



Forest Hill Road Group Practice Patient Participation Group Meeting			
February 2014			
Date and Time	24/04/2014, 18:30	Minute Taker	Ruby Homawala (Patient)
Location	Forest Hill Road Group Practice	Date Published	
Chair	Elizabeth Rylance-Watson (Patient)	Date Approved by FHRGP PPG	

Agenda Item	Discussion
Introductions with introduction to agenda (attendance sheet)	<p>The Chair introduced herself and gave overview and context of agenda items. She explained why the special meeting had been called and the format of the meeting. All those present were requested to sign in.</p>
Agree Minutes and follow up actions	<p>Actions:</p> <ul style="list-style-type: none"> • Everyone to look at the Website and give feedback: The Website did have many visitors and one patient mentioned that all information was up to date. • Everyone to try and persuade more patients to attend the next meeting: It was good to see so many attendees at the meeting. • Discussion on sharing of information with other practices with a view to sharing good Practice: The Chair welcomed the Chair of the Camberwell Road PPG • Everyone to send in questions/points to be raised in Medications questionnaire: Only one question had been sent in by a patient. The chair suggested that 'Medicines' would be a part of a PPG week in the first week of June. <p>The Minutes of the meeting on 20/02/2014 were agreed with the following amendments:</p> <p>On page 1 of the minutes: Tina had raised the topic of Repeat Prescriptions at the Locality meeting which would be discussed at a future Locality Meeting.</p> <p>Page 3: Practice based counselling: a meeting was requested for further consultation at the Locality Meeting.</p>

**Feedback
from Locality
PPG Meeting
of 1 April
2014**

1. There has been a recent survey for patients and one for Practice staff to gather views on experiences of PPG meetings. . Training courses have been developed and these will be delivered as part of a rolling programme.
2. Many patients had problems with waiting Times at Kings, especially for bariatric surgery and A&E. Patients were advised to report any problems to the Practice so they could raise these issues through the Quality Alerts System.
3. Tina gave an update on Dulwich Hospital. Those who want to follow the debate should go to the Southwark website.
4. Cathy Jeffrey was retiring and this was her last meeting.

Tina's notes of the locality meeting were distributed at the meeting. The Locality minutes had only just been received from the SCCG and they were still in draft form. Therefore, they would be reviewed at the next PPG Meeting.

**Care.Data
Project Panel
Discussion**

Elizabeth introduced Robin Burgess, Regional Head of Intelligence NHS England and welcomed him to the Practice. She read out the title of the session as presented in the flyer for this special agenda item.

Robin started by informing the meeting that he was Head of Care.Data in London and part of a team across England. He said that some mistakes had been made in the lead up to the use of Patients' data.

The purpose of the data being collected was to pull together Health Care data from GPs, Hospitals, Social Care, Community Care and wherever patients were seen.

At the moment only Hospital Data is being used – Hospital episode statistics are sent to secure NHS Organisation Information Centres who hold or send out data to various organisations for the purpose of helping care.

Data is used for the purpose of improving care. GPs already send some data to improve the care you receive.

The project was launched in January with the intention of using some GP data to get a picture of Healthcare Data

Because of the reaction from the public, NHS England have halted the project to listen to patients and gather views, and these will be communicated to the Centre to make sure they hear your views. Robin said he was aware that people are concerned.

He then asked for questions.

- One question was about how vulnerable people would be protected from being targeted by unscrupulous or organisations. The person asking the question was worried about security of data, and the risk of commercial bodies getting hold of it.(Cold calling, email etc)

Robin responded that pseudonomised data was a major problem as there was concern that the protection which supposedly was there was not very good. It was OK if this data went only to the NHS. The NHS has to think very carefully and rethink the concept of pseudonomisation.

- Another questioner was worried that with the NHS contracting out to private companies (on contracts over £75,000) there was a risk that data would flow from the provider's side to external bodies.

Robin replied that the NHS should not release data without anonymising and protecting people's identity.

- Just as Bank information is sold and people are sent information on financial products, this questioner was worried that a similar thing would happen to NHS data and commercial companies would try and exploit it to sell health products

- Another questioner, with experience of working with IT in the public sector, had concerns regarding computer systems themselves. When the Government tried to merge several systems they collapsed. Data is only as good as the operators/ programmers and the risk of leaks, with information going to commercial interests, is very likely.

Robin answered that the intention is to release data gradually
The proposal for the release of Tax data is similar. The release of data must be such that people are not identifiable.

The NHS is huge with millions of staff and patients and one must have large data sets to make it useful. If we link it all together we get benefits. He then gave two examples of the benefits of large research studies, on hip and knee replacement joints where data from the UK and Australia was compared and the huge number of results indicated the possibility of the joints causing cancer, helped to stop the use of certain types of joints. Similarly, extensive, collected data research on Thalidomide at that time could have had a very different outcome. Thus pooling large data has healthcare benefits.

- A questioner commented no one was against the use of data for medical purposes, but Government policy is taking public data and money is being funnelled into private pockets. What are the controls and measures taken to prevent the data falling into private hands.

Robin explained that data is anonymised at source so it never goes to the Centre in an identifiable way. There should be transparency released so you can see who they release the data to. A new committee will be formed made up of an independent group who will offer their opinions on who the data can be released to. There will be a clause which will prohibit certain uses of data. The minister has put in a new clause in the law. The clause is subject to amendment in Parliament and in the Lords on 7 May. The public has to judge if the clause offers enough assurance of privacy of data and make up its own mind. There is also an amendment: Fines will be levied on using data and re-identifying people. Some have argued that a suggested fine of £500,000 is nothing to large Pharmaceutical companies for example, and furthermore, the policing will be done by the same information centre which has released the data.

- What are the reassurances that data will be released only for Healthcare uses? 'Healthcare' is a very general term. It could open up a very large door for private interests.
Robin answered that one has to read all the information that is out there and make one's own judgement.
- Another question was: Why does the Post Code have to be given? The Official answer is that leading researchers say the more accurate the information, the more valuable it is for research purposes. Predictive value cannot be achieved without 95% accuracy of data.
Someone said if you use the first part of the Post Code you can get a profile of the area.
The questioner asked if the Post Code of the Practice could be used rather than the patients' Post code.
Robin answered that if you are doing research, you look at data and ask specific questions. On the other hand, Care.data is a huge pile of data and if someone wants to look at detailed question, it is designed to provide all the details.
- Another patient mentioned that the Opt-out was not a good way of doing it and people should be asked to Opt in if they wanted their data to be used. Robin asked for a show of hands on who would prefer the 'opt in' option. The overwhelming majority of people raised their hands
There was a discussion on the leaflet that was sent to people. Many people didn't receive it. Others thought it was junk mail and threw it out. It was not written with sufficient clarity or information.
Robin said it was Junk Mail. The first time he saw the leaflet it had already been printed and it had been rushed through.
He told us the reason was financial; the leaflet cost just over a million pounds, an addressed letter to every household would have been £30 million.
- A patient remarked that Robin had mentioned great benefits from the research, but with that come great risks and great consequences, and a fine of \$500,000 was miniscule compared to profits the Private companies could make.
- Another patient remarked that it should be Opt in not Opt out and said none one trusted any Government system. If we were sure the data was secure and only for the use of the NHS, one wouldn't worry about it.

	<ul style="list-style-type: none"> • Another patient suggested anonymisation of data at source and said that the fine should be £500,000 per patient; severe penalties should be set. It would ensure that data was not used illegally. She also asked if we could consent to part of the information being passed on and not all information. or segregated consent, for example, Opt in for NHS uses and Opt out for Commercial use. <p>Robin said only selected items of data would be given to commercial organisations. A great deal of data would be redacted before it would be sent, but it would be too difficult and complicated to achieve segregated consent.</p> <p>Robin mentioned that following a Freedom of Information request a Member of NHS England had said that if too many people opted out of allowing their data to be used, they would withdraw the right to Opt out. It is not a legal right to Opt out. A future Secretary of State could rescind the right to Opt out.</p> <p>Allowing your SCR extract of data to be shared was in your own interest. If you were to be in another part of the country and had an accident and were taken to hospital, the hospital could look at your SCR and take care of you, knowing any medication allergies you suffered from or medical problems which could affect your treatment.</p> <p>A discussion on different Opt outs followed.</p> <p>Dr Raman was asked to give his views and he said it was all about patient trust. This was something doctors were taught from the time of their initial training. If trust is lost and there was a suspicion that trust was lost, it would alter and damage Doctor/Patient Trust.</p> <p>Robin said that Care Data was episode based, no historic data was collected.</p> <p>Robin concluded by saying that the intention was that more information over time would be collected, but that it was unlikely that 'Free Text', i.e. a detailed description of discussions with the patient would be collected.</p> <p>The meeting concluded at 8.00pm with thanks to Robin Burgess for coming to talk to us and answer questions.</p>
<p>Future Meetings</p>	<p>Date of next PPG meeting: Thursday 11 September 2014(18.30-20.00) at FHRGP</p> <p>.</p>