coordinator ext 5947 or email [Patient.Partners@stgeorges.nhs.uk](mailto:Patient.Partners@stgeorges.nhs.uk) to discuss the user group and what help and advice is needed to promote and support the new user group.

The division/ department will need to provide secretarial cover for the entire user group meetings, whether they are during the day or in the evening. Minutes of this will be available to be uploaded to the Patient partnership section on the Trust website

1. **Recruitment and Appointment Guidelines for Patient User Group Members**

Members should be recent (within the last 12-18 months) users (or carers of a recent user) of services or representatives from appropriate organisations able to represent user experiences.

Patient Partnership Group members may find out about becoming involved in a number of ways:

* Via an informal approach from an existing group member or member of staff
* Through an event such as an open day or coffee morning or Patient Partner stakeholder events
* Via a formal application – completion of patient partner or volunteer application form. (appendix 4)

The forms should be returned to the Patient Partnership Coordinator or emailed to [Patient.partners@stgeorges.nhs.uk](mailto:Patient.partners@stgeorges.nhs.uk)

The Patient Partnership coordinator will review the form initially to ensure it is an appropriate application for a particular group.

The form will be forwarded to the appropriate chair who is then responsible for interviewing the prospective member and deciding if they are suitable to join the group. This should be done in conjunction with the Trust lead.

The Patient Partnership coordinator can provide support and additional guidance on the interviewing and selecting of members.

The interview should be informal and cover:

* The background and aims of the group – including the Terms of Reference and an overview of the group structure, meeting times/ dates, confidentiality and link with the Patient Partner Engagement and Experience Group ( PEEG )
* An overview of what they can expect from the Trust – role of Trust lead, paying expenses, training etc, role of Patient Experience lead
* An explanation of what will be expected of them – regular attendance, participation etc
* Additional requirements – Do they need an interpreter (BSL, Language Line) to enable attendance and participation? Do they need transport to be arranged? Hearing loop? Etc
* What are their particular areas of interest and background?
* Any questions they may have.

The Patient Partnership coordinator should be informed of the outcome – they can then provide any additional information they need before they start attending the group.

1. **What are the Roles and Responsibilities of Those Involved?**

(See Appendix 3 – Guidance on Roles and Responsibilities)

The Trust lead and other members of the group must understand what is expected of them, the boundaries and the commitment and time required to undertake specific roles in the group.

The Trust lead must attend patient user group meetings or, if unable to attend, arrange for another senior member of staff to deputise in their absence.

It is important that everyone is clear about their role in the group, as no single person can represent the views and needs of the many diverse groups who make up a patient population. For Patient Partners, this area can be quite difficult for some people to grasp, as it raises issues about who they are actually representing, their own personal experiences or the wider community's?

A member of a Patient Partner group may decide to focus specifically on feeding in the views and concerns of a support group, a community group, sheltered housing complex or their own personal experience. Members must make it clear if they are their own experiences or those of the network they are drawing their views from and when the experience happened.

It is important that people who join a Patient Partner group are encouraged to share their experiences and views and that all the members of the user group take responsibility in enabling them to do this.

Members and Trust staff must abide by the Patient Partner group's Terms of Reference.

**Remember the four R’s**

**Role**

* Is each member clear about his/ her particular role?
* What contribution does each person think he/ she is able

to offer?

* What do members think each other’s' roles are?

People may make assumptions about the roles of the different group members based on the professional’s title, the individual, the group or voluntary organisation that the person belongs to. Does this mean that he/ she is a representative of an organisation or are they bringing their own individual perspective to the discussion?

**It is important to check this out so that everyone is clear.**

**Remit**

* Does the group have clear Terms of Reference?
* Does everyone have a copy?
* Has the meaning been discussed so that everyone has the same understanding of what they are there to do?

If not, people may be ‘travelling’ in different directions and working at cross-purposes.

**Responsibilities**

**Relationships**

* What is the group responsible for and to whom? (See the Terms of Reference)
* Is the group clear about issues of responsibility, or is it all left to the chair?
* Does the whole group take responsibility for seeking user views, putting items on the agenda and ensuring that members have sufficient information for discussion and decisions?
* Is the group clear how decisions that they make are fed into the wider change agenda within the Trust?

If this is not clear, it might be helpful to do a mapping exercise to see where the lines of communication from the group go. How does the user group fit in with other groups and committees which are also working in the area of PPEE?

* Does the group feel like a working team?
* Do people share a common purpose and goals? Have they ever been discussed?
* Do you know each other as people, or are you strangers bound by your roles?

It will make a difference to how open and honest people are able to be about the issues they are discussing and may well influence the way decisions are made.

1. **The Planning Meeting**

Before starting a Patient Partner group there should be a planning meeting. The Trust lead should discuss with the Patient Experience lead which Trust staff and other organisations should be approached to join the Patient Partner group.

If the Trust lead has been working with patients and their carers on any specific projects, support groups, surveys etc then it would be beneficial to involve them in the planning of the new Patient Partner group.

Contact the key individuals and invite them to a planning meeting to share their ideas and thoughts about establishing a new Patient Partner group and the best way to promote it to reach the people who use the various services.

**Planning Meeting – Agenda**

You may wish to discuss items, as suggested below, so that everyone is clear about the purpose of the user group, the roles and responsibilities of those involved and the standards the Trust expects in developing Patient Partnership Groups. Suggested areas to discuss:

* Trust lead of the group
* Purpose of the group
* Roles and responsibilities
* Membership
* Promotion and publicity
* Secretarial support
* Finance
* Action plan

The Patient user Group will need to decide ways in which it can be promoted to encourage new members.

Some of these items may need to be discussed again at the first and second meeting of the Patient Partner group so that all the members are involved in the development of the Patient Partner group. Suggested Agenda Items:

* Ground rules
* Purpose of the group
* Format of the group (day/ date/ time/ venue)
* Membership and chair
* Terms of Reference
* Travel/ Expenses
* Health and safety
* Promotion
* Action plans

**Ground Rules**

It is important that members set up ground rules to enable and support each other to participate fully in the user group. It is good practice to come back to these ground rules from time to time to remind members what they have agreed or to give an opportunity to add other comments/ suggestions.

Some examples from established user groups:

* Members should be encouraged and supported to share their experiences/ views of services that they have used.
* Members should respect other people’s views and comments and not be judgmental about other's contributions.
* Members should allow each other time to speak, as some people may not be used to speaking in a group/ committee situation or they may have a disability, which affects their speech etc.
* Confidentiality – issues, comments, views should not be discussed outside the meeting, unless members agree that they can be shared or minuted.
* If you do not understand what has been said, ask the person to explain again more clearly.
* No abbreviations... No jargon...
* Check at the end of the meeting how people found it.
* Have fun!

**Promoting the New Group**

The Patient partnership Coordinator can assist in various ways to promote the user group. However, the Patient Partner group needs to be fully involved in how and where they would like it to be publicised. The group once established will appear on our “map of Patient Partnership Groups” visible on our internal and external websites

1. **Expenses**

Payment of expenses is very important. It ensures that potential members are not excluded, for example: due to low income, if they are carers or if they have to travel long distances to attend meetings. Members are also giving up their time to attend meetings and should not be expected, in effect, to donate money as well. The Trust is committed to support members to attend meetings, workshops, training, conferences etc. whilst there is no central allocated budget for this, each Division will be expected to fund this.

Information about claiming expenses is available from the Patient Experience Office.

1. **Transport**

Service users will be encouraged to make their own transport arrangements where possible and mileage or bus fares will be reimbursed if claimed by prior agreement. Members will need to register with the Patient Experience coordinator for expenses.

For those members who attend the meetings at the hospital by car – a car park pass is available, which enables free parking for the duration of the meeting.

It is the responsibility of the secretarial support to individual patient partnership Groups to issue the car park passes.

1. **Interpreters and Special Equipment**

If a member needs an interpreter, including sign language, or a personal hearing loop system etc., the Trust lead should contact the Patient Experience Office who will make the necessary arrangements.

1. **Health and Safety**

It is the policy of the Trust, so far as it is reasonably practicable, that the health, safety and welfare of members is not exposed to any avoidable or unacceptable risks. The health and safety of members of the user group is the responsibility of the Trust lead, including directing people to safety in the case of a fire or an emergency evacuation of the building.

1. **Booking Venues**

The Trust lead/ secretarial support is responsible for venue booking.

Always make sure that rooms/ venues are booked well in advance. Providing a map is also helpful if people do not know the hospital very well. Always make sure that members have a contact number to call in case they cannot attend the meeting – this should normally be the secretarial support.

Ensure rooms are accessible for those with a disability. Rooms off-site should not normally be booked, unless by prior agreement with the Patient Experience lead/Patient Partnership Coordinator.

1. **Training and Support**

Patient Partner group members often have personal experience of a disease, condition or using health and/ or social care services. Some people are used to committees, groups, meetings etc., but some have never been involved in situations like this before.

Training can be provided to support individuals' involvement – contact the Patient Experience lead for further information.

1. **Equal Opportunities**

The Trust is committed to preventing discrimination and stimulating equality of pportunity. All employees and volunteers are expected to comply with the Equal Opportunities Policy and to ensure that it is implemented.

Throughout the Trust it is recognised those involved in patient and public involvement play a very important role and contribute to the Trust’s success.

The Trust actively seeks to encourage people to become involved in patient and public involvement regardless of gender, sexuality, marital or family status, disability, age, race, colour, nationality, ethnic origin, creed or religion, faith or belief.

The Trust requires all employees and service users to respect the rights and dignity of others. The Trust fully embraces the zero tolerance approach towards violence, verbal abuse, harassment and discrimination and will not tolerate breaches. The Trust is committed to protecting its independence and privacy.

1. **Insurance**

Patient Partner group members must sign a Participation Agreement. This will ensure that they are indemnified by the Trust for any work undertaken as part of the Participation Agreement on or off the hospital site.

1. **Data Protection Act 2018**

The Data Protection Act 2018 is the UK’s implementation of the General Data Protection Regulation (GDPR) and governs the way in which the Trust collects and uses personal data.

Data Protection Principles are strict rules that must be followed. Any information about an individual must be kept confidential and not passed on to any other member of staff, without that person’s permission. Any paper information must be kept in a locked cabinet.

•used fairly, lawfully and transparently

•used for specified, explicit purposes

•used in a way that is adequate, relevant and limited to only what is necessary

•accurate and, where necessary, kept up to date

•kept for no longer than is necessary

•handled in a way that ensures appropriate security, including protection against unlawful or unauthorised processing, access, loss, destruction or damage.

1. **Freedom of Information Act 2000**

The Freedom of Information Act 2000 aims to ensure that public authorities, such as the Trust, are open in the way that they conduct their business. In compliance with the Act, the Trust has developed a Publication Scheme, which details all the information that it routinely publishes. This includes minutes and notes of meetings. Patient Partner groups will need to agree how they record members' names under attendance/ apologies and abbreviate people's names mentioned in the minutes.

1. **Conflicts of Interest**

There may be times when involving patients, their family carers and the public with certain projects may raise issues around conflicts of interest with the individual or their family members.

People who become involved with Patient partnership Groups will be asked to register and declare any activities / interests which could cause a conflict of interest. The following are examples of possible conflicts of interest:

* An individual involved in consultation or through a Patient partner group and may be asked to make recommendations for structural improvements to a ward and a relative is a builder who may tender to make these improvements.
* An individual works for a publishing company and the Patient Partner group is looking for someone to publish a leaflet.
* An individual is working on a project, which is looking for voluntary sector partners in the community and they work with a voluntary organisation, which is a suggested partner.

A conflict of interest does not automatically mean that they will be unable to take part in discussion or decision making, but the Trust has to be open and fair about what influences its decision making.

If members become involved in projects where companies tender for work and they have a conflict of interest, it is essential that it is declared, so neither the person or the Trust faces potential legal action by a third party.

Contact the Patient Partnership Coordinator for more information.

1. **Monitoring and Evaluation**

It is important that the Patient user groups have regular reviews to monitor for example:

1. Membership
2. Equal opportunities
3. Access to the group
4. Terms of Reference
5. Action plans
6. Achievements
7. Promotion
8. Information

This will enable Patient Partner groups to develop and enable new people to join and share their experiences, comments and views.

1. **What Problems Might I Experience?**

The following information may be helpful to staff who are currently involved with an established group or are in the process of setting up a new Patient Partner group or project group.

|  |  |
| --- | --- |
| PROBLEM | POSSIBLE SOLUTION |
| Patient Partner group members may:   * feel reluctant to get involved * question how these groups will be able to influence change * see themselves as a token gesture to * meet the requirements of PPEE * wonder if the Trust will listen and act on the issues raised * Wonder if the group has any real power. | Ensure that your Terms of Reference are clear and the group understands the purpose and aim of the Patient Partner group.  Review the membership, especially the seniority of health professionals on the Patient Partner group to take issues forward or make decisions.  Review agenda and minutes. Make sure they include the salient points, actions to be taken, who is responsible for actions and feeding back. |
| Lack of resources | Ensure that time is allocated to enable work of the Patient Partner group to be completed and that administration support is provided. |
| Ensuring effective inclusion and equality may be difficult, for example: reaching and supporting minority ethnic groups, carers, older people, people with learning disabilities etc. | Review membership and access to the Patient Partner group eg venue, time of meetings etc.  Look at ways in which hard to reach groups can be reached, through contact with local organisations, voluntary groups, community leaders etc.  Visiting groups, community meetings, questionnaires. |

|  |  |
| --- | --- |
| PROBLEM | POSSIBLE SOLUTION |
| Similar groups may already exist or are being developed. | Research what is available in the local area to prevent duplication and wasting valuable time and resources. |
| The same people and organisations get involved in Patient Partner groups/ more than one Patient Partner group. | Agree Terms of Reference and the period of time people can be a member of a Patient Partner group to enable new people to join along with new ideas and feedback. |
| Some people who attend groups only have one agenda, which may jeopardise the relationship and working of the Patient Partner group. | Review membership and training needs. Discuss the individual concern outside the Patient Partner group and how it may be affecting development. Support concern by information, signposting, PALS, complaints procedure etc. |
| User groups may be too big and difficult to manage or too small and command little interest or credibility. | Agree Terms of Reference and maximum number of members for the Patient Partner group. Set up sub-groups for certain pieces of work.  Publicise the Patient Partner group to try to attract members or look at other ways of getting feedback from patient Partners. |
| Patient Partner groups can be confused with focus and support groups, which have different aims and objectives. | Make sure your Patient Partner groups role is clear and separate from focus/ support groups. |
| Some members do not attend meetings. | Review membership.  Ask those who don't attend why they don’t attend.  Encourage deputies or substitutes, if appropriate.  Review the time and place of meetings.  Develop roles and responsibilities. Promote claims for expenses.  Consider if information needs to be  provided in different formats.  Consider if team building activity may help a group to develop. |

**Appendix 1**

##### SERVICES

##### CHILDREN AND YOUNG PEOPLE ‘VOICE 4 CHA

**Appendix 1**

Example of Terms of Reference for Patient Partner Groups

(Group name) **Group**

Terms of reference and membership

Purpose of the document

The purpose of this document is to set out the scope of the (group name) and provide guidance on how the group will function.

Introduction

The (Group name) was established in (date) with the purpose of improving patient experience through supporting, developing and promoting improved services at St George’s Hospital.

Membership of the (Group name) is one of a number of ways to get involved with improving the patient experience. By sharing experiences of the services used, the (Group name) can help identify areas of good practice and areas of concern. This will help ensure that the services the Trust provides reflect the needs and views of the people who use them.

The Trust is committed to improving the patient experience and to listening to and involving people who use their services. Feedback will be used to steer continuous improvement, adopting best practice where possible.

Membership

The (Group name) is a group of people affected by (group focus). Members include (define the membership focus here).The group seeks to represent the whole community and to be accessible, inclusive, openly run and courteous. Members have a full understanding of the need for confidentiality and respect.

* It is anticipated that the total number of (Group name) members shall be in the order of up to (how many?) members, which will enable meetings to be attended by up to (Quorum?) members.
* The term of membership of the (Group name) will be for (time period) in the first instance to enable new members to have the opportunity to join. However, members who have completed their term will be allowed to extend their membership if no one else has registered an interest.
* Membership will be reviewed yearly to ensure that as far as possible, it represents the local community. In particular, the (Group name) wants to reflect the views of ‘hard to reach’ communities, where there may be barriers preventing or inhibiting individuals from having a voice. Yearly review also provides an opportunity for members to consider their level of involvement if their personal circumstances change.
* A Chair Person will be elected by the members and serve one year in the first instance. This will be reviewed annually and the appointment may be extended by a further two years up to a maximum period of three years.
* A Vice Chair will be elected, who in the absence of the Chair, will assume the role of chair. The Vice Chair and may or may not be the Chair Designate. The appointment will be for one year in the first instance, which may be extended by a further two years up to a maximum period of three years**.**
* The Chair and Vice Chair will be elected by members of the (Group name) following an agreed selection process for the roles, depending on the number of expressions of interest.
* Co-opted members will be invited to join the group as and when required.
* A quorum will be required as the minimum for any decisions taken, to consist of Chairman/Vice Chair, plus three members (4).
* Any potential conflicts of interests should be declared by members.

Commitment to equality and diversity

* St George’s encourages representation of people from diverse backgrounds but where this is not possible, strategies will be put in place to support communication and participation through links with established community groups in the practice locality.

Scope of the User Group

* The (Group name) is **not** a support group or the place to raise individual complaints or issues about services, departments etc. outside the remit of the group.
* Work with the Trust on a variety of projects where the contributions of patients and carers can improve the experience of patients cared for by the Trust.
* To be a source of advice to (name the area/department that you support here).
* To become an informed source of user/carer feedback to which relevant healthcare professionals may refer.
* Work with the Trust in seeking the views of patients and the public to highlight areas of good practice and make recommendations for improving services for patients and other service users.
* Liaise with other patient and carer involvement groups, community groups and ‘hard to reach’ groups to ensure that services are designed and developed to respond to the needs of individual patients.
* Raise the profile of user involvement within the (name the area/department that you support) and its value in helping to achieve improvements.
* Serve as an advisory group for other Trust committees and working groups which request patient or carer input.
* Liaise with other local service user groups.
* Identify specific areas where improvement is needed and, co-operating with relevant managers and health professionals ensure that patient experience makes a difference to the development of services.

Meetings

* Meetings will normally take place (meeting schedule –eg. Monthly and venue). Members will decide appropriate days / times for meetings, to enable as many groups, organisations and individuals as possible to be represented. Members will decide if other meetings need to be arranged depending on the importance of issues to be discussed.
* Members are expected to attend meetings regularly and to inform the Chair or representative if they are unable to attend a meeting.
* Notes will be taken as a record of the meeting, capturing agenda items discussed, decisions made, resulting actions with names and timelines.
* Any items to be included in the agenda should be sent to the Chair in advance of the agenda being distributed.
* The agenda, notes from the previous meeting and any other papers will be sent out by email a week in advance of the meeting.

Ground rules for meetings

All members are asked to abide by the ground rules to ensure that meetings are properly run. The ground rules will need to be continuously reviewed by the group.

* Everyone is responsible for ensuring the success of the meeting.
* Meetings should start on time, and keep to time, unless under exceptional circumstances.
* Meetings should be chaired effectively.
* Everyone is responsible to adhere to and promote the ground rules.
* All members will promote an environment where individual members feel confident in communicating their own views, in the knowledge that they will be allowed time to speak and will be listened to.
* Members will bring with them different views and experiences. Each member is expected to respect the views and comments of others, while accepting they may not necessarily agree with these views.
* Everything discussed during the meeting remains confidential unless agreed otherwise.
* While sharing personal stories enables lessons to be learnt from experience and can inform the group’s work, members should be mindful that the (Group name) is not a support group.
* Only one person should speak at a time.
* Jargon or acronyms should be avoided where possible and fully explained when they are used.
* If a member does not understand what has been said, they should feel comfortable asking the person to explain again.
* Members may wish to contact each other in between meetings and will have access to each other’s contact details, as agreed by each individual.

Conflicts of interest

Any potential conflicts of interests should be declared by members.

* There may be times when involving (Group name) members with certain projects may raise issues around conflicts of interest with the individual or their family members.
* People who become involved with the (Group name) will be asked to declare any activities / interests which could cause a conflict of interest.

Support and training

* The (Group name) is supported by the (Hospital Representative) at St George’s.
* Support will be given to encourage and empower members who may have communication difficulties.
* All new (Group name) members will be offered an induction pack and will be mentored by an established (Group name) member.
* Training opportunities will be offered to equip people with the knowledge and skills needed to undertake relevant (Group name) roles.

Confidentiality

* The (Group name) members will be required to work within the Trust’s policies, procedures and guidelines. They may be party to sensitive discussions in particular, information relating to the diagnosis and treatment of patients and individual staff information, and have access to confidential information that should not be passed on or shared outside the (Group name) meetings.
* The contact details of individual members will be stored on a database and will be kept in line with data protection guidelines. These details will be shared with (Group name) (as agreed by each individual) so that members can contact each other in between meetings**.**
* All the (Group name) members will be expected to sign a Confidentiality agreement as part of their induction process and agree to abide by the ground rules for meetings. Any breach of confidentiality, will result in membership of (Group name) being immediately terminated by the Chair.

Accountability and reporting arrangements

* People affected by (your health focus) who become members of other (similar health focus/ support) groups will be expected to feed back to the (Group name) on the progress of these groups.
* The (Group name) will advise, liaise with and convey views to the (name your support area/Department or Directorate.)
* The (Group name) will advise, liaise with and convey views to the Trusts Head of Patient Partnerships and Experience
* The (Group name) will hold an annual meeting to discuss membership, appointment of (Group name) roles (if relevant) and review the objectives for the following year.
* The (Group name) will produce an annual review of activity and achievements and will present this report to the Patient Partnership and Experience Group.

Transport

(Group name) members will be encouraged to make their own transport arrangements where possible and travel expenses (see (Group name) expenses claim form) will be reimbursed if claimed by prior agreement.

For those members who attend the meetings at the hospital by car, free parking in the Trust car park is available for the duration of the meeting/event. This will need to be agreed with the (your Hospital Representative) and a form will be given to present at the security office.

Free parking is available onsite after 5pm and weekends.

Financial support

Members will not receive any salary or attendance allowance. However, the following expenses will be reimbursed, subject to prior agreement and approval.

* Travel expenses to:
  + (Group name) meetings.
  + When representing the (Group name) on Trust committees and working groups including the Directorate meetings and work stream groups.
  + (Group name) events.
  + Training.
  + Other public and patient involvement activities agreed in advance

For further information about claiming travel expenses, please contact the (your Hospital Representative).

Review of Terms of Reference

The (your Hospital Representative) Terms of Reference will normally be reviewed every two years.

**Appendix 3**

Guidance on Roles and Responsibilities

To be added

**Appendix 4**

**Volunteer or \*Patient Partner Application Form \***Delete as appropriate

If you would like assistance completing this form please contact us on 020 8725 1452

|  |  |
| --- | --- |
| **A** | **About you** |

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Title: | Surname: | | First Name: | | |
| Home Address: | | | | | |
| Town/City: | | | Postcode: | | |
| Daytime Tel: | | Mobile: | | | |
| Email: | | | | Date of Birth: | Male/Female |

|  |  |
| --- | --- |
| **B** | **Volunteer or Patient Partner roles you are applying for** |

|  |  |
| --- | --- |
| 1st Choice |  |
| 2nd Choice |  |
| 3rd Choice |  |

|  |  |
| --- | --- |
| **C** | **\*Availability\*- Volunteer application only** |

Please tick when you would be available to volunteer:

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
|  | Monday | Tuesday | Wednesday | Thursday | Friday | Saturday | Sunday |
| Morning |  |  |  |  |  |  |  |
| Afternoon |  |  |  |  |  |  |  |
| Evening |  |  |  |  |  |  |  |
| Are you able to give a commitment of at least 6 months? Yes No | | | | | | | |

|  |  |
| --- | --- |
| **D** | **Motivation** |

Please tell us why you want to volunteer at St George’s Hospital and what you hope to gain from volunteering with us.

|  |
| --- |
|  |

|  |  |
| --- | --- |
| **E** | **Experience** |

Please tell us about your work and/or volunteering background, including examples of these important qualities:

* Excellent customer service
* Reliability
* Caring and compassion
* Team work

|  |  |
| --- | --- |
|  | |
| **F** | **Other information** |

|  |
| --- |
| Do you consider yourself to have a disability? Yes No |
| If yes, what support or adjustments do you think you will need to attend interview or take up a volunteering post with us? |

|  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Ethnicity – Please tick one option | | | | | | | | | | | |
| **White:** | British |  | **Mixed white:** | Black Caribbean |  | **Asian British:** | Indian |  | **Black British:** | Caribbean |  |
|  | Irish |  |  | Black African |  |  | Pakistani |  |  | African |  |
| Other |  | Asian |  | Bangladeshi |  | Other |  |
|  | | | | Other |  | Other |  | **Other:** | Chinese |  |
|  | | | | | | **Other ethnicity: (please state)** | | | | | |

|  |  |
| --- | --- |
| Emergency contact – Please give details of someone we can contact in case of an emergency | |
| First name | Surname |
| Address | Relationship to you |
| Home telephone | Mobile telephone |

|  |  |
| --- | --- |
| **G** | **References** |

Please supply details of two references. If you are currently, or have recently been in employment or involved in any voluntary work, one of your references should be from that organisation. Other references must be from people who are over 18 and who have known you for at least one year.

Relatives or partners cannot act as referees.

|  |  |
| --- | --- |
| Referee one | Referee two |
| Name | Name |
| Address | Address |
| Telephone number | Telephone number |
| Email | Email |

|  |  |
| --- | --- |
| **H** | **Declaration** |

|  |  |
| --- | --- |
| **REHABILITATION OF OFFENDERS ACT 1974**  Due to the nature of healthcare work, volunteers are exempt from the provisions of the Rehabilitation of Offenders Act. Therefore, you must not withhold any information about convictions (including those which for other purposes are considered “spent” under the Act), previous or pending prosecutions, cautions or bind overs applicable either in the UK or abroad.  Any information provided will not necessarily prevent you being appointed unless the particular conviction, previous or pending prosecution, caution or bind over means you are unsuitable for the role.  Failure to declare a conviction, previous or pending prosecution, caution or bind over, either in this county or abroad, will disqualify you from the application process. All successful applicants will be checked by the Disclosures and Baring Service (Criminal Records Bureau) before they are able to take up their post.  Please note that you will be asked to provide details, including approximate date, the offence and the authority and country which dealt with the offence, if you are shortlisted for a role. | |
| Are you currently bound over or have you ever been convicted of a criminal offence, cautioned, warned or reprimanded in the UK or in any other country? | Yes No |
| Are you aware of any current police investigation in the UK or any other country following allegations made against you? If yes, please use separate sheet for details. | Yes No |
| Does your name appear on the Protection of Children Act List? | Yes No |
| Are you legally entitled to work in the UK? | Yes No |

|  |  |
| --- | --- |
| In accordance with the 2018 Data Protection Act it is agreed that St George’s University Hospitals NHS Foundation Trust may hold and use personal information about me for placement reasons and to enable St George’s University Hospitals NHS Foundation Trust to keep in touch with me. This information can be stored in both manual and/or computer form, including the data in section 2 of the Data Protection Act 2018.  I understand that in order to be considered for a role as a volunteer I will be asked to produce evidence of identification, address, and status in the UK when applicable.  I declare that the information given on this form is true and complete. I understand that any false information may result in the withdrawal of any offer of voluntary role or my dismissal if accepted as a volunteer. | |
| Your Signature: | Date: |

**Appendix 5**

Patient Partner/Volunteer Agreement

St George’s University Hospitals NHS Foundation Trust values the contribution made by volunteers to the Trust’s aims and services. This document sets out the responsibilities it bears to support volunteers and the expectations it has of volunteers in respect of their individual placements. This is not a contract and there is no intention to create a contractual relationship between St George’s University Hospitals NHS Foundation Trust and the volunteer signatory.

Patient Partner/Volunteer Rights

* Patient Partners/Volunteers should receive regular support and supervision, and training as applicable.
* Patient Partners/Volunteers are not to be regarded as a substitute for paid staff. Services provided by volunteers complement those provided by paid staff.

Patient Partner/Volunteer Responsibilities

* Patient Partners/Volunteers must be reliable in their commitment and should inform the Voluntary Services Manager as early as possible if they are unable to continue.
* Patient Partners/Volunteers should keep within the boundaries of agreed tasks and not undertake duties which are normally covered by portering or domestic services.
* Patient Partners/Volunteers are bound by Trust policies, which include Health and Safety, and Equality.
* Patient Partners/Volunteers should always conduct themselves in an appropriate manner and not behave in a way likely to bring the Trust into disrepute.

I understand that anything I see or hear in the Hospital must be treated as strictly confidential at all times.

I realise that I must not divulge any information concerning patients and that this includes patient’s names and addresses.

I understand that the Hospital cannot be held responsible for the loss or damage to personal property.

Patient Partners/Volunteer Name: …………………………….……………Area:………………

Sign: ………………………………………………….. Date: ………………………………………

Foundation Trusts are membership organisations and you will automatically become a member unless you opt out.

**Becoming a member is free and demonstrates that you:** Support us, Believe in our values (Kind, Excellent, Responsible, Respectful), Care about the services we provide, Want to hear more from us and celebrate our success

**Members will:** Receive regular news and information from the trust, Receive invitations to exclusive events and seminars Be entitled to vote for and elect the council of governors, Be able to stand for election to the council of governors

Please tick the box if you would like to Opt Out

**Appendix 6**

**Best Practice when Involving Patients, Their Family Carers and the Public-**

The following points have been suggested by Patient Partners who are involved in Patient Partnership Groups at the Trust and with other organisations:

1. **Good Communication**

* Be clear about the task – this will enable individuals to make an informed choice about whether they want to participate.
* Be clear about the basis for involvement – are you looking for a personal perspective or do you need people who can consult with their peers or organisations to offer a ‘broader’ view?
* Patient Partners/ Carers need to be greeted. Ensure that someone meets them at reception or inform the receptionists where the meeting is being held, so that they can direct people.
* Briefing papers, minutes etc should be written in easily understood English, without jargon and abbreviations.
* A telephone/ email reminder is often useful to ensure that professionals, staff invited to the meeting remember to attend.
* Don’t use jargon or abbreviations during meetings.
* Make sure members understand what is being said. Enable and empower them to feel comfortable about asking for points to be repeated or explained.
* Be sensitive to cultural and/ or language needs. Book an interpreter (language or sign) or any special equipment such as a loop system.
* Make sure that people know whom to contact in case there is a problem or if they require more information.
* It is important that members know the names of other members attending similar groups and that a support framework is established. It is very important that members are in agreement for you to give out personal details.
* Evaluation events are a very good way to bring all members together to share good practice and lessons learnt from successes and failures.

1. **Be Aware of the Barriers**

* Individuals may be unwell and not able to attend every meeting.
* Recognise that people’s abilities and understanding may be different and find

ways to support, include and empower all Patient Partners group members.

* Individuals who care for others may have difficulties in attending meetings.
* Be aware of accessibility, including timing, for example around religious events.

1. **Be Honest and Open**

* Let the Patient Partner group set its own ground rules and review these from time to time, so that everyone included is working together as equal partners.
* Value individuals' involvement, views, comments and suggestions.
* Listen and respect what is being said – be aware that emotions may run high.
* Don’t patronise or be judgmental.
* Admit mistakes.
* If difficult decisions have to be made, be honest and open about them.

**4. Support People**

Members and their carers need to be valued, trained and supported, for example: prompt and appropriate expenses payments, access to training, being respected and taking their individual needs into account.

* Make sure that individuals are reminded about claiming their expenses and that a car parking pass is sent well in advance of the meeting.
* Check that there is good access for people with a disability, for example: parking/ transport arrangements, the venue, toilets and lifts.
* If you are asking members to share personal experiences, think about how this may affect others in the group, particularly if the member has had a bad experience. How can you use their experience, good or bad, in a positive way

to improve services or share good practice? Be prepared for different reactions from individuals in the group. Staff and service users may have different views and ideas. How will you deal with this in a professional manner and how will you support those sharing their experiences?

* Encourage individuals to attend personal development training to build on their knowledge, confidence and skills.
* Do not let dominant individuals take over the group. You may need to discuss this with the person outside of the meeting. Remind the group of the agreed ground rules.
* Inform members about the emergency exits and where the assembly points are in case of a fire or major incident.

**5. Arranging Meetings**

* Be creative, inclusive and sensitive to the needs of the members.
* Give plenty of notice, and details about the meeting: date, venue, time etc.

Include a map.

* Try not to cancel meetings. Members will probably have to make arrangements to enable them to attend a meeting. It will not always be easy for them to re-arrange their diaries.
* Time the meetings with care – not too early or when people may need to collect children from school etc. Consult with members to find the best times.
* Introductions are very important and name cards are also useful.
* Make sure that service users understand their role and the roles of other members.
* Make sure members have all the relevant, user-friendly and clear information required for the meeting and ask members how they would like to receive information.
* Consider the length of the meeting and provide breaks if required.
* Papers tabled at meetings should be for information and discussed at future meetings if required. Don’t overload members with papers.
* The Trust lead and the chair agree the agenda for the next meeting. Try not to have too many agenda items, be realistic.
* The minutes of the meeting are a record of the proceedings. They should be a brief report of what was discussed, agreed and the action points.
* Allow sufficient time between meetings for people who use services to consult with their peers or their organisations.
* The Trust lead should contact the responsible individuals to check that action points have been followed-up.