

Exercise 0.3

Collecting a patient/ citizen story



In this exercise you will be collecting your own story from a patient/citizen that you support. The story approach used here is based on the story collection protocol created as part of the learning platform (which you can also access as a separate handout) and has been used to collect many of the patient and citizen stories available on it. There are many different approaches to collecting patient, carer and staff stories.

0.3.1

Story collection protocol

First talk through the protocol outlined below and then with a patient/citizen, complete as many sections as you are comfortable with, coming back together to talk about this process and the stories that you have collected.

In the process of story collection you are encouraged to respond to what participants want to talk about and enable them to lead as much as possible. The areas below should therefore be considered more as a list of prompts rather than questions that need a direct answer.

Helpful phrases to elicit free-flowing conversation; 'tell me more', 'can you give me an example', 'how did that come about?', 'how do you feel about that?' 'please explain', 'I'm interested in what you said about...' etc. It is also effective to reflect back to participants what they have said, checking for understanding/asking for elaboration/reflecting emotions, as this also demonstrates interest and engagement. The use of a visual prompt to aid discussion during sessions could be considered e.g. objects/timelines/calendars.

Story cards drawing on the main questions and some of the prompts can be created to give to participants to illicit narratives.

Consider the ethical aspects of this within your institution. It is usual when using stories in research to ask participants to sign a consent form which specifies that they can withdraw at any time and that their stories will be treated anonymously. Always inform participants if you will take notes or use audio-recording or video and ensure they give their consent. The setting should be as relaxed and friendly as possible.

0.3.2

Story prompts

Thinking about your everyday life

What are the weekly/other patterns?

Describe your everyday life and routine

Describe your family and your closest personal contacts

What you do socially, what activities you participate in?

What do you most enjoy doing?

Your aspirations for the future

What do you currently find most important in life?

What do you value?

What are your most important hopes and wishes for the future?

What would you describe as your ideal situation in coming years?

What would you like in the future that is currently not happening?

Describe some important choices that you have made for yourself. What was difficult (or not) about making these?

Who do you turn to for help in making choices? Who do you discuss choices with?

Your health

How would you describe your health?

How do you support your health on a daily basis? How would you ideally support your health if there were no obstacles?

What do you incorporate into your lifestyle to support your health?

Who do you feel is responsible for your health? Who supports you?

Who else would you would like to be involved in supporting your health, and how might they support you?

What else missing in terms of support for your health?

How do you feel about the information you receive about healthy habits and disease prevention?

What sources do you use?

How do you deal with the recommendations you get about your health?

What changes have you made to your lifestyle/habits recently?

What lifestyle changes would you like to make and who would be involved?

What motivates you/would motivate you to make a change in your lifestyle?

The impact of illness on your life

What illnesses have you had?

What comes to mind when you think about this?

What has this meant in your daily life can you describe a good day and a bad day?

Which issues or symptoms have had the biggest impact on you?

What are the main things that disrupt your daily routine and how do these make you feel?

Who are you seeing for treatment?

How do you go about/feel about the treatment that is recommended to you?

Can you describe how you go about your prescribed medication?
(How do you feel about the medication you're taking for your disease?)

What motivates you to take this medication? What hampers you in taking this medication?

If there were anything you could change about your treatment/medication, what would this be?

Who is involved in helping you manage your illness and supporting you?

Who else would you like involved?

How do you feel about how practitioners approach and interact with you?

Do they take your views and feelings into consideration?

What are the main challenges and barriers – and what do you think are the ways to make this better?

0.3.3

On coming back together to share the stories you have collected, think about the following in relation to collecting the stories:

How often do you think they are asked to reflect on these aspects of their health and wider lives? In what contexts? Why?

How would you support them if the narrative process became difficult for them?

What do you think that an elderly patient or citizen might feel/how might they respond to their challenges after describing them?

How could you use or adapt this protocol for use in your own organisation?