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WHAT IS A PATIENT GROUP?

A selection of patients and practice staff who meet at regular intervals to decide ways of making a positive contribution to the services and facilities offered by the practice to the patients.

Purpose of Patient Participation Groups

- To give practice staff and patients the opportunity to discuss topics of mutual interest in their Practice
- To provide the means for patients to make positive suggestions about the Practice and their own healthcare.
- To encourage health education activities within the Practice.
- To develop self-help projects to meet the needs of fellow patients
- To act as a representative group that can be called upon to influence the local provision of Health and Social Care
- To involve further patients from the wider population

6 Main Areas of Work

- Providing Feedback from patients
Providing feedback from consumers e.g. appointment systems, consultation times, need for notice board
- Health Promotion
e.g. Diabetes awareness day, first aid training, taking ownership of your own healthcare
- Voluntary activities
e.g. walking groups
providing transport
establishing carers group
- Fundraising
To fund group costs
For equipment e.g. patient wheelchair, refreshment machine.
- Information
Practice leaflets
Newsletters
Local facilities

Health care information

- Representation
Acting as a representative group that can be called upon to influence the local provision of health and social care

Patient Participation Groups

Positive Outcomes of Patient Participation Groups

Improving Services provided by the Surgery

- Carrying out surveys into a whole variety of subjects e.g. health needs/expectations & major cause of ill-health in a particular area.
- To explore the changing needs of patients
- Measure patient satisfaction
- Gather ideas for improvements or modifications needed for the delivery of services
- Discussions at meetings

Offering support to other patients, including:

- Bereavement support
- Carers group
- Hospital visiting
- Shopping and support for housebound patients
- Home visits for the isolated

Improving facilities at surgery

- Fundraising for new furniture, toys or decorating
- Keeping the plants or gardens of the surgery maintained
- General environmental improvements

Providing social activities for patients

- Trips and holidays for the elderly
- Exercise classes
- Walking for health group
- Creating babysitting circles
- Voluntary/honorary grand parenting

Providing Information

- Organising a health fair
- Offering handouts and support on special days e.g. National No Smoking Day
- Individual patients as teachers and expert patients with long term illnesses to newly diagnosed e.g. Diabetics etc
- Producing patient newsletters for the practice
- Ensuring that patient information and advice is as user friendly as possible
- Representing your practice locally and nationally when patient voices are needed

Arranging special health events

- Training in basic first aid for patients
- Training new parents to distinguish when to call for medical assistance and when to self treat
- Awareness around particular illnesses e.g. breast cancer
- Awareness for particular cultural groups around issues that relate to them more specifically

Potential Problems

Whilst these points cannot be overlooked, they are all things that can be overcome if handled in the right way if the practice takes advantage of help that is offered to them when setting up a group.

1. Practices fear that the group becomes exclusive and that it is not representative of the general make up of the patient population.
2. Patients think that by joining such a group they will experience better service from the doctors, nurses, and practice generally.
3. Fear that patients will see a PPG as a forum for airing any moans they may have to.
4. Fear that the GP will spend a lot of time answering personal queries or complaints rather than achieve anything positive for the practice

TIPS FOR DEVELOPING A SUCCESSFUL PATIENT GROUP

Promotion and Recruitment of Patient Group

The most obvious channels for promotion are:-

- On surgery notice boards
- At surgery User Groups e.g. baby clinic
- By word of mouth
- Through leaflets/ handouts at Reception
- Through leaflets in Repeat prescriptions
- Practice Newsletters
- Approaching people directly
- Ensure membership is ongoing to make up for members who leave

Planning agenda items and group objectives

Having a focus for the group is very important as it maintains interest and gives the group a clear aim. Agenda items should take into account the views of Practice staff and patients. This is more likely to ensure that GP's and Practice staff view the group in a positive as opposed to a threatening way.

- Feedback from surveys with patients, suggestion boxes, practice staff and patients. This ensures the interests of all parties are met.
- Up-to-date information provided about the practice
- See the attached tool "planning agenda and focusing activities of group"
This may be helpful in prioritising groups activities
- Group objectives should be drawn up which are realistic and achievable

Committee

The classic tried and tested set up of a group committee consists of

- An elected chairperson – who manages the meetings
- An elected Secretary – responsible for taking minutes, general Admin
- An elected Treasurer – responsible for taking care of funds and finances

Sharing the Work

Although in order for a group to be successful at least a couple of members need to be very committed, it is important that all the work does not fall on the hands of one person. In such cases, the group is likely to run into difficulties if this key player leaves.

- Establish roles and responsibilities and review these regularly
- Look into training for members so that they can develop their skills and play a more active role e.g. chairing meetings, fundraising.
- Use a rota system e.g. for taking minutes.

Communication Channels

Within the group

Patient groups tend to operate most effectively if representatives from the practice as well as patients are present. This ideally means a GP and practice Staff. This allows up to date information to be given to patients and will inform what decisions can be influenced and what cannot. It will also allow the practice staff to gain an understanding from the patient's perspective. It may also be useful for the chair to have meetings with the Practice Manager on a regular basis or attend management meetings of the practice. This ensures that two way communication is achieved.

Feeding Back

Group activities should be fed back to all practice staff and to the rest of the patient population. This will ensure that everyone is aware of the activities of the group and may increase involvement and interest.

Ground Rules

These are important as a point of reference if a difficult situation arises. Some ground rules to consider could include:-

- Group should not be seen as a complaint gatherer
- Patient Confidentiality
- Everyone's view is as valid as another
- Racism and discrimination will not be tolerated
- You may also wish to decide how often the group meets at this point

Funding Issues

It is inevitable that the group will incur some costs. These may either be minimal running costs for admin etc, or the greater costs of funding some of the more ambitious objectives e.g. a wheelchair for the practice.

Some funding ideas are listed below:-

- Membership Fee
- Fundraising at community events
- Coffee mornings
- Jumble Sales
- Raffles
- Quiz nights
- Applying for small grants

Things that can't be avoided

It is unlikely that the group membership will have representatives all of sections of the population due to people's different priorities and time commitments. However, the group itself can focus on involving the wider population.

- The times of meetings will never be suitable for everyone
- Any group takes work and commitment of members

The Main Reasons Groups fail

- Lack of focus
- Poor planning
- Poor communication to and from the group
- Hostility between group and Practice or vice versa
- Relying too heavily on one or two people
- Poor Ground rules

Remember – Although Patient Groups can be very successful if time and commitment are given and thought is put into the planning process, they are not the only, or necessarily the best way of involving patients. Other alternatives to a

patient group may include a Patient Panel whereby members of the patient population agree to be consulted on a variety of issues.

Available Help and Advice

Lewisham PCT Siobhan Power, Public and User Involvement Facilitator,
Lewisham PCT, 26 Admiralty Close, SE8 4SS 020 8694 6894 ext 259

The PCT may be able to help with newsletter design, recruitment, qualitative interviews with patients and practice staff, and will help you assess your needs.

V.A.L. (Voluntary Action Lewisham) 020 8314 9411

N.A.P.P (National Association for Patient Participation) 0151 6305786 or
www.napp.org.uk

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Sample constitution of Patient Group

1. To provide resources and services for the good of the Practice population which would not otherwise be provided by Statutory Services
2. To encourage a spirit of self help and support amongst patients to improve their health and well being
3. To improve communication between the service providers, the group, and the wider population.
4. To promote a patient perspective and enable patients to access and make the best use of available health care.

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Sample Objectives for the group

Short term objectives

1. Produce a newsletter which reports on results of recent survey
2. introduce a children's area in the waiting room
3. Make a link with the local voluntary Transport Scheme for our patients.

Medium term objectives

1. Establish a link with the church to provide a support group for the elderly/lonely
2. Arrange a diabetes awareness day
3. Produce a practice leaflet with up-to-date information

Long term objectives

1. Site up an information web site for the practice with information about health issues
2. Explore the use of alternative treatments at the practices which may be partly funded through the funds raises.

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SCENARIOS

Below are a series of dilemmas designed for the use in work groups.

These are the designed with the objectives of:-

- Highlighting some potential issues arising with Patient Groups from varying perspectives.
- Problem solving ways around these issues before they arise.

- Dealing with potential problems.

It is intended that the scenarios can be used as a tool for working with those who wish to set up patient groups and those who are already involved with patient groups.

SCENARIOS

1.

You have been involved with setting up a patient group at your practice. There were 20 patients present at the first meeting. It is now the third meeting and there are only 5 patients present. You are concerned that the group will eventually fade out completely.

- How might this situation be avoided?
- How can this issue be addressed?

Issues covered: loss of interest, apathy, lack of focus etc

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2.

You are the Practice Manager and have taken on the responsibility of attending your practice's Patient Group. It has been running well for a year due to a very committed Chair Person. The Chair Person is now relocating to Scotland at the end of the month and no one seems to want to take her place. You are worried about the future of the group.

- How might this issue be resolved?
- Is there any thing that could have prevented this situation from arising?

Issues covered: relying on one key player, contingency planning, on-going recruitment, offering training (either chair person, or external) etc

3.

You are an active member of your Patient Group. You bump into your GP outside the local Post Office one day who says she saw you coming to the Patient Group last week as she was leaving to go home. You ask her what she thinks of the new proposed appointment system and she replies "it's the first I've heard about that."

- How might this situation be avoided?
- How can this issue be addressed?

Issues covered: channels of communication between group and staff, group being misled about the changes they can influence, actions agreed by group not being taken forward etc

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4.

You decide you want to attend your Practices Patient Group which has been running for the last eleven months. When you arrive you are not introduced to the rest of the group and find it very hard to follow what is going on. You are beginning to wish you had never come along.

- How might this situation be avoided?
- How can this issue be addressed?

Issues covered: Exclusivity of group, welcome policy, background info for new members etc, feedback mechanisms etc

5.

You are at your patient group. While waiting for everyone to arrive, you overhear one patient say "I don't think Juliette should come to these meetings any more, she is far too old and doesn't have anything to offer. Anyway, I'm sure she can't hear what's going on."

- What issues does this scenario highlight ?
- How should this issue be addressed?

Issues covered: Dealing with inappropriate behaviour, need for agreed ground rules etc

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6.

You are trying to start a patient group and have received a lot of interest at reception with 60 patients registering interest. As part of the process you have asked people to indicate what their availability is. When you look at this you notice that there is never a time when more than 7 patients can attend.

- What would you do in this situation?
- Are there any ways you could ensure that all interested members are able to get involved?

Issues covered: Looking outside of the group to involve patients, establishing systems for all patients to feed into etc

7.

You are a GP and attend every third Patient Group. You are concerned about the purpose of the group and that it seems to be turning into a social club. One member suggests bringing in a good video his son brought him for his birthday.

- How might this situation have arisen?
- How can this issue be addressed?

Issues covered: Differing needs and expectations of staff and patients, lack of structure, is there an unmet need for a social club? etc

8.

You have voluntarily agreed to take be the secretary for your patient group. However, you did not realise how much of a commitment this was as you have been spending along time typing up minutes and agendas ... not to mention the postage costs.

- How might this situation have arisen?
- How can this issue be addressed?

Issues covered: sorting out practical issues initially (e.g. reimbursing expenses), reviewing, support.

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9.

As the Practice Manager, you are the only member of the Practice team who attends the monthly patient meetings. The patients normally bring up items for the agenda. You are sure that many of the doctor's would not support patients discussing certain issues but are not sure how to tell the group.

- What do you do in this situation and why?
- Are there any ways this scenario could be avoided?

Issues covered: All parties being represented at meetings. Decision making processes fully explained.

10.

You are a GP attending a patient group meeting for the first time. The group seem very negative are complaining about the waiting times and the length of time it takes to get repeat prescriptions back. Another patient complains that when she visited her doctor last week he only spent two minutes with her.

- How might this situation be avoided?
- How can this issue be addressed?

Issues covered:: need for clear information and feeding back of practice policies, deciding what decisions can be influenced by patients, finding more positive focus etc.

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