

Patient Involvement

A guide to involving patients
and carers in GP practices



Reader information box

Title	A step by step guide to involving patients and carers for GP practices and patients.
Description	The aim of this guide is to offer some support and practical guidance to GP Practices, who are interested in involving patients and carers in the running of their practice. The guidance will also support practices in achieving their Patient Participation Directed Enhanced Service (PPDES).
Audience	Practice managers, GPs and other general practice staff.
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With thanks to	NHS Norfolk

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1 Welcome and introduction

The aim of this guide is to offer some support and practical guidance to general practices who are interested in supporting patients to get more involved with their local healthcare. The toolkit will also support practices in implementing the requirements of the 2011/12 PPDES by using this logo to indicate which aspects of involvement will be audited.



The Future Forum agrees with us that patients and carers should be at the heart of the NHS, through shared decision making about their care and meaningful involvement in how health services are organised. We view these core strands of our modernisation plans as essential if we are to achieve healthcare outcomes that are among the best in the world.

Government response to the NHS Future Forum report, 2011

In June 2011, following a listening exercise, the NHS Future Forum published key recommendations to Government on the future for NHS modernisation. Public accountability and patient involvement remain central to Governments commissioning agenda and commissioners will be expected to demonstrate how they have involved the public on 'any changes that affect patient services, not just those with a "significant" impact'

Public and patient involvement should be integral to the work of consortia. The consortium must be accountable to patients and the public who will need to participate in such decisions.

The principles of GP commissioning, BMA, 2010

The Patient Participation 'Directed Enhanced Service' (DES) is a new nationally negotiated enhanced service which aims to incentivise best practice for patient participation. It aims to ensure that patients are involved in decisions about their practice and that practices are encouraged and rewarded for routinely asking for and acting on the views of their patients. As part of the PP DES practices will need to set up a Patient Reference Group (PRG). It is important to note that the PRG is for people interested in helping practices to improve the practice. The PRG is not a meeting for people who want to complain about the practice. If patients have a specific complaint they should be advised to contact the practice manager and follow the practice complaints procedure.

Each GP practice will be individual and will reflect the unique aspects of the practice and its population. This toolkit is intended as a guide only and should be adapted to suit the needs and ideas of local groups.

An electronic and word version of the pack can also be found on the NHS Leeds intranet here: <http://nwww.inet.leeds.nhs.uk/index.pl?iid=12806>

This guide is based on a similar document produced by NHS Norfolk. It has been produced in consultation with patients, the public and local Clinical Commissioning Groups. We would like to thank NHS Norfolk for sharing their ideas and experience and supporting us to develop this toolkit.

2 What is patient involvement?

Patient involvement is about involving patients, carers and the public in the planning, delivery and evaluation of your services.

Why do we involve people?

By involving patients and the public in shaping services, professionals are able to understand the needs of their community and provide a better service. There are many benefits to involving patients and the public in your work.

- **Better and more patient-centred care**
 - It can improve the quality of the care you provide.
 - It helps you to tailor treatment packages to the needs of individual patients.
 - It supports your patients to manage their own care - especially those with long-term conditions - by improving communication.
 - Volunteering can have a positive effect on a person's sense of happiness.
 - It can help you promote understanding of call and recall processes within practices with your patients which may assist you in meeting some of your key primary care targets i.e. Quality Outcomes Framework (QOF) indicators, cytology and immunisations.
- **Greater trust**
 - It can improve patient's experience of using your services.
 - It demonstrates openness by ensuring patients are aware of changes in the service.
 - It explains to patients why decisions have been made.
- **Stronger patient choice**
 - It promotes public health and helps reduce inequalities.
 - It ensures that you are transparent, responsive and accountable to the people you serve.
 - It encourages active citizenship.
- **Validating the PPDES**
 - In March 2011 the government announced a new patient participation Directed Enhanced Service (DES) which seeks to promote 'active engagement' between GP surgeries and patients.
 - Practices will be asked to demonstrate that they have:
 - ~ set up a patient reference group (PRG);
 - ~ prioritised activity using the PRG;
 - ~ developed and circulated a survey for patients;
 - ~ taken survey findings to the PRG;
 - ~ agreed an action plan with PRG; and
 - ~ publicised what actions have been taken.

- **Statutory duties**

- Commissioners of healthcare services also have a duty to involve patients and the public. The NHS Act 2006, section 242 states that we should involve our patients in planning, developing and operating the services we provide. These duties will be transferred to GP Clinical Commissioning Groups in 2013.

What are the principles of involvement?

The NHS National Centre for Involvement suggests the following key principles for Patient and Public Involvement.

- **Be clear about what involvement means** - ensure you have a clear understanding of roles and responsibilities
- **Focus on improvement** - rather than fault-finding
- **Be clear about why you are involving patients** - be clear about the objectives of the work and be honest about what you can change.
- **Identify and understand your stakeholders** - make sure your stakeholders are appropriately involved and that involvement activity is relevant to your stakeholders' interest.
- **Involve people** - promote opportunities to get engaged and make sure people have the support they need.

How do we involve people?

There are three ways you can involve people in your work.

- **By giving them information**

Providing patients with information can increase confidence, knowledge and improve the patient's experience. You can use:

- newsletters and websites;
- notice boards;
- posters / leaflets; and
- events / information giving sessions.

- **By asking them what they think**

Carrying out surveys on proposed changes that could impact on your patients enables you to identify issues before they occur. You can:

- carry out local patient surveys;
- hold consultations; and
- provide comments boxes.

- **By actively engaging with them**

The most rewarding type of patient involvement is active participation. This gives the practice an opportunity to develop strong links with the local community, and it gives patients an opportunity to participate in decision making. You can:

- hold patient reference groups;
- carry out interviews; and
- hold events.

Try to use an involvement method appropriate to the issue you are addressing and try to use approaches from each of these three groups. Using different methods allows you to engage with diverse groups and gather feedback from a range of different people.

3 A step-by-step guide to involving patients

Use this tool to assess your current level of patient involvement and to make future plans. The tool can be filled in as you work through your training session and used to make notes. The document may also be useful to guide you in the implementation the PPDES.

Stage 1: Celebrate what you are already doing

Leeds has some good examples of effective patient engagement. Many practices already run successful patient reference groups which have supported significant service development. Practices in Leeds often develop surveys to canvas the opinion of patients on specific topics and respond to postings on NHS Choices. Many practices hold events to inform patients of proposed service changes and the majority of practices have patient newsletters, websites and practice leaflets.

Comments boxes, patient surveys and complaints procedures are all valuable tools for gathering patient experience information and all these methods form part of patient involvement.

Give examples of how you involve people at your practice

- | | | |
|--|--|--|
| <input type="checkbox"/> Social networking | <input type="checkbox"/> Patient drop-in | <input type="checkbox"/> Posters in the waiting area |
| <input type="checkbox"/> Patient reference group | <input type="checkbox"/> Patient surveys | <input type="checkbox"/> Comments box at reception |
| <input type="checkbox"/> Patient Newsletter | <input type="checkbox"/> Practice leaflet | <input type="checkbox"/> Practice website |
| <input type="checkbox"/> Responding to postings on NHS Choices | <input type="checkbox"/> Responding to postings on Patient Opinion | <input type="checkbox"/> Other (please state) |

What changes have you made as a result of patient involvement?

Notes

Stage 2: Identify a keen member of staff

Having a patient involvement champion for each GP practice will really help you get this work off the ground. It doesn't need to be a big job but it will provide patients and other staff with a point of contact for issues relating to patient involvement.

A patient champion would benefit from having the following skills and competencies:

- Experience of working with members of the public
- An understanding of and commitment to the principles of patient involvement
- Good listening skills and an ability to empathise
- An ability to communicate information
- Problem solving skills
- An ability to facilitate groups
- An ability to dedicate some time to this role

In addition to identifying a patient involvement champion, you should make sure that all your staff are aware of your patient involvement plans and are invited to regularly attend patient events.

What other qualities do you think a patient involvement champion might need?

How will you involve the rest of your team in patient involvement?

Who will you ask to be a patient involvement champion?:

.....

Notes

Stage 3: Set up a Patient Reference Group (PRG)





A patient reference group (PRG) aims to give practices and patients an opportunity to work together to improve services. A PRG does this by meeting regularly to discuss topics of mutual interest. A virtual PRG (vPRG) is an email or web-based community who do not meet face-to-face but provide the practice with feedback and comment online.

The PRG is for people interested in helping you to improve the practice. The PRG is not a meeting for people who want to complain about the practice. If patients have a specific complaint, they should contact the practice manager and follow the practice complaints process.

A PRG or vPRG might be set up to explore a specific topic such as a move to a new building or it might be a long-term forum to address ongoing issues. The group should be part of a wider patient involvement strategy that provides patients and carers with different ways to feedback to the practice.

If possible, consider asking interested patients to help you set up the group. This will help ensure that the forum is appropriate, will save you time and demonstrates best practice. Don't be tempted to only invite people who will say nice things – this won't be representative and won't help your practice develop.

PRGs are an important part of the new Patient Participation Directed Enhanced Service (PP DES). As part of the PP DES, GP surgeries will be expected to demonstrate that:

-  • they have established 'a Patient Reference Group comprising only of registered patients';
-  • it 'uses its best endeavours to ensure its Patient Reference Group is representative of its registered patients';
-  • the practice
 - 'informs the Patient Reference Group of the findings of the local practice survey';
 - 'provides an opportunity for the Patient Reference Group to comment and discusses the findings; and
 - 'agrees with the Patient Reference Group an action plan setting out priorities of findings and any proposals arising out of those findings'.
-  • if, as a consequence of the findings or proposals arising out of the local practice survey, the contractor wishes to implement changes in the manner in which it delivers primary medical services, the contractor must:
 - (i) seek the agreement of the Patient Reference Group to implement such changes; and
 - where such changes are significant and the Patient Reference Group does not agree to such changes or the changes relate to, or impact on, the terms of the primary medical services contract, discuss the proposed changes with the Primary Care Trust and obtain agreement of the Primary Care Trust before such changes are implemented.

Stage 3: continued...

The following tools will help you set up your PRG:

- 'Setting up a PRG' Appendix A (page 20)
- 'Setting up a vPRG' Appendix B (page 26)

Set a date for your 1st PRG:

What methods will you use to invite patients to your PRG?

How will you ensure that you invite patients from a representative sample of your practice population?

How many times a year will you hold your PRG?

☐

Less than
three

☐

three

☐

four

☐

five or
more

What will you talk about at the first meeting?

How will you distribute the minutes of the PRG to your patients?




Notes

Stage 4: Ask patients what they think

Asking patients for their feedback on your practice should be an ongoing process using a variety of methods and approaches.

A patient survey is an example of a simple tool for obtaining feedback from the people who use your services. A survey could be used to explore a specific topic such as a proposal to deliver a new service or it might be a generic survey to capture patient experience of using your practice. Surveys can provide a snapshot or can be used to explore patient experience over a longer period of time.

Patient surveys are an important part of the new PPDES. There are no set parameters for the size of the survey but GP surgeries will be expected to demonstrate that they have:

-  • developed, 'in consultation with the Patient Reference Group, a local practice survey to obtain the views of a cross-section of the contractor's registered patients'
-  • 'agreed with the Patient Reference Group the issues which are a priority and which are to be included in a local practice survey'
-  • carried out and collated 'the findings of a local practice survey
 - at least once in the period commencing on the date the contractor enters into the arrangements and ending on 31st March 2012; and
 - where the contractor has entered into arrangements in respect of the twelve month ending 31st March 2013, at least once in that period;'

Stage 4: *continued...*

The following tools will help you set up your PRG:

- 'Writing a patient survey' Appendix C (page 27)
- 'Patient survey template' Appendix D (page 30)

A patient survey should be part of a wider patient involvement strategy that provides patients and carers different ways to feedback to the practice.

What methods will you use to ask patients what they think?

How will you show that you have involved patients in the development of the patient survey?

When do you plan to send out your survey?

Give an overview of the demographics of your population

How will you distribute your survey and how will you ensure that the survey reaches a representative sample of your practice population?

When do you plan to feedback the results of the patient survey to your PRG?

Notes

Stage 5: Use the patient reference group (PRG) to develop an action plan

Patients should be given a variety of ways to feedback to your practice. Your PRG can use this feedback to identify common themes and issues at the practice. These themes should be used to develop the objectives which make up your patient involvement action plan. This plan needs to be focussed on service delivery and you should be clear about who will lead on each objective. You should also indicate any outcomes from the work you undertake.



Developing an action plan is an important part of the new PPDES. Practices will be expected to:



- 'agree with the Patient Reference Group an action plan setting out priorities of findings and any proposals arising out of those findings'.

You will use your action plan to write your yearly patient participation report which outlines the involvement work you have undertaken with your patients.

The following tool will help you and your patients develop your action plan:

- 'Patient involvement action plan' Appendix E (page 34)

When will you write your patient involvement Action Plan?

How will you demonstrate that your patient involvement action plan has been influenced by patients?




Based on your knowledge of the practice, what key themes do you think might emerge? (it is important to base your action plan on patient comments rather than your assumptions)


Notes

Stage 6: Don't forget to feedback

Patient involvement should be a 'conversation' between patients and staff. As part of this conversation, staff should talk to patients about how they have responded to comments made about the practice by its members. This is sometimes called 'you said, we did'. It is important to always feedback, even if you are unable to make changes.


Feeding back to patients and the PCT is an important part of the PPDES. The Primary Medical Services (Directed Enhanced Service) Directions 2011 ask for practices to feed back to patients in the following ways:

-  • 'a website to include information on the services provided by the contractor under the terms of its primary medical services contract'
-  • 'a copy of a report to the Primary Care Trust (to be known as "the Local Patient Participation Report")'.
-  • 'a Local Patient Participation Report ("LPP Report") on the contractor's website:
 - where the contractor entered into the arrangements under the Scheme during any part of the twelve month period ending on 31st March 2012, a first LPP Report no later than 31st March 2012, and a second LPP Report no later than 31st March 2013; and
 - where the contractor first entered into the arrangements under the Scheme after 31st March 2012, a LPP Report, no later than 31st March 2013.

 **Practices will also be asked to write a local patient participation report (LPP) which should include:**

- i. a description of the profile of the members of the Patient Reference Group;
- ii. the steps taken by the contractor to ensure that the Patient Reference Group is representative of its registered patients and where a category of patients is not represented, the steps the contractor took in an attempt to engage that category;
- iii. details of the steps taken to determine and reach agreement on the issues which had priority and were included in the local practice survey;
- iv. the manner in which the contractor sought to obtain the views of its registered patients;
- v. details of the steps taken by the contractor to provide an opportunity for the Patient Reference Group to discuss the contents of the action plan;
- vi. details of the action plan setting out how the finding or proposals arising out of the local practice survey can be implemented and, if appropriate, reasons why any such findings or proposals should not be implemented;
- vii. a summary of the evidence including any statistical evidence relating to the findings or basis of proposals arising out of the local practice survey;
- viii. details of the action which the contractor:
 - aa and, if relevant, the Primary Care Trust, intend to take as a consequence of discussions with the Patient Reference Group in respect of the results, findings and proposals arising out of the local practice survey; and
 - bb where it has participated in the Scheme for the year, or any part thereof, ending 31st March 2012, has taken on issues and priorities as set out in the Local Patient Participation Report;

Stage 6: continued...

- ix. the opening hours of the practice premises and the method of obtaining access to services throughout the core hours; and
 - x. where the contractor has entered into arrangements under an extended hours access scheme, the times at which individual healthcare professionals are accessible to registered patients.
-  • There is also 'a requirement that the contractor consider whether any amendments are necessary to any of its published information relating to the services provided by the contractor as a consequences of the implementation of any changes following a finding or proposal arising out of the Local Practice Survey;'

The following tool will help you write your patient participation report:

- 'Patient Participation Report' Appendix F (page 37)

What information will you feedback to your patients?

- | | | |
|---|--------------------------------------|---|
| <input type="checkbox"/> Results of patient survey | <input type="checkbox"/> PRG minutes | <input type="checkbox"/> What action you have taken as a result of patient engagement |
| <input type="checkbox"/> Other (please state) | | |

How will you feedback to your patients?

- | | | |
|---|--|--|
| <input type="checkbox"/> Social networking | <input type="checkbox"/> Posters in the waiting area | <input type="checkbox"/> Patient reference group |
| <input type="checkbox"/> Patient Newsletter | <input type="checkbox"/> Practice website | <input type="checkbox"/> Dedicated patient noticeboard |
| <input type="checkbox"/> Other (please state) | | |

When do you plan to write your 'patient participation report'?

Notes

The following tools will also help you feedback to your patients:

- 'Setting up a PRG' Appendix A (page 20)
- 'Setting up a vPRG' Appendix B (page 26)
- 'Writing a patient newsletter' Appendix G (page 40)
- 'Patient newsletter template' Appendix H (page 43)
- 'Developing a website and using social media' Appendix O (page 58)

4 Glossary of terms

Active engagement

An approach to participation which encourages self-questioning, deeper thinking and problem solving.

BMA (British Medical Association)

The British Medical Association is the professional medical association and trade union for doctors and medical students.

The BMA have put together a toolkit to support General Practitioners (GPs), Practice Managers and consortia meet the requirements set out in the Health and Social Care Bill 2011.

You can find the toolkit here:

http://www.bma.org.uk/images/ppitoolkit_tcm41-207789.pdf

Clinical Commissioning Groups

These are groups of GPs that will, subject to legislative approval from April 2013, be responsible for designing local health services in England.

They will do this by commissioning or buying health and care services including:

- Elective hospital care
- Rehabilitation care
- Urgent and emergency care
- Most community health services
- Mental health and learning disability services

Your clinical commissioning group can support you develop your patient involvement work. Contact details for the CCGs can be found below:

Consortia	Address	Contact email
Leodis	Leodis 4210 Park Approach Avenue Ground Floor Thorpe Park LEEDS LS15 8DG 0113 295 1091	debra.backhouse@nhs.net
H3+	H3+ Suites 2-4 Ground Floor Wira House West Park Ring Road Leeds LS16 6EB 0113 843 7470	H3plus.pbcgroup@nhs.net

Glossary of terms: continued...

Consortia	Address	Contact email
Calibre	Calibre c/o The Street Lane Practice 12 Devonshire Avenue LEEDS LS8 1AY	Petra.morgan@nhs.net
Independent Practices	c/o Angela Bettison / Lisa Maginnis PBC Locality Managers NHS Leeds North West House Ring Road West Park LEEDS LS16 6QG	Angela.bettison@nhsleeds.nhs.uk Lisa.maginnis@nhsleeds.nhs.uk
NHS Leeds PBC Lead	Kirsty Turner Senior Locality Commissioning Manager NHS Leeds North West House Ring Road West Park LEEDS LS16 6QG 0113 305 7437	Kirsty.turner@nhsleeds.nhs.uk

Diversity, Inclusion and Vulnerable groups Team

The Diversity, Inclusion and Vulnerable Groups team are part of the Corporate Development Directorate based on the first floor of North West House. The team has two functions that compliment each other and help NHS Leeds to maximise the impact of our work in relation to equality, diversity and vulnerable groups.

We work with directorates to embed equality and diversity firmly within the governance structures and processes within NHS Leeds to ensure we promote equality of opportunity in relation to the services we commission and for our workforce.

You can contact the team on: 0113 305 7447.

Glossary of terms: continued...

Leeds LiNk

Local Involvement Networks (LiNks) are made up of individuals and community groups, such as faith groups and residents' associations, working together to improve health and social care services.

Leeds LiNk may be able to support you recruit members to your PRG. For more information contact Leeds LiNk on 0113 388 5099.

NAPP (National Association of Patient Participation)

Formed in 1978, NAPP promotes and supports patient participation in primary care.

Find out more here:

["http://www.napp.org.uk/"](http://www.napp.org.uk/) <http://www.napp.org.uk/>

NHS Brand Guidelines

These guidelines show you how to use the NHS brand properly and effectively. They can be used to develop practice leaflets, surveys and newsletters.

There is specific guidance to support general practitioners.

["http://www.nhsidentity.nhs.uk/all-guidelines/guidelines/general-practitioner/introduction"](http://www.nhsidentity.nhs.uk/all-guidelines/guidelines/general-practitioner/introduction) <http://www.nhsidentity.nhs.uk/all-guidelines/guidelines/general-practitioner/introduction>.

NHS Institute for Innovation and Improvement

Assists the NHS in transforming healthcare for patients by developing and spreading new work practices, technology and improved leadership.

The organisation has developed a number of resources to support patient and public involvement.

Find out more here:

HYPERLINK ["http://www.institute.nhs.uk/commissioning/tackling_tough_choices/patient_and_public_involvement.html"](http://www.institute.nhs.uk/commissioning/tackling_tough_choices/patient_and_public_involvement.html) http://www.institute.nhs.uk/commissioning/tackling_tough_choices/patient_and_public_involvement.html

Appendix A

Setting up a Patient Reference Group (PRG)

The stages below will help you set up your PRG.

1. Get some support

Staff are available to support you in setting up your PRG. They will be able to give you advice and guidance on making your PRG effective. For more information, contact your patient involvement and communications representatives. Details of your Patient, Carer and Public Information Team can be found in the 'Reader Information Box' at the beginning of this document.

2. Organising the first meeting

Consider when and where you will hold your first meeting. Be aware that the time, venue and date may exclude some members of the community. Consider what you will do to ensure that as many practice members as possible get an opportunity to contribute.

Set a date for the first meeting. Give yourself a few weeks to promote the forum.

3. Recruit to the group

Identifying people to invite to a PRG can be challenging. The interest level is usually dictated by the level of promotion and the practice population.

a. Firstly consider which of the following groups you will run:

Open	These groups are open for any patient to attend.
Invited	An invited group is formed by inviting patients directly who are known by the practice and its staff. This is a particularly useful method if you set up a group to look at a specific topic. You should be aware that you will be asked to demonstrate that you have invited people who are representative of the communities served by the practice.
Application	If you have a large number of people interested in the group you might consider an application method. This invites people to apply to attend the group and the practice can choose the people who attend. Again, you should be aware that you will need to demonstrate that you have chosen people who are representative of the communities served by the practice.
Virtual PRG	A virtual PRG is an email or web-based community where people can get involved online. This can be a great way to involve people who cannot attend meetings.

It is worth remembering that the more restrictive you are with recruitment the harder it is to recruit. You might like to try more than one of the above groups and see which one, or one's are most effective. The PPDES requires practices to ensure their groups are representative of the practice population but does not state a minimum number of participants. A group is usually most effective when it is attended by between 8 to 15 people.

b. Consider how you will promote and recruit to your group. There are a number of ways that you can do this:

- Posters and flyers
- Electronic message board
- Newsletters and newspaper articles
- Visit local community groups
- Notes on prescriptions
- Inform your patients using email or letter
- Consider inviting people who you and your staff think will be interested
- Contact Leeds LINK (for details see the glossary of terms on page 17)

Ideally you should invite all your patients to get involved in the PRG by writing to them individually. In reality this can incur a large cost. Burton Croft and Holly Bank practices, which have recently moved, used their re-location comments form to invite every patient at the practice to join the PRG. This method enabled them to develop a database of people who were interested in getting involved at the practice. This approach will still require the practice to review their membership regularly to ensure that the group is representative. It is more common for practices to identify PRG members through newsletters, posters and electronic noticeboards. You might want to consider inviting people to the PRG that staff feel would be interested in getting involved. If this approach is used it is important that the group reviews its membership to ensure it is representative. Other ways PRGs have recruited members include inviting all patients who have gone through the practice complaints process and encouraging existing PRG members to invite friends and family who are registered at the practice.

c. You might like to consider what commitments your PRG members will need to make to be part of the group. These might include:

- Attending meetings spread throughout the year
- Reading the meeting papers in advance of meetings
- Contributing to discussions during meetings
- Providing a representative view of the practice
- Assisting the staff in understanding the perspectives of patients and the public, including identifying other potential opportunities / roles for patients / the public to be effectively involved
- Maintaining confidentiality where appropriate
- Providing feedback on documents, such as patient information leaflets and newsletter content
- Considering ways in which wider patient and public involvement can be achieved
- Declaring any conflicts of interest where appropriate
- Undertaking training as necessary to the role
- Identifying any personal needs for training or support

4. The first meeting

Your first meeting is an opportunity to get to know each other and set the agenda for future meetings. You might like to consider the following at your first meeting:

- **Keep it short.** One to one-and-a-half hours initially.
- Make sure that you **make notes and write down action points**.
- **Ask people to introduce themselves.** You could ask people to tell the group what interested them in attending or ask them to share something interesting about themselves.
- If patients raise **specific complaints** simply explain that the forum cannot resolve these. Advise them to discuss the issue with you outside the meeting and give them a copy of the complaints procedure / PALS number.
- **Set groundrules.** Explain that groundrules are essential for the group to function effectively and safely. Ask the group what, if any, groundrules they would like. Following this, suggest the rules you would like the group to function by - here are some examples;
 - 'The group should represent the views of the practice population'.
 - 'The group is not a forum for individual complaints or single issues'.
 - 'All views are valid and will be listened to'.
 - 'No phones or other disruptions'.
 - 'We will start and finish on time and stick to the agenda'.
 - 'We advocate an open and honest debate'.
 - 'Confidentiality should be maintained at all times'.
- Ask the group to tell you their **expectations of the PRG**. Write their ideas on a flipchart. Briefly discuss your vision of a PRG. Point out that the direction of the group will be decided by all its members but that you expect the group to focus on:
 - Identifying aspects of the practice that need to improve
 - Identify aspects of the practice that are appreciated by patients
 - Improving the quality of the service
 - Improving access to the service
 - Overseeing significant changes to the service
 - Improving communication between patients and the practice
- Give the participants a brief **Introduction to Involvement**. Your PPI rep might be able to help you with this. You should cover the following areas:
 - What is PPI?
 - Why is it important?
 - What are the principles of involvement?
 - What does 'being representative' mean?

- Talk to the group about your role and give information about the practice and policy context.
 - When was the practice established?
 - Who works there and what services do they offer?
 - Key achievements?
 - Challenges?

- **Agenda items**

There are a number of items you could include on your agenda. Here are some ideas for discussion:

Feedback complaints

You could use the meeting to feedback to the PRG the complaints you have had over the last few months. You should remove any patient identifiable information before doing this. Remember that the discussion should be focussed on making improvements. Ask the group to identify which issues they feel are most important. These issues should be themed and developed into objectives.



Write your patient survey (Appendix C)

You may want to use your first PRG to develop your patient survey.



Start writing your patient involvement action plan (Appendix E)

You may want to use your first PRG to develop your patient involvement action plan.

Feedback suggestions

If you have a suggestion box consider feeding any suggestions back to the group. Ask the group to identify which issues they feel are most important. These issues should be themed and developed into objectives.

Practice assessment

You could use groupwork to help you identify what you are doing well, what you could improve and should give you ideas about how you can improve. Ask the group to split into small groups and give them a sheet of flipchart paper, post-it notes and pens. Ask the group to write examples of the following on individual post-it notes and add them to the flipchart paper

- What does the practice do well?
- What does the practice do less well?
- How could we make the practice better?

Ask the group to identify which issues they feel are most important. These issues should be themed and developed into objectives.

Hopes and fears

This groupwork will help you to develop your 'terms of reference' for the group by identifying what people want to get out of the group (aims/objectives) and what barriers they might face. Ask the group to split into small groups and give them a sheet of flipchart paper, post-it notes and pens. Members should consider what they are hoping to get out of the group (personal, community or professional development) and any concerns they have about attending the group. Ask the group to write each hope and fear onto individual post-it notes and add them to the flipchart paper.

- Don't forget **AOB, Evaluation** (ask the group how they have found the meeting), **Date of next meeting** and **Thanks**.
- Using your notes from the meeting you should write a draft '**terms of reference**' for the group and send this out for comment.

5. Future meetings

To keep your group going, consider the following actions:



- The priority at your next meeting might be to **develop your patient involvement action plan** which sets out your objectives for the PRG.
- **Involve your members** in every aspect of the forum; planning, delivery and evaluation.
- Ensure you have **good communication** with all your members.
- Keep all correspondence **simple and to the point**.
- Send out documents to members a week before the meeting so that they arrive **prepared and informed** of the agenda.
- **Reiterate your groundrules** at the beginning of each meeting
- Consider what standard **agenda items** you might need. These may change and should always reflect the needs of both practice and patients. Consider including:
 - the results of your most recent patient survey;
 - themes from complaints;
 - CQC feedback to the practice; and
 - topics of interest to the local community.
- **Review your terms of reference** regularly and always agree these with your forum members.
- Review your members regularly and consider how you can **increase the diversity of the group**.
- Avoid saying 'no' straight away (even if you know that something cannot be done). **Explore the issue**, look at the benefits and drawbacks.

- Always **thank your patients** for attending.
- Most importantly, **feedback to your group** on the issues they raise - even if this is simply to explain which of their ideas cannot be taken forwards.

6. Feedback

Don't forget to feedback the discussion and outcomes from the meeting to all your patients.

- Make minutes available at the practice or on the website
- Include a 'you said, we did' section in your newsletter
- Add information to the electronic noticeboard in the waiting area

A number of other useful PRG tools have been made available in this pack. These include:

- 'PRG Meeting Poster / Flyer template' Appendix I (page 46)
- 'PRG invite letter' Appendix J (page 47)
- 'First PRG Meeting agenda' Appendix K (page 48)
- 'Sample Terms of Reference' Appendix L (page 49)
- 'Subsequent PRG Meeting agendas' Appendix M (page 52)
- 'Ensuring diversity' Appendix N (page 56)
- 'FAQ' Appendix P (page 61)

Appendix B

Setting up a virtual patient reference group (vPRG)

Regularly attending a meeting at your practice will be difficult for some sections of the community. A virtual PRG can give some of these people the opportunity to get involved without the additional commitment of coming to meetings. A virtual PRG might be used by a practice who do not believe that a PRG will be successful in their area. Some practices might use both types of group so that they can engage with a more representative section of the community. It is worth remembering that practices who only use a virtual reference group still need to demonstrate that they have engaged with a representative section of their community.

To decide how viable a vPRG would be for your practice you could ask a related question in your patient survey.

When recruiting to your PRG collate the email addresses of people who would like to join a virtual PRG. Set up a distribution list of all the members of your vPRG.

The group can be used for:

- Sending out the patient survey;
- Sending out documents relating to the PRG meetings;
- Setting the agenda for the PRG; and
- Feedback of practice documents.

When sending a distribution list email to multiple patients it is important to use the 'Bcc' (blind carbon copy) field to maintain confidentiality. The 'Bcc' facility enables you to send one email to lots of different people without revealing all the email addresses to each participant. People receiving a Bcc email will only be able to see your email address.

Appendix C

Writing a patient survey

The following the stages will help you develop your patient survey.

1. Get some support

Staff are available to support you in putting together your patient survey. They will be able to help you format your survey and questions in a way that makes it most effective. For more information contact your patient involvement and communications representatives Details of your Patient, Carer and Public Information Team can be found in the 'Reader Information Box' at the beginning of this document.

Some Clinical Commissioning Groups (CCGs) might want all their practices to ask the same core questions and may contact you to discuss this.

2. Decide what information you want to capture

In order to write your patient survey you will need to know what your patients feel are the key issues at your practice. You should ask your PRG to help you develop your patient survey. Alternatively, you could use a vPRG, a one-off event or responses to a previous patient survey to develop the survey.

Consider what themes have arisen from previous patient events, previous patient surveys, your PRG or your complaints process. Think about what information you are required to provide to the CQC and the PCT / local commissioning group.

Common themes associated with practices, might include:

- Access to appointments
- Practice environment
- Clinical care
- Attitude of staff
- Public health
- Information and advice

The patient survey is also a good opportunity to promote and recruit to your PRG and vPRG.

3. Keep the survey as short as possible

People don't generally fill in long surveys, so aim to have no more than ten questions.

4. Make sure the survey follows a logical order

Start the survey with a short introduction. The introduction should include:

- What you are asking the patient to do - to share their experience of using the practice.
- Why you are asking them - to improve the service you offer
- Information on confidentiality

- Contact details for people who need support filling in the survey
- A deadline for filling in the survey

Group similar questions together and keep any profile questions (such as age and gender) at the end.

5. Keep the questions as simple as possible

There are three types of question you could use:

- **Open questions**, where respondents can write whatever they like. These questions take considerably more effort to fill in and should be kept to a minimum.

Think about when you last contacted our practice and tell us what was good or less good about your experience.

- **Multiple choice questions**, where respondents select one or more answers from a list. These can be filled in quickly and will improve your response rate.

How would you like to contact our practice to make an appointment?

Telephone ☐
Email ☐
Text ☐
In person ☐

- **Scaled questions**, where respondents can rate the answers they give. These questions enable you to quickly see what areas you need to improve. If you use scaled questions try to use the same scale throughout the survey.

Please tell us how you feel about the following ways to contact our practice.

	Very dissatisfied	Dissatisfied	OK	Satisfied	Very satisfied	Don't know
Telephone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Email	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Text	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
In person	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

6. Consider how you will roll out the survey

There are a number of methods you could use to collect the information for your survey:

- **Paper surveys** are a useful way for the majority of patients to feedback. These can be sent out with letters and left in the reception area.
- **Online surveys** are a popular and convenient method for a large section of the population. It is a relatively cheap way for practices to get feedback and will improve the return rate, especially amongst younger patients and those who rarely attend the practice. You could send a copy of your survey to your patients by email or use one of the many companies who can help you create a free online survey.

Using a variety of methods to disseminate the survey will increase your return rate and help you gather responses from a more representative section of your patients. You could use the following methods to share your survey with your practice members:

- Provide a link to your survey from your website
- Ask clinical and/or reception staff to hand out your survey at the end of an appointment
- Provide copies of the survey in your waiting area

Ensure that people are able to feedback anonymously and that the survey is confidential. You could use a 'comments box' for people to return the survey anonymously.

7. Some other useful tips

- Ask interested patients or your PRG for help. They may have ideas about what questions to ask or have skills they can offer to support the project such as IT skills.
- Avoid leading questions
- Keep the survey focused. Avoid asking questions that are just 'nice to know'.
- Consider how you will demonstrate that you are reaching diverse communities i.e. equality monitoring
- Ensure that you use the survey to promote your PRG - give patients details of how they can get involved at your practice
- Test the survey before you send it out
- Include information on how the survey will be distributed
- Thank your patients at the end of the survey

8. Act on the results!

Once the results are in, you should ask your PRG to help you identify any themes. Use the patient involvement action plan to prioritise the issues and develop objectives. It's OK to agree that some issues are too difficult to address, but be open-minded and encourage the group to find creative and innovative solutions.

Make sure that you share the findings and actions with the wider practice population. There are a number of ways you could do this:

- Newsletter
- PRG
- Website
- Posters
- TV information service

Appendix D

Patient survey template

The following document is a template patient survey. You may want to use this template to help you develop a survey which meets the needs of your patients and your practice.

Feel free to make any amendments and don't forget to populate the survey with specific information about your practice.

For an amendable word version of this tool please visit the NHS Leeds intranet here:
<http://nwww.inet.leeds.nhs.uk/index.pl?iid=12806>

Spring / Summer / Autumn / Winter 20XX

Practice logo
Consortia logo

The survey is confidential and you don't need to fill in your name.

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Postcode:

1. Appointments

Considering this appointment system, please tell us how much you agree with the following statements

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
If I need an urgent appointment I am usually seen the same day.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If I need a non-urgent appointment I am usually seen within one week	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am happy with the current appointment system	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2. Opening times

We appreciate that many patients need flexible opening times. Our current opening times are:

Mon	Tues	Wed	Thurs	Fri	Sat	Sun
8am - 6pm	8am - 6pm	8am - 6pm	8am - 6pm	8am - 6pm	8am - 6pm	8am - 6pm

Considering our opening times, please tell us how much you agree with the following statements

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
The practice is open at times when I can attend an appointment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am happy with the current opening times.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3. Our surgery

We want to make your visit to the surgery as pleasant as possible. Please tell us how much you agree with the following statements

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
The practice is easy to get to.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The staff are friendly and approachable.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The practice is clean and tidy.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Overall I think the practice is welcoming.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4. Clinical care

Providing excellent clinical care is our priority. Please tell us how much you agree with the following statements

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
I feel listened to by the clinical staff.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The clinical staff treat me with dignity and respect.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The clinical staff communicate their message clearly and effectively.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am confident in the treatment I receive from the clinical staff.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am happy with the clinical care I receive.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

6. Getting involved

Did you know that we hold a patient reference group (PRG) four times a year? Did you know that we have a virtual PRG which allows you to get involved online? This group gives our patients the opportunity to get involved in helping improve the practice. If you are interested in finding out more about our patient reference groups tick the box below and make sure you have filled in your contact details on the front of this form.

I would like to find out more about the patient reference group. ☐

5. Other comments

Equality monitoring

By filling in this equality monitoring section you will help us ensure that we get feedback from all the different communities in our area. Filling in this section is optional. Any information is kept in strict confidence.

Are you?

<input type="checkbox"/> Male	<input type="checkbox"/> Female	
<input type="checkbox"/> Heterosexual / Straight	<input type="checkbox"/> Lesbian / gay woman	<input type="checkbox"/> Gay man
<input type="checkbox"/> Bisexual		
<input type="checkbox"/> Under 16	<input type="checkbox"/> 17 - 24	<input type="checkbox"/> 25 - 34
<input type="checkbox"/> 35 - 44	<input type="checkbox"/> 46 - 54	<input type="checkbox"/> 55 - 64
<input type="checkbox"/> 65 - 74	<input type="checkbox"/> 75 - 84	<input type="checkbox"/> 84+
<input type="checkbox"/> White British	<input type="checkbox"/> White Irish	<input type="checkbox"/> Gypsy or Irish traveller
<input type="checkbox"/> Mixed White & Black Caribbean	<input type="checkbox"/> Mixed White & Black African	<input type="checkbox"/> Mixed White and Asian
<input type="checkbox"/> Asian / Asian British Indian	<input type="checkbox"/> Asian / Asian British Pakistani	<input type="checkbox"/> Asian / Asian British Bangladeshi
<input type="checkbox"/> Black / Black British Caribbean	<input type="checkbox"/> Black / Black British African	
<input type="checkbox"/> Chinese	<input type="checkbox"/> Arab	<input type="checkbox"/> Other
<input type="checkbox"/> Disabled		

How often do you visit our surgery?

<input type="checkbox"/> Regularly	<input type="checkbox"/> Occasionally	<input type="checkbox"/> Very rarely
------------------------------------	---------------------------------------	--------------------------------------

Please return this survey by **XXXXXXX** using our 'comments box' or post to **address**.
Your comments are confidential.

Thank you for taking the time to fill in this survey. We will be feeding back the results of this survey in the next few months. If you would like to know what other people think of our practice look out for our next newsletter or visit our website at: **website address**

Appendix E

Patient involvement action plan

Writing an action will help you and your PRG members stay focused and demonstrate your progress to other patients. Write the plan at your first patient reference group.

For an amendable word version of this tool please visit the NHS Leeds intranet here:

<http://nwww.inet.leeds.nhs.uk/index.pl?iid=12806>

You should make sure that you action plan is **SMART**, that is:

- **S**pecific
- **M**easurable
- **A**chievable
- **R**ealistic; and
- **T**ime-based

1. Project Aims

The aim of our patient involvement work is to...

2. Issues

Discuss the issues raised through patient surveys, the PRG and other feedback methods and identify the themes that are emerging.

The issues are...

3. Prioritise the themes

Once you have a list of themes ask the group to prioritise which they feel are most important and set an objective for each. Explain how you will address this by splitting the objectives into individual tasks - use the objectives sheet on the next page to help you.

4. Assign tasks

Ask a member of staff or a patient/carer to take the lead on each task and set a timescale for completing the work

5. State the outcomes

Once the tasks have been completed write down the outcomes.

6. Review the objectives

Review each objective at the next PRG. Identify barriers to achieving the objectives and feedback to your patients on the progress.

Objectives Sheet

Issue / theme	Objective	Tasks	Task lead	Completion date	Outcome
Patients struggle to get an appointment within 24 hours	To improve access to emergency appointments	a. Including an access question on our next patient survey b. Increase the number of phones lines at the practice c. Provide patients with information on booking appointments	practice manager	date	Survey showed similar experience for other patients. Added phone line and included an article in newsletter outlining rights and responsibilities of patients.

Issue / theme	Objective	Tasks	Task lead	Completion date	Outcome

Issue / theme	Objective	Tasks	Task lead	Completion date	Outcome

Issue / theme	Objective	Tasks	Task lead	Completion date	Outcome

Appendix F

Writing a patient newsletter

Patient newsletters are a great way to communicate with your patients about things that matter to them and to you! Here are some of the reasons for having a newsletter:

1. To educate your patients about important health matters
2. To inform your patients about important changes and feedback the outcomes of patient involvement
3. To encourage your patients to take responsibility for their own health
4. To involve patients in the running of the practice
5. To enhance the status of your practice
6. To advertise your services and recruit to your PRG

The stages below will help you produce your patient newsletter.

1. Get some support

Staff are available to support you in putting together your patient newsletter. They will be able to help you format newsletter in a way that makes it most effective. For more information contact your patient involvement and communications representatives. Details of your Patient, Carer and Public Information Team can be found in the 'Reader Information Box' at the beginning of this document.

2. Keep it simple

Avoid jargonistic, medical and over-complicated language. For more advice refer to the NHS Brand guidelines website. Contact details can be found in the glossary of terms on page 17.

3. Involve your patients

Ask your patients to get involved to ensure that the content is easy to read and appropriate.

- Include 'patient stories'
- Respond to queries raised at the patient forum
- Advertise your patient reference groups
- Ask patients to proofread your newsletter

Consider the needs of a diverse community (sensory impairment, non-English speakers, low literacy levels). For more ideas about communicating with different communities read Appendix N 'Ensuring diversity' on page 56.

4. Grab your readers attention and hold it

Newsletter articles should attract attention immediately. Use catchy, concise headlines and state your key message in the first sentences or paragraph of the article to draw the reader into the story.

- Think of a catchy names for your newsletter (Touching Base etc)
- Give different sections catchy names (tech talk, newsround, Q&A etc)

5. Select topics of interest to your patients

Aim to strike a balance of topics with something of interest to everyone in each edition, young and old, men and women. Keep it personal and local.

- Special events
- New services
- Seasonal health focus - hay fever / keeping warm / avoiding sunburn.
- Community events
- Feedback on achievements

For more ideas see Appendix H 'Patient newsletter template' on page 43.

Don't forget to include information on the NHS Constitution. This is an opportunity to tell patients what their rights and responsibilities are.

6. Make the page layout visually appealing

A page of crowded text is very uninviting for most readers. The appearance of the text can be broken up by using strong headlines, subheadings and bullet points. Further interest can be added with artwork, photographs and graphic elements, such as lines, borders, shadow boxes and backgrounds

- Add a logo
- Use photographs
- Run a seasonal photo competition

7. Lighten up with gimmicks

Appropriate cartoons and medical jokes help to provide light relief from the serious medical content.

- Quizzes
- Puzzles
- Games
- Cartoons
- Competitions
- Top 10 fastest, tallest etc
- Votes/polls (report back in the following newsletter)
- Did you know...(interesting facts)

8. Include up-to-date practice information

Incorporate important details about your surgery such as opening hours, house call policy, services provided, after hours arrangements and office staff.

- Newsletter date/issue number
- Other useful contacts

9. Distribute the newsletter to all your patients

Newsletters handed personally by the doctor to the patient are valued most highly.

- Send out with recalls and reminders
- Don't forget that not everyone has access to email!

Case Studies

Here are some examples of newsletters produced by GP practice and voluntary/statutory services in Leeds. You could use these to help you develop your own newsletter:

http://www.oakwoodsurgeryleeds.nhs.uk/website/B86654/files/oakwood_practice_leaflet.pdf

<http://leedsvoice.files.wordpress.com/2011/01/leeds-voice-newsletter-january-2011.pdf>

<http://www.leeds.nhs.uk/Downloads/Have%20your%20say/Patient%20Voice%20Issue%203.pdf>

Appendix G

Patient newsletter template

The following document is a patient newsletter template. You may want to use this template to help you develop a patient newsletter which meets the needs of your patients and your practice.

Feel free to make any amendments and don't forget to populate the newsletter with specific information about your practice.

For an amendable word version of this tool please visit the NHS Leeds intranet here:
<http://nwww.inet.leeds.nhs.uk/index.pl?iid=12806>

Main story



Feature on key issue.

- Government changes to the NHS
- Relocation of service
- Patient survey results
- Include a photo

Seasonal Health Focus

- Focus on seasonal issues
 - Hay fever
 - Keeping warm
 - Avoiding sunburn
 - Travel vaccinations
 - Flu clinics

Patient Reference Group

- Feature giving details of your patient reference group activities
 - Meeting summary
 - Dates of meetings
 - 'You said, we did'

Address and telephone number

Meet the staff

- Feature interviewing members of staff at the practice
 - Role at the practice
 - Length of time at the practice
 - Photo
 - Likes/dislikes

Promotion weeks

- Focus on national promotion weeks
 - Non-smoking day
 - Carers week

Local services

- Focus on local services
 - Information on a local community/voluntary services

Other news

Details of how to access out-of-hours care.
Latest DNA's and in on appointments

Comments compliments and complaints.

We welcome feedback about our services.

If you have any comments suggestions or concerns please contact the practice manager or call PALS (Patient Advice and Liaison Service). You can also tell us what you think by visiting www.patientopinion.org.uk

Freephone **0800 0525 270** **NHS**
Leeds Patient Advice and Liaison Service



Address, telephone number and website

Page 2

Appendix H

PRG Meeting Poster / Flyer templates

The following document is a PRG meeting poster / flyer template. You may want to use this template to help you develop a poster or flyer to advertise your PRG.

Feel free to make any amendments and don't forget to populate the poster / flyer with specific information about your practice.

For an amendable word version of this tool please visit the NHS Leeds intranet here:
<http://nwww.inet.leeds.nhs.uk/index.pl?iid=12806>

Patient Reference Group

Do you have ideas about how we can improve our practice?

We are setting up a Patient Reference Group and are looking for patients from all age groups, social and cultural backgrounds to join us.

Our next meeting will be held on:

Date:

between XXX and XXX

practice name

If you would like more information about the group please speak to one of the receptionists or a member of staff.

**Are you interested in helping
us improve our service?**

**Do you have ideas about how
we could do things better?**

There are lots of ways you could get involved!

- Fill in one of our **patient surveys**
- Contribute to our **patient newsletter**
- Fill in one of our **comments forms**
- Come along to our **patient reference group**

Our next event will be held on:

Date:

Time:

Venue:

**For more information
speak to one of our receptionists!**

Appendix I

Sample PRG invite letter

Practice logo
Consortia logo

Practice address

Date

Re: Patient Involvement

Dear Patient

We want to know what you think of our practice so that we can continue to improve the services we offer. There are lots of ways you can tell us what you think:

- Use our practice website;
- Fill in our annual patient survey;
- Write something and post it anonymously in our comments box; or
- Speak to our practice manager.

If you would like to get more involved in our practice you could join our patient reference group (PRG). The group meets X times a year to discuss issues which impact on patients and the practice. The PRG is for people interested in helping us to improve the practice. The PRG is not a meeting for people who want to complain about the practice. If you have a specific complaint, please contact the practice manager and follow our complaints process.

We also have a virtual patient reference group that allows patients to get involved online without having to come to meetings.

If you are interested in these groups please speak to a member of staff or call the **practice manager on XXXXXXXXXX**.

Your contact details will be kept separate to your medical records and will only be used for the purposes of patient involvement.

Yours sincerely

XXXXXXXX

Practice Manager / GP / Patient Champion

Appendix J

Sample First PRG meeting agenda

XXXXXX Patient Reference Group

Practice logo
Consortia logo

Meeting Agenda

date at venue

1. Welcome and introductions
2. Groundrules
3. Introduction to Patient Involvement
 - a. What is patient involvement?
 - b. Why is it important?
4. Introduction to the PRG
 - a. What is the PRG?
 - b. How will the meetings work?
5. Agenda items (which may include)
 - a. Filling in the patient involvement action plan
 - b. Developing the patient survey
6. AOB (any other business)
7. Evaluation of the meeting
 - a. How has the meeting gone?
 - b. How do we feed back what we talked about to all our patients?
 - c. How can we improve the meeting?
 - d. How can we ensure that it is representative?
 - e. When should we hold future meetings?
 - f. Date and time of next meeting
8. Thanks

Appendix K

Sample Subsequent PRG Meeting agendas

XXXXXX Patient Reference Group

Practice logo
Consortia logo

Meeting Agenda

date at venue

1. Welcome and introductions
2. Reiterate groundrules
3. Previous minutes
4. Agenda items (which may include)
 - a. Reflecting on the patient involvement action plan
 - b. Feedback from the patient survey
 - c. Developing a terms of reference
5. AOB (any other business)
6. Evaluation of the meeting
 - d. How has the meeting gone?
 - e. How do we feedback what we talked about to all our patients?
 - f. How can we improve the meeting?
 - g. How can we ensure that it is representative?
 - h. When should we hold future meetings?
 - i. Date and time of next meeting
7. Thanks

Appendix L

Sample terms of reference

The following document is a template terms of reference. You may want to use this template to help you and your patients develop a terms of reference for your PRG.

Feel free to make any amendments and don't forget to populate the terms of reference with specific information about your practice.

Patient Reference Group

Terms of reference

Practice logo
Consortia logo

A 'terms of reference' or 'TOR' simply outlines why a group is meeting. It ensures there are clear guidelines so that the group can function properly.

1. Name of the group

These are the terms of reference for the XXXXXX Patient Reference Group.

2. Purpose

The patient reference group has been set up to give the practice and its patients an opportunity to work together to develop the practice.

The group will enable patients and carers to comment on and influence:

- the development of patient literature including a regular patient newsletter;
- the quality and range of services offered;
- the development of new or extended services;
- standards of care at the practice;
- consultations with the wider practice population

3. Roles and responsibilities

The patient reference group should represent the wider community by offering advice and information to the practice, enabling them to:

- provide services which meet the needs of the practice population;
- develop new services which meet the needs of the practice population;
- promote the health and wellbeing of the local community;
- provide services which are accessible by all;
- communicate effectively with their patients;
- provide services of a high quality, and;
- engage with the practice population before making significant changes.

The practice is not obliged to act on recommendations or proposals from the patient group. The practice does, however, commit to consider and respond to all recommendations and proposals, as appropriate.

4. Membership

The membership of the group will be made up of practice staff, patients and carers. Membership will be reviewed after two years.

The Chair of the group is: XXXXXXXXX

The minute taker of the group is: XXXXXXXXX

5. Frequency of the meeting

The group will meet X times a year (or as necessary).

6. Reporting

Minutes will be taken at each meeting and shared with all members of the group. The minutes will also be made available to the wider practice population via the practice website.

Agendas and papers will be sent to members 7 days prior to the meeting.

Approved on:

Approved by:

Review date:

Appendix M

Ensuring diversity

A common criticism of many PRGs is that they are not representative of the practice population. It is always going to be difficult to get a group that exactly reflects the demographics of the local population, and volunteer roles tend to attract those who have a certain level of confidence, free time and have flexibility about working and earning money. However, a PRG can still listen to and respond to the opinions and ideas of people who cannot attend the meetings.

Ensuring that feedback is representative of the whole community is not only good practice, it is also an important part of the PP DES. Practices will need to demonstrate that they have attempted to engage as representative a group of patients as possible. There are a number of ways you can increase the diversity of your feedback.

1. Get some support

Staff at your CCG may be able to support you in getting representative feedback. For more information contact your diversity representative. Details of the Diversity, Inclusion and Vulnerable Groups Team can be found in the glossary of terms on page 17.

2. Consider the demographics of your practice population

Consider your local profile and try to ensure that you have representatives from the different groups which make up your community. The categories of patient covered by equalities legislation includes;

- people with differing working patterns;
- those who are unemployed;
- Black and Minority Ethnic Groups (BME)
- carers; and
- those whose first language is not English.

For more information on working with different patient groups consider using the tools available on the NHS Brand Guidelines - <http://www.nhsidentity.nhs.uk/tools-and-resources/patient-information/communicating-with-different-patient-groups>

3. Provide patients with a range of methods to feedback.

People like to tell you what they think in different ways. By giving people a wide range of ways to get involved you will increase the diversity of feedback. Here are some of the ways you could use:

- a. Verbal (for the visually impaired and people with low literacy levels)
 - Patient reference group
 - Discussion with practice manager

b. Online (for people with children / young people and those with limited time)

- Website
- Twitter
- Facebook
- Virtual patient reference group
- NHS Network (<http://www.networks.nhs.uk/>)

c. Written (for people without internet access)

- Letter
- Patient notice board
- Practice leaflet
- Practice newsletter

4. Target groups of people who are not represented on the group

Some population groups in your area will not be represented on your group. If this is the case discuss with the PRG about how you can gather the views of these communities and feed them back into your service development plans. Some local communities may already have their own support group. Consider tapping into the resources of these groups and using them to gather feedback for your practice.

5. Consider using certain representative for specific pieces of work

Some areas of public health have significant impact on specific population groups. For example, South Asians are at relatively high risk from diabetes and heart disease. If you and your PRG were to initiate a project on these health topics you might consider targeting members of the South Asian community to support you.

For more information on making your group representative of the local community, consider reading the BMA Patient Liaison Group's 'checklist on how to encourage participation among hard to reach groups' - http://www.bma.org.uk/images/ppichecklist_tcm41-207299.pdf

6. Get the language right

Many terms used by the general public are not acceptable to people with a disability. Even among people with a disability, there is not always agreement regarding what is acceptable. Some of the more commonly used terms - both acceptable and unacceptable - are described on following pages.

Bisexual	A term used to describe men or women who are emotionally and / or sexually attracted to people of both sexes.
Black and minority ethnic (BME)	A term used to describe people from a wide range of minority groups including those of eastern European origin and Irish people.
Disabled People / People with a Disability	Refers to people experiencing disability in any way. The group includes people with sensory impairment as well as physical, mental health or learning disabilities.
Dyslexia	Dyslexia is often grouped under the same heading as learning difficulties but this can cause offence. Most people with dyslexia prefer the term to be used separately.
Gay / Gay man	Men who are emotionally and / or sexually attracted to other people of the same sex.
Hetrosexual	Heterosexual is the term which refers to a man or woman who is emotionally and sexually attracted to people of the opposite sex.
Hidden disability	Refers to an impairment which is not obvious at all times e.g. epilepsy, diabetes.
Learning difficulties	A condition that prevents someone from learning basic skills or information at the same rate as other people. This may include problems with reading, writing or numeracy due to emotional difficulties that may have sufficiently disrupted schooling, influencing achievement. In addition learning difficulties may also be a result of conditions like A.D.H.D.(Attention Deficit Hyperactivity Disorder) or hyperactive disorder, Aspergers and dyslexia.
Learning disabilities	A significant reduced ability to understand new or complex information to learn new skills (impaired intelligence) with a reduced ability to cope independently (impairment of social functioning) which started before adulthood with a lasting effect on development.
Lesbian / gay woman	A term which refers to women who are emotionally and / or sexually attracted to people of the same sex. (It should be noted that some women do not like the term lesbian, and prefer to describe themselves as gay).
Mental Health Needs / Problems	Refers to mental illness; there is some concern that the use of the word "problem" can result in the individual being seen as the problem.
Non-disabled Persons	Often preferred to able-bodied, as it is neutral and does not claim a monopoly on ability or fitness.

Physical Disability	Refers to limitation of a physical function; sometimes used as if synonymous with physical impairment.
Sensory Impairment	Refers to limitation of a sensory function, i.e. hearing, sight, taste, smell, touch; sometimes called sensory disability.
Transsexual	Transsexual people have the deep conviction that their gender identity does not match their appearance and / or anatomy. (Believing oneself to be a man or a woman). This is recognised medically as gender dysphoria or gender identity disorder . The incongruity between identity and body can be so strong that individuals are driven to presenting themselves in the acquired (opposite) gender.
Transgender	An umbrella term which includes transsexual people, those with gender dysphoria and transvestites (cross-dressers).
Transvestite	The clinical name for a cross-dresser. A person who dresses in the clothing of the opposite sex. Generally, these people do not wish to alter their body.

7. The Equality Act 2010

The Equality Act 2010 prohibits the discrimination against anyone from the following nine “protected groups”

- Age
- Disability
- Gender reassignment
- Marriage or civil partnership
- Pregnancy and maternity
- Race (this included ethnic or national origins, colour or nationality)
- Religion or belief (including lack of belief)
- Sex
- Sexual orientation

It also places on public bodies, including the NHS the “equally duty” to:

- Eliminate discrimination, harassment and victimisation
- Advance equality of opportunity
- Foster good relations

For more information on making your group representative of the local community, consider reading the BMA Patient Liaison Group’s ‘checklist on how to encourage participation among hard to reach groups’ - http://www.bma.org.uk/images/ppichecklist_tcm41-207299.pdf

You can also visit the Diversity, Inclusion and Vulnerable Groups page of NHS Leeds Intranet here: <http://www.inet.leeds.nhs.uk/index.pl?iid=4401>

Appendix N

Developing a website

Making your website accessible: things to consider

Making your website accessible for all users is important in helping to deliver an equitable service for all your patients. Using accessibility guidelines to develop your website also helps you design a site that is easy to use for the wider public who do not have any accessibility issues. Remember it is more expensive and time consuming to make a website accessible **after** you have designed it.

Accessibility statement

All websites should include an accessibility statement showing how the organisation is committed to accessibility. It should include details of how someone can get in touch with you with any suggestions on improving the site.

Language and text

All text should be left aligned to make it easier to read. You should use non-serif text such as Arial or Helvetica.

You should keep sentences short and free of jargon. Reading online is different to reading a printed copy so you should keep text to a minimum to reduce excessive scrolling on a page. You should avoid underlining text as this is used for hyperlinks, if you need to emphasise anything you should **embolden** text.

Text only site

A text only option version of your website should be provided. The industry standard options suggested are:

- yellow text on black background;
- black text on a white background;
- white text on a blue background; or
- black text on a cream background.

Low graphic version

All websites should ideally offer people the chance to use a text only or low graphic version. This helps people with visual impairments and can also be useful for people who have slow network connection speeds. In addition to this, low graphic versions are easier to print off.

Use of images / Alternative (alt) text

Images can be a useful way of breaking text up or making it easier for people to understand the type of content on a page. Images should be saved as low resolution so that they can open quickly regardless of network speeds or the type of device being used to access a website for example a laptop or a mobile phone. Ensuring images are low resolution will also save on web/server space which will help keep the costs of your site down.



Alternative text, often referred to as alt text, should be used to describe any images on a site. This helps people who use assistive technology such as screen readers. The alt text should be as descriptive as possible for example 'two healthcare professionals looking at an x-ray'.

Measuring accessibility

To make your website truly accessible you may consider **involving your patients in the design of the site** as well as referring to guidance documents freely available. Once your site has been designed you might like to 'user test' it by selecting a random sample of patients and asking them to find content on the site to see how easily they can do this.

Software

When procuring either off-the-shelf or paid for content management systems you should ensure they meet industry standards in terms of accessibility.

The **minimum standard of accessibility** for all public sector websites is Level Double-A of the W3C Web Content Accessibility Guidelines (source: Central Office of Information).

Cascading Style Sheets (CSS) can help you develop a consistent layout and design for each page on your site.

Assistive technology

Where possible you should look to incorporate assistive technology onto your site. The most common feature is text to speech software also known as screen readers. Screen readers read text on a page as well picking up alt text (which is why it is important that images have an alt text attached to them).

Useful resources

BBC - My Web My Way: www.bbc.co.uk/accessibility/

Central Office of Information:

Delivering Inclusive Websites: <http://coi.gov.uk/guidance.php?page=129>

Equality and Human Rights Commission - General Web Accessibility Guidance:

www.equalityhumanrights.com/footer/accessibility-statement/general-web-accessibility-guidance/

W3C - Web Content Accessibility Guidelines: www.w3.org/TR/WCAG10/

Appendix O

An introduction to social media

Social media is a term used to describe tools or websites which allow users to interact with each other in some way - by sharing knowledge, opinions, information and interests. Social networking is any information that is self-published using social media. Examples of self-publishing can include websites, blogs, instant messaging websites, photo or video-sharing channels, bulletin boards or forums.

GP practices could use social media to engage, empower and educate their patients. The approach could support practices in achieving their PPDES as well as promoting public health and marketing the practice.

1. Benefits of social networking

If used appropriately there are a number of benefits of social networking which are listed below.

- It helps you to engage people who normally would not respond to NHS messages.
- You can use social networking to 'listen' to indirect feedback by finding out what is being said online, offering an opportunity for two-way communications and to respond to negative comments quickly.
- Social networking can be used as part of a wider strategic approach to communications and engagement.
- It provides an opportunity for real-time updates – this is particularly useful in an emergency scenario.
- It is convenient and free to use, the only cost is staff time.
- It gives staff an opportunity to be ambassadors for your practice.

2. Examples of social networking

There are many ways practices can use social networking to improve the practice and support patients:

- Twitter (an online social networking site which allows people to send and read short 'posts') could be used to:
 - post practice updates such as new staff or services;
 - share success stories;
 - promote events at the practice;
 - inform patients of changes to the practice;
 - explore patient opinion; and
 - respond to negative/positive comments
- Blogs (a personal diary linked to a website) could be used by:
 - a patient at the practice to write a diary sharing their experience of managing a

- specific health condition, or
- by GPs to blog a commentary on their work around a specific health issue.
- Online forums (an online discussion site where people can hold conversations by posting messages) can be useful in:
 - Providing a platform for professionals to respond to postings ensuring that accurate health information is provided and healthy behaviours are promoted
 - Providing patients with an opportunity to interact with professionals (not for consultations)
 - Providing a platform for patients to share their experiences with other patients

You will need to provide people with a link to a social media disclaimer which explains the terms of networking. This might include:

- Information on moderation of comments;
- Outlining that the views expressed are not necessarily the views of the practice; and
- Explaining that medical information posted is not intended to replace a consultation with a qualified healthcare worker

You should also ensure that your practice partners and staff always act professionally and respect patient confidentiality.

3. Risks to your practice

To ensure that you can receive the maximum benefits from using social networking you need to consider some of the risks associated with this form of communications.

We have highlighted the main risks below however you may have some issues that are local to your practice which you may wish to mitigate against.

As a general rule you should not post any information or messages on the internet that you would be unwilling to say in public.

Legal

Social networking gives you the opportunity to publish information quickly and cheaply. However because it is so easy to circulate information once published it is important that you check what you have written before publishing. It is recommended that staff are offered the opportunity to take part in training that covers data protection, patient confidentiality and information governance.

Reputation

Anything you publish online can be viewed by anyone in the world. Staff need to be made aware of their responsibility in safeguarding the reputation of your practice, as well as the wider NHS, before they publish anything.

Please note: you might like to consider asking your staff to state that they work for the NHS prior to making a comment. You might also like your staff to state that the views they express are their own and not the views held by your practice.

Confidentiality and invasion of privacy

It is essential that any material produced for social networking does not break any laws governing the use of personal data and that patient confidentiality is not compromised. It is important that individual patient queries or complaints are not handled using social networking.

Staff using social networking during their own time

It is worth reminding staff that they are ambassadors for your practice. Therefore they need to ensure that they are aware of their responsibilities when using social networking for personal purposes during their own time.

4. Further information

Chartered Institute of Public Relations

Social Media Guidelines -

<http://www.cipr.co.uk/sites/default/files/Social%20Media%20Guidelines.pdf>

Communities and Local Government

Online Social Networks Research Report -

<http://www.communities.gov.uk/documents/communities/doc/1061606.doc>

NHS Information Governance

Information Risk Management Guidance: Blogging and social networking -

<http://www.connectingforhealth.nhs.uk/systemsandservices/infogov/links/blogging.pdf>

Appendix P

Frequently Asked Questions (FAQs)

Q. What do I have to do to achieve the PP DES?

- A.** The specific requirements of the PPDES are set out in the 'The Primary Medical Services (Directed Enhanced Services) (England) (Amendment) Directions 2011' pages 12 - 15. The document can be found here: http://www.dh.gov.uk/en/Publicationsandstatistics/Legislation/DH_125872

If you want support to understanding the requirements you should contact the Primary Care Contracting Team on 0113 203 3485

Q. How can I manage challenging patients?

- A.** It is tempting to avoid inviting patients to your PRG who have a reputation for complaining, however, excluding certain patients is usually unjustifiable. Fears about 'difficult' patients disrupting PRGs are often unfounded, however it is worth putting things in place to make this less likely. There are a number of things you can do to stop this sort of behaviour:
- Ask the group to develop ground rules for the PRG (see 'Setting up a PRG' Appendix A page 20)
 - Ensure the group understand that the PRG is not a forum for single issues
 - Ensure that members understand that they are there to represent the wider community
 - Explain the complaints process to patients and advise them to follow that process rather than bring specific issues to the group
 - If the problem continues ask your involvement facilitator to attend the group to help you manage the patient.

Q. What if I can't answer a question?

- A.** Not knowing the answer to every question is OK. Tell the group you are not sure, but that you will find out the answer and feedback.

Q. What if patients make unreasonable requests?

- A.** Some patients may not understand the complexities of managing a practice, but the majority will appreciate that some requests are simply not viable. Never say 'no' outright because people will feel dismissed. Agree to discuss with your partners and feedback. Ensure that you explain clearly why something is not possible and if people are still not satisfied ask them to put their request in writing.

Q. What will patients ask for?

A. Patient requests are practice specific but might include the following:

- to simply listen to their ideas and concerns;
- to seriously consider their comments and feedback;
- to influence the questions in your patient survey;
- to explore a specific issue which is impacting on patients;
- for support to set up a separate group to support patients
- to make general improvements to the environment such as pictures on the wall or a water cooler in the waiting area
- to provide better information on specific issues

Q. How much will it cost to involve patients?

A. It should cost very little to involve your patients. The following costs may be incurred:

- **Venue** - if you choose to meet somewhere other than your practice
- **Travel** - offering to pay the travel expenses of members can be costly but might increase participation amongst those on a low income
- **Refreshments** - it is good practice to offer drinks and biscuits to people attending your PRG
- **Website** - feeding back to patients via a website is part of the DES requirements. The cost of this can be as low as a few pounds a year. Speak to your involvement facilitator for more information.

For more FAQs about the PPDES visit the British Medical Association here:

http://www.bma.org.uk/images/patientparticipatDESfaqsjul2011_tcm41-207352.pdf