Collecting Patient Reported Outcome Measures in Lung Cancer

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BACKGROUND

- Wales has the worst lung cancer 5-year relative survival in Europe: Males 8%, females 9.5%.
- To help address this the Welsh Government has:
  - instigated the development of a new single cancer pathway to reduce time from diagnosis to treatment.
  - included Lung Cancer PROMs in its VBHC programme to help NHS Wales take a data driven approach to improving care.
- The objective of this project was to overcome the obstacles to capturing PROMs (EORTC C30 and LC13) in clinical settings.
- PROMs data collection took place at Withybush General Hospital in Pembrokeshire, Wales, UK.
  - Withybush serves a predominately rural population of 125,000, of whom 25% are aged 65+.
  - Lung cancer incidence in Pembrokeshire has increased by over 20% in the last 15 years to around 105 new cases per year.
  - Late stage presentation is most common (56% stage IV, 18% stage III, 11% stage II, 15% stage I).

METHODS

- Patients attending the nurse led clinic for suspected lung cancer were:
  - invited to complete PROMs during the visit at which they had been informed of their diagnosis.
  - given a tablet to self complete the PROMs in the clinic.
  - asked to complete follow up PROMs at three, six and twelve months and annually thereafter from December 2017 onwards.
- PROMs were initially collected in the nurse led clinic before being expanded to the Rapid Access Lung Clinic in Withybush and now to clinics in Prince Philip Hospital, Llanelli.

RESULTS

- Very high participation rates have been achieved (97%).
- PROMs data collection is now adopted as business as usual and patients are attending expecting to complete PROMs.
- PROMs data collection was expanded to include the Rapid Access Lung Clinic in Withybush and then to Prince Philip Hospital, Llanelli.

LESSON 1: ENGAGE WITH I.T. FROM THE OUTSET

Do:
- get named and dedicated IT support from the outset.
- have a standard set up for your devices (same password etc.)
- test Wi-Fi connectivity in all data collection areas.
- have sufficient devices to cover concurrent patient attendances.

LESSON 2: MAKE IT EASY FOR THE PATIENTS

Do:
- get the clinic administrator to log the patients into the tablet
- ensure the clinic administrator can give basic technical support.

Don’t:
- assume patients won’t want to participate
- assume patients aren’t IT literate or capable of learning
- allow the clinic administrator to help patients complete PROMs.

LESSON 3: BUSY/MIXED CLINICS ARE NOT A BARRIER

Don’t:
- assume PROMs can’t be collected in mixed waiting areas.
- assume any elevation in the risk of information disclosure.
- assume discomfort about answering questions in a public space.
- assume PROMs data collection will impact on flow.

LESSON 4: CLINICAL STAFF ENGAGEMENT IS CRITICAL

Do:
- meet staff beforehand and allow concerns to be raised.
- help enthusiastic staff to spread that enthusiasm.
- provide regular contact, assurance and feedback.
- have project support on site to troubleshoot for a few weeks.
- ensure staff understand the benefits of PROM collection.

Don’t:
- insist on 100% completeness, ultimately it is patient choice.
- let project support assist patients to complete PROMs.

PROMs data are starting to be used alongside other data sets including the national lung cancer audit.

When we have collected sufficient data we will be evaluating its use in treatment planning.

SEE POSTER 109 for details of our concurrent work to develop PROMs use in daily clinical practice.