Implementing your own MDC patient experience survey

In May 2016, the independent Cancer Taskforce heard throughout their engagement on the strategy how distressing poor experiences can be, and heard concerns from patients particularly about poor communication; the information and support they were given to help manage their health and consequences of cancer in their wider lives, and the way they were able to access information.¹

Gathering patient feedback is vital in developing effective and high-quality health services. Survey tools are one of the most common methods used to collect information on cancer services. Several survey tools have been developed, most notably the National Cancer Patient Experience Survey (NCPES) which records the experiences of all adult patients with a confirmed primary diagnosis of cancer.²

In 2017, when the NHS decided to pilot a new Multidisciplinary Diagnostic Centre (MDC) symptom based pathway they wanted to ensure patient experience was part of the evaluation, including the view of patients who do not receive a cancer diagnoses. Accordingly, Newcastle University developed a specific suitable 21-item survey tool. This document draws on learning from conducting a patient experience survey amongst ACE MDC pilots, and may support the implementation of patient surveys in similar symptom based pathways.

How the survey has been validated:
The survey has been validated and its feasibility of use in routine care has been confirmed. We recommend that it be adopted for the routine monitoring of patient experience as MDC type pathways are more widely implemented.

A number of questions in the ACE Wave 2 Patient Experience survey were drawn from the NCPES, and the Manchester Cancer Survey. Not all are directly comparable, as while they use the same wording, they are about different aspects of the cancer pathway or are for different patient groups.

These surveys were mapped against the MDC pathway to identify the most relevant items. Where necessary, questions were modified to reflect the fact that only a minority of patients attending an MDC would receive a cancer diagnosis. A new question was also created to gather information about whether lifestyle advice was given (question 16), as the feedback from the two Manchester sites considered this to be an important part of the service they provided. The survey was designed so that each site could insert their pathway name into questions where necessary.

Who took part:
The patient experience survey was implemented at six pilot MDC sites between May 2017 and February 2018. During this period, 854 patients were seen and 256 completed surveys were received (30% response, range 16-44%).

Survey questions:
The questions all centered around patient ‘care and treatment’ at the MDCs. The survey asked questions around whether patients understood the MDC pathway and if they were satisfied with the level of care, support and access to information they received. Overall, the survey was split into four overarching themes:

1. Before the patient was given a diagnosis
2. Tests that took place at the MDC appointment
3. When patients were first given a diagnosis
4. Patient experience as a whole

A full list of questions is provided in Appendix B.

Distributing the survey:
Unlike NCPES, this survey was only available in paper form, with no online or telephone option available. Having an online web-based survey tool, alongside the paper form may increase access and the response rate; it will also reduce the number of errors due to the printing and compilation of paper-based surveys. The ACE sites issued the survey to patients when they were discharged from the MDC or referred onwards to another service if appropriate.

Scoring the survey:
For the questions that directly relate to patient experience the responses were scored as positive, negative, or neutral as has been done in the NCPES. Each answer option was identified as either positive (1), negative (0) or neutral (-). Where appropriate, the responses were presented as the proportion of responses (expressed as a percentage) that were positive. To calculate the percentage, neutral scores were excluded, positive scores used as numerator and the total positive and negative scores were used as denominator. An example of a fully scored survey has been included in appendix C.

The surveys tools used to measure patient experience should produce consistent results and measure the concept that they intend to. A number of errors can arise using surveys and should be guarded against. These include:

- Coverage errors:- arises when the survey sample does not represent the population being investigated
- Sampling errors:- occurs when some people are surveyed and others are missed out
- Measurement error:- occurs when inaccurate answers are given either due to people unwillingness to give responses or due to problems with the survey questions themselves
- Non-responses error:- occurs when only the some of the sampled group give answers.
Benchmarking progress
This survey should be sent to all patients on the MDC pathway on a continuous basis. The ACE/MDC survey can then be used as a benchmark to compare results from one year to the next, assuming you use the same questions and scoring mechanism to ensure the quality of care service remains consistent or is improving. Yearly surveys can also be benchmarked against the most recent NCPES. It is important to keep the survey going all year round to ensure the service is meeting needs and patients continue to be supported along the pathway.

The survey questions can be found on the following page
ACE Programme Wave 2
Multidisciplinary Diagnostic Centre based pathways for the diagnosis of Cancer.

Patient Experience survey
<SITE>

This questionnaire is about your care and treatment at the Multidisciplinary Diagnostic Centre (MDC). Its purpose is to provide information which can help us monitor and improve the quality of health services for future patients.

Who should complete this questionnaire?

The questionnaire should be answered by the person who attended the MDC clinic at <site>. If that person needs help to complete the questionnaire, the answers should be from their point of view, not the point of view of the person who is helping.

Completing the questionnaire

For each question please tick clearly inside the box that is closest to your views. Don't worry if you make a mistake; simply cross out the mistake and put a tick in the correct box. Please DO NOT write your name or address anywhere on the questionnaire. The questionnaire should take 5 to 10 minutes to complete.

Taking part in this survey is voluntary

If you have questions about the MDC and your care please contact: <site contact>
Please return complete questionnaires to: <SITE>
The first questions are about before you were given a diagnosis:

1. How long was it from the time you first thought something might be wrong with you until you first contacted your GP?

☐ I did not see my GP before being diagnosed
☐ Less than 1 week
☐ Less than 1 month
☐ 1 to 3 months
☐ 4 to 6 months
☐ More than 6 months ago
☐ Don't know

2. Before you were told that you needed to go to hospital about your symptoms, how many times did you see your GP about your health problems?

☐ I did not see my GP before being diagnosed
☐ I saw my GP once
☐ I saw my GP twice
☐ I saw my GP three or four times
☐ I saw my GP five times or more
☐ Don't know / can't say

3. Did your GP explain why they had referred you to the MDC?

☐ Yes, I had a full explanation
☐ I had some explanation
☐ I had a little explanation but would have liked more
☐ I had no explanation
☐ I did not see my GP/I went directly to the hospital

4. Were you given an explanation of the purpose of the visit and what it would involve?

☐ Yes, completely
☐ Yes, to some extent
☐ No, but would have liked an explanation
☐ I had no explanation
☐ Don’t know / I can’t remember

5. Before your visit to the MDC, were you given written information about what to expect at your visit?

☐ Yes, it was easy to understand
☐ Yes, but it was difficult to understand
☐ No, but I would have liked written information
☐ I did not need written information
☐ Don’t know / can’t remember
6. Before your visit to the MDC, were you told you could bring a relative or friend with you?

☐ Yes  
☐ No  
☐ It was not necessary  
☐ I was told by phone or letter  
☐ Don’t know / can’t remember

The next questions are about the tests that took place at the MDC appointment. Thinking back to the appointment….

7. On the day, did you have all the information you needed about your tests? (tick all that apply)

☐ Yes  
☐ No, I would have liked more written information  
☐ No, I would have liked more verbal information  
☐ I did not need/want any information  
☐ Don’t know / can’t remember

8. Overall, how did you feel about the length of time it took for the tests to be done?

☐ It was about right  
☐ It was a little too long  
☐ It was much too long  
☐ Don’t know/can’t remember

9. Were the results of the tests explained in a way you could understand?

☐ Yes, completely  
☐ Yes, to some extent  
☐ No, I did not understand the explanation  
☐ I did not have an explanation, but I would have liked one  
☐ I did not need an explanation  
☐ Don’t know / can’t remember

The next questions are about when you found out what was the matter with you. Thinking back to when you were first given a diagnosis or told you needed ongoing treatment or investigations outside the MDC.

10. Who first told you about your diagnosis?

☐ Hospital Doctor  
☐ Nurse Specialist  
☐ GP (Family Doctor)  
☐ Another health professional  
☐ Family member / friend
11. When you were first told your diagnosis, had you been told you could bring a relative or friend with you?

☐ Yes
☐ No
☐ It was not necessary
☐ I was told by phone or letter
☐ Don't know / can’t remember

12. Did you understand the explanation of what was wrong with you?

☐ Yes, I completely understood it
☐ Yes, I understood most of it
☐ No, I did not understand it
☐ Can’t remember

13. When you were first given your diagnosis, were you offered written information about what would happen next?

☐ Yes and it was easy to understand
☐ Yes but it was difficult to understand
☐ No
☐ Don’t know / can’t remember

14. Were you given the opportunity to ask questions?

☐ Yes
☐ No
☐ I felt I could not ask
☐ Don’t know / can’t remember

15. Were you offered a record/written summary of your consultation and next steps at the clinic or by post?

☐ Yes
☐ No
☐ Don’t know / can’t remember

16. Did MDC staff give you information about lifestyle or other advice to improve your health or manage your condition?

☐ Yes
☐ No, but I would have like information
☐ It was not necessary
☐ Don’t know / can’t remember
The next question relates to your experience as a whole . . .

17. Did the different people treating and caring for you (such as GP, hospital doctors, specialist nurses and navigators) work well together to give you the best possible care?

☐ Yes, always
☐ Yes, most of the time
☐ Yes, some of the time
☐ No, never
☐ Don’t know / can’t remember

About you

18. What is your sex?

☐ Male
☐ Female
☐ Prefer not to say

19. What age are you?

☐ 16 – 24
☐ 25 – 34
☐ 35 – 44
☐ 45 – 54
☐ 55 – 64
☐ 65 – 74
☐ 75 – 84
☐ 85+

20. What is your ethnic group?

☐ White
☐ Mixed / multiple ethnic groups
☐ Asian / Asian British
☐ Black / African / Caribbean / Black British
☐ Prefer not to say

21. Are your day to day activities limited because of a health problem or disability which has lasted, or is expected to last, at least 12 months? (Include any issues related to old age)

☐ Yes, limited a lot
☐ Yes, limited a little
☐ No
☐ Prefer not to say