Community Voices – Developing Virtual Patient Participation

Background

This summary provides key highlights from the Community Voices project that enabled four practices to set up and communicate to a virtual patient group of up to 100 patients each, simply and effectively.

This project was undertaken as part of the Department of Health Responsive Practice workstream which concluded in March 2010. As part of that work we listened to Patient Participation Groups (PPGs) and practices to try to understand how we could get more PPGs established and how those PPGs could be more effective.

These conversations highlighted two key problems:

1. For those practices without a PPG – the setting up of a PPG was seen as time consuming and difficult to recruit to.
2. The majority of PPGs found it very difficult to form a group that was representative of their practice population.

We wanted to test out the hypothesis that a virtual group could be easy to recruit to and more representative of their practice population than a ‘real’ group which meets face to face to discuss issues.

Getting started

A simple support pack was developed to help practices get started. We provided specialist support by phone and email. Practices used the Getting Started Guide [link] to recruit patients to an email group and then used a simple online survey tool to communicate with the group.

We worked with four practices. All the practice managers had heard of online survey tools but none had used them before. Questions were developed that reflected what the practice wanted to find out about e.g. “Are you aware we have introduced a new telephone line specially for ordering prescriptions?” and “If you contacted the practice by telephone was the phone answered quickly?” Each practice developed its own questions.

Providing support

During the pilot we provided a small amount of virtual support by telephone and email. Practice managers engaged their colleagues in the process by being able to show how simple it was to compile a cohort of up to 100 patients to test ideas and changes. One practice said:

“My staff are super at my own surgery and indeed they had no problem in recruiting over 100 patients to our group. We stopped at 100 but we could have easily got more. I think if this proves successful then we may add it to our new patient registration forms.”
Keeping and recording information and data
A common concern for all practices was the potential for problems with a database that was created by anything other than the live clinical record. One practice said, “Unless we record this in the main clinical record we run the risk of always having to maintain the group which in itself would be a time consuming burden”. Each practice was able to overcome this issue in its own way, e.g. by recording a specific read code for those patients that had given permission to be contacted.

Recruitment
One practice recruited 50, another 73 and the other two 100 patients to the virtual group. Each practice approached the task in a different way depending on local time and resources. One practice recruited 100 people in two days. At this practice the first ‘pilot’ survey went out to the group on the same day they were recruited! The other practices took varying approaches and timescales varied from one week to six weeks to recruit the virtual group members.

The vast majority of people invited to join the groups who had an email address responded positively. Recruitment across all time periods, e.g. across a whole day and a whole week, can support the achievement of a more representative sample of patients. Asking all new patients who register if they would like to join is an ideal way to achieve greater representativeness of the group over time.

Communicating with the virtual group
All four practices found the task of recruiting to the virtual group and running a short survey easier than they had anticipated. Continuing to use the groups and regarding them as more than an ‘e-survey’ panel is key. If used to their full effect, each group can form an essential part of the practice’s relationship with patients and be used to decide how services are commissioned, planned and developed.

All of the practices enjoyed using the online survey tool, finding it a quick and easy to use resource. Many survey tools are free, which enabled practices to trial them with no pressure to commit resources. One practice said, “It was excellent, will use it again and again and tell others”.

The response rate from virtual group members was 40%, which is generally regarded a good response. All practices intend to use the groups again for purposes such as:
- targeting groups of patients with long term conditions to understand how they see services;
- developing the group for long term use to build into an effective ‘real’ patient participation group within the practice;
- using the approach for all the practices in their Practice Based Commissioning consortia to improve how they can communicate across the practices; and
- gathering information to inform commissioning.

One practice said:
“I am absolutely thrilled that having had no-one come forward to join our patient participation group that was advertised on the web, that so many patients signed up. This will lead to a much more representative selection of patients”.

Existing Patient Participation Groups

Making use of virtual PPGs allows practices to gain a more representative view from the practice population but does not replace the role of a ‘real’ PPG group which meets face to face and works closely with the GPs and staff within the practice.

Existing groups will have an important role in the formation and choice of virtual PPG survey questions by ensuring that surveys reflect patients’ priorities. It is also important that the questionnaire allows respondents to raise issues which are important to them in the form of open questions in addition to requesting feedback on the questions put by the practice. The ‘real’ group will play a role in discussing what changes the practice makes in response to the feedback it receives.

Practices may find that some of the patients who are on the virtual PPG are willing to join the ‘real’ group. Inviting members of the virtual group to get more involved can be a good way of expanding and refreshing membership of the ‘real’ group.

It is essential to communicate with survey respondents to provide feedback on the changes and outcomes realised by the practice based on survey responses. Many practices and PPGs have adopted the approach of a response that says ‘You suggested….. We did…..’ to ensure people know their voice has been heard.

Commissioning Consortia

The roll out of a commissioning consortia model will enable all practices to more easily communicate with their patients and obtain representative views about their services. Each practice could have its own virtual group that the consortia could use to consult on commissioning decisions. With such a large number of patients involved, the consortia could start to consult specific patient groups e.g. diabetic patients, elderly patients or groups that are usually absent from ‘real’ groups, such as teenagers.

Going from no formal or established mechanism for engagement to having direct contact with up to 100 patients from each practice - ‘from nothing to something’ - is a real first step. This has shown to be a cost efficient solution that was implemented with limited support.

If you would like to start up or improve a PPG in your practice or consortia, please make use of the ‘Getting Started Guide’ below which provides practical information and tools.
The practice managers who were involved in the Community Voices project are happy to be contacted by email and their contact details are:

vanessa.young@nhs.net
geraldine.taggart-jeewa@nhs.net
lindsay.coleman@nhs.net
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This project was commissioned by the Department of Health and delivered by Jessie Cunnett from Patient and Public Involvement Solutions who can be contacted at:

Jessie@patientpublicinvolvement.com

If you have any other questions or would like to discuss this further it may be worth speaking to your Public and Patient Engagement Lead at your PCT or contact me directly at:

mike.warburton@dh.gsi.gov.uk
Annex
Creating a Virtual PRG - Getting Started Guide

For more information about the tools contained in this guide please contact Mike Warburton, National Director for Dental and GP Access at the Department of Health at mike.warburton@dh.gsi.gov.uk

Introduction
This Getting Started Guide has been created to help practices set up virtual Patient Reference Groups (PRGs). It contains a few simple tools that practices can use at the various stages of setting up a PRG. The Department of Health commissioned the development of this guide in consultation with patients, staff and patient group representatives. It is deliberately simple and ‘low-tech’ in the hope that it provides a range of quick and easy ways to create a list of patients willing to help practices by giving their views. Email is a fast and effective way to carry out simple surveys to get feedback from patients. Your practice may or may not already have in place a ‘real’ PRG which meets face to face. If it does, it may be simplest to use the ‘real’ PRG as the main point of email contact. If you do not already have a ‘real’ PRG, creating an email contact list is a good starting point. There are a number of online survey tools available which are simple to use and have clear instructions on how to set up a survey. Once you have finalised your survey questions it takes just minutes to set up the survey online. Links to some free survey tools are set out below:

- www.surveymonkey.com/
- www.kwiksurveys.com/
- www.esurveyspro.com/
- www.smart-survey.co.uk/

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2. Sample contact form
3. Developing your survey
4. Script for patient group members
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6. Script for staff in practices without a Patient Reference Group
7. Suggested wording for an LED display
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1 Common patient questions and answers

Q Why are you asking people for their contact details?
A We would like to be able to contact people occasionally to ask them questions about the surgery and how well we are doing to identify areas for improvement.

Q Will my doctor see this information?
A This information is purely to contact patients to ask them questions about the surgery, how well we are doing and ensure changes that are being made are patient focussed. If your doctor is responsible for making some of the changes in the surgery they might see general feedback from patients.

Q Will the questions you ask me be medical or personal?
A We will only ask general questions about the practice, such as short questionnaires.

Q Who else will be able to access my contact details?
A Your contact details will be kept safely and securely and will only be used for this purpose and will not be shared with anyone else.

Q How often will you contact me?
A Not very often… [insert how often you plan to contact patients]

Q What is a patient group/patient participation group?
A This is a group of volunteer patients who are involved in making sure the surgery provides the services its patients need.

Q Do I have to leave my contact details?
A No, but if you change your mind, please let us know.

Q What if I no longer wish to be on the contact list or I leave the surgery?
A We will ask you to let us know by email if you do not wish to receive further messages.
2 Sample contact form

If you are happy for us to contact you periodically by email please leave your details below and hand this form back to Reception, a Patient Group representative or post in the ‘secure box’.

Name: 
Email address: 
Postcode: 

This additional information will help to make sure we try to speak to a representative sample of the patients that are registered at this practice.

Are you? Male □ Female □

<table>
<thead>
<tr>
<th>Age:</th>
<th>Under 16</th>
<th>17 - 24</th>
<th>25 – 34</th>
<th>35 – 44</th>
<th>45 – 54</th>
<th>55 – 64</th>
<th>65 – 74</th>
<th>75 - 84</th>
<th>Over 84</th>
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To help us ensure our contact list is representative of our local community please indicate which of the following ethnic background you would most closely identify with?

| White British Group □ Irish □ | White & Black □ White & Asian □ |
| Mixed | White & Black Caribbean □ | White & Black □ White & Asian □ |
| Asian or Asian British | Indian □ Pakistani □ Bangladeshi □ |
| Black or Black British | Caribbean □ African □ |
| Chinese or other ethnic | Chinese □ Any Other □ |

How would you describe how often you come to the practice?

Regularly □ Occasionally □ Very rarely □

Thank you.

Please note that no medical information or questions will be responded to.

The information you supply us will be used lawfully, in accordance with the Data Protection Act 1998. The Data Protection Act 1998 gives you the right to know what information is held about you, and sets out rules to make sure that this information is handled properly.
3 Developing your survey

An important goal as a survey author is to construct clear, direct questions and answers using the language that survey participants will understand. Whilst there are no set rules on the wording of these survey questions, there are some basic principles that do work in improving the overall design.

Constructing good questions

1. Be Brief – Keep questions short and ask one question at a time

2. Be Objective
   a. Avoid leading questions, e.g. “We have recently upgraded this site’s features to become a first class tool. What are your thoughts on the new site?”
      Replace with: “What are your thoughts on the upgrades to this site?”
   b. Avoid loaded questions
   c. Avoid built-in assumptions about things the respondent may or may not know about

3. Be simple
   a. Avoid jargon
   b. Avoid using extremes such as ‘never’, ‘always’ or ‘only’

4. Be specific
   a. Avoid asking things that are too general, too complex or undefined

Question types

The question type determines the type of information collected;

1. Open-ended - where respondent has free text to write what they want.
   a. Pros; good to use when asking for attitude or feelings, likes and dislikes, memory recall, opinions
   b. Cons; some respondents don’t find it easy and so put ‘I don’t know’, it can take the respondent longer to fill in and can take you longer to analyse

2. Close-ended - where respondents answer ‘yes’ or ‘no’, or from multiple choice list.

3. Ranked - where respondents rank what is most/least important, on a scale from 1-5.
   a. 1-5 is thought to be the right number of options (i.e. no more)
   b. Generally, you would have two negative, two positive and a neutral, to make it balanced
c. If you remove the neutral option, you force the respondent to choose either a negative or positive. There’s no fixed rule on whether this is right.

4. **Rating** - is a popular way of collecting subjective data where you want to measure the ideas of a respondent (e.g. opinions, knowledge, or feelings). There are two types;
   a. Create a statement and ask respondents to rate how they feel about it, e.g. *Strongly disagree/Disagree/Neutral etc.*
   b. Provide respondents with a scale, e.g. from ‘Improved’ to ‘Not improved’ and ask them to rate their opinion on this scale.

**Encouraging respondents to complete the survey**

1. Asking people to participate in advance can boost response numbers
2. Have an introduction that briefly explains what the survey is about.
   Within the introduction, you may want to include:
   a. the name of the organisation conducting the survey,
   b. the confidentiality information,
   c. how the data collected will be used
   d. how long it will take to complete
3. Make the first couple of questions easy and quick
4. Thank respondents for completing your survey
5. Pilot your survey to make sure the questions make sense and that you get the information you are looking for.

Further information on developing effective questionnaires can be found at:

- [www.patientpublicinvolvement.com](http://www.patientpublicinvolvement.com)
- [www.pickereurope.org/](http://www.pickereurope.org/)
- [www.drfosterhealth.co.uk/](http://www.drfosterhealth.co.uk/)

4 **Script for patient group members**
Hello,
I am a member of a patient group [insert name of group]. We want to ensure that the views of patients are fed into the practice regarding the services they deliver and any changes or new services that are being considered.
To do this we are compiling a contact list of email addresses so that we can contact you by email every now and again to ask you a question or two.
Are you interested in giving your views?
Please provide your contact details on this form; we will only use information to contact you and will keep your details safely.

5 **Script for staff in practices with a Patient Reference Group**
Hello,
Our Patient Participation Group [insert name of group] is encouraging patients to give their views about how the practice is doing. They would like to be able to ask the opinions of as many patients as possible and are asking if people would like to provide their email addresses so that they can contact you by email every now and again to ask you a question or two.
Are you interested in leaving your email contact details?
If you could fill in this quick form and hand it back to reception (or provide your
details over the phone to me) we will pass the details to the Patient Participation Group.
Your contact details will only be used for this purpose and will be kept safely.

6  Script for staff in practices without a Patient Reference Group
Hello,
We are encouraging patients to give their views about how the practice is
doing. We would like to be able to find out the opinions of as many patients as
possible and are asking if people would like to provide their email addresses so
we can contact you by email every now and again to ask you a question or
two.
Are you interested in leaving your email details?
If you could fill in this quick form and hand it back to reception (or provide your
details over the phone to me) we will add your email address to a contact list.
Your contact details will only be used for this purpose and will be kept safely.

7  Suggested wording for an LED display
THE PATIENT GROUP [INSERT NAME OF GROUP] NEEDS YOUR VIEWS!
PLEASE ADD YOUR EMAIL TO THE FORM AT RECEPTION TO JOIN OUR
CONTACT LIST.
This information could also be added to prescriptions.
Copies of the contact form should be available at reception with the
option of a secure box to drop them into

8  Suggested leaflet/flyer content
Would you like to have a say about the services provided at [insert name of
practice]?
The [insert name of group or surgery] would like to hear your views.
By providing your email details we can add them to a contact list that will mean
we can contact you by email every now and again to ask you a question or
two.
Fill in the details on the reverse side of this leaflet and hand it back to reception
or post it into the secure box and we will add your email address to a contact
list.

9  Suggested Poster Content
Would you like to have a say about the services provided at [insert name of
practice]?
The [insert name of group or surgery] would like to hear your views.
By leaving your email details we can contact you every now and again to ask
you a question or two.
Contact forms are available from reception and on the back of the leaflets that
are available in the waiting area.