1st touch communication approach: a case study

Accelerate, Coordinate and Evaluate (ACE) Programme

CANCER RESEARCI UK

Context

This case-study describes the elements of a first touch communication approach, introduced by Liverpool University Hospitals NHS Foundation Trust (at Aintree University Hospital), and the Liverpool Heart and Chest Hospital NHS Foundation Trust (at Liverpool Lung Cancer Unit), for newly diagnosed patients with lung cancer. The study reports on the positive connectivity between the patient and healthcare professional initiated at the start of the pathway that helps to improve patient and carer participation in their care, preventive health behaviours and optimal treatment.

Cancer Research UK present this first touch approach as part of the ongoing Accelerate, Coordinate, Evaluate (ACE) Programme, which works collaboratively to support innovation in cancer services. The current ACE focus is to provide service design solutions to those factors that are driving unwarranted variation in accessing optimal standards of diagnostics and treatment, for patients diagnosed with lung cancer.

In sharing the first touch approach as exemplar good practice, ACE encourages other NHS respiratory teams to consider their communication strategies with lung cancer diagnosed patients, as part of their optimal pathway arrangements.

Methods

To understand the key elements of the first touch approach and acknowledge its impact on patients and healthcare professionals, a semi-structured group interview was held in January 2021, involving respiratory teams from Aintree University Hospital and the Liverpool Lung Cancer Unit (LLCU), and representatives from Cancer Research UK.

The overall objectives of the group interview were to:

- 1. understand if there are any key differences in the approach between early stage diagnosed patients and more complex, borderline cases
- 2. explore the positive dialogue and methods used to encourage curative intent treatment and recognise the key messages of reassurance that help patients overcome their expressed negativity, low mood or poor expectation in living beyond cancer
- 3. understand how the different patient behaviours are managed, for example, how to allay the fear and stigma often associated with a lung cancer diagnosis and the ability to pick up on non-verbal cues within virtual clinic settings
- identify any quantified evidence on the impact of the approach, for example, within increased resection rates, improved patient experience or feedback from patient surveys etc.,
- 5. consider the options to develop a communication resource that describes the key elements of the approach, including examples of positive dialogue that can be used by health professionals to encourage curative intent treatment

The interviews have been evaluated by health research analysts at Cancer Research UK, using a framework analysis technique. The framework structure is based on the open coding of data at each stage of the communications approach and for the different patient scenarios. The resultant underpinning themes include the impact on patients, healthcare professionals and the lung service pathway. The results of this analysis will inform the consideration to develop a first touch communication resource (objective 5).



Why was the first touch approach developed?

Improvements to support accelerated patient access to initial diagnostic investigations, eg chest x-ray and CT-scan, (from 2014 onwards) provided the impetus for the first touch approach. Such diagnostic improvements were confirmed within the introduction of the National Optimal Lung Cancer Pathway (NOLCP) by NHS England in 2017.² The optimal pathway is designed to improve outcomes in lung cancer by encouraging best practice, reducing variation, and reducing delays in diagnosis, staging and treatment. It encourages lung teams to review and reorganise their services to ensure accelerated intervention from referral to diagnosis and onto treatment without compromising patient experience.

Sustained spotlight audits (in 2017 and 2019) by the National Lung Cancer Audit (NLCA) also provided motivation to implement the first touch approach. These audits looked at reasons why eligible patients did not undergo thoracic surgery (potentially curative treatment), and their findings reported nationally that 31% and 15% of patients (respectively) did not have surgery because of personal choice rather than suitability for surgical treatment.³

Similarly, there is also a perceived blame and stigma associated with a lung cancer diagnosis, particularly as a self- inflicted smokers' disease, with a public belief that lungs are not a treatable organ and a common lay explanation for poor survival.

What is the first touch communication approach?

Essentially the first touch approach focuses on the affirmative options for encouraging proactive treatment, for all patients referred to the respiratory service. It is based on maintaining a positive dialogue with all patients, who may present with low mood and expectation, and a real fear of a lung cancer diagnosis and prognosis.

It is rooted in providing patient-centred, informative communication, that matters so much to patients. There is a plethora of research evidence on how effective communication is linked to positive health outcomes for patients;⁴ and this positive connectivity between patient and health professional at the very start of the pathway improves patient participation in their care, encourages preventative health behaviours – eg smoking cessation, pre and post-operative rehabilitation - and eventual optimal treatment.

Many patients don't realise there is something wrong until the disease has begun to spread and once a referral has taken place, there is a need for acceleration at this front-end of the

pathway to reach a confirmed diagnosis. Patients must come to terms with a potential cancer diagnosis very quickly, and high-quality communication with their healthcare professionals is essential.

There are two initial stages to the first-touch approach:



Following the triage of abnormal chest x-ray and/or CT scan results, a lung assessment intervention takes place, that involves a telephone call to the patient from the designated clinical nurse specialist (CNS) in lung cancer. The outcomes of these investigations are discussed with each patient and the lung CNS completes a full holistic assessment and schedules the next diagnostic phase of appointments, including PET-scan and pulmonary function testing.

In some instances, however, this first step does not always take place, either because the patient chooses to attend a face to face outpatient consultation, or it is more clinically appropriate for the patient to attend an outpatient consultation in person.

Step 2 At Aintree University Hospital patients are then invited to attend a face to face outpatient consultation, where they meet the respiratory team for discussion and clinical examination, before finally attending more invasive investigations that may be required, eg EBUS (if not already taken place), CT guided biopsy etc.,

Patients at LLCU proceed through their pathway having further investigations (EBUS, CT-guided biopsy), at which time they meet the respiratory team, before subsequently attending a face to face outpatient consultation, for discussion of results/diagnosis and treatment plan together with any further investigation that may be required.

What does the approach include?

The respiratory teams ensure the structure of their first touch approach is both engaging and patient-centred by incorporating a full holistic needs assessment within the initial telephone consultation described in Step 1 above. This considers all the physical, psychological, spiritual and social needs, with the focus on the whole person, that can have a significant impact on patient experience and quality of life.^{5,6}

The process follows the completion of an assessment proforma, respecting each patient's preferences and dignity, within an open, therapeutic, non-judgemental style of communication, recognising that the patient's emotional wellbeing can often exacerbate physical presentation.

The holistic assessment includes details of:

- Physiological: symptom & medication assessment, smoking/alcohol/performance status
- Psychological: daily activity, cognitive function, mental health & emotional wellbeing status
- Sociological: ability to self-care, family & social networks, accommodation type
- Spiritual: religious and spiritual practice
- Cultural: diet, values and culture-specific requests

Themed analysis

The following key insights have been identified from the group interviews and the resulting framework analysis:

1. Emotional & physical preparedness of the patient

Perhaps the most impactful insight recognisable with the approach, is what the respiratory teams described as..." **the positive ethos of patients"...** following the telephone assessment, together with an overriding ability to engage in a richer information exchange and understanding to attend further and often immediate diagnostic interventions.

"Everything you now say is so much better than the patient first imagined....and when they eventually come to see us face to face in the clinic.... they are so much better prepared for what lies ahead. I can genuinely feel the positive difference between those patients that have the virtual assessment and those that don't."

The respiratory teams stressed the importance of informing the patient about a potential cancer diagnosis as "the earlier the better", with a recognisable positive difference in patient presentation, when they next attend hospital. The approach succeeds in preparing the patients and their families both emotionally and physically for a potential cancer diagnosis, enabling them to better plan and accommodate the further pathway interventions and appointments and other personal activities eg work, family commitments etc.

Reaction to a potential cancer diagnosis can inevitably be traumatic, and whilst the patient will often ask, "Have I got cancer" or "Am I going to die", the responding lung CNS dialogue remains empathetic, yet positive and encouraging. Though there is no formal script as such to follow (other than the assessment proforma) for this element of the approach, the CNS uses their well-developed counselling skills to comfort, empathise and reassure. If on occasion patients are struggling to comprehend the information being given, the CNS will acknowledge this cue, empathise, pause and reinforce the key information as necessary, once the patient is comfortable enough to proceed.

Although family members are encouraged to be present during the telephone assessment, they tend to remain in the background supporting the patient, unless they specifically speak on their behalf as necessary eg, if the patient is finding it too stressful. The CNS always leave their

contact details with each patient and there is often interim communication between investigations and hospital appointments as the relationship develops.

2. Streamlined pathway arrangements

The approach has enabled the lung pathway to become more streamlined, in line with the NOLCP2 and the British Thoracic Society Guidelines7, by coordinating diagnostic tests required concurrently to take place within one visit to the hospital, where possible.

In most circumstances, Step 1 of the approach, that involves a telephone assessment call to the patient from the designated lung CNS (within 24 hours of clinical triage) is adhered to. It provides an important opportunity for the CNS to understand what the patient knows about their condition at this stage, without assuming a level of knowledge, and discuss this in a private environment, with the support of family members, and enabling patients the time to make an informed choice.

The LLCU virtual arrangements enable patients to accelerate through these early stages of the pathway following the telephone assessment, with cost savings made from eliminating the first outpatient attendance at the hospital, whilst not compromising on patient experience, and making enhanced use of their CNS expertise and skills.

3. Delivers empathetic two-way communication

Embedding holistic assessment within the approach ensures a tailored, personalised care plan is taken forward for each patient. This process stimulates conversation with the patient to agree a clinically appropriate management plan and come to terms with what has happened to date, and what happens next, essentially further diagnostic test appointments. The approach provides patient-centred, two-way informative communication, that ... "matters so much to patients".

The lung CNS teams acknowledge with empathy what they hear throughout the consultation. They gather all concerns, anxieties, and expectations from each patient, followed by the necessary health requirements (medical history and symptoms), acknowledging and exploring to understand any further issues, constantly providing advice, reassurance, and safety-netting... "though there is inevitably essential information we need to convey to patients, we are genuinely led by them, in terms of pace, tone and the overall detail of the conversation."

Given the recognised challenges of telephone communication⁸ and the lack of visual clues and cues (video is not currently used), the CNS acknowledge the importance of utilising enhanced listening skills to ensure the key information is both actively gained from, and fully understood by each patient. Three main types of listening most commonly used within interpersonal communication are interchangeably used by the CNS – informational listening to actively learn about the patient's condition; critical listening to evaluate and analyse; and therapeutic or empathic listening to understand the patient's feeling and emotion.⁹

As a direct result of the assessment, a strong relationship develops between the diagnosed patient and dedicated CNS, based on trust, familiarity, recognition and empathy. Patients are

keen to maintain this supportive relationship through the remainder of their pathway and there is enhanced job satisfaction, moral and motivation amongst the nurse specialists.

4. Responsive to each patient's needs

The assessment can take between 20-60 minutes, depending on the patient's medical history, symptoms, awareness and response. The conversations are not a-typical, as... "no one conversation is the same as the next", yet all require scheduled time and flexibility.

"Some patients we ring are totally clued up and have more information than we could hope to offer; others seem very much in the dark and appear quite shocked at the call to begin with...yet a very trusting relationship soon begins to develop as the conversation evolves and we learn more about the patient's holistic condition, family dynamics, mind and spirit."

The conversation helps to clarify and problem-solve any issues for the patient, such as symptom management, diagnostic preparation and support, whilst encouraging preventative life-style behaviours, eg smoking cessation, exercise etc., and though a structured framework is followed, the conversation is very much patient-centred ensuring all aspects are covered, that may otherwise be overlooked.

"A very open dialogue is encouraged with all patients, and you have to actively listen and respond as they offload and share all their particular concerns; that is a fundamental part of the assessment."

Integrating all these aspects into the full holistic assessment can also help to identify underlying conditions (Aintree Hospital diagnosed stress fractures following pain in shoulder) or whether

other factors have delayed initial presentation that could impact potential treatment and recovery.

Referral to clinical psychology for more dedicated counselling services are available for those patients who present with more severe low mood and depression. Most patients however, express complete gratitude for the telephone contact; and though each patient is assessed individually they all generally absorb the information and are ready to move on to the next phase in the pathway.

Transport to and attending the hospital can be an issue for some patients, eg patient is too poorly, and so this virtual assessment by telephone is a real benefit to some less mobile patients.

5. Optimises informed patient choice

Though the intended diagnostic plan may be different between early stage and more complex, borderline patients, there is no recognised key differences in the approach used. However, in some instances, either because of patient choice, or it is more clinically appropriate, the patient attends a face to face outpatient consultation, rather than the telephone assessment.

Likewise, the lung CNS determine the appropriateness of each telephone assessment as it progresses.... "You learn very quickly into the conversation whether the patient can proceed with a telephone approach. Some of the patients contacted can be very breathless or they are not sufficiently cognitive, so there is always the option to reschedule and arrange a face to face out-patient appointment in clinic, to suit the patient."

Though potential treatment options are not generally discussed at this stage, the approach is regarded by the clinical teams as the first step in informing and preparing the patient to choose and agree a curative intent management pathway, defined in the NOLCP guidelines.²

It starts to help patients feel supported in their decision making about their diagnosis and consider the personal value they place on benefits vs harms of diagnostic and treatment options.

Though there is limited overall qualitative evidence from patients on their experience of the approach, the LHC report that their virtual pathway arrangements have generated good patient and primary care feedback in response to surveys they have undertaken (2019). Patients comment how ... "informed, prepared and satisfied..." they were with the experience, with 100% of respondents supporting the initial telephone assessment.

6. A more empowered clinical nurse specialist in lung cancer

The approach enhances the primary and responsive role of the lung CNS both within the optimal lung pathway and amongst multidisciplinary colleagues, building on the vocational attributes of the role ..." and though some of the conversations with patients can be tough, the impact on patient outcomes, and in encouraging curative treatment is most rewarding."

The lung CNS is emotionally responsive with a high regard for empathy and has the required competencies and relational abilities for the often-difficult conversations that ensue with patients. The approach requires advanced communication skills, agility, and the adeptness to nurture and sustain therapeutic engagement with patients during further conversations throughout the pathway.

They prepare themselves and the environment to ensure patient confidentiality; they are confident in knowing what advice, further support or signposting some patients may require (some ask for financial advice); they are clear which health professional the patient will see next, given their in-depth knowledge of the pathway, and they use defining terminology and encouraging language to ensure the patient understands what's expected of them.

Developing an additional communication resource

Both respiratory teams acknowledge the benefit in developing an additional communication resource for use by healthcare professionals to support their initial conversations with patients. The content should include the positive aspects of centralisation and optimum curative-intent treatment; the benefits of patients travelling to specialist centres for diagnostics and treatment, and key dialogue and phrases that can be used to help remove the fear and stigma often associated with a lung cancer diagnosis.

There are opportunities to develop this resource with input from behavioural science colleagues at CRUK and specialist communication experts from within the NHS. With the help of the Aintree and LHC respiratory teams, CRUK plan to explore this further.

Key insights summary

- The first touch approach provides patient-centred, engaging, two-way informative communication, that ... "matters so much to patients"
- It succeeds in preparing patients and their families both emotionally and physically for a
 potential cancer diagnosis and acknowledges the importance of informing patients of the
 diagnosis as "the earlier the better"
- It focuses on the affirmative options for curative treatment and is based on maintaining a positive dialogue with patients
- It helps patients feel supported in their decision making about their diagnosis and potential treatment options
- Healthcare professionals acknowledge the positive ethos of patients following the approach, and how they more responsively attend further intensive and immediate diagnostic interventions
- It enhances the role of the clinical nurse specialist in lung cancer, building on their vocational attributes and though ... "some of the conversations with patients can be tough, the impact on patient outcomes, and in encouraging curative treatment is most rewarding"

Behavioural Science Analysis

A link to the full analysis annotated by the Cancer Research UK Behavioural Science team, using a framework analysis technique is <u>available here</u>. The results of this analysis will inform the options to develop a first touch communication resource for healthcare professionals.

Effective virtual consultation

Since the COVID-19 pandemic began in March 2020, healthcare professionals across the NHS have managed patient contact as safely as possible. This has been especially important for lung cancer patients who are at particular risk of complications due to their underlying condition, common co-morbidities (such as COPD) and the immunosuppression associated with many cancer treatments. The shift from in-person to 'virtual' consultations was essential for a period, and it is likely this trend will continue to a variable extent as a delivery care option in the future NHS.

In the right circumstances, and with the necessary infrastructure and support for healthcare professionals, more virtual consultations (via video and telephone) could offer lung cancer patients accelerated access to the expertise needed for their care. Since the start of the pandemic, healthcare professionals have been developing the skills needed for effective virtual consultation — especially in communication, organisation, and prioritisation. However, as the first touch communication approach highlights, relationship-building, trust and non-verbal communication are all a vital part of care across the lung pathway, and for these reasons, virtual consultation will always complement rather than substitute face to face appointments.¹⁰

Group discussion participants

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