Using Patient Stories in NHS Lothian

The purpose of this document is to define how the use of Patient Stories as a service evaluation tool will be managed in NHS Lothian. This is in order to protect patients, carers, and staff, and address issues surrounding how data will be generated, stored and presented.

What are Patient Stories?
Patient Stories, also known as patient narratives, is an established method of generating recorded interviews with patients and/or relatives or carers, about their experience of receiving care.

They can be used as a tool to evaluate a healthcare service and are seen to promote patient involvement (Department of Health, 2004). The method is recognised as a powerful way of getting patients to identify areas for quality improvement and to find out which aspects of their care experience they particularly value. The content of each interview is led by the individual patient/client. Relatives, carer or staff stories can also be used.

Background to the use of Patient Stories
Over the past 7 years Patient Stories have been used as a tool in NHS Lothian on the Royal College of Nursing (RCN) Clinical Leadership Programme (CLP) and were governed under the licence of this programme.

The intention now is to be able to use Patient Stories in a wider range of programmes and clinically based activities. Also since the RCN programme is no longer running there is a need to define the governance processes including informed consent, data protection and quality control.

It is envisaged that Patient Stories will be used in the following situations in the future:
- By participants on formal leadership programmes and workshops
- By the organisation as part of a specific initiative e.g. Patient Stories Week
- As part of specific projects e.g. Leadership in Compassionate Care
- To generate audio material to use in teaching sessions
- As an integral part of improving and learning from the Patient Experience

The overall process of using Patient Stories is sponsored and supported by the Nurse Director in NHS Lothian. In all circumstances stories will only be undertaken by healthcare professionals who have had recognised training, (for example RCN CLP participants, staff who have attended needs-led workshops) or who have the support and assistance of staff such as clinical leaders/clinical leadership facilitators, who are experienced in story taking. Within NHS Lothian’s Continuing Professional and Practice Development (CPPD) team, the Lead Practitioner for Clinical Leadership will act as a specific resource who can be contacted for advice and information and will aim to ensure overall quality and monitoring of the story taking.

Inclusion Criteria
Criteria for inclusion should be agreed according to the nature of the participating clinical area and are dependent on the patient’s condition and his/her ability to give informed consent to the process. In terms of vulnerable groups such as children under 16, adults with learning disabilities and patients with mental illness, it is important not to exclude
such patients. Their inclusion will be carried out in collaboration with families and carers, particularly around capacity to provide consent, and they will be given appropriate support.

In order to ensure a representative view and avoid the risk of bias in terms of perhaps including patients known to have a positive view, the aim is to select patients through some kind of random process based on the total numbers who are able to participate in a particular setting. The selection is undertaken by the person conducting the recording rather than by ward/departmental staff. It is recommended that at least 6 patients per area be selected.

Method
A quiet private area within or out with the ward area is required to ensure privacy and no disturbances during the story taking process. All patients are issued with an information leaflet (attached in Appendix 1) outlining the purpose and method of obtaining a patient story. It is made clear that their participation is voluntary and they have the right to withdraw from the process at any time. Anonymity is assured.

There are key skills required to undertake patient stories:
- Active listening and the ability to establish rapport with interviewees
- Ability to engage with patients and enable a sense of security
- Ability to ask open ended questions and not “lead patients down a particular path” (examples given in Appendix 2)
- An understanding of the context of quality improvement
- Ability to actively listen to potentially stressful or difficult stories without passing judgement verbally or non verbally
- Preparation and planning
- Consideration and communication with clinical teams who are involved in the patient’s experience to ensure an understanding of the process, cooperation and support.

The process should encourage a natural discussion about care experiences, which can trigger significant memories and thoughts. Patients may become upset, angry or distressed when recalling specific incidents or experiences and information may be particularly sensitive. This requires professionalism and respect for individuals whilst maintaining a non-judgemental response.

Once the story is recorded, the patient is thanked for their participation and the interviewer then arranges to listen to the recording soon afterwards (within 48 hours where possible). A mind map is produced whilst listening to the story and themes identified. Where appropriate a colleague or facilitator then listens to the recording and adds to the mind map anything omitted or highlights in red any recurring or key themes or points of particular significance. Themes from several stories can then be collated, explored and action plans identified.

If the patient raises issues that are of cause for concern, the individual conducting the interview will discuss this with them, and with their agreement take this information to an appropriate individual such as Senior Charge Nurse, Clinical Nurse Manager or Patient Liaison Officer.
Data Management
Patient stories are collected using digital recorders (or tape recorders). The data collected may be handled in two ways; detailed transcription or audio review, which leads to mind mapping or other form of note taking. Most recordings will not be downloaded to computers nor transcribed; however, in some instances this may be appropriate. Where this is the case the resulting transcription will not include any patient identifiers and the transcript will be kept in a locked filing cabinet. Computers will only be those licensed by NHS Lothian and will be password protected.

Equipment required includes a digital recorder (or tape recorder and tapes), batteries and documentation to record the mind map when listening to the story. Recorders must be stored in a locked filing cabinet and are the responsibility of the professional undertaking the story at that time. The recordings (or tapes) must be deleted (or destroyed) once the mind maps are completed and all information has been recorded. Recordings will normally be deleted within six months.

Use of Findings
Clinical teams can then use this information to plan improved care pathways. The challenge is to then provide this information to key stakeholders within the organisation and contribute to the "bigger picture". Actions can be at a local level with an immediate effect or contribute to providing evidence for existing work such as Patient Liaison work examining complaints and communication issues. Articulating the impact is probably the biggest challenge when undertaking stories. Informing patients and interviewees, providing examples of actions and outcomes, within the areas involved, is also vital to the process. Identification of good practice and providing positive feedback to the clinical areas and also to the key stakeholders is essential and highly motivational for staff. Sharing good practice is encouraged and patients are then able to see how their story has contributed to improving the quality of service and care we provide.

Feedback and themes identified in the stories can be disseminated in written reports, conference presentations, written publications and letters to participants/staff/teams and patients involved.

For further information please contact:
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Mobile: 07740841626

Approved by: __________  Designation: Nurse Director

Date: 13 May 2009

Appendix 1

Information Sheet

Patient and Relative Stories (using emotional touch points)

Please take time to read the information carefully and ask any questions.

What are patient and relative stories about?

You have been invited to take part in patient or relative stories because NHS Lothian staff are keen to hear from patients, clients and relatives about what aspects of care they value and what aspects of care we could improve.

What would I have to do?

Think about key times in your hospital experience that you would like to share with us. This might be coming into hospital, going for tests, mealtimes, or visiting times. We would like to know how you felt about your experience and will ask questions about this, so information can be obtained about your experience of care.

Where will the interview take place?

The interview will take place in a quiet area within the ward or hospital or health centre or at home.

How long will it take?

The interview will take from 15 minutes up to an hour depending on how much time is appropriate for you.

What will happen if I do not understand the questions?

You will be asked to share with us whatever aspects of your experience you would like to talk about. There is no right or wrong answer. Much of the time you will be telling your story about your experience rather than answering a set of questions. We are particularly keen to hear about how the experience felt and will use some prompt cards to help us to discuss this.

What information will be shared with others?

After the interview the staff member will type up your story and give this back to you to read within 48 hours. When you read the story you can check to see if it is accurate and whether you would like to share it with other staff in the organization so that they can learn from this. Your name will not be used in the story. There would be a date of the interview and a code to identify your recording. All
information and recordings will be anonymous. Confidentiality is of utmost importance.

What are the benefits of taking part in patient or relative stories?

NHS Lothian staff will be able to listen to your story, and understand aspects of care that you really do appreciate. We will also be able to learn about how the experience felt for you and make improvements to the service.

What are the possible risks of taking part?

Sometimes patients may become upset or sad when telling their story. If at any time you wish to stop or withdraw from the interview you may do so. Any recordings will be destroyed.

Will this change the care I receive?

Taking part will not compromise your care or the care of your relative in any way. By increasing our understanding of what is important to you and by acknowledging any negative experiences, we can look at ways to improve and develop the care we deliver. We will also share examples of good practice.

What will happen to my story once it has been completed?

We will share the story with other staff. We will have discussions about the main points in your story to help us understand what we do well and also to learn what we can do better. We will develop sets of actions in response to your story that aim to develop the service.

Who is organising and supporting this work?

This work has been organised by NHS Lothian and is supported by the Nurse Director. In addition the work is linked to the Leadership in Compassionate Care Project which is supported by NHS Lothian and Napier University.

What if I want to talk it over with someone who is not involved in the patient stories?

Please contact:
Juliet MacArthur, Lead Practitioner-Research, NHS Lothian
Tel: 0131 242 1752
Appendix 2

Using Patient stories in NHS Lothian

Examples of prompt questions for interviewing patients

These prompts are not in order and you may wish to add to or adapt them so they are more suitable for your patient group

- Tell me about when you became unwell
- Tell me about when you went into hospital/tell me about when you began to receive care at home
- What do you remember most?
- What was it like in the ward?
- Tell me about your care/operation/clinic appointment
- Is there anything significant or particularly memorable about your stay in hospital?
- Tell me about when you left the ward/clinic
- Was there anything that surprised/worried/upset/pleased you?
- Tell me more about....
Patient/Relative Story Consent Form

*Please delete as appropriate

Have you read the information sheet? YES/NO*

Have you had an opportunity to ask questions and discuss the process of story taking? YES/NO*

Have you received satisfactory answers to all your questions? YES/NO*

I hereby agree to participate in the patient/relative stories on the understanding that I can withdraw this agreement at any time and that my current care and treatment will not be affected.

I understand that all the information gained will be anonymised and that information which is recorded or taped will be confidential.

After the interview the tapes will be listened to, themes from the stories will then be collated and explored, to identify areas of good practice and areas for development and improvement. The recorders/tapes will be kept in a locked filing cabinet and only used under the supervision of an experienced healthcare professional.

I give my permission for the recordings/tapes to be used for teaching purposes within NHS Lothian.

Date ________________________________

Signature or mark ________________________________

Name (Block letters) ________________________________

I confirm that I have explained to the patient/client the purpose and nature of the patient stories.

Date ________________________________

Signed ________________________________

Name (Block letters) ________________________________