

## **Community Voices – Developing Virtual Patient Participation**

### **Background**

This summary provides key highlights from a project that enabled 4 practices to set up and communicate to a virtual patient group of up to 100 patients each, simply and effectively.

This work was undertaken as part of the Responsive Practice workstream which concluded in March 2010. As part of that work we listened to 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.

### **Getting started**

A simple support pack was developed to help practices get started. Specialist support was provided by phone and email. Practices used the support pack to recruit patients to an email group and then used a simple online survey tool Survey Monkey to communicate with that group

We worked with 4 practices. All the practice managers had heard of Survey Monkey but had not used it before. Questions were developed that reflected what the practice wanted to find out about eg “Are you aware we have introduced a new telephone line specially for ordering prescriptions?” and direct, “If you contacted the practice by telephone was the phone answered quickly?” Each practice developed their own questions.

### **Providing support**

During the pilot we provided a small amount of virtual support, by telephone or email. Practice managers overcame the challenge of getting and keeping colleagues on board by being able to show the simplicity and good value for the time spent in creating a cohort of up to 100 patients to test ideas and changes.

*“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 in its own way, eg 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 people. Each practice approached the task in a different way depending on local resources and time. One practice recruited 100 people in two days. The first ‘pilot’ survey went out to the group on the same day they were recruited! Other practices took varying approaches and timescales varied from 1 week to 6 weeks to recruit the virtual group members.

The vast majority of people invited to join the groups who had an email address responded positively. By ensuring recruitment happens across all time periods eg across a whole day and a whole week, it can support the achievement of a more representative sample. 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 group**

All practices found the task of recruitment and running a short survey easier than they had anticipated. Continuing to use the groups and seeing them as more than an ‘e-survey’ panel will be key. Each group can form an essential part of the practices relationship with patients and be used to assess their view on how services are commissioned, planned and developed.

Each of the practices enjoyed using Survey Monkey, finding it a quick and easy to master solution. Survey Monkey is free, this enabled practices to ‘have a go’ 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 examples include: 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 PBC consortia to improve how they can communicate across the practices and to gather information to inform commissioning.

*“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 PPGs**

This approach helps PPGs gain a more representative view from the practice population but does not replace the role of a ‘real’ PPG working closely with

the GP's and staff within the practice. Existing PPG's will have an important role in the formation and choice of questions to ensure the surveys are reflecting patients' priorities. It is also important that the questionnaire allows for respondents to raise issues that are important to them in the form of an open question in addition to giving feedback on the questions put by the practice. The PPG will have a role in discussing what changes the practice makes in response to the feedback. The virtual PPG may also be a real source of new PPG members facilitating, and being a catalyst for, the development of 'real' PPG's which will hopefully grow from the virtual group momentum and population.. Communication back to the survey respondents is essential providing 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 model such as this will enable all practices to more easily communicate with their patients and obtain some representative views on their services. It is easy to visualize each practice having its' own virtual group that can be used by the consortia to consult on commissioning decisions, and with such a large number of patients involved the consortia could start to consult specific patient groups eg Diabetic patients, elderly patients or groups that are usually absent from PPGs, like 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 take this forward for your practice or consortia use the 'Getting Started Guide' below which provides the information you require. The practice managers who were involved are happy to be contacted by email and their contact details are:

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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 (PPE Lead) at your PCT or contact me directly;  
[mike.warburton@dh.gsi.gov.uk](mailto:mike.warburton@dh.gsi.gov.uk)

## **Creating a Virtual PPG- Getting Started Guide**

E-mail is a great way to carry out simple surveys, and get feedback from patients. This starter pack sets out a few simple tools that may help you to create an email Patient Participation contact list.

The pack has been developed with patients, staff and patient group representatives. We have kept it 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.

Your practice may or may not have a patient participation group (PPG). If it does have a PPG it may be best to use the group as the main point of contact. If you do not have a patient participation group creating the email contact list may be a good starting point.

Survey Monkey is very simple and has excellent guidance on how to set up a survey. Once you are clear about your survey questions it takes just minutes to set up. Find it at [SurveyMonkey.com](http://SurveyMonkey.com)

### **Contents**

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## 1 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

Insert Practice  
Name/Logo

## 2 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

Age:	Under 16	<input type="checkbox"/>	17 - 24	<input type="checkbox"/>
	25 – 34	<input type="checkbox"/>	35 – 44	<input type="checkbox"/>
	45 – 54	<input type="checkbox"/>	55 – 64	<input type="checkbox"/>
	65 – 74	<input type="checkbox"/>	75 - 84	<input type="checkbox"/>
	Over 84	<input type="checkbox"/>		

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?

<b>White</b>				
British Group	<input type="checkbox"/>	Irish	<input type="checkbox"/>	
<b>Mixed</b>				
White & Black Caribbean	<input type="checkbox"/>	White & Black African	<input type="checkbox"/>	White & Asian <input type="checkbox"/>
<b>Asian or Asian British</b>				
Indian	<input type="checkbox"/>	Pakistani	<input type="checkbox"/>	Bangladeshi <input type="checkbox"/>
<b>Black or Black British</b>				
Caribbean	<input type="checkbox"/>	African	<input type="checkbox"/>	
<b>Chinese or other ethnic Group</b>				
Chinese	<input type="checkbox"/>	Any Other	<input type="checkbox"/>	

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

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

*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 SurveyMonkey’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 SurveyMonkey?”*
  - 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. *Pro’s*; good to use when asking for attitude or feelings, likes and dislikes, memory recall, opinions
  - b. *Con’s*; 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 2 negative, 2 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 2 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.

*DN Further information on developing effective questionnaires can be found at: a few examples here- eg Picker /Dr Foster and*  
W: [www.patientpublicinvolvement.com](http://www.patientpublicinvolvement.com)

#### **4 Script for Patient Group Members**

Hello,

I am a member of a patient group (*name of group*). We want to ensure that the views of patients are fed in to 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 Reception and Other Staff in Practices with a Patient Participation Group**

Hello,

Our Patient Participation Group (*name*) 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 reception and other staff in practices without a Patient Participation 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 the LED display – *Copies of the contact form should be available at reception with the option of a secure box to drop them into***

THE PATIENT GROUP [INSERT NAME] 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.*

## **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 patients group or name of 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 patients group or name of 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.