

Patient/ Carer's Stories Guidelines for Collection and Identification to the Patient Experience Team

What are 'patient and carer's stories'?

Patient and carer stories, also known as narratives, are recorded (audio, written or video) interviews with patients and/ or their carers about their experience of receiving care. This is a very powerful way of getting patients and carers to help us, as a caring organisation, to identify areas for quality improvement and to find out which aspects of their experience they value.

Patient stories are not something to be judged or defended, they are events that happened to the patient or carer and they are their personal thoughts, feeling and memories about their experience. They can be positive or negative, however they often contain a mix of positive and negative experiences.

The strength of this intervention is that the content of each interview is led by the individual patient / client and / or carer. This means that it is unlike any other method used to elicit patients' and carer's views. For instance, in patient satisfaction questionnaires the questions are often devised by health care professionals and reflect the issues that they feel are important, rather than showing the things that really matter to patients and carers.

Patient/ Carer Story Process

- 1) Patient and/ or Carer Selection
 - Any member of staff can identify a patient or carer who may like to share their story
 - Any patient or carer who has had experience of our services is eligible to share their story.
- 2) Explanation to the patient about the reason for stories
 - Wider sharing across the Trust as learning
 - Celebration of positive experience
 - Service improvement
 - Providing a method for patients and carers to have their voices heard
 - Assure the patient or carer that the story will be anonymised
 - Not another way to make a further complaint or air hidden agendas
- 3) Arrange a convenient time and place for the interview
 - Taking into consideration accessibility needs and communication needs such as interpreter
 - Allow at least an hour for the interview to take place
 - The most convenient location may be the patient's home
- 4) During the interview
 - Take equipment to record the interview e.g. Dictaphone, video (communications team can assist with this) or notepad.
 - Obtain consent from the patient/carers for the method of recording the interview (template in Appendix 1)
 - Confirm consent for sharing the story across the wider Trust, including the Trust Board which may have public or press in attendance

- Help the patient/carer relax by spending time asking some easy general questions before recording the story
- 5) Questioning and practical recording suggestions when carrying out audio or video
 - Always use open questions such as what, who, why, how rather than closed questions which may illicit a yes or no answer
 - Ask the patient to start their story from the beginning and talk through their experience as they remember.
 - The best stories flow from beginning to middle and end
 - Try to encourage conversation flow by nodding and smiling encouragement rather than constant questions as they will be more difficult to edit out.
 - If there is need to ask a question, try to leave a gap between the question and answer for ease of editing.
 - Let the patient/carer tell all their story, don't rush them
 - Do not belittle their experience or try to explain reasons or find excuses for poor experience
- 6) After the interview
 - Explain that the story will need some editing in order for us to use it effectively
 - Tell the patient / carer that you will send a copy of the story to them to agree before it is used
 - Give them the opportunity to change their mind about the story if they are not satisfied with it.
 - Ask if they would like to be kept informed about changes that are implemented as a result of their story, however explain that these may not be immediate changes.
- 7) Submitting the story to the patient experience team
 - Stories should be sent to the patient experience team for editing to a suitable format and length for use within the Trust.
 - Once edited a copy of the story will be provided to the individual and the patient

NB....If you wish the patient experience team to collect a patient story, then please make sure you have all the details required to contact them as detailed in Appendix 1

Patient Experience Team

	<u>Internal</u>	<u>External</u>
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Appendix 1
Identification and consent sheet

Name of Patient/ Carer	
Name of relative/ carer if applicable	
Address	
Preferred contact method (please circle)	Telephone/ email/ face- to-face
Contact details (email address/ telephone number)	
Additional needs/ requirements e.g. interpreter	
Type of record e.g. written, audio, video (please circle)	Audio Written Video
Type of story (please circle)	Inpatient Outpatient Carer Domiciliary care
Consent to share story throughout the Trust, including Trust Board where public and press may be present	Signed _____ Print _____ Date _____