Guidance for setting up a Practice Patient Participation Group in Mid Essex

This guidance aims to provide information and guidance to GPs, Practice Managers and Practice staff interested in setting up a Patient Participation Group for their Practice.

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Acknowledgements

This document draws on information from the following documents:-

- The patient participation DES
- ‘Patient participation groups in primary care’. BMA, 2009
- ‘Patient participation DES – Frequently asked questions (FAQs)’. GPC document from BMA, June 2011
- ‘Patient and Public Engagement Toolkit for World Class Commissioning’ – South Central.

My gratitude also goes to:-

- Colin Steward, Health Intelligence Manager, Mid Essex PCT
- Sally Wallis-Boore, Communications, Mid Essex PCT
- Georgina Howard, Primary Care Manager, Mid Essex PCT
- Julie Bradshaw, Head of Primary Care, Mid Essex PCT
- Jan Sweeney, Assistant Commissioning Manager, Mid Essex PCT
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Introduction

There is now greater emphasis than ever on the need for patient and public participation in health care. Practice patient participation groups (PPGs) can provide benefits to patients, practices and communities and fit into the wider commissioning agenda.

The Patient Participation DES¹ provides a means of financial remuneration to practices that undertake this valuable area of work. This guidance aims to provide the information requested at the recent Accelerated Design Event and lots of further information and details of resources to help support Practices set up successful Patient Participation Groups.

Please note, that a Practice must have a website in order to be able to achieve the steps of the Patient Participation DES. The National Association for Patient Participation³ comments that setting up a website need not be a costly job and suggests putting a call out to Patient Participant Group members and other patients to see if anyone has relevant skills they could offer.

This document is intended as guidance only.
What is a patient participation group (PPG)?

The document entitled ‘Growing Patient Participation’ states that a PPG is:-

‘A) Patients working with a practice to:

- contribute to the continuous improvement of services;
- foster improved communication between the practice and its patients;
- help patients to take more responsibility for their health; and
- provide practical support and help to implement change.

B) Varied to suit local needs

- Each group determines its own activities according to the needs of the community and the Practice itself.

C) Based on co-operation

- PPGs work by building a relationship between the practice and its patients that breaks down barriers and shares information.
- PPGs can develop to influence the wider NHS, most notably the decisions that are made on behalf of patients about the services that are to be available to them.

Patient participation is not:

A) A forum for complaints

- Clear ground rules are needed to ensure that PPG members do not use the PPG as a vehicle to resolve their own personal issues. (However, PPGs often lead to a reduction in the number of complaints overall.)

B) A doctors’ fan club

- In order to be valuable, PPGs must have the confidence to challenge the practice in line with the critical friend model.

C) A time-consuming activity for practice staff

- Some effort is required to get PPGs going but thereafter they should be self-organising and patient led and will often undertake activities that save the practice time.’
What are the benefits of PPGs?

PPGs are:

**Good for patients because:**

- Patients will be more responsible for their own health.
- Patients will have a better understanding and knowledge of the practice and its staff.
- Patients will be consulted about arrangements for their primary healthcare before decisions are made.
- Patients will benefit from improved communications with staff.
- Patients will have a forum to suggest positive ideas and voice concerns.

**Good for practice staff because:**

- GPs and their staff will be able to plan services jointly with patients in order to increase their effectiveness.
- They will be able to help patients with non-medical and social care issues.
- They will be able to get help from patients in meeting targets and objectives.
- They will have a forum to voice concerns, ideas and suggestions to patients.
- They will get closer to the community for whom they care.

**Good for the community because:**

- Patients will have an organisation through which they can identify their own needs.
- Patients will be able to get an idea of what is needed to improve healthcare, and make sure that the patient view is always represented.
- Patients will maintain an open dialogue with GPs and other healthcare professionals.
- Patients will have an opportunity to become involved in other community initiatives such as their Local Involvement Network (LINK) and their Clinical Commissioning Group.
What are the benefits of PPGs? - The bigger picture

The NHS Plan in 2000 emphasised the importance of patient and public involvement so that the NHS can better shape services around the needs of patients, their families and carers. This was subsequently given legal force as Section 242 of the consolidated NHS Act 2006.

The Local Government and Public Involvement in Health Act 2007 placed a duty on PCTs to involve and consult patients and the public in service planning and operation, and in the development of proposals for changes. This is a statutory duty, which means consulting and involving patients in ongoing service planning, in the consideration and development of proposals, and in decisions about general service delivery, not just major changes.

Following the Government White paper ‘Liberating the NHS’ in 2010, there is now greater emphasis than ever on the importance of patient participation and there continues to be a requirement ‘to involve the public on any changes that affect patient services, not just those with a significant impact’.

PPGs are one significant way to involve people in local healthcare decision-making. Indeed, many Clinical Commissioning Groups (CCGs) have found that patients recruited for practice participation groups have also been willing to provide valuable input at a locality level through locality sub groups of the CCG, or at regional level directly through the CCG. Engaging practice patient representatives in this bigger picture also has relevance at a practice level, not least because two of the QOF indicators with a cumulative value of 38.5 points, involve engaging with the development and following of care pathways.
The Patient Participation DES

A participating Practice will receive an overall payment of £1.10 per registered patient based on its achievement of the various steps.

The PCT are considering setting indicative numbers of patients that are dependent on list size and if the PPG has fewer members, Practices must be able to evidence that they have studied the demographics for their practice and describe the actions they have taken to obtain a representative sample of their patient population. This is currently under discussion and to be confirmed.

The DES criteria do not include any requirement for a minimum group size and adequate representation of the Practice demographics is more important than numbers. It is important to note that the GPC has published a Q and A document⁴ that states:-

‘There is no minimum number of participants or a minimum percentage of the patient list that must be included. Practices should set up a PRG that is of sufficient size to be as representative as possible of their practice population. If this is not possible, Practices should be able to show the steps they have taken to try and achieve this.

It will be up to Practices to justify to their primary care trust (PCT) why they have chosen to use a particular format for their PRG and show that they have attempted to make it as representative as possible. However, the DES does not permit PCTs to specify that a PRG must be of a minimum size.’

Furthermore, as per GPC guidance, practices with an existing PPG may have to look beyond their current membership to achieve sufficient representation.

This GPC guidance discusses this in more detail. It also addresses other frequently asked questions related to this DES such as content of the survey etc.
What would you like your PPG to achieve?

Patient participant groups can be multi-functional and participants are likely to vary in their experiences, interests and the level of commitment they are able to offer. Therefore, it is important to determine what you want your patient participation group to achieve. It may be worth considering generating a tier system of involvement so that different participants can be involved to the level that they wish. Allowing patients to explicitly determine their level of commitment may also aid recruitment.

Functions of a PPG\(^{2b}\) include:-

- **Developing a local patient survey**
  The second and third steps of the DES are:-
  - Step 2 - Agree areas of priority with the PPG
  - Step 3 - Collate patients views through use of the survey

- **Improving Practice services**
  The fourth and fifth steps of the DES are:-
  - Step 4 - Provide the PPG with opportunity to discuss survey findings and reach agreement with the PRG on changes to services,
  - Step 5 - Agree an action plan with the PPG and seek PPG agreement to implementing changes

- **Self-maintenance**
  The growing patient participation document states that ‘Some effort is required to get PPGs going but thereafter they should be self-organising and patient led and will often undertake activities that save the practice time.’

- **To work together with other PRGs in the locality/ Mid Essex**
  This would allow discussion and the sharing of ideas and best practice across a wider group

- **Promotion of health education**
  This could be through the development of self-help projects to meet the needs of fellow patients or organisation of meetings on topics of local interest or publication of newsletters that incorporate articles on self-help.

- **Involvement with the wider commissioning agenda**
  Members of the Practice Participation Group who have particular interests or are willing to give additional commitment may wish to get involved with the redesign of local patient services and referral pathways. In order to seize the opportunity to influence or redesign new innovative local care pathways, the DOH is clear that we ‘will have to involve the public on any changes that affect patient services, not just those with a significant impact’. There is an opportunity for this to feed into to QOF because two of the indicators, with a cumulative value of 38.5 points, involve engaging with the development and following of care pathways.

- **Fundraising**
  Many existing PRGs undertake fundraising. Fundraising can raise ethical and legal issues for the practice. (For more details, see Patient Participation Groups in Primary Care, BMA 26 January 2009\(^3\)).
Recruitment - Methods

There are numerous ways of recruiting patients such as:-

- Flyers
- Through the practice website
- Articles in practice newsletter
- Details on an electronic or non-electronic notice board
- Notes at bottom of prescriptions or information attached to scripts
- Articles in town and parish newsletters
- Practice open day
- Using local community groups to share information – please see appendix for list of local community groups
- Advertising through local businesses
- Selecting key patients (e.g. practice or NHS staff) and recruiting further through word of mouth and the snowball effect
- Advertising through Practice information leaflets,
- Seeking permission to e-mail patients e.g. through script messages
- Recruiting patients who have made constructive complaints in the past
- Recruiting users of particular services
- Recruiting parents through local schools
- Recruiting adolescents through links with local secondary schools and colleges and Duke of Edinburgh schemes. One practice has an arrangement with a secondary school that enables participation in a patient group to be incorporated into a further education course
Recruitment - Ensuring Representation

It is important that the PPG is as representative of the patient population as possible. Representation can be increased through:

- A detailed knowledge of practice demographics, beyond age and sex, and an understanding of the best means of communicating with each sub group
- An understanding of how to target ‘hard to reach’ groups

A) Through detailed knowledge of practice demographics and an understanding of the best means of communicating with each sub group

The health intelligence manager at the PCT is able to provide lots of useful Practice demographic data. At a basic level, he can provide detailed information about the Practice age and sex distribution and how this compares with Mid Essex or other Practices within the locality. Practices can also be provided with additional data such as unemployment figures.

Of a more complex nature, he can provide ‘geo-demographic data’ for practices by using the ‘mosaic public sector’ resource. Basically, this is a tool that classifies every single postcode into 15 groups based on 440 data elements. Therefore, for each Practice, it is possible to produce a map that shows the demographic group of every postcode within the Practice boundary and draws together the data into chart format that demonstrates the number of each postcode group within the Practice boundaries.

This is based on the assumption that people living within the same post code have similar demography, behaviours and lifestyle characteristics. For each group, detailed demographics, behaviours and lifestyle characteristics are described and this includes the best means of communicating with that particular group, knowledge which may be very helpful when trying to ensure representation of all groups.

To demonstrate, I’ve listed each group and the some of the associated implications on communication based on the descriptive data for each group:-

<table>
<thead>
<tr>
<th>Group</th>
<th>Brief Description</th>
<th>Communication Implications</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>Residents of isolated rural communities</td>
<td>Tend to have poor access to broadband communications but are now willing users of the internet as well as call centres.</td>
</tr>
<tr>
<td>B</td>
<td>Residents of small and mid-sized towns with strong local roots</td>
<td>Usually prefer to engage with small businesses such as GP surgeries</td>
</tr>
<tr>
<td>C</td>
<td>Wealthy people living in the most sought after neighbourhoods</td>
<td>Media such as the financial press, leading business publications and through sponsorship of major sporting events.</td>
</tr>
<tr>
<td>Group</td>
<td>Brief Description</td>
<td>Communication Implications</td>
</tr>
<tr>
<td>-------</td>
<td>-------------------</td>
<td>-----------------------------</td>
</tr>
<tr>
<td>D</td>
<td>Successful professionals living in suburban or semi-rural homes</td>
<td>Rely on national media, particularly quality national newspapers, to obtain information. This is a population that is influenced by evidence rather than “hard sell”</td>
</tr>
<tr>
<td>E</td>
<td>Middle income families living in moderate suburban semis</td>
<td>More likely to respond to advertisements in regional newspapers, direct marketing and door-to-door campaigns.</td>
</tr>
<tr>
<td>F</td>
<td>Couples with young children in comfortable modern housing</td>
<td>Frequent users of internet and the telephone</td>
</tr>
<tr>
<td>G</td>
<td>Young well educated city dwellers</td>
<td>Internet is an important source of information</td>
</tr>
<tr>
<td>H</td>
<td>Couples and young singles in small modern starter homes</td>
<td>Transact via internet or telephone; an increasing demand for information to be sent via text messaging rather than direct mail.</td>
</tr>
<tr>
<td>I</td>
<td>Lower income workers un urban terraces in often diverse areas</td>
<td>Many residents in these neighbourhoods belong to groups that have recently arrived in the UK; language may be a barrier. Gain information from shops and established residents</td>
</tr>
<tr>
<td>J</td>
<td>Owner occupiers in older-style housing in ex-industrial areas</td>
<td>Responsive to door-to-door distribution and addressed mail. Many know how to use the internet and have access to broadband but are infrequent users;</td>
</tr>
<tr>
<td>K</td>
<td>Residents with sufficient incomes in right-to-buy social housing</td>
<td>Characterised by informal community networks, often centred around family and former school friends. Home computer tends to be used for entertainment only.</td>
</tr>
<tr>
<td>L</td>
<td>Active elderly people living in pleasant retirement locations</td>
<td>Social networks may be centred on low intensity activities such as golf or bowls, plus organised clubs such as Women’s Institute. Little use of the internet</td>
</tr>
<tr>
<td>M</td>
<td>Elderly people reliant on state support</td>
<td>Lack of familiarity with information technology. Respond to direct mail.</td>
</tr>
<tr>
<td>N</td>
<td>Young people renting flats in high density social housing</td>
<td>Group of people that is characterised by a culture of dependency and has no family or community structures to provide a sense of social cohesion.</td>
</tr>
<tr>
<td>O</td>
<td>Families in low-rise social housing with high levels of benefit need</td>
<td>Use of internet low Poor access to community services such as pubs, leisure facilities, and community centres.</td>
</tr>
</tbody>
</table>

The data can also allow your postcode group proportions to be compared with others e.g. in Mid Essex or within your locality. For more information regarding this resource and examples, see www.publicsector.experian.co.uk

If you wish to have any of the data described above for your Practice, please contact me and I’ll liaise with the Health Informatics department of the PCT.
B) Through targeting ‘hard to reach groups’

Past experience has shown that there are many groups who have been difficult to engage\(^6\). These include:

- People with mental health conditions
- People with learning disabilities
- People with physical disabilities
- Gypsies and travellers
- Older and younger people
- Pregnant and breastfeeding women
- Asylum seekers
- Refugees
- Carers
- People on low income or benefits
- People in rural settings
- People from deprived areas
- People in residential or care homes
- ‘Looked after’ children and adolescents
- People who do not speak English as a first language;
- Homeless people
- People who have previously experienced, or continue to experience, discrimination such as racism or homophobia

Marginalised groups are users of mainstream and specific services and may have unmet health needs. Their views are equally as important as those of members of the wider public.

In order to identify population sub groups and ‘hard to reach groups’ that you may wish to target, it is important to compare the characteristics of patients within your practice population with the characteristics of those already involved. You may wish to consider using a wide range of different engagement methods that include those tailored to meet the needs of particular groups\(^6\).

Our public health colleagues often do targeted work with specific groups that health services find ‘hard to reach’ and may be able to recommend forums or other engagement methods. If you wish to have some advice regarding how to engage with a particular cohort of your population, please contact me and I’ll liaise with Public Health.
Methods of Engagement with Recruited Members

There are many methods that could be used to allow engagement with recruited members and a combination of methods is likely to be the most successful. Methods include:

- **Online engagement**
  
  Online engagement can include both the use of a website and social networking sites.
  
  1. **Website**
     
     The document ‘Growing Patient Participation Communications Toolkit for PPGs’ suggests:
     
     ‘A good, informative website can be a great way of connecting the PPG and the practice to the local population, particularly younger patients who are harder to reach….. Information on the site could include details of practice services, information on common illnesses, and updates on PPG-run events and initiatives.’ The document also describes a case study in which a website was used to allow two-way communication with patients with a ‘Have your say’ section, to allow registered members to post their comments etc.
     
     More information regarding setting up of virtual groups can be found at [www.napp.org.uk/resources/virtual-ppgs](http://www.napp.org.uk/resources/virtual-ppgs)

  1. **Social networking sites**
     
     The document, ‘Growing Patient Participation Communications Toolkit for PPGs’ also states:
     
     ‘The more interactive you are online, the more you will be able to engage with the local community. If you have someone within the PPG who could take responsibility for running your online activity, you could also try providing updates on the practice and PPG initiatives through social networking sites such as facebook (www.facebook.com) or twitter (www.twitter.com). …..For further information and advice on undertaking activity online, contact NAPP at audrey.hoggard@napp.org.uk.’

- **Waiting room/front desk**
  
  These areas could be used to encourage people to complete questionnaires and therefore may be a useful tool for the local survey

- **Meetings**
  
  Face to face meetings are useful. These could be for focus groups to identify and discuss important issues. Furthermore, they can be used as a means of engaging with certain ‘hard to reach’ groups of people.

- **Appreciative enquiry**
  
  This is a means of encouraging people to talk about ‘what works’ and could be organised and run by the PPG.
The First Meeting

There is good guidance on the first meeting in the documents:-

- ‘Patient participation groups in primary care’, produced by the BMA in 2009

- ‘Growing Patient Participation Getting started – A step-by-step guide for practices to setting up a Patient Participation Group’, which was developed as a joint initiative run by the National Association for Patient Participation, Royal College of General Practitioners, British Medical Association and NHS Alliance.

The latter guidance makes the following points/suggestions regarding the first meeting:-

- The first meeting will be used to decide whether people wish to continue to participate
- Having practice staff present demonstrates that their time and commitment are valued
- Keep meeting short
- Try to agree consensus regarding aims of the PRG
- Reinforce that the PRG is not a forum for complaints or single issue campaigns which should be addressed through other means, such as Practice complaints procedure
- Use the item ‘next steps’ to ensure that everyone is still happy with being a member and address any final concerns
- Try to arrange a further meeting within 4-6 weeks to maintain enthusiasm

It also includes details and advice on many aspects including ground rules and suggests a model agenda. I have included this in the appendix.
The Second Meeting

The guidance ‘Growing Patient Participation Getting started – A step-by-step guide for practices to setting up a Patient Participation Group’\(^2\) also has useful suggestions for the second meeting. In brief summary, important points include:

- The second meeting can be used to address administrative and organisational issues.
- A chairperson should be elected to manage the meetings. This should be undertaken by a patient participant.
- A secretary should be elected to take responsibility for taking minutes and general administration. This may be undertaken by a member of the practice or a patient participant.
- Review the aims and objectives and agree a terms of reference.
- Decide on timing, frequency and venue for the meetings.

Communication and Reporting Back

PRGs tend to operate most effectively if they involve representatives from the practice, ideally clinical and management staff, meeting on a regular basis. This allows members to be provided with up to date information and provide clarification about what issues can, and cannot, be influenced. It may be useful for the chair to meet regularly with the practice manager to feed back. There also needs to be consideration about how the work of the PPG will be disseminated to the wider practice population e.g. through Practice and Parish newsletters, Practice website etc.

Survey Methodology

This is outside the remit of this document but I can draw together further guidance regarding this area if Practices feel that this would be useful.
Appendix 1: PCT’s Recommended Timetable for Year 1 of Implementation of Patient Participation DES

The following information has been taken from the Mid Essex PCT document ‘Guidance and Audit Requirements for Patient Participation DES’:

<table>
<thead>
<tr>
<th>Step</th>
<th>Year 1</th>
<th>PCT’s Recommended Timescale</th>
</tr>
</thead>
</table>
| Step 1 | Establish a structure for a PRG that will enable the practice to obtain feedback from its patient population.  
· Ensure PRG membership is as representative as possible.  
· PRGs may be developed through the use of volunteers, regular face to face meetings and/or an e-mail community.  
Practices should:  
· Have the ability to develop a virtual group  
· Have their own websites in place before the end of March 2012.  
N.B. Practices that do not have their own websites are strongly recommended to arrange implementation as soon as possible and not wait until the end of the year. Current DoH advice states that the NHS Choices website will not be modified to allow practices to lodge their year end reports. | Recommended end of October 2011 |
| Step 2 | The practice and PRG will discuss and agree the key areas for inclusion within the local survey. | Recommended November 2011 |
| Step 3 | Develop a local practice survey using the information from the issues agreed.  
· Collate and analyse patients’ views from the survey results.  
· Share these results with the PRG. | Recommended end of December 2011 |
| Step 4 | Provide opportunity for PRG to discuss survey findings and reach mutual agreement on changes to service.  
· Practices must contact the PCT before implementing any significant service changes that have not received support from their PRGs. |  |
| Step 5 | Agree a Plan with the PRG that sets out the priorities identified by the practice survey and describes the actions that will be undertaken to address them. | Recommended end January 2012 |
| Step 6 | Publicise the Local Patient Participation Report on the practice website and update the report on subsequent achievement | Mandatory 31/3/12 |

Please see the Mid Essex PCT document ‘Guidance and Audit Requirements for Patient Participation DES’ for further details.
Appendix 2: Community Groups in Mid Essex

<table>
<thead>
<tr>
<th>Group</th>
<th>Frequency</th>
<th>Location</th>
<th>Interest</th>
<th>Previous PCT Involvement</th>
<th>Comments</th>
<th>Contact Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Access Group</td>
<td>Ad hoc</td>
<td>East Thames Care</td>
<td>Learning disabilities</td>
<td>Ad hoc attendance</td>
<td>Excellent group for access to those with learning difficulties</td>
<td>Christine.Barrett @east-thames.co.uk</td>
</tr>
<tr>
<td>Althorne Ladies Club</td>
<td>Ad hoc</td>
<td>Althorne</td>
<td>Local health issues</td>
<td>PALS attendance</td>
<td>Very active and supportive group</td>
<td>Janet Cloke, Althorne</td>
</tr>
<tr>
<td>BDVSA</td>
<td>Ad hoc</td>
<td>Braintree</td>
<td>Community voluntary service</td>
<td>PPI</td>
<td>Very useful links with Braintree community</td>
<td><a href="mailto:jayne@bdvsa.org">jayne@bdvsa.org</a></td>
</tr>
<tr>
<td>Chelmsford CVS</td>
<td>Ad hoc</td>
<td>Chelmsford CVS offices</td>
<td>Community voluntary service</td>
<td>PPI</td>
<td>Very useful links with Chelmsford community</td>
<td><a href="mailto:chelmsford.cvs@btinternet.com">chelmsford.cvs@btinternet.com</a></td>
</tr>
<tr>
<td>Compact</td>
<td>3 times per year</td>
<td>Causeway House Braintree</td>
<td>BDC - feeds into Essex Compact</td>
<td>Public Health / PALS attendance</td>
<td>Very good way of liaising with local council and voluntary agencies</td>
<td><a href="mailto:judycuddeford@bdvsa.org">judycuddeford@bdvsa.org</a></td>
</tr>
<tr>
<td>CYPSP Core Group</td>
<td>Quarterly</td>
<td>Chelmsford</td>
<td>Children and young people</td>
<td>HCD attendance / Vicky Waldon</td>
<td>Excellent way of engaging with children and young people</td>
<td><a href="mailto:zoe.oddy@midesexpct.nhs.uk">zoe.oddy@midesexpct.nhs.uk</a></td>
</tr>
<tr>
<td>Essex Against Domestic Violence</td>
<td>Twice a year</td>
<td>Essex County Council</td>
<td>Domestic Violence</td>
<td>HCD attendance</td>
<td>Possible way of reaching vulnerable/low self esteem people</td>
<td>john.niland@mid Essexpct.nhs.uk</td>
</tr>
<tr>
<td>Essex Multi-Agency Meeting</td>
<td>Bi-monthly</td>
<td>County Hall</td>
<td>Travellers, difficult to reach</td>
<td>Attended by PALS</td>
<td>Very useful group in engaging with hard to reach groups</td>
<td><a href="mailto:stephen.andrews@essexcc.gov.uk">stephen.andrews@essexcc.gov.uk</a></td>
</tr>
<tr>
<td>Essex Strategic Partnership Meeting</td>
<td>4 times per year</td>
<td>Connexions</td>
<td>Essex Wide - Young People issues</td>
<td>Chelmsford PCT PPI attendance</td>
<td>Attended by Essex wide authorities ie ECC, Police etc</td>
<td><a href="mailto:Lynda.Thomson@estconnexions.co.uk">Lynda.Thomson@estconnexions.co.uk</a></td>
</tr>
</tbody>
</table>
## Community Groups in Mid Essex (continued)

<table>
<thead>
<tr>
<th>Group</th>
<th>Frequency</th>
<th>Location</th>
<th>Interest</th>
<th>Previous PCT Involvement</th>
<th>Comments</th>
<th>Contact Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Halstead Patient User Forum</td>
<td>4 times per year</td>
<td>Mill House, Halstead</td>
<td>Health issues in Halstead</td>
<td>Venue/refreshment provided by PCT</td>
<td>Do not appear to be very active or focused. Advertising for new members.</td>
<td><a href="mailto:bramley@beeb.net">bramley@beeb.net</a></td>
</tr>
<tr>
<td>Health Housing and Social Care Group</td>
<td>Bi-monthly</td>
<td>Galleywood</td>
<td>Health, Housing and Social Care</td>
<td>HCD / PPI</td>
<td>Good way of learning about housing issues - more Chelmsford focused</td>
<td><a href="mailto:Natalie.Lloyd@chelmsford.gov.uk">Natalie.Lloyd@chelmsford.gov.uk</a></td>
</tr>
<tr>
<td>Health Watch</td>
<td>4 times per year</td>
<td>Chelmsford</td>
<td>Active on all health issues</td>
<td>Venue/refreshment provided by PCT</td>
<td>Very focused and action driven group, not just for Chelmsford</td>
<td><a href="mailto:cheryle.mack@midessexpct.nhs.uk">cheryle.mack@midessexpct.nhs.uk</a></td>
</tr>
<tr>
<td>Maldon Carers Centre</td>
<td>Ad hoc</td>
<td>Maldon</td>
<td>Support to carers</td>
<td>Helping with respite care - HCD</td>
<td>Excellent focus for providing help to carers - supports around 1,000</td>
<td>Claire Beatty 01621 851640</td>
</tr>
<tr>
<td>Maldon CVS</td>
<td>Ad hoc</td>
<td>Heybridge</td>
<td>Community voluntary service</td>
<td>PPI</td>
<td>Very useful links with Maldon community</td>
<td><a href="mailto:lindsey@maldoncvs.co.uk">lindsey@maldoncvs.co.uk</a></td>
</tr>
<tr>
<td>Maldon DAARG</td>
<td>Quarterly</td>
<td>Maldon</td>
<td>Drugs and Alcohol Awareness Group</td>
<td>HCD attendance</td>
<td>Possible way of reaching vulnerable/low self esteem/young people</td>
<td><a href="mailto:zoe.oddy@midessexpct.nhs.uk">zoe.oddy@midessexpct.nhs.uk</a></td>
</tr>
<tr>
<td>Maldon District Access Group</td>
<td>Bi-monthly</td>
<td>St Cedds, Maldon</td>
<td>Disabled Persons</td>
<td>PPI attendance</td>
<td>Excellent group for access to those who are disabled</td>
<td>David Rookard, Acting Chairman</td>
</tr>
<tr>
<td>Maldon Domestic Violence Forum</td>
<td>4 times per year</td>
<td>Maldon District Council</td>
<td>Domestic Violence</td>
<td>HCD attendance / Karen Moore</td>
<td>Possible way of reaching vulnerable/low self esteem people</td>
<td><a href="mailto:karen.moore@midessexpct.nhs.uk">karen.moore@midessexpct.nhs.uk</a></td>
</tr>
</tbody>
</table>
## Community Groups in Mid Essex (continued)

<table>
<thead>
<tr>
<th>Group</th>
<th>Frequency</th>
<th>Location</th>
<th>Interest</th>
<th>Previous PCT Involvement</th>
<th>Comments</th>
<th>Contact Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maldon Parkinsons Branch</td>
<td>Monthly</td>
<td>Maldon Town Football Hall</td>
<td>Parkinsons Disease</td>
<td>Attended by PALS</td>
<td>Very successful group having recently become a branch of Parkinsons Society</td>
<td>Derek Martin, 01621 850654</td>
</tr>
<tr>
<td>Mid Essex Sexual Health Action Group</td>
<td>Bi-monthly</td>
<td>Mid Essex</td>
<td>Sexual Health issues</td>
<td>HCD attendance</td>
<td>Possible way of reaching young people</td>
<td><a href="mailto:zoe.oddy@midessexpct.nhs.uk">zoe.oddy@midessexpct.nhs.uk</a></td>
</tr>
<tr>
<td>MSLC</td>
<td>Bi-monthly</td>
<td>Broomfield Hospital</td>
<td>Maternity</td>
<td>PCT commission service - to update</td>
<td>Desperate for PCT involvement from commissioning</td>
<td>Roder Yvonne (RQ8) Mid Essex Hospital</td>
</tr>
<tr>
<td>Patient Involvement Group (PIG)</td>
<td>Ad hoc</td>
<td>Danbury</td>
<td>Patient care in Danbury</td>
<td>HCD / PPI</td>
<td>Strong community focus within Danbury</td>
<td>Eleanor Dove 01245 225225</td>
</tr>
<tr>
<td>Right Tracks Committee</td>
<td>Bi-monthly</td>
<td>Station House Southminster</td>
<td>Improving quality of life in Southminster</td>
<td>HCD attendance</td>
<td>Excellent community centre for a deprived area of Mid Essex</td>
<td><a href="mailto:zoe.oddy@midessexpct.nhs.uk">zoe.oddy@midessexpct.nhs.uk</a></td>
</tr>
<tr>
<td>RUSTIC</td>
<td>Ad hoc</td>
<td>Dengie Project Base</td>
<td>Rural Support Team Intermedia Care</td>
<td>PALS and Healthcare Developmen t</td>
<td>Supports older people in their own home after hospital treatment / admission</td>
<td>01621 773733</td>
</tr>
<tr>
<td>SWANS</td>
<td>Ad hoc</td>
<td>St Cedds, Maldon</td>
<td>Disabled Adults</td>
<td>PALS involvement</td>
<td>Excellent charity for assisting adults in Central Essex who are disabled</td>
<td><a href="mailto:julia@swans.org.uk">julia@swans.org.uk</a></td>
</tr>
</tbody>
</table>
### Community Groups in Mid Essex (continued)

<table>
<thead>
<tr>
<th>Group</th>
<th>Frequency</th>
<th>Location</th>
<th>Interest</th>
<th>Previous PCT Involvement</th>
<th>Comments</th>
<th>Contact Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>SWF Healthcare 2000</td>
<td>Bi-monthly</td>
<td>SWF Clinic</td>
<td>SWF Health Needs Assessment</td>
<td>Health Needs Project Work for SWF</td>
<td>Very SWF orientated. Demand for articles in SWF Focus</td>
<td><a href="mailto:preacherman@pewend.org">preacherman@pewend.org</a></td>
</tr>
<tr>
<td>U3A University of 3rd Age</td>
<td>Ad hoc</td>
<td>Chelmsford CVS offices</td>
<td>Elderly</td>
<td>Presentation s at meetings from PCT</td>
<td>Keen to engage with PCT with adhoc presence at their meetings</td>
<td>Alan Jones 01376 561440</td>
</tr>
<tr>
<td>Views Count</td>
<td>4 times per year</td>
<td>Spring Lodge, Witham</td>
<td>Minor injuries in Witham</td>
<td>Venue/refreshment provided by PCT</td>
<td>Group lost interest after no minor injuries unit</td>
<td><a href="mailto:cheryle.mack@midsexpct.nhs.uk">cheryle.mack@midsexpct.nhs.uk</a></td>
</tr>
<tr>
<td>Views Count</td>
<td>4 times per year</td>
<td>Braintree Museum</td>
<td>Braintree Hospital</td>
<td>Venue/refreshment provided by PCT</td>
<td>Disabled access needed for meeting</td>
<td><a href="mailto:cheryle.mack@midsexpct.nhs.uk">cheryle.mack@midsexpct.nhs.uk</a></td>
</tr>
</tbody>
</table>
# Appendix 3: Parish Councils in Mid Essex

<table>
<thead>
<tr>
<th></th>
<th>Parish Name</th>
<th></th>
<th>Parish Name</th>
<th></th>
<th>Parish Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Alphamstone and Lamarsh</td>
<td>25</td>
<td>Great Baddow</td>
<td>55</td>
<td>Roxwell and Good Easter</td>
</tr>
<tr>
<td>2</td>
<td>Althorne</td>
<td>26</td>
<td>Great Bardfield</td>
<td>56</td>
<td>Sandon</td>
</tr>
<tr>
<td>3</td>
<td>Belchamp Walter</td>
<td>27</td>
<td>Great Braxted</td>
<td>57</td>
<td>Shalford</td>
</tr>
<tr>
<td>4</td>
<td>Birdbrook</td>
<td>28</td>
<td>Great Maplestead</td>
<td>58</td>
<td>Sible Hedingham</td>
</tr>
<tr>
<td>5</td>
<td>Black Notley</td>
<td>29</td>
<td>Great Notley</td>
<td>59</td>
<td>Silver End</td>
</tr>
<tr>
<td>6</td>
<td>Boreham</td>
<td>30</td>
<td>Great Totham</td>
<td>60</td>
<td>South Woodham Ferrers</td>
</tr>
<tr>
<td>7</td>
<td>Borley</td>
<td>31</td>
<td>Great Waltham</td>
<td>61</td>
<td>Southminster</td>
</tr>
<tr>
<td>8</td>
<td>Bradwell-on-Sea</td>
<td>32</td>
<td>Halstead</td>
<td>62</td>
<td>Springfield</td>
</tr>
<tr>
<td>9</td>
<td>Broomfield</td>
<td>33</td>
<td>Hatfield Peverel</td>
<td>63</td>
<td>Stambourne</td>
</tr>
<tr>
<td>10</td>
<td>Bures Hamlet</td>
<td>34</td>
<td>Heybridge</td>
<td>64</td>
<td>Stock</td>
</tr>
<tr>
<td>11</td>
<td>Burnham</td>
<td>35</td>
<td>Highwood</td>
<td>65</td>
<td>Stow Maries</td>
</tr>
<tr>
<td>12</td>
<td>Castle Hedingham</td>
<td>36</td>
<td>Kelvedon</td>
<td>66</td>
<td>Terling</td>
</tr>
<tr>
<td>13</td>
<td>Chignall</td>
<td>37</td>
<td>Latchingdon</td>
<td>67</td>
<td>Tillingham</td>
</tr>
<tr>
<td>14</td>
<td>Coggeshall</td>
<td>38</td>
<td>Little Baddow</td>
<td>68</td>
<td>Tollesbury</td>
</tr>
<tr>
<td>15</td>
<td>Cold Norton</td>
<td>39</td>
<td>Little Waltham</td>
<td>69</td>
<td>Toppesfield</td>
</tr>
<tr>
<td>16</td>
<td>Colne Engaine</td>
<td>40</td>
<td>Maldon</td>
<td>70</td>
<td>West Hanningfield</td>
</tr>
<tr>
<td>17</td>
<td>Cressing</td>
<td>41</td>
<td>Margaretting</td>
<td>71</td>
<td>Wethersfield</td>
</tr>
<tr>
<td>18</td>
<td>Danbury</td>
<td>42</td>
<td>Mayland</td>
<td>72</td>
<td>White Colne</td>
</tr>
<tr>
<td>19</td>
<td>Earls Colne</td>
<td>43</td>
<td>North Fambridge</td>
<td>73</td>
<td>White Notley</td>
</tr>
<tr>
<td>20</td>
<td>East Hanningfield</td>
<td>44</td>
<td>Panfield</td>
<td>74</td>
<td>Wickham Bishops</td>
</tr>
<tr>
<td>21</td>
<td>Feering</td>
<td>45</td>
<td>Pebmarsh</td>
<td>75</td>
<td>Witham</td>
</tr>
<tr>
<td>22</td>
<td>Galleywood</td>
<td>46</td>
<td>Pentlow</td>
<td>76</td>
<td>Woodham Ferrers/Bicknacre</td>
</tr>
<tr>
<td>23</td>
<td>Gosfield</td>
<td>47</td>
<td>Rayne</td>
<td>77</td>
<td>Woodham Mortimer</td>
</tr>
<tr>
<td>24</td>
<td>Great and Little Leys</td>
<td>53</td>
<td>Rettendon</td>
<td>78</td>
<td>Woodham Walter</td>
</tr>
<tr>
<td>25</td>
<td>Great Baddow</td>
<td>54</td>
<td>Rivenhall</td>
<td>79</td>
<td>Writtle</td>
</tr>
</tbody>
</table>
Appendix 4: Patient Flyer

–Adapted from ‘Growing patient participation – Getting started’

XXXXX SURGERY

Are you interested in finding out more about XXXXX Surgery?

Would you like to influence the development of local health services?

We are keen to set up a patient Representation group, so why not come along and meet us?

The meeting will take place at XXXX

A date and time will be confirmed when a number of people have expressed an interest.

If you would like to come along to the meeting or if you would like to find out more, please contact (named Practice lead)
Appendix 5: Sample Agenda for first meeting

–Adapted from ‘Growing patient participation –Getting started’^{2a}

XXXX Practice

Patient Representation Group Introductory Meeting

Date X X XX

Ground rules

- This meeting is not a forum for individual complaints and single issues
- We advocate open and honest communication and challenge between individuals
- We will be flexible, listen, ask for help and support each other
- We will demonstrate a commitment to delivering results, as a group
- Silence indicates agreement –speak up but always go through the chair
- 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

Agenda

1. Aims and objectives
2. Welcome and introductions
3. What do we want from this meeting
4. What do we want from a PRG
5. How can we increase representation
6. Ground rules
7. Next steps
8. Date of next meeting
Appendix 6: Sample Agenda for Second/On Going Meetings
–Adapted from ‘Growing patient participation –Getting started’

XXXXX Practice

Patient Representation Group Meeting

Date XXXX

Ground rules

- This meeting is not a forum for individual complaints and single issues
- We advocate open and honest communication and challenge between individuals
- We will be flexible, listen, ask for help and support each other
- We will demonstrate a commitment to delivering results, as a group
- Silence indicates agreement –speak up but always go through the chair
- 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

Agenda

1. Welcome and introductions

2. Group business
   - Election of chair and secretary
   - Terms of reference –agreeing the aims, ground rules, membership and responsibilities
   - Frequency of meetings

3. News from the Practice
   - Local survey update
   - Feedback regarding on going issues
   - New issues
   - Feedback of patient engagement news from MECCG

4. Date of next meeting

5. Any other business
Appendix 7: Sample Terms of Reference

–Adapted from ‘Growing patient participation –Getting started’

This PPG will:-

1. Create a PPG that is representative, equitable and, where possible, covers all sections of the practice population

2. Identify key issues for an annual survey that will be published with the findings

3. Discuss survey findings and reach agreement with the Practice on changes to services

4. Agree an action plan with the Practice that enables the agreed changes to services to be made

5. Contribute to practice decision making and consult on service development and provision

6. Provide feedback on patients’ needs, concerns and interest and challenge the Practice constructively whenever necessary

7. Serve as a safety valve for dealing with grumbles and complaints about the Practice-representing patients but also helping them to understand the practice’s viewpoint

8. Assist the practice and its patients by arranging voluntary groups/support within the community

9. Communicate information about the community that may affect healthcare

10. Give patients a voice in the organisation of their care

11. Promote good health and higher levels of health literacy by encouraging and supporting activities within the practice and promoting preventative medicine

12. Influence the provision of secondary healthcare and social care locally

13. Monitor services e.g. hospital discharge and support when back in the community

14. Liaise with other PPGs in the area

15. Be offered the opportunity to be involved with the commissioning of services within the Practice locality via Practice locality group and within Mid Essex via MECCG
Appendix 8: Agreeing Areas of Priority with the PPG

The DES states: ‘It may be that a standard way or proforma of asking patients about their priorities is developed and agreed between the practice and the PPG.’

Sample proforma

xxxx Practice survey

–Letting us know what is important to you

We are currently developing a survey that will help us to understand how we can improve the services we provide to you and others in the Practice.

We would like to know what things are important to you. Please list these things in the box below. You can include as many as you like!

| What issues should be focus on in a local survey to help us to improve the service that we provide to our patients? |

Appendix
## Appendix 9: Sample Patient Participation Sign Up Form

<table>
<thead>
<tr>
<th>Name</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Address</td>
<td></td>
</tr>
<tr>
<td>Telephone</td>
<td></td>
</tr>
<tr>
<td>e-mail</td>
<td></td>
</tr>
<tr>
<td>GP Practice</td>
<td></td>
</tr>
</tbody>
</table>

**Are you:**

- [ ] Male
- [ ] Female

**Under 16 years**

<table>
<thead>
<tr>
<th>17-24 years</th>
<th>25-34 years</th>
<th>35-44 years</th>
<th>45-54 years</th>
</tr>
</thead>
<tbody>
<tr>
<td>55-64 years</td>
<td>65-74 years</td>
<td>75-84 years</td>
<td>Over 84 years</td>
</tr>
</tbody>
</table>

**A patient?**

<table>
<thead>
<tr>
<th>A carer?</th>
<th>A patient representative?</th>
</tr>
</thead>
</table>

**White**

- [ ] British
- [ ] Irish
- [ ] Any other

**Mixed**

- [ ] White and black Caribbean
- [ ] White and black African
- [ ] White and Asian
- [ ] Any other mixed background

**Asian or Asian British**

- [ ] Indian
- [ ] Pakistani
- [ ] Bangladeshi
- [ ] Any other Asian background

**Black or black British**

- [ ] Caribbean
- [ ] African
- [ ] Any other black background

**Other ethnic groups**

- [ ] Chinese
- [ ] Any other ethnic group

**How would you like to be involved?**

- [ ] Virtual involvement?
- [ ] Information/newsletters
- [ ] Patient meeting
- [ ] Project groups

**Are there any areas you are particularly interested in e.g. mental health, diabetes?**

………………………………………………………………………………………………

**Do you represent an organisation, if so which?**

………………………………………………………………………………………………

**Please return to XXXXXXXX**

If you are not happy for us to share this information with our central Mid Essex Public and patient engagement team please tick here. (Please note that this information will not be passed on to any other body) ☐
Appendix 10: References and Further Resources

Referenced Resources

1. **Patient participation directed enhanced service (DES) for GMS contract.**
   Guidance and audit requirements for 2011/12 -2012/13.
   This can be accessed via the link:-
   
   [www.nhsemployers.org/Aboutus/Publications/Documents/Patient-participation-directed-enhanced-service.pdf](http://www.nhsemployers.org/Aboutus/Publications/Documents/Patient-participation-directed-enhanced-service.pdf)

2. **Growing Patient Participation** was developed as a joint initiative run by the National Association for Patient Participation, Royal College of General Practitioners, British Medical Association and NHS Alliance. This campaign provides useful resources that are now hosted by NAPP.

   More information can be found at the link:-
   
   [www.growingppgs.com/home](http://www.growingppgs.com/home)

   There are two documents that may be of particular interest:-


   This can be accessed via the link:-


   b. ‘**Growing Patient Participation Communications toolkit for Patient Participation Groups**’. National Association for Patient Participation, 2009

   This can be accessed via the link:-

3. **NAPP**

The National Association for Patient Participation (NAPP) is the umbrella organisation for patient-led groups within general practice. It provides a variety of guidance, resources and support in addition to the guidance above. This organisation can be accessed through the website:

www.napp.org.uk

Of note, resources that Practices may find particularly helpful include:

a) guidance regarding virtual groups which can be found at:

www.napp.org.uk/resources/virtual-ppgs/

b) guidance regarding Sample survey Questions extracted from existing surveys which can be found at:

www.napp.org.uk/resources/sample-questions

4. **Patient participation DES – Frequently asked questions (FAQs).** GPC document from BMA, June 2011

This can be accessed via the link:


5. ‘**Patient Participation Groups in Primary Care’.** BMA, 2009

This can be found at:

www.bma.org.uk/patients_public/ppgintro.jsp?page=1

6. **Patient and Public Engagement Toolkit for World Class Commissioning –South Central.**

This guide is targeted to commissioners based in PCTs, but provides managers from all parts of the health service and their front-line staff with an effective toolkit to help engage people. This can be accessed via the link:


7. **Mosaic Public Sector resource**

Further details and examples of geo-demographic data can be accessed via the link:

www.publicsector.experian.co.uk
   
   This can be found at:-
   
   www.bma.org.uk/patients_public/toolkitforpatientandpublicinvolvement.jsp

---

**Further Resources**

1. **MECCG**
   
   In the foreseeable future, there will be an up-and-running ‘Patient and Public Participation’ arm of the MECCG that Practices will be able to use as a resource and for support and advice. In the meantime, if I can offer any further help or information, for example regarding your Practice demographics, please do not hesitate to contact me via e-mail at

   lisa.harrod-rothwell@nhs.net

2. **Developing General Practice - Listening to Patients**, GPC 11 June 2009.
   
   This was published by the General Practitioners Committee (GPC) in response to its 2009 consultation on patient engagement. It explains the benefits of patient engagement and highlights priority areas for patients.

3. **The Picker Institute**
   
   Invest in Engagement website - A comprehensive review of the best worldwide evidence of what works to engage patients and the public in healthcare

4. **NHS Evidence** –
   
   Patient and public involvement website - A specialist collection of NHS evidence on patient and public involvement

5. **Department of Health:**
   
   There are many relevant documents available from the department of health that can be found at the link:-

   www.dh.gov.uk

   One of the documents, entitled ‘**Understanding What Matters**’, is a guide to using patient feedback to transform services. It is best practice guidance setting out the key principles for collection and use of patient experience feedback to drive improvements in the quality of services.
6. **The Practice managers’ Network** also provides resources. This can be found at:-


7. **Companies**

   There are also community interest and private companies willing to offer support at a cost, such as the NHS Primary Care Commissioning Community Interest Company (PCC-CIC), the details of which can be found at:-

   [www.pcc-cic.org.uk/pcc-essentials](http://www.pcc-cic.org.uk/pcc-essentials)

**Please note:-**

   The number of resources available continues to increase and some projects in development are innovative, such as patient participation purpose designed ‘facebook-type’ web pages and phone apps. Watch this space!
# Appendix 11: Glossary

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>B.M.A.</td>
<td>British Medical Association</td>
</tr>
<tr>
<td>C.C.G.</td>
<td>Clinical Commissioning Group</td>
</tr>
<tr>
<td>G.P.C.</td>
<td>General Practitioners’ Committee</td>
</tr>
<tr>
<td>M.E.C.C.G</td>
<td>Mid Essex Clinical Commissioning Group</td>
</tr>
<tr>
<td>N.A.P.P.</td>
<td>National Association for Patient Participation</td>
</tr>
<tr>
<td>Patient participation D.E.S.</td>
<td>A two year Directed Enhanced Service effective from 4/11-3/12</td>
</tr>
<tr>
<td>P.P.G.</td>
<td>Patient Participation Group. Also called a Patient Representative Group (PRG)</td>
</tr>
<tr>
<td>Public and patient engagement</td>
<td>The process of seeking the views of patients, the public, or other partners. One purpose can be to feed into the commissioning cycle. Engagement comes in many forms and can be delivered in many ways.</td>
</tr>
</tbody>
</table>

For any further information or queries, please contact:-

Lisa Harrod-Rothwell  
Mid Essex Clinical Commissioning Group  
lisa.harrod-rothwell@nhs.net