NHS
East and North Hertfordshire
Clinical Commissioning Group

GATHERING PATIENT STORIES: A PRACTICAL GUIDE

East and North Hertfordshire Clinical Commissioning Group

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GATHERING PATIENT STORIES: A PRACTICAL GUIDE

Thank you for being part of our new patient stories project at East and North Hertfordshire Clinical Commissioning Group (CCG).

Following on from the involvement of patient members in quality assurance visits, we see patient stories as another important contribution to improving the quality of services for people living in east and north Hertfordshire. Patient stories offer a fantastic opportunity to get a rich level of detail from individuals on the care they receive. Stories collected by patient members will offer different perspectives that are hopefully built on trust, understanding and confidence in the process.

PATIENT STORIES OFFER A FANTASTIC OPPORTUNITY TO GET A RICH LEVEL OF DETAIL ON THE CARE THEY RECEIVE.

This guide will give you a sense of what your role as patient story collector will involve as well as signposting you to other areas that might be of interest.

We will initially be **prioritising particular themes** and asking GPs and other staff members to identify appropriate patients to interview as part of this project. If you feel you know a patient that might have an interesting story to share from their healthcare experiences then please get in touch with the public engagement team.

PREPARING

The Public Engagement team at East and North Herts CCG will be responsible for identifying patients to give their story, and will then match them with a suitable (and fully trained) patient member.

You will then be responsible for contacting and arranging a mutually agreeable date, time and location for the story gathering. You should try and arrange the meeting on suitable premises, you may want to make sure there are people around you. You can arrange the meeting at someone's house or in a community venue only if you are happy to and you manage the lone working implications that come with that.

You will need to prepare yourself for the story telling session. Make sure you have spare information leaflets, consent forms, voice recorder (check that it works and is fully charged), if appropriate a ‘do not disturb’ sign for the door, water and tissues.

It is often useful to think and plan your opening sentences as they are the most difficult. Don’t be afraid to write them down and take some notes in with you just in case. If you know you have them you will probably find that you don’t need them but they can be useful as a back-up.

IT IS OFTEN USEFUL TO THINK AND PLAN YOUR OPENING SENTENCES AS THEY ARE THE MOST DIFFICULT.

It is really important that we maintain the story teller’s confidentiality and respect their wishes if they choose to remain anonymous. They are telling us some very personal information and we are privileged to listen to it. The stories that they tell us do not automatically become our ‘property’ once we have heard them and we must be very aware of this all the way through this process. Each story is valid at the time it is told and we need to consciously think about how we may react to what we hear. You may hear some difficult things and you need to maintain a healthy balance of empathy without seeming overly shocked if someone says something bad. But at the same time you couldn’t sit there with no reaction as that would be maybe more strange!

It is really important that the person feels able to talk. It is recommended that you do not listen to someone’s story if you have been directly involved with that person. This will make it easier for them to tell you about the bad as well as the good! This will also help you to hear what they have to say in an objective way, it is hard for us humans to hear the things we don’t want to and easy for us to excuse or dismiss the things that we are very familiar with!

Be aware of how much you say in the story and try to avoid speaking over the patient. Sometimes if we want to use any audio from the story it can be ruined if the listener has *ummed and ahhed* over the patient – try and leave some silence in between them and you if you can. Remember to take a breath! This is a simple way of creating a natural pause but also to make sure that the story teller maintains the lead, and you don’t appear to be rushing them on to the next bit.

CONSENT

When you meet with the person, you will need to follow the process below.

You need to be certain that the person telling their story understands why this is happening and what will be done with their story. They and you need to sign a consent form and these should to be returned to the public engagement team at the Clinical Commissioning Group.

You may need to explain more about why we are doing this and what your role is. You should clarify that you are not there to solve or fix anything; you are there to listen to what is being said. It is worth checking that they are happy with being recorded and explain that it is to help you as it will mean you don't have to take notes and you can listen to their story properly. The beauty of a recording is that you can pause, rewind and listen again.

It is OK to say that this is your first story! It helps to make you appear more human too and avoids that trap of trying to be an 'expert'.

There are different options that they can consent for. Make sure they know it is their choice and that they are free to change their mind at any time. You need to point out however that if they raise something of great concern you will have to stop the story and act upon it.

An example consent form can be found in the appendices of this guide.

GATHERING THE STORY

The start is often the hardest bit, especially the first time. Don't worry if it feels a bit false and strange. You will settle into it. Don't be afraid to tell the story teller how you feel - they may feel nervous too and sometimes it is easier to talk if you feel on more of an equal footing with the other person. You don't have to launch straight into the story, you can 'set the scene' for a relaxed conversation first if you want by asking about other things such as how their day has been, the weather, how they got there, etc.

People often ask ‘where do you want me to start?’ You should say that it is up to them but maybe they would want to start before they came into hospital or went to their GP, for example.

Use open not closed questions and be aware of what you say. A closed question is one where the other person has a yes/no response which will mean you don’t get as much out of them as you would like. Don’t panic if you do because you can always then say something like ‘Can you help me to understand why you felt like that please?’ Don’t lead them into anything e.g. “Did you find the food horrible?” which hints to the person that you think it is so you want them to say yes and agree with you! You would be better asking something like ‘Can you tell me what you thought of the food?’

USE OPEN NOT CLOSED QUESTIONS AND BE AWARE OF WHAT YOU SAY.

Don’t be afraid to go back to something they said earlier. For example, they may say something that you want to explore further but move on straight away. You can say, ‘you mentioned such and such earlier, can I ask you to help me understand what you meant by that a bit better please?’

Other questions that you may find useful are:

- Tell me about when you became unwell...
- Tell me about when you came into hospital...
- What do you remember most?
- What was your care like?
- Do you have a significant memory of your care?
- Was there anything that surprised/worried/pleased you?
- Tell me more about....
- You said this [ ], can you help me understand that a bit better please?
- How did that make you feel?

Think about your body language and your facial expressions. Try and keep the conversation open and relaxed whilst maintaining a sincerity which values the person telling you their story.

Be aware of our natural hard-wiring to ‘fix’ things – we are used to hearing something and then making a decision about what can be done about it. This is not your role when listening to a story. Your role is to facilitate as much of the story to be told as possible and in a safe way. Some people find this more challenging than others. The downside of this is you will start to become acutely aware of how we tend to do this and notice how often we do this in on a day-to-day basis!

At the end of the story please remember to thank the person and explain what will happen next. Check if they want to receive any feedback about what we do with the stories and make sure you have their contact details if so.

Please explain that the whole process will take time so not to expect anything straight away. There is nothing worse than promising the world and not being able to keep it!

THEMING THE STORY

Once you’ve completed your meeting with the storyteller you will first of all need to sit down and listen to the story a short while (I suggest ideally within a few days) after gathering it. Sit somewhere quiet where you can listen to the story and reflect on what’s being said. Mind mapping is a useful technique to use to draw out the issues and themes of what is being said.

MIND MAPPING IS A USEFUL TECHNIQUE TO USE TO DRAW OUT THE ISSUES AND THEMES.

The RCN (Royal College of Nursing) approach to theming stories recommends the use of mind mapping. Start with the patient in the middle and as they talk about different aspects write them down. You might want to use a whole quote from a patient – sometimes a sentence may be so poignant you want to use it again – you can write this down in the map. The process is in 2 stages:

- **Stage 1** – listen to the recording and create a mind map. This is where you listen to the story, pausing and rewinding as necessary, and pull out the different issues and themes that the patient talks about. For example, they may talk about the need to use their buzzer, the way people talked about them, their understanding of what was happening to them – all of which could be themed as ‘communication’.

- **Stage 2** – identification of areas for quality improvement and indicators of good practice. It is important to do both of these, not to simply focus on the negatives.

The diagram at the end of this pack is an example used by the RCN of a mind map of a story.

FOLLOWING UP

Once you have your notes ready and are clear on the themes that have come from the story we will ask you to return the voice recorder to the patient engagement team at the CCG, along with any notes that may help with the transcription process.

A member of the team will transcribe the story and will then ask to meet with you to discuss the story and agree what the key themes are and ask how you felt the story went, and ensure that any transcription or written version of the story is a fair representation of the views of the patient and the collector.

Stories will be used internally to improve our quality monitoring intelligence and potentially share them at events such as board meetings.

DEALING WITH DIFFICULT SITUATIONS

Most of the time you will be able to gather a story with no complications; if however, someone raises something that causes you concern for example a patient safety hazard, you should contact the public engagement team as soon as practicably possible. If you or the story teller is traumatised by the process, you should contact the team to see if further support is needed.

FURTHER INFORMATION OR GUIDANCE

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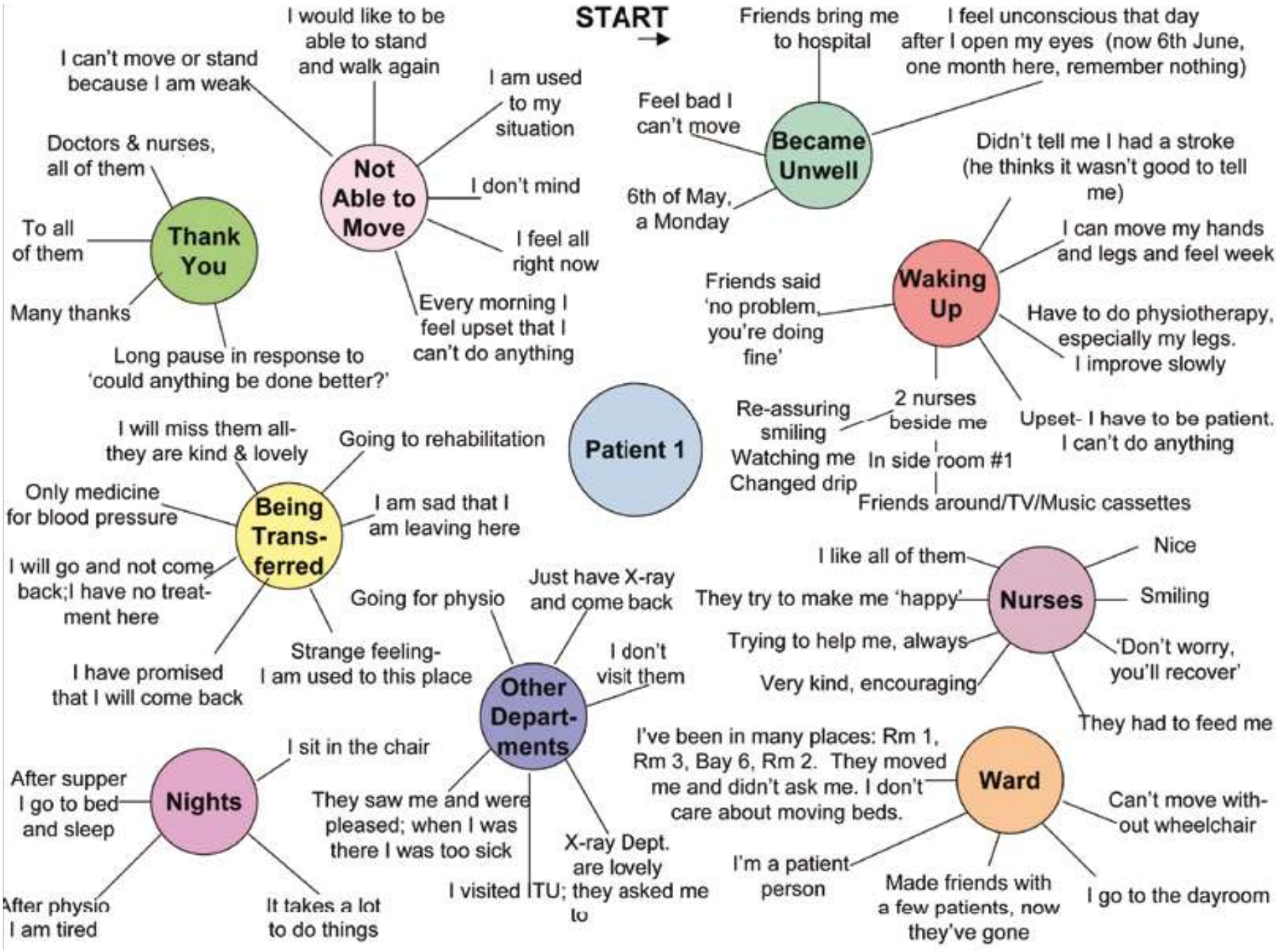

ROYAL COLLEGE OF NURSING THEMING STORIES APPROACH

OTHER SOURCES OF INFORMATION

Patient Voices
www.patientvoices.org.uk

When Doctor's become patients blog
http://abetternhs.wordpress.com/2014/01/27/dr-patients/

A friendly introduction can transform patient experience
http://www.theguardian.com/healthcare-network/2014/may/21/friendly-introduction-transform-patient-experience

Patient and family centred care Innovation Centre
http://www.pfcc.org/

Faculty of Medical Leadership and Management
https://www.fmlm.ac.uk/news-policy-and-opinion/opinion/articles/fmlm-and-the-francis-report

CONFIRMATION LETTER

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www.enhertsccg.nhs.uk

Dear {*person's name*}

Thank you very much for agreeing to take part in our work. We are very grateful that you would like to participate and share your story about your experiences of care, specifically ……

We will use your story about your experience to improve the services that we commission from hospitals and other health services.

I would like to confirm what we agreed on the telephone. We said that our patient member *insert name* will contact you to agree a time to meet at *insert location*.

The session should last for about an hour and *insert name* will use a voice recorder to record the conversation. This is so that they can listen to you talking rather than take notes and will help us to review and analyse your story afterwards.

Please find enclosed a consent form that I hope you can look at before the two of you meet. You can go through it with *insert name* and you can complete it then. Provided you are happy to give your consent, we can record your story; it would then be my intention to share the messages that you give insert name within the Clinical Commissioning Group.

I would be grateful if you could consider whether you would wish for your name to be shared or if you would prefer to remain anonymous. You can tell *insert name* what you would prefer when you meet.

Please be assured that there is no requirement for you to take part in this work. If having considered this information you would prefer not to take part, please let me know on {insert telephone no}. You may also withdraw your consent at any time, even after telling your story, and this will have no effect on any future care that you may receive.

Once again thank you in advance for taking the time to participate.

Yours sincerely

PATIENT STORY CONSENT FORM

NHS
East and North Hertfordshire
Clinical Commissioning Group

This form is to give my agreement as a patient to tell my story about my experience of health care. I have been given information about what will happen. I have been able to ask questions about the things that I do not understand and believe that they have been answered to my satisfaction.

PLEASE TICK YES OR NO IF YOU ARE HAPPY WITH THE STATEMENTS.

	YES	NO
My story will be digitally recorded and used to improve health services in the future.		
I am under no obligation to tell my story and I can change my mind at any time, even after I have told my story, without giving a reason, and this will not affect in any way any future care that I or my relatives may need.		
If I raise any issues that cause concern for patient safety I accept they will need to be looked at by the organisation.		
East and North Herts CCG might need to contact me again about this story and I am happy for them to do so.		
Some of the words that I say may be used in reports as quotes.		
I am happy for my name to be used in conjunction with my story which I understand will make me identifiable.		
You may want to use some of the audio recording for training purposes and I am happy for you to do so.		
My story might be shared with other NHS and partner organisations so that they can learn too and I am happy for this to happen.		
I freely agree to tell my story about my experience.		

Patient signature:	
Date:	
Name (PLEASE PRINT):	
Staff signature:	
Date:	
Name (PLEASE PRINT):	
Job title:	

Office use: story reference code: 201_/

FEEDBACK LETTER

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Dear {*patient name*}

I am writing to thank you for taking the time to tell your story about your experience of {*insert*}.

Since recording your story, I have listened to it again and analysed what I heard you say. As *Insert name* explained when you met, the main reason that we are keen to listen to experiences is to improve the services that we commission. We can learn from the things that are done well, as well as the things that you think could be improved.

As a result of your story we will be able to do the following:

ACTION POINTS

Can I please take this opportunity to thank you again for your time and for sharing your experience, it is very much appreciated.

Yours sincerely