

Leeds Cancer Programme

Engagement Summary

Name of Project Engaged about: ACE Patient Feedback Survey

Engagements Dates: Engagement took place through May 2019-31st July 2019.

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Overview of ACE:

‘Accelerate, Coordinate, Evaluate’ (ACE) Multidisciplinary Diagnostic Collaborative (MDC) is an innovative diagnostic pathway that challenges ‘silos’ in healthcare.

The ACE pathway sets out to improve patients experience and outcomes by providing rapid access to achieve a diagnosis (one of which could be cancer, but this is not exclusive) for people with non-specific, but concerning symptoms.

ACE was initially rolled out in January 2017 (with Leeds being one of 6 places in UK to pilot ACE). Unlike the existing Two Week Wait (2WW) pathway, the Leeds ACE pathway is unique in that the focus is on providing a diagnosis not simply cancer exclusion. This has vastly improved patient experience, as instead of spending long periods bouncing from one diagnostic pathway to another patients are cared for under one service until a diagnosis is reached.

We now want to conduct a survey to gain feedback from patients who have recently been through ACE to gain a better understanding of the quality of care and service we provide to our patients. Opinions and suggestions are important to us and will help us improve the Leeds ACE MDC service.

Project background Overview:

A survey was created to gain insight into patient’s experiences of the ACE pathway. The aim of this survey was to help us to get a better understanding of the patient’s experiences at the start of the pathway; the aim being to ask further questions at different stages of the ACE patient journey.

Patients who had recently accessed the ACE pathway (within a month of them accessing it) were asked if they would complete a simple survey. People had the option of completing it via a scheduled telephone call (supported by Leeds Hospital Teaching Trust Patient Involvement Team) or via paper survey, or via an online link.

Learning from this engagement process:

- In total we had 55 responses
- Take up on the survey was initially very slow. The survey was extended from May to the end of July because of this. 26 people responded via a telephone interview, despite more people saying they were interested. When they were contacted there were sometimes issues with people saying they didn’t have time to complete the survey, or due to hearing problems struggled to complete it.
- There needs to be clarity on whether or not Carers are able to complete the survey on behalf of someone being cared for and what other formats the survey is available in.
- Due to the initial slow uptake on this survey we expanded the offer to paper and online formats. In this instance Paper survey appeared to be most accessible to people, however it is unclear how many were offered the option of completing it online. 1 person responded via electronic link and 26 responded via paper survey.

- Moving forwards, the survey will be available for ACE patients to complete online. For those who this is inappropriate for, they will have the option of a paper survey.
- On analysing the information it is clear that not all questions were answered by everyone, however there was enough responses to pull out some important information which can be found below.

Key themes on ACE from Patient feedback:

Feedback on seeing the GP & experience of previous tests prior to referral to ACE

- It was a fairly even split between the number of times people had seen their GP before being referred to ACE; however 31% (most) people were referred after seeing their Dr 2-3 times.
- Again, similar findings in the amounts of those people who had been referred to tests previously (51% had previous tests, 46% didn't)
- 39 % of respondents said the GP explained what ACE was
- 39% of respondents said that the Dr explained why they had been referred. Some of the comments in cases where the Dr hadn't done this expressed a lack of clarity, or thinking they were being referred for something else. One patient even said:
- "I think the GP's probably needed to explain more as I thought it was just a series of tests for weight loss & unaware that it was an urgent referral. Thus, when I received an information leaflet along with my appointments saying 'possible cancer/serious illness referral' it was a bit of a shock"
- 65% of respondents were not given a leaflet explaining ACE, 50% of those who commented that they had one, found it explained the service clearly.
- Feedback on wait times once referred to ACE and instructions to attend appointment:
- 84% of respondents felt their wait time from seeing the GP to the CNS was 'completely reasonable'. 57% of respondents were also told they could bring someone with them.
- 81% of people felt that the instructions about their CNS appointment was clear and simple, with 68% of respondents saying they had a choice as to where they wanted to attend. 70% of respondents received a reminder text with the right clinic details (with 5% of respondents being texted a reminder with the wrong clinic details)
- Feedback on seeing a CNS:
- 96% of respondents had confidence in their CNS appointments, with 98% of respondents saying the next steps were clearly explained.
- 98% also said that they were given contact details of a named CNS if they had any questions. The feedback regarding nurses was overwhelmingly positive. With general feedback about them being:
 - *"Absolutely fabulous. Nurse was so easy to speak to and ask questions made me feel at ease"*
 - *"Nurse was brilliant"*
 - *"The nurse was excellent and explained things clearly and in detail. Excellent service. Thank you."*

Feedback on the location of appointments:

- The majority of respondents (78%) were seen at St James' with the next most popular site being Seacroft.
- 98% of respondents said that the setting met their needs
- It was a relatively even split (39%/27%/33%) as to where people would chose to be see (Dr's or Hospital) however some of the feedback stated that patients felt they had more time to speak freely at a hospital appointment, than at a GP appointment as GP surgeries are busy.

A number of comments did state that it was easier to access a GP surgery in terms of location and at lower costs (no parking/longer journeys)

Comments included:

"My Dr's is just a 7 minute drive from home and easy free parking. My husband will not drive into Leeds so we have to get a taxi which costs £20 return"

"It's near to my home and I don't have to walk far from the car park"

"At hospital you have to access other specialists and departments"

Overall Comments:

From the feedback received so far, patients were extremely happy with the ACE process. It appears patients found it easy to access, fast and efficient. Patients had confidence in the process and the discussions with their CNS. As one patient commented:

"Thank you for the opportunity to express our appreciation for the journey so far. The system worked quickly and efficiently. The clinical Nurse was absolutely lovely, calm manner, explained everything that had happened so far and the next steps that were to happen in understandable manner. Rang back as soon as the next step was done and explained what was to happen next. If all departments were this efficient the NHS would have far fewer problems. Thank you."

However there are always opportunities to make improvements. This is mainly around making sure patients are given clear, simple explanations as to:

- What ACE is
- Why a patient is being referred – this prevents any unexpected shocks as one patient commented "I think the GP's probably need to explain more as I thought it was just a series of tests for weight loss & unaware that it was an urgent referral. Thus, when I received an information leaflet along with my appointments saying 'possible cancer/serious illness referral' it was a bit of a shock". This helps manage patient expectations as to what is being done and why.
- It is also important that patients are given the patient leaflet as of those that had it, half of respondents found it helpful to have something to refer to. As 23% of respondents said the leaflet wasn't really helpful it is suggested as an action that it is re-looked at and reviewed to make sure it covers all necessary information in accessible format. It is recommended it is then reviewed by the CCG Reader Group/Leeds cancer programme Engagement Network for their comments. It may also be helpful to create a simple video explaining ACE as some people may find this more accessible.

What will we do with the information & next steps:

- Some participants requested feedback on the responses to the survey. Therefore this will be shared with those individuals.
- Some participants wanted to take part in future ACE surveys. Therefore they will be contacted when this opportunity is available.
- This Engagement Summary will be shared with the Leeds Cancer programme Engagement Network & CCG Reader group as part of a 'You said, we did' process.
- This Engagement Summary will be available to access on the Leeds Cancer programme Website.

Suggestion	Action
Needs to be clarity on whether or not Carers are able to complete the survey on behalf of someone being cared for and what other formats the survey is available in.	The survey has been amended to make this clearer.
39% of respondents said that the Dr explained why they had been referred	<ul style="list-style-type: none"> • Share findings from this engagement with GP's. • Highlight the importance of explaining what ACE is and what a patient is referred. • Ensure patients are offered the ACE leaflet to take home and read for their information.
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