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Effective patient partnerships

An introduction to setting up a patient user group

November 2020

Introduction

This document provides an introduction to setting up a patient support group at St George's.

St George's recognises the important work of its existing user groups and we are keen to encourage and support you to form a group in your clinical area.

We have set up the Patient Partnership and Experience Group (PPEG), which can support all patient and carer engagement across the Trust.

PPEG is happy to offer help and advice and you can reach us at Patient.Partners@stgeorges.nhs.uk or call 020 8725 1452.

In this document we cover the initial steps you'll need to take to set up a new patient user group, including considering your purpose and forming your group.

Please visit our website here for more information and guidance on how to set up your group, as well as a range of hints and tips based on good practice.

These include:

- National and local background on service user and carer engagement

- Information about existing user groups at St George’s and hints and tips on running your group
- Sample terms of reference for a patient group
- Essential guidance covering issues such as data protection, equal opportunities and expenses,. It is important that you note all these issues
- A chart showing how individual user groups fit within the management and accountability structures at St George's.

“I can honestly say that it has been the most rewarding role and has brought me into contact with so many lovely people.

I enjoy the chance to hear the opinions and ideas of the patients and have the satisfaction of feeding them back to the Trust and then seeing the changes that are made and the improvements to the experience of the Cancer patients at St George’s Trust.”

Sue Fox, Chair of Voice, the Cancer Patient Support Group at St George’s

Engagement during the Covid-19 pandemic

Clearly the Covid-19 pandemic poses some challenges to running a patient user group. However, it may also present opportunities. Some patients and carers may find it easier to engage remotely.

When setting up your group it will be helpful to consider:

- Who is comfortable coming to an in-person meeting and where? Are the numbers compliant with government regulations?
- What technology users have and the online platforms that they are able and willing to use
- The extent that they are willing and able to communicate directly with each other – ie sharing contact details

Please ensure you are aware of the Trust's policies regarding online contact and use of technology. Contact patient.partners@stgeorges.nhs.uk for further information.

Guide to planning and setting up your group

Step 1: consider your purpose

Patient user groups can help you to:

- Understand the needs and views of the patients and carers in the St George's community
- Shape services that meet those needs – for individuals and the community
- Ensure that patients and carers feel involved and engaged in services
- Provide insights into how services impact on those who use them and how any proposed changes might work
- Share good practice and raise areas of concern
- Build better working relationships with local communities, statutory and voluntary groups
- Help the Trust to communicate about services in ways that are accessible to patients and carers

- Suggest areas for change and development.

A group can consider a wide range of issues including:

- Specific issues of interest or concern to their patient group
- Operational issues eg appointment systems, referrals
- Issues raised through patient surveys/questionnaires
- Local/national frameworks or standards
- Research and development
- Development of patient friendly information publications.

Who should you involve?

It is a good idea to have a range of stakeholders such as:

- Individual service users
- Relatives and carers
- Trust clinical staff relevant to the group
- Members of relevant patient groups, self-help groups and voluntary organisations: and community groups both local and national, as guest attendees.

You may sometimes want to invite representatives from:

- Clinical commissioning
- Social care services

What are you asking patients to do?

- 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 its services
- Provide insights into how health issues and treatment impact on people's wider lives, for example, employment, housing, religious and cultural factors, emotional and practical issues
- Representatives of community and voluntary groups will have specific insights into the needs of particular groups such as people with a disability, older people, and all minority groups.

Patient User Groups are not:

- The place to raise complaints. This should be done via the Patient Advice and Liaison Service (PALS) and/or by informing people about the NHS Complaints Procedure

- 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 place to raise issues about services and departments outside the remit of the group
- Just information-passing groups. They should have agreed terms of reference and achievable action plans
- A token gesture.

Agreeing terms of reference

It is essential to have clear terms of reference (ToR) so that everyone is clear about the purpose and remit of the group. The terms can also reference relevant directives and standards such as National Service Frameworks, NHS initiatives and national and local development plans and policies.

Currently within the Trust, user groups have adopted a range of models. Please visit here to see a sample ToR and also specific ToRs adopted by current groups at St George's.

You should regularly review your ToRs and may need to change them as your group develops.

Step 2 – forming your group

One or more patients can decide to set up a patient group. The first step is to talk to the division or department to agree who will be the lead staff member for the group. This person will need to be able to support, facilitate and take issues forward on behalf of user group members. You will need a range of inputs from the Trust:

- Secretarial support including notices of meetings, producing minutes, and uploading them to the Trust website, and booking rooms. Note: some meetings may take place outside normal office hours
- Occasional presence of senior clinicians for relevant agenda items
- Upon request, support from the Trust's communications team
- Regular communication with the Trust's Patient Partner Engagement and Experience Group (PPEG).

Engaging patients and carers

Members should be recent service users of the Trust or carers of a recent user of services. They can also be representatives from appropriate organisations able to represent user experiences.

You can promote membership in various ways:

- Informally via an existing group member or member of staff
- Using fliers or posters in outpatient and inpatient areas
- Through an event such as an open day or coffee morning or patient partner stakeholder events
- Via relevant community and voluntary groups and, where appropriate, their social media networks.

All relevant service users and carers should be able to join the group. If you have a large membership, you may find it helpful to have an organising committee.

As the group grows, it will be important to consider whether the people involved broadly represent the people who use the service. You may need to actively reach out to achieve a diverse perspective.

Roles and responsibilities

- It is essential that the Trust lead attends meetings or sends a suitable substitute
- It is also important that patients and carers understand their role:
- They are giving their own perspective and should not be expected to speak for all users
- Or they may be additionally involved-with community or

voluntary groups in which case they will usually have a wider perspective

- Some patients may choose to be part of the organising committee and take on specific roles
- You will need to elect a chair. We strongly suggest that you have two co-chairs: one from the Trust and one service user/carer
- Secretarial/administration support is essential. You will need to make sure that this person has the capacity to do the job
- Clarify other tasks and who will do what from the Trust and amongst users and carers.

Please visit our website for more useful information on setting up your group, including:

- Suggestions for issues the group could consider including ground rules, monitoring and evaluation
- Tips on running the group, how to communicate about your group and how to promote it.


WELCOME

Finally...

We hope you have found this introduction helpful and strongly encourage you to look at the next steps as well as the wealth of other information on our website.

Don’t forget that the Patient Partnership and Engagement Group is here to help you, promote you and learn from your experiences.

You can email us at Patient.Partners@stgeorges.nhs.uk or call 020 8725 1452.

We welcome your feedback on this document and the resources available on our website.

“PPEG is keen to support you in creating new user groups and in running established ones.

“We want to create dialogue so groups learn from each other, and the Trust hears patient and carer voices across many areas - and learns from their feedback.
I encourage you to read this resource and take your group forward. It’s rewarding to meet other patients and staff - and you can make a real difference.”

Liz Aram, Co-chair of Patient Partnership and Engagement Group (PPEG).