Liverpool Healthy Lung Programme

Preliminary report for the first three neighbourhoods: Everton, Picton and Speke

A report prepared for Liverpool Clinical Commissioning Group by:

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Executive Summary

The introduction of lung cancer screening is being considered in the UK, post the UK Lung cancer Screen trial (UKLS). Lung cancer screening could significantly reduce deaths in high risk groups, without causing participants undue stress sometimes associated with medical tests. The Liverpool Healthy Lung Programme (LHLP) is part of a national ACE collaboration of Liverpool Clinical Commissioning Group with HNS England, Cancer Research UK, and Macmillan Cancer Support aimed at improving respiratory health and diagnosing respiratory disease at a more treatable stage. This report is an independent summary of the activities of the programme and a preliminary evaluation of its effect.

General practice (GP) records were used to select ever-smokers and subjects with COPD, aged 58-70 from Everton, Picton, and Speke. This report is based on patient consented information from Monday 18th April 2016 when clinic started until 31st of January 2017. There were 2,171 lung health check consultations from the three neighbourhoods, with a 40% uptake from the total eligible invited population. Excluding the patients who opted out of data sharing, 1,576 (≈ 73%) records from lung health checks consultations stored on the EMIS system.

This is a preliminary report, based on activity in three neighbourhoods, thus, numbers of clinical endpoints such as lung cancer diagnoses are relatively small. However, a number of observations are clear. This programme is likely to detect substantial numbers of so far undiagnosed cases of COPD, with the opportunity for prompt treatment and management to alleviate symptoms and slow down progression. Secondly, 75% of the lung cancers diagnosed so far had very early stage disease (TNM Stage T1a/1b, which is known to have a very good clinical outcome). This corresponds to a substantial improvement in expected 5-year survival. This was achieved with only a 10% rate of further investigation of nodules, a considerably lower burden of diagnostic activity than was observed in the CT screening trials. Thirdly, preliminary cost-effectiveness analysis suggests a substantial gain in quality adjusted life years, for modest expenditure, with estimated incremental cost-effectiveness ratios of the order of £4,000 per quality adjusted life year gained, which compares well with breast, bowel and cervical screening. The majority of the quality adjusted life years gained were derived from early

diagnosis and treatment of COPD (67%), with 17% from early detection of lung cancer and 16% from smoking cessation. Finally, levels of patient satisfaction are high. The substantial time devoted to each consultation and the manner of the consultations are clearly appreciated. In addition to the clinical evaluation, we asked patients to fill in a survey questionnaire on their experience. High levels of patient satisfaction were expressed, and 96% of participants reported that if a friend asked them if they should attend, they would encourage or strongly encourage the friend to do so.

A number of recommendations arise in respect to both delivery and evaluation of this service.

(1) On the basis of results so far, the programme is effective and cost-effective and should continue.

(2) The expansion of the age range to encompass ages 71-75 would increase the cancer detection rate and further improve cost-effectiveness.

(3) Recommend exploring whether the consultation could be trimmed to 30 minutes, especially if the eligible population is to be expanded.

(4) There is a need for highly targeted information and support for those undergoing CT scans. The CCG and the secondary care departments carrying out the scans should liaise to decide the best way to provide this.

(5) There is also a need to revisit the protocol of delivery of results of the CT scans. It would free up specialist nurses' time if they were not charged with conveying normal scan results to participants by telephone.

(6) The timing of CT scan results needs some thought. Patients need to be told when to expect results. Means of achieving this should be explored.

(7) Consider whether a simpler pragmatic summary of findings, and immediate implications for the patient could be developed, in addition to the radiologist's report.

(8) Clearly the second letter and phone call are worthwhile in increasing the participation rate. It is also worth exploring other methods of increasing the participation rate, such as text message reminders, including publicity around the results, which so far are certainly favourable.

(9) For evaluation, and production of the final report on the LHLP, additional data items would be helpful, including:

a. More granularity of smoking data collected on EMIS.

b. Secondary care data, including MDT pathway referral.

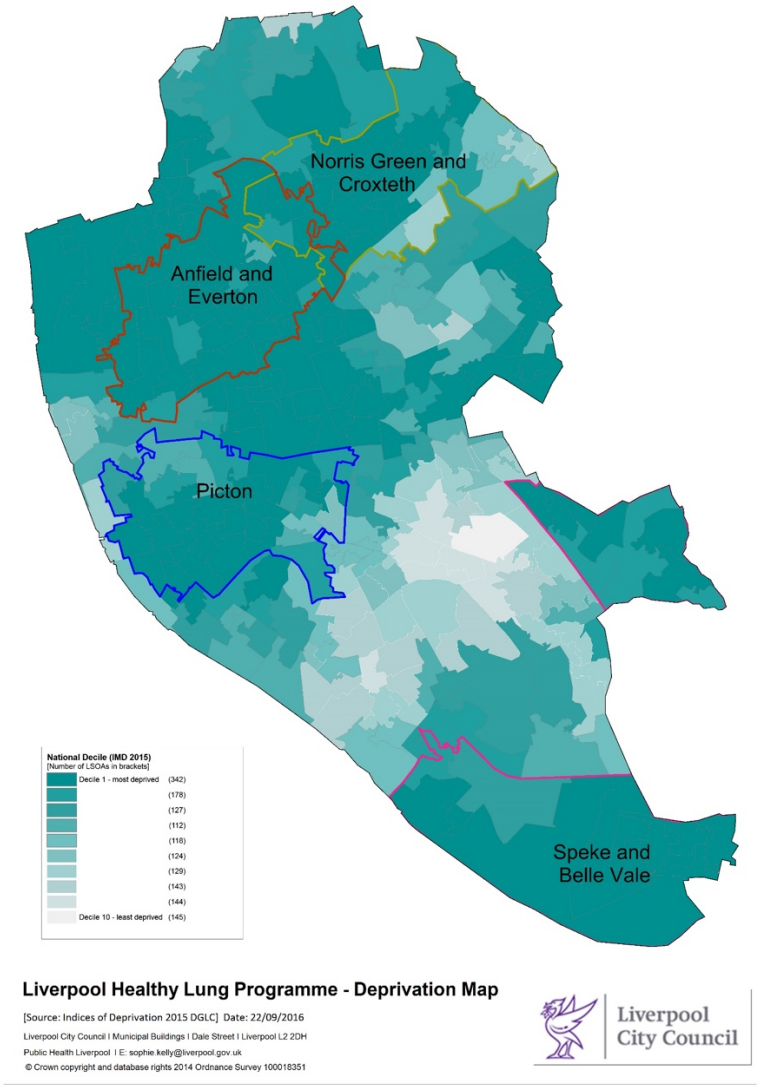
Finally, it should be noted that the programme is on target to save substantial numbers of life years and potentially can save more if expanded. to include patients up to age 75 years.

Background

The Liverpool Healthy Lung Programme (LHLP) is an initiative aimed at improving respiratory health and diagnosing respiratory disease at a more treatable stage, taken by the Liverpool Clinical Commissioning Group working with communities across Liverpool. This report is an independent summary of the activities of the programme and a preliminary evaluation of its effect. The programme has been piloted in the NHS GP neighbourhoods of Everton, Picton and Speke, and Norris Green. This report is based on first results on consented patients from the three neighbourhoods of Everton, Picton and Speke. These districts are characterized by deprivation and high risk of chronic disease. Compared to the Liverpool average of 22.7%, significantly higher prevalences of smoking have been reported in Everton (30.2%), Picton (28.2) and Speke (28.1%). Figure 1 is a deprivation map of the piloted neighbourhoods of Everton, Picton, Speke and Norris Green.

Liverpool has one of the highest respiratory morbidity rates in England, with double the national lung cancer incidence, particularly in lower socioeconomic groups. The Liverpool Healthy Lung Programme was initiated in response to both the clinical problem and the health inequality. The programme has 2 sequential phases.

Figure 1 Liverpool Healthy Lung Programme neighbourhoods deprivation map



1. Phase I of the programme –Breathe Freely healthy lung community events

By means of a series of co-ordinated focused public engagement events throughout the city, starting in areas with the highest lung cancer incidence, the aims were to promote positive messages around lung health, and address the attitudes of fear and fatalism around lung cancer. This was widely advertised in the target areas together with posters about the Lung Health clinics. Figure 2 shows examples of the publicity material used.

The community health lung events attracted over 2,100 members of the public with the service, and 800 individuals completed spirometry and around 18% of these tests were abnormal which triggered a referral to primary care.

Figure 2 Poster advertising the LHLP events

The evaluation of the Breath Freely events has been commissioned by Public health Liverpool City Council and Liverpool CCG. The evaluation report "Healthy Lung Phase 1 Events Evaluation Report' 23rd March, was undertaken by Research Works Ltd.

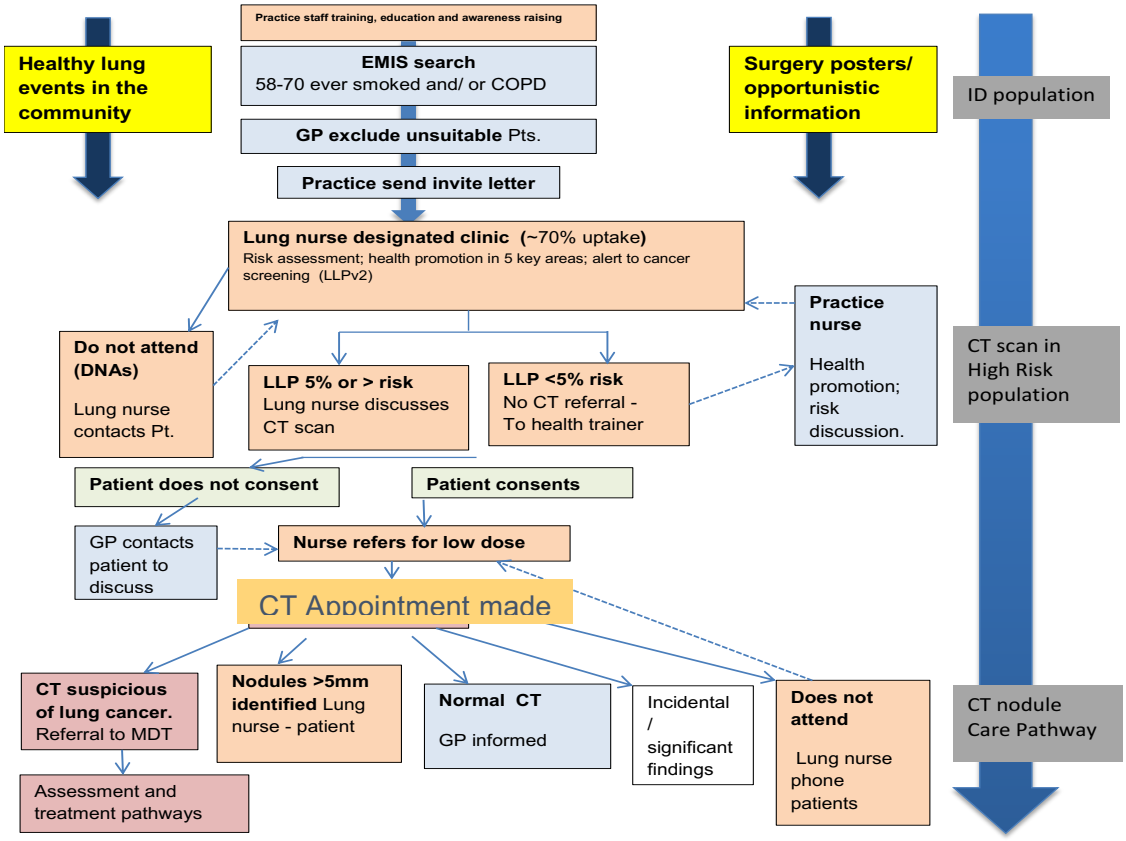
2. Phase II of the Programme – lung nurse clinics for targeted eligible populations

General practice (GP) records were used to select ever-smokers and subjects with COPD, aged 58-70 from Everton, Picton, and Speke. Figure 3 summarises the process of consultation and possible referral for further investigations or services. The recruitment process involved GP practices sending out a letter of invitation to a healthy lung check to the eligible patients. This was followed by a second letter if the patient did not attend. If the patient did not respond to the second letter, the programme administration team attempted to contact the patient by telephone. Selected patients were invited for a 45-minute lung health check appointment with a respiratory nurse in a community health hub setting.

At the appointment, a detailed risk assessment was conducted: height and weight were measured to calculate the BMI; spirometry was used to assess lung function (FVC and FEV1 were measured and

the ratio FEV1/FVC was calculated); information about risk factors of lung cancer such as emphysema, bronchitis, COPD, tuberculosis, exposure to asbestos, family history of lung cancer, history of malignancy and smoking duration were elicited from patients. In addition, smoking advice and referrals to smoking cessation clinics were provided. MyLungRisk calculator, based on the Liverpool Lung Programme risk model that quantifies risk as the probability of individuals with risk score ≥ 5% of developing lung cancer over 5 years, was used for selecting patients for CT screening. Consent was requested from the participating patients to share their data, suitably anonymized, with the analysis team for evaluation purposes.

Figure 3 Liverpool Health Lung Programme Flow Chart



3. Implementation of the LHLP

As of 30th January, the LHLP team has sent 1,508 letters to patients in Everton, 2,466 letters to patients in Picton and 1,498 letters to patients in Speke. There were 2,171 lung health check consultations from the three neighbourhoods, a 40% uptake rate. Excluding the patients who opted out of data sharing and those from the neighbourhood of Norris Green, there were 1,576 (≈ 73%) lung health checks consultations, following 812 letters sent to patients in Everton, 839 letters sent to patients in Picton, and 1,061 letters sent to patients in Speke. Table 1 shows the number of letters sent and interview conducted in Everton, Picton and Speke.

Table 1 LHLP Patients approached

Neighbourhoods	Everton	Picton	Speke
No of 1st letters sent	414	631	531
No of 2nd letters sent	407	244	531
No of telephone calls	108	168	143

4. Recruitment

After receiving the 1st letter, 394 patients (25%) of the 1,576 from the three neighbourhoods booked appointments, 763 patients (48%) booked appointments after the 2nd letter, and 419 (27%) patients of the 419 booked appointments after receiving a telephone call. Thus the second letter increased the numbers participating by around 200% and the second letter plus the telephone call increase the numbers participating by 300%. Therefore, second letters and a third contact by telephone were effective, and indeed a substantial majority of the participants needed a second or third contact.

Among those who booked appointments, five patients needed an interpreter. Three of those who needed an interpreter were from Picton and they all used telephone interpreters. The other two patients who

used an interpreter were from Speke: one of these used a British sign language interpreter, while the other used a telephone interpreter. Although Picton has the highest number of patients that needed interpreters, this number is smaller than might be expected from the general population. Therefore, ways of targeting black and ethnic minority patients and patients with English as an additional language should be explored.

As noted above, 1,576 patients providing consent to share data (Everton = 414, Picton = 631 and Speke = 531) underwent lung health check consultations between April 2016 and January 2017. There were 800 (50.8%) males and 776 (49.2%) females with median age 65, range 53-71 years. These patients are demographically comparable to those who were invited but did not attend (52.8% male, median age 64). This implies that this evaluation population represents the whole community invited to LHLP clinics.

Table 2a Attributes of LHLP patients attending GP clinics

Total number of lung health checks	1,576
Gender:	
Male	800 (50.8%)
Female	776 (49.2%)
Median age (range)	65 (53-71)
Ever smokers	1,517 (96.3%)
Previous COPD	377 (23.9%)
Previous malignancy	261 (16.6%)
Emphysema	42 (2.7%)
Pneumonia	271 (17.2%)
Bronchitis	522 (33.1%)
Tuberculosis	32 (2.0%)
Asbestos exposure	517 (32.8%)
Family history lung cancer	535 (33.9%)
Median smoking years (range)	40 (0-60)
Median 5-year lung cancer risk (range)	4.2% (0.2%-45.6%)
Patients given smoking cessation advice	331 (20.4%)
Most deprived IMD quintile	1,282 (81.4%)

5. Clinical and epidemiological attributes of the participants

Table 2a shows the attributes of the 1,576 patients undergoing a healthy lung check. Of these, 1,517 (96.3%) were ever smokers; the median of smoking years was 40, range 0-60; 377 (23.9%) had a pre-existing COPD diagnosis, and 261 (16.6%) had a previous diagnosis of malignancy. The median age was 65, with a range from 53 to 71 (indicating that although the 58-70 age group was targeted, some subjects were recruited outside this range). Notably, 535 (33.9%) had a family history of lung cancer. The median 5-year lung cancer risk was 4.2%, range 0.2%-45.6%. 331 (21.0%) patients were given smoking cessation advice. 1,062 (67.4%) of patients were in the lowest decile of the Index of Multiple Deprivation (10% most deprived) and 220 (14.0%) in the next lowest decile, so 81.4% of the patients of the study were in the most deprived quintile.

Table 2b shows the demographics in more detail, and characteristics of patients who underwent lung health check consultations separately for the three districts. The youngest patient aged 53 years is from Picton. Briefly, 800 males (209 from Everton, 333 from Picton and 258 from Speke) and 776 females (205 from Everton, 298 from Picton and 273 from Speke) attended the healthy lung check. Of those that attended, there were 401 ever smokers from Everton, 599 ever smokers from Picton and 517 ever smokers from Speke.

6. Clinical and diagnostic events

As noted above, the median 5-year lung cancer risk was 4.2% (range 0.2%-45.6%): 3.9% (0.4%-28.7%) in Everton, 4.4% (0.2%-45.6%) in Picton and 4.0% (0.4%-42.3%) in Speke. Spirometry was offered to 1,104 subjects, all attenders excluding the 377 patients who did not already have a pre-existing diagnosis of COPD, and those for whom spirometry was contraindicated (95 patients). Of the 1,104 offered the testing, 921 had spirometry, and 390 (41% of those tested) were found to have abnormal lung function. While definitive diagnosis of these is ongoing, previous results suggest that 63% would be expected to be diagnosed with COPD, so we anticipate that in this population, 246 subjects will have a diagnosis of COPD, and will have access to treatment earlier than they would otherwise.

There were 660 patients with 5-year lung cancer risk greater than or equal to 5% (42% of the total and 43% of the 1,518 with a risk score calculated) and 658 (42%) were recommended for a CT scan. Of these, 594 (38% of total, 90% of those recommended) had a CT scan at the time of close of data collection, 31st of January 2017, for this report. 61 (10%) patients who had a CT scan required further investigation (follow-up CT scan at 3 or 12 months) and 8 (1.4%) patients were diagnosed with lung cancer. The results are summarised in Table 3a.

Of the 1,576 patients who underwent lung health checks, 331 (21.0%) of patients were given smoking cessation advice. Of the 331 patients, 88 (26.6%) patients were from Everton, 147 (44.4%) were from Picton and 96 (29.0%) were from Speke. While we did not have data on whether ever-smokers were current or ex-smokers, the post-check patient survey suggested that 27% of ever smokers were current smokers. This would imply that 409 patients were current smokers, so more than 80% of current smokers agreed to receive cessation advice. In addition, 63 (15% of estimated current smokers) agreed to be referred to a smoking cessation clinic.

Of the patients scanned, 103 patients had incidental/significant other findings. 32 (31.1%) of these patients were from Everton, 40 (38.8%) from Picton and 31 (30.1%) from Speke.

Table 2b Neighbourhood – patient demographics

Characteristics	Neighbourhoods			All subjects
	Everton	Picton	Speke	
Age (years)				
53	0	1	0	1
58	10	4	18	32
59	26	53	37	116
60	25	53	50	128
61	36	45	39	120
62	25	48	37	110
63	35	51	38	124
64	32	42	58	132
65	43	51	34	128
66	31	56	45	132
67	27	40	40	107
68	30	53	39	122
69	39	54	44	137
70	47	55	39	141
71	8	25	13	46
Median age (range)	65 (58-71)	65 (53-71)	64 (58-71)	65 (53-71)
Gender				
Female	205	298	273	776
Male	209	333	258	800
Smoking status				
Ever smokers	401	599	517	1,517
Median smoking duration	36 (0-59)	40 (0-59)	40 (0-60)	40 (0-60)
Previous COPD	92	162	123	377
Previous malignancy	69	111	81	261
Previous emphysema	3	22	17	42
Previous pneumonia	81	99	91	271
Previous bronchitis	152	193	177	522
Previous tuberculosis	3	18	11	32
Asbestos exposure	144	203	170	517
Family history of lung cancer	159	183	193	535
Median 5 years lung cancer risk	3.9% (0.4%-28.7%)	4.4% (0.2%-5.6%)	4.0% (0.4%-42.3%)	4.2% (0.2%-5.6%)
IMD rank				
1	334	326	402	1,062
2	57	140	23	220
3	8	49	27	84
4	8	39	5	52
5	2	32	10	44
6	0	18	2	20
7	2	10	54	66
8	1	11	5	17
9	0	4	2	6

Table 3a LHLP diagnostic cascade

Outcome	Numbers	Percentage
No of patients invited	5471	-
Patients attending	2171	40% (of those invited)
Patients consenting to take part in this evaluation	1,576	73% (of those attending)
Spirometry	921	59% (of consenting attenders)
CT scan recommended	658	42% (of consenting attenders)
CT scan carried out	594	38% (of consenting attenders)
Further investigation	62	10% (of scanned)
Lung cancer	8	1.4% (of scanned)

CT scans were recommended for 658 patients. 62 patients had CT-detected pulmonary nodules for which at least a further scan was recommended. To date, 32 repeat scans have been carried out.

Eight patients have been diagnosed with lung cancer.

Table 3b Neighbourhoods – COPD and lung cancer tests

Characteristics	Neighbourhoods			All subjects
	Everton	Picton	Speke	
Attended health check	414	631	531	1,576
Spirometry	239	366	316	921
Abnormal spirometry	101	160	129	390
CT scan recommended	176	259	223	658
CT scan carried out	156	233	205	594
Pulmonary nodules*	10	29	23	62
Lung cancer	1	4	3	8

*Nodules requiring further investigation, at least a repeat scan.

7. Cancers Diagnosed

Table 4 shows the epidemiology and clinical characteristics of the 8 cancers detected as a result of the CT scans. One was from Everton, four from Picton and 3 from Speke. The majority of cancers detected were stage T1a/1b N0 M0, 6 (75%) patients from the 8 cancer patients detected. Of the 8 lung cancers detected, there was one carcinoid, one small cell lung cancer, three adenocarcinomas, two squamous

cell carcinomas and one clinically diagnosed with no information on histological type, and for whom no further information was available. Five have been operated on so far.

The stage distribution of the cancers diagnosed is considerably more favourable than that which prevails generally. Typically, we would expect around 70% of cases to be at stage III or IV at diagnosis. On the basis of the results here, we would expect overall around 30% five-year survival compared to the 10% or less usually observed.

Of the lung cancers diagnosed, 6 (75%) were in male patients. with age from 58 to 71 years, all had a long smoking history and risk score > 5%. Seven out of the eight patients diagnosed with lung cancer had information on IMD. Six out of the seven patients belong to D1 (10% most deprived) and one belongs to D2 (10% to 20%). All patients diagnosed had at least one of the major risk factors of lung cancer in addition to smoking, such as personal history of malignancy, prior history of respiratory disease, exposure to asbestos and family history of lung cancer.

Table 4 Characteristics of 8 patients diagnosed with lung cancer

Cancer number	Stage	TNM Stage Group	Pathology	Treatment	Age	IMD-rank	Sex	BMI	Smoking duration	Risk score	Other risk factors of lung cancer
1	T1a N0 M0	1a	Carcinoid	Resected	70	2	female	27.6	40	9.28	Personal history of malignancy
2	T1a N1	1a	SCLC	Resected	58	1	male	37.6	41	8.71	Personal history of malignancy, exposure to asbestos
3	T1a NO M0	1a	Adenocarcinoma	Resected	70	1	male	27.4	51	11.43	Personal history of malignancy, family history of lung cancer
4	T2a NO M0	1b	Squamous	Resected	71	1	male	30.4	48	7.03	Family history of lung cancer
5*	T2a N0 M0	1b	Clinic Cancer	Stereo/ Radiotherapy							
6	T3 N3M1b	3	Squamous	Radiotherapy	66	1	male	24.5	50	14.35	Bronchitis, exposure to asbestos
7	T4 N3 M1b	4	Adenocarcinoma	Awaiting Oncology	67	1	female		42	11.65	Family history of lung cancer, COPD, Bronchitis
8	T1b N0 M0	1b	Adenocarcinoma	Resected	65	1	male		50	8.16	Pneumonia, COPD, Bronchitis

*Patient epidemiological data is not available.

8. Risk profiling

Table 5a below shows the numbers with risk score above and below 5% for patients in the three neighbourhoods.

Table 5a. Risk scores of invited LHLP patients

Risk scores	Everton	Picton	Speke	Total
Risk scores <5%	226 (56.2%)	338 (56.4%)	294 (56.9%)	858 (56.5%)
Risk scores higher than 5%	176 (43.8%)	261 (43.6%)	223 (43.1%)	660 (43.5%)
Total	402 (100%)	599 (100%)	517 (100%)	1,518 (100%)

The median risk score and range of the 594 that received a CT scan was 8.95 (5.1-45.6). Table 5b shows the median and the range of risk scores for CT scanned subjects across the three neighbourhoods.

Table 5b. Median risk scores for LHLP screened patients

Neighbourhoods	Median	Minimum	Maximum
Everton	8.59	5.1	28.67
Picton	9.34	5.1	45.6
Speke	8.89	5.1	42.34

10. Economic evaluation

For this we used the online estimation toolkit provided by Dr Hinde at the University of York (https://sebhinde.shinyapps.io/proactive_lung/). It is still in development so results here should be regarded as preliminary. The programme is based on published results of the effects of on survival and quality of life of smoking cessation, prompt diagnosis and treatment of COPD and stage at diagnosis of lung cancer. It takes as input the resources expended in publicity, invitation, consultation, onward referral, further investigations, including of course CT scans, and treatment, and the clinical endpoints including COPD and cancer diagnoses. The major output is the incremental cost-effectiveness ratio. It also divides the quality adjusted life years gained into those attributable to smoking cessation, early detection of COPD and early detection of lung cancer.

For inputs, we used costs provided by the CCG, and clinical and diagnostic activities within our dataset of 1576 subjects, weighted upwards pro rata by a factor of 2171/1576= 1.38, to take account of resources costs and health outcomes in those who declined to have their data shared.

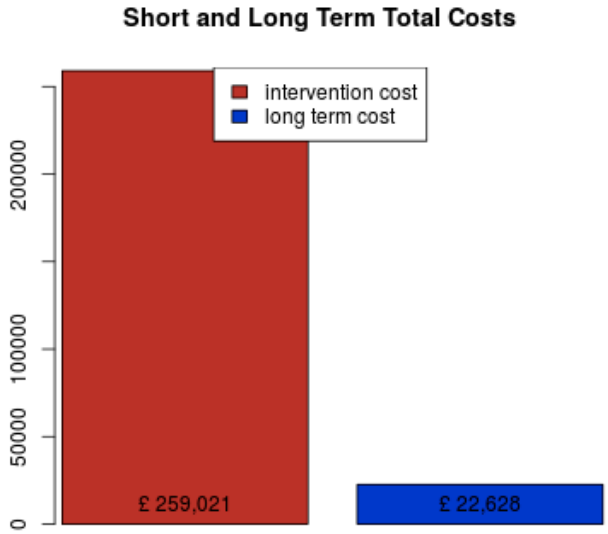
The inputs to the toolkit are derived from expenditure details supplied by the CSG, standard NHS Unit costs, and activities and clinical events from tables 2-4 above (e.g. numbers of consultations, spirometry data, CT scans, diagnoses of COPD and cancer). Apart from the cancers diagnosed, these were weighted upwards by a factor of 38% to take into account that our figures are based only on those who consented to data sharing, and to render them consistent with the total number of healthy lung consultations (2171/1576 = 1.38).

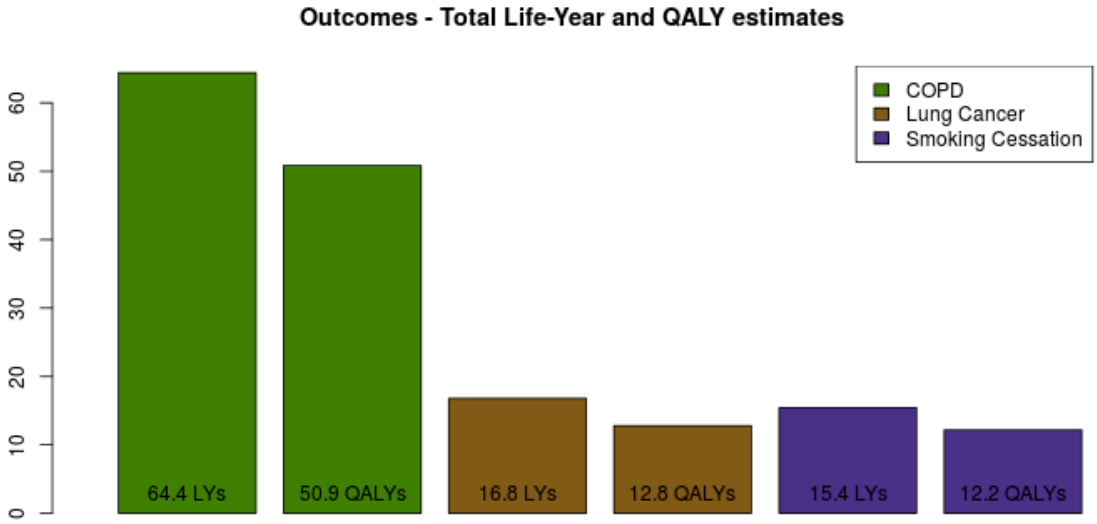
Figure 4 shows the outputs from the toolkit. The programme estimated an incremental cost-effectiveness ratio of £3,714 per quality adjusted life year. The majority of the quality adjusted life years gained were derived from early diagnosis and treatment of COPD (67%), with 17% from early detection of lung cancer and 16% from smoking cessation.

We carried out a sensitivity analysis in which we doubled the number of invitations to reflect that substantial numbers of subjects required a second or third contact before attending, and also inflating the number of cancers diagnosed by 38%, as diagnostic workup of some nodules is still ongoing, due to 3-month and 12-month repeat scans. This gave an incremental cost-effectiveness ratio of £4,298 per quality adjusted life year. Again, the majority of quality adjusted life years (QALY's) gained were from early diagnosis and treatment of COPD, at 63%, compared to 22% for early detection of lung cancer and 15% for smoking cessation. The QALY is the generic measure of life with disease/treatment burden including both the quality and quantity of life. For example, if a specific treatment increased the length of life by ten years but conferred debilitating side effects, the QALY's would be less than ten years, down-weighted for the side effects.

Figure 4. Results of online cost-effectiveness analysis

Cost of the intervention £ 259,021
Long term incremental cost of the outcomes £ 22,628
Total cost £ 281,649
Long term incremental life-years of the outcomes 96.6 LYs
Long term incremental QALYs of the outcomes 75.8 QALYs
Cost per life-year gained £ 2,915 /LY
Cost per QALY gained (ICER) £ 3,714 /QALY





11. Patient satisfaction, knowledge, attitudes and intentions following the lung health check

We carried out two surveys, one of subjects immediately following the lung health check, and one of subjects who had undergone a CT scan (excluding those with a diagnosis of cancer). Both surveys consisted of a paper form with simple multiple choice questions. The post-check forms were given to participants at the consultation. Participants were asked to either fill these in there and then, immediately after the lung health check, or return them by post (prepaid). The post-scan forms were sent by post to subjects who had received a CT scan and who had not subsequently been diagnosed with lung cancer. The survey questionnaires addressed patients' satisfaction with and attitudes to the service, and information deficits in relation to respiratory health, and to the LHLP interventions, activities and procedures. We will briefly summarise the main results here. More detailed results with respect to knowledge of symptoms and risk factors, and stratified results by demographic and risk status, will be included in the final report.

To date, 71 patients have returned post-lung health check questionnaires. Levels of satisfaction with the lung health check consultations were generally high. Table 7 shows responses to questions in relation to the experience of the consultation. There was a high level of satisfaction, with 14% reporting being satisfied and 86% very satisfied, with the overall experience of the lung health check. Two patients clearly had problems with the interaction with the consulting nurse, but all subjects reported that the appointment was helpful, and 96% reported that if a friend asked them if they should attend, they would encourage or strongly encourage the friend to do so.

One area which merits further investigation is that some participants may be experiencing noticeable stress, and the consultation needs to be sensitive to this. Those with pre-existing COPD may be stressed from the physical effort, whereas those without disease may be intimidated by a consultation which might in turn lead to diagnosis of a life-threatening illness.

Table 6. Survey responses in relation to the experience of the lung health check consultation

Question	Response %			
	Strongly disagree	Disagree	Agree	Strongly agree
The nurse considered any stress I was facing	3	31	26	40
The nurse helped me to identify what I needed to know to make decisions about my lung health	0	0	27	73
I feel better about my lung health after meeting the nurse	0	3	20	77
The appointment was about the right length of time	0	0	25	75
The nurse was concerned about my wellbeing	0	3	21	76
The appointment was helpful to me	0	0	20	80
Question	Response			
	Very	Moderately	A little	Not at all
Did the nurse in your appointment seem well informed?	99	0	0	1
Did the nurse in your appointment seem caring?	99	0	0	1
Did the nurse in your appointment seem rushed?	1	1	1	97
Did the nurse in your appointment seem overworked?	3	7	1	89
Question- satisfaction with	Response			
	Very dissatisfied	Dissatisfied	Satisfied	Very satisfied
Information you received before your appointment?	0	3	34	63
Booking your appointment?	0	0	33	67
Waiting room facilities?	0	0	30	70
Clinic room?	0	0	26	74
Nurse at your appointment?	0	0	10	90
Conversation you had about stopping smoking?	2	2	26	70
Conversation you had about your lung health?	0	0	19	81
The way your risk of lung cancer was explained?	0	0	19	81
The decision whether to refer you for a CT scan?	0	0	23	77
Overall experience of the lung health check?	0	0	14	86

Table 8 shows the survey results with respect to how informed the participants perceived themselves to be following the consultation. Generally, a strong majority felt quite informed or well informed, although there was an information deficit with respect to the process, benefits and risks associated with a CT scan. This may reflect the fact that those not referred for a scan did not need detailed information on the subject.

Table 7. Survey responses in relation to how informed the participants felt following the consultation

Question. How informed do you feel about	Response %			
	Not informed	Quite uninformed	Quite informed	Well informed
What I can do to improve my lung health?	1	1	7	91
What I can do to increase my chances of stopping smoking?	4	7	9	80
The stop smoking services available to me?	2	2	11	85
My risk of lung cancer?	3	3	14	80
My risk of lung diseases, such as emphysema, bronchitis or COPD?	1	3	10	85
The process of having a lung CT scan?	7	4	26	63
The benefits of having a lung CT scan?	6	4	21	69
The risks of having a lung CT scan?	7	7	23	63

Interestingly, levels of worry about lung cancer did not increase as a result of the invitation to the lung health check. Prior to receiving their invitation, 61% of subjects reported being at least slightly worried about their chances of developing lung cancer. Only 46% reported being worried since the invitation to the health check.

Among smokers, 75% reported wanting to stop smoking. 5% reported intending to stop in the next month and 10% in the next three months. A further 20% reported an aspiration to stop soon.

12. Participant satisfaction, knowledge and intentions following a CT scan

To date, 60 completed post-CT scan questionnaires have been returned. Of the 60 participants, 24% were ex-smokers, 69% current smokers and 7% occasional smokers. 79% reported having a normal result. Of those with an abnormal result, 56% were referred on for further investigation and 44% referred back to their GP. Table 9 shows levels of satisfaction with aspects of the CT scan referral and process.

Table 8. Survey responses in relation to the experience of the CT scan

Question- satisfaction with	Response %			
	Very dissatisfied	Dissatisfied	Satisfied	Very satisfied
The information given before you had a CT scan?	10	2	22	66
The time of your CT scan appointment?	10	2	27	61
The location of your CT scan appointment?	8	0	25	67
The way your lung CT scan was performed?	8	2	17	73
The time it took to receive your CT scan results?	10	3	20	67
The information provided with your CT scan results?	9	7	26	58
The way your scan results were explained to you?	9	9	25	57

Overall, levels of satisfaction were high, but the results suggest an information deficit with respect to CT scans. There were 16% who reported dissatisfaction with the information provided with the CT scan results and 18% with the way the results were explained to them. Whereas only 2% reported unanswered questions at the time of the scan, 20% reported unanswered questions after receiving the results of the scan. When subjects were asked what would be helpful if they were to have the scan again, 31% would want more written information, 52% would want simpler information and 39% would want to spend longer talking to the nurse.

There was also a level of dissatisfaction with time taken to receive the results (10% very dissatisfied). The questionnaire allowed a space for free text comments, and these were consistent with this. Comments included:

- *I was called less than 24 hours after my CT scan, I missed the phone call just before 17:30. Tried to call back (Department closed for the night). Thinking the worst, my wife and I had a restless night. Called next [day] and found out everything OK.*
- *The results of the CT scan took more than two weeks to arrive at my GP's. I was then unable to get an appointment before going on holiday but was able to talk to my doctor by phone and was told everything was normal. I am not sure how it could be improved, possibly the delay was at GP's.*

When asked if they would recommend a friend to have a CT scan, 96% reported that they would encourage it. All subjects reported that they were glad they had had the scan.

Table 9 shows results with respect to worry in relation to the CT scan. 63% of subjects reported at least being slightly worried on being referred for the scan. Since the scan, 46% were at least slightly worried about the results, and 68% at least slightly worried about the chances of lung cancer. While a degree of worry is inevitable, 15% reported being quite a bit or extremely worried about the results.

Table 9. Worry in relation to the CT scan

Question	Response %				
	Not at all	Slightly	Moderately	Quite a bit	Extremely
After you were referred, how worried were you about having a CT scan?	37	29	19	14	1
Since your CT scan, how worried have you been about the results?	54	22	8	12	4
Since your CT scan, how worried have you been about your future chances of developing lung cancer?	32	41	17	8	2

A possible positive effect of the anxiety was that 65% of smokers reported having made a serious attempt to stop smoking since the lung check appointment.

There was also a free text box on the questionnaire for general comments on the LHLP, and these were for the most part very positive, including:

- *I think it is a brilliant project which is really well run and well organised.*
- *Healthy Lung Project is a very good thing, especially in areas where there is a high rate of lung cancer. Please keep it up. Thank you.*
- *Having recently lost my husband thru lung cancer and not knowing until it was too late (he hadn't smoked for 18 yrs) I think this project is what is needed to highlight this problem and prevent unnecessary deaths.*

The positive response to patients reflects the impression the evaluation team received when they attended some of the consultations. The team were very impressed with the manner and approach of the consulting nurse, and the non-threatening and non-judgemental manner in which difficult clinical and lifestyle issues were addressed.

13. Qualitative results

In addition to the written survey, in-depth, semi-structured telephone interviews were conducted, with open-ended questions and answers, in order to identify themes and issues for the user community which were not elicited by the survey. Interviews were conducted with participants who had only had a lung health check consultation, and with participants who had also had a CT scan (excluding those with cancer diagnosed). Four interviews lasting from 40 to 60 minutes each, have been conducted so far. Interviews were recorded and transcribed verbatim. Transcribed interviews are undergoing thematic analysis to identify commonly occurring issues in terms of knowledge, awareness, attitudes and information needs. In the interim, a number of quotations from the interviews follows, sorted by topic. A number of themes are suggested by these quotations, including:

- A level of awareness of risk attributable to smoking and other exposures, and the need for investigation to resolve worries and give peace of mind as a motivation for participating;
- Ambivalence about knowing one's personal risk of lung cancer;
- Stoicism about the possible results of investigations;
- An element of fatalism, particularly in relation to continuing or giving up smoking;
- A tendency not to read the information provided in detail;
- A need for more support, information and reassurance when undergoing CT scan;
- A high level of satisfaction with the Programme, praise for the nursing staff involved and a willingness to encourage participation in others.

1. Reasons for attending

"*I was a smoker as well, and then most of the factories I'd worked in, in warehouses and working on machinery and stuff like that, so I've always worked in a risky environment, if you like, for lung cancer. So that came to mind when I was asked to do this sort of – have this scanned and see what's gone on*" (**6138**)

"*I would rather find out than not... there's the possibility of getting it put right. There's also the possibility of not getting it put right but I mean I've done alright. I'm 70 years of age, so it's not like I'm going to miss out on most things*" (**6138**)

"*Peace of mind. Peace of mind in respect of it's advanced health, or it's advanced, and if it has advanced and it's gone through a critical stage, what sort of lifespan I'd have left*" (**7016**)

"*I did say to them* [Radiographers] *before they did the scan, "Look, I've got this thing on my left lung, it's on the upper left lobe, so I just want to know if it's gone any further or whatever*" (**7016**)

"The invitation came and I just thought, 'Go, get checked out, make sure there's nothing wrong and put your mind at ease." (7356)

2. Reasons patients perceived they had been invited

"*It was probably my age. Probably my lifestyle. I don't know whether I was just pulled out of a hat or whether they looked at my records and found out that I had a lot of chest infections. I don't really know*" (**6138**)

"*Because I've got severe emphysema... I thought, yes, go and get checked out. I haven't had an x-ray on my chest for a while, so I don't know how far things have spread. Because I had a growth on my lung and I had a lobectomy, but the operation failed*" (**7016**)

"I think at first when she said, 'You fit the criteria to go,' it was a bit worrying, and then when she explained everything, I think she said, 'it's not that you've got cancer or anything like that, it's just that with your family history, just go and get it checked out,' because my dad died with lung cancer. So maybe that was the factor." (7356)

"you sometimes wonder why did they pick me, obviously. You start thinking all kind of things like do they know something I don't know?" (7534)

3. Discussion of lung cancer risk

"*She may have done* [told level of risk] *but not that I really... she didn't give me a percentage. I think that might frighten you off*" (**6138**)

"*Hindsight is a wonderful thing. I wish I had never started smoking for one. I wish I'd never messed around with asbestos sheets when I was a kid*" (**7016**)

"*She said something about the readings, with some of them there's a higher percentage of being at risk of a lung disorder and other people wouldn't be in that… I think it came down to 25%. I can't actually remember at the moment but she did explain fully about the percentages*" (**7016**).

4. Satisfaction with nurse discussion

"*Well, she* [the nurse] *just laid out what would happen and what they were actually looking for, and if anything was found, there would be biopsies and how sometimes there's freckles in the lungs and some of them are benign and some of them are not and explained everything that would go on step by step and go for a CT scan and stuff and it was very good.... I didn't know that there were actually things like that in my lungs. I just thought you'd either got cancer or you hadn't got cancer*" (**6138**)

5. Anxiety or concerns preceding/surrounding lung health check appointment

"*Not at all. No anxiety about it or anything like that*" (**6138**)

"*I hadn't built myself up to find anything or not to find anything. I was just so relaxed about it. If there had been anything, I probably would have been worried, but I wasn't at that stage where I felt there was anything wrong*" (**6138**)

"*No* [concerns about the lung health check]*, not at all, because you can't avoid the inevitable regardless*" (**7016**)

"*I didn't have any. It's just one of them things. I brought it upon myself with smoking, well, among other things. So it was just one of them, get it checked and find out what the situation is*" (**7016**)

"*Get it done because it does put your mind at ease. One way or the other you know where you stand. It's a good thing*" (**7016**)

"*When I went in I didn't have to wait too long, so I didn't have long enough to start panicking, different things go through your mind. I just felt at ease over the whole thing*" (**7016**)

"*because I knew there was something there already I was prepared to… I was ready in my own mind that something worse could have happened*" (**7016**)

"A little bit nervous because you don't know what you're expecting but, as I say, everything was fine. It was really good. I was in and out no problems." (7356)

"…I think you just get nervous before anything, don't you? Even if it's just the dentist. In the back of your mind, you're saying, 'I hope everything comes back okay.'

"The only thing I did find was you know when you have to blow into the machine? I got a terrible pain in my back. Like in your lung, so that worried me a bit, but they just said that I must have strained it; you know where they make you breathe really hard?...It's put me off going back for the spirometry test." (7356)

"If you asked me 20 years ago, I'd most probably be terrified mentioning the word 'lung cancer', but as you get older I think you just accept these things more." (7356)

"I had a few concerns about going for the scan because I'm a bit frightened of those machines." (7534)

"No, I didn't know anything about it, no, because I thought it was a death certificate, a death sentence." "I don't think I would be as scared as I would have been before because I know now if they catch it early enough they can treat it to a certain degree and I didn't know that. That's a plus thing." (7534)

6. Smoking and smoking cessation

"*even though I've packed in for the length of time I've packed in for, the cravings are still as strong. It's like a daily battle... Well telephone support is okay. But if it comes down to leaflets and stuff, I'm afraid… I mean, personally speaking, I've had my fill of leaflets*" (**7016**)

"*I've been made aware that due to my smoking I'm… what I've done in the past, the fact that previous to that I was like* [unclear 0:16:24.9], *I was packing in smoking, but since then I've sort of seen the light and packed it in* [did not attribute to lung health check]... *What I did was I read an article on smoking and the stages of emphysema, what happens and all the rest of it and it was that that sort of persuaded me to have a go*" (**7016**)

"*She asked me if I still smoked. I said, "Yes." She said, "How many a day?" I explained. She said, "Well basically that's going to make your condition worse and* [unclear 0:21:57.5]*." It was like in one ear and out the other and that was it... I still think like that. I've packed in smoking too late in life for it to make any difference*

to my health. Bearing in mind that I packed it in and I don't feel any different it seems like it's strengthened the thoughts that I have about it" (**7016**)

"*whatever you can do to extend your life, not just extend it but to make the rest of your life a bit more bearable for you being able to do things that you want to do without being a burden to other people, that's it, and if packing in smoking is going to do that for me then I'm all for it*" (**7016**)

"*It was only when the doctor informed that I could be like COPD and progress to stage 3, I think it was, severe emphysema. With that 'severe' that was like a shot across the bowels sort of thing, that worried me, time for fun and games is over and I've got to take the situation more serious*" (**7016**)

7. Information needs

"[the nurse told them] *about what could happen and what wouldn't happen. So I was quite happy with that*" (**6138**)

"*As she said, I just go there and go through the polo mint and it was quite informal. I had no worries at all*" (**6138**)

"*I just skipped over it* [the information received with the invitation]" (**6138**)

"*that was just a phone call, and she phoned me up and said there were no problems and everything was clear*" (**6138**)

"*when I went into the room they did explain to me exactly what was going to happen... They explained about the machine... They said there's not really any noise attributed to the machine, so there's nothing to really worry about in that respect and it would only be two or three passings through the machine and that's it*" (**7016**)

"*I was told everything I needed to know before my appointment and during my appointments. There's nothing at all left that needed to be… for me to be informed about*" (**7016**)

"[the staff] *felt it was their duty to explain fully what to expect from the scan*" (**7016**)

"*when I first saw how severe emphysema I had it, it knocked me back a bit because I didn't ask the questions that I needed to ask, but when the call came from the nurse later… might have been a few days or a few weeks but it gives you time to sort things out in your head and to know what questions you needed to ask if you needed to ask any*" (**7016**)

"*I'll be honest, no* [did not read information booklets given/sent]*... didn't want to know anything as regards packing in smoking and at the time, as I say, I knew all about the CT scan and what to expect from it and all the rest*" (**7016**)

"I think it was explained in the leaflet, that it was a scanning machine, so I more or less knew what to expect." **(7356)**

"Yes. I did ask a few questions when she asked. I think it was more like, 'How come you're asking me to go. Is there something wrong with me?'" **(7356)**

"I think if they just explain to people and just say, 'You're just going to go in the machine, it'll only take a few minutes, you don't have to panic or worry and it'll all be over and done within a minute,' I think that'd help a lot of people." **(7356)**

"I would just like them to say 'You are going for a scan, it's a CAT scan and a CAT scan is… Have you seen these things that look like big polos?' Explain to you like that, so it's open-ended, so that if you are claustrophobic like me, you are not panicking yourself." **(7534)**

"I would have liked them to say, 'You hear certain noises and don't be scared, it's only this, that and the other and you'll see lights and there will be some movement. If at all any stage you're at all panicked or anything just tap the machine,' or something. Just some words of information really." **(7534)**

(regarding results) *"In good plain English and nothing too technical. Very good, yes."* **(7534)**

8. Satisfaction overall (including recommending to others)

"*I go to the pool five or six times a week, and I was explaining it to the lads there, and a couple of them volunteered to do it... A couple of them are smokers and still smoked and they've gone through the same system and they're quite happy with what's happened to them*" (**6138**)

"*one of the chaps I know in the swimming pool, he still smokes, but he's a good swimmer, like, but he's 65 and when I mentioned it to him, he said, 'Ooh,' and he uses the same doctor as me, so he toddled along to the doctor's and volunteered*" (**6138**)

"*First-class. Honestly. I really do think it was first-class*" (**6138**)

"*I'd recommend anyone else goes and gets it done, puts their mind at ease... Get it done because it does put your mind at ease. One way or the other you know where you stand. It's a good thing*" (**7016**)

"*No, except it wouldn't bother me in the least if I had to go there again for another check-up because… I won't say it's a nice experience, because it's not a nice experience but they go out their way to make sure they don't scare you, so it's not a scary experience and the end result is that you don't come away with more knowledge of your health at the time but you get that knowledge by a phone call or by a visit to your GP a few weeks later*" (**7016**)

"I just kept the appointment and it was very quick and efficient and it was all over and done with. I suffer bad with arthritis. So it was a bit difficult getting on the bed, you know, to do it, but the man was good, he lowered everything down" (7356)

(recommending to others) "Yes, definitely, because there's always that risk, there's always that bee in your bonnet," (7534)

9. Satisfaction with waiting times, appointments, process, etc.

"*I arrived about five minutes earlier, by 9 o'clock I'd had a CT scan and I was walking out of the hospital ten minutes later. So things were really good*" (**6138**)

"*It was only a matter of weeks [waiting for result]... I wasn't looking at the phone every morning waiting for a phone call or waiting for a letter to drop through the door. I'd dismissed it really*" (**6138**)

"got the results through pretty quick and had a phone call from the nurse that had done the initial test to give me the details as well" (**7016**)

"the whole procedure that I went through put my mind at ease. When I went in I didn't have to wait too long, so I didn't have long enough to start panicking, different things go through your mind. I just felt at ease over the whole thing" (**7016**)

"It was quick. I didn't wait that long to get seen to. I think if they make appointments for you and they're months ahead, you can either forget about the appointment or you sit and worry about the appointment. So I was glad that it was a quick appointment." (7356)

"Fine. As I say, it was nothing to complain about, but I just remember the way they were rushing you, maybe it was because they were late, maybe they had to be as quick as they could." (7356)

10. Opinions of staff

"*Fabulous. Really good... They were polite and engaging and put me at ease, no problem at all, very good... it was just very relaxed. I was very relaxed about it. I had no concerns. Yes, just very nice and just a nice conversation*" (**6138**)

"*there was no pressure on me. You could refuse it if you wanted to. The way I was dealt with at the CT scan and the way she realised that I couldn't take the blow test because of my cataract. But that wasn't necessary because*

I was going for the CT scan anyway, and everything was really – a great way. It was done really professionally and really nicely as well" (**6138**)

"*First-class* [attitude of the staff]" (**6138**)

"*they were brilliant*" (**7016**)

"*they were tired, run ragged. They still had patience for the patients, if you know what I mean, because they did explain everything they were supposed to explain*" (**7016**)

"*she was brilliant* [the lung health check nurse] *because she, even after my initial appointment with her, she made sure that she phoned me back to give me the results of the CT scan even though I explained to her that I'd been told by my GP what the results were*" (**7016**)

"*sometimes the nurse or someone else can tell you more than what your GP can, because a lot of the time the GP just can't… doesn't appear to be too bothered to tell you everything they should do because the push for how many patients they've got to see, they are going to just get rid of you out the surgery*" (**7016**)

"Well the nurse's manner was excellent, she was obviously very knowledgeable about what she was talking about, which gave you a sort of sense of security kind of thing." **(7534)**

14. Discussion and likely impact

This report is a preliminary one, based on activity to date in three neighbourhoods. As such, numbers of clinical endpoints such as lung cancer diagnoses are relatively small, although consistent with expected findings. However, a number of observations are clear. First, the programme is likely to detect substantial numbers of so far undiagnosed cases of COPD, with the opportunity for prompt treatment and management to alleviate symptoms and slow down progression. Second, of the lung cancers diagnosed so far, 75% have been stage I. This suggest a potentially large increase in length of life of the lung cancer patients. Thirdly, preliminary cost-effectiveness analysis suggests a substantial gain in quality adjusted life years, for modest expenditure, with incremental cost-effectiveness ratios of the order of £4,000 per quality adjusted life year gained. Finally, levels of patient satisfaction are high. The

substantial time devoted to each consultation and the manner of the consultations are clearly appreciated.

A number of issues arise from the results so far. First, although lung cancer tends to have the highest profile in programmes such as this, the effect of the programme on COPD morbidity and mortality may actually be the greatest benefit resulting from the intervention. The programme is diagnosing large numbers of COPD cases.

Second, the numbers of CT scans resulting in a need for further diagnostic investigation is around 10%, a considerably smaller burden than was observed in the randomised trials of CT screening. The LHLP used the recent British Thoracic Society pulmonary nodule guidelines (2016), which supersedes the UKLS radiology protocol.. Follow-up for future lung cancer, in those scanned and in the overall LHLP population will give valuable information to identify populations which currently slip through the net, in turn suggesting improvements to the service.

It is difficult to interpret the prevalence of lung cancer in those scanned with the small numbers available. The eight cancers so far is slightly less than we would have expected, but this may be due to chance. However, a higher upper age limit of 75 years would certainly increase the harvest of lung cancers detected. The favourable stage of the cancers diagnosed indicates that the early detection activity is worthwhile.

A number of issues emerged from the patient questionnaires and in-depth interviews. These include first and foremost the high level of satisfaction with the service. However, areas where improvement are possible include information and support, particularly on the occasion of the CT scan. It seems that information provided in advance of the scan is not fully assimilated and there is a need for greater support and information when the subject attends for the scan. From both the questionnaire and the interviews, it is apparent that those undergoing a scan would benefit from further information, support and reassurance there and then, and face-to-face rather than written. While this has serious resource issues, it is at least worthy of consideration.

Two related issues of the patient experience are that even at the initial health check, participants can be under some stress, as the possibility of serious respiratory disease is intimidating. While the consulting nurses are clearly sensitive and were highly praised by participants, it is as well for all staff involved to be continually aware of this. The other issue is that of timing and explanation of results of the CT scans. The results of the survey suggest that it would be of value to tighten protocol and practice with respect to informing patients of scan results. Experience from existing cancer screening programmes suggests that anxiety is kept at bay if subjects know when to expect results and receive them when they are expected. In addition, as the CT scan is an investigation with potentially complex results, further consideration needs to be given as to how best to explain these to the participants and how to support them in the event of abnormal results.

The opportunity in terms of encouraging cessation of smoking might be built upon further. Some of the quotations above from the telephone interviews suggest a fatalism and feeling on the part of some participants that it is too late for them to give up. Consideration should be given as to how best to counter this attitude. One possibility might be to emphasise the virtually immediate reduction of cardiovascular risk on giving up smoking. At any rate, the message that it is never too late to stop has not completely got through.

Finally, it should be noted that the programme is on target to save substantial numbers of life years and can save more if expanded.

16. Recommendations

A number of recommendations arise in respect to both delivery and evaluation of this service.

1. On the basis of results so far, the programme is effective and cost-effective and should continue.
2. The expansion of the age range to encompass ages 71-75 would increase the cancer detection rate and further improve cost-effectiveness. Detailed numbers from UKLS to back this up have already been shared with the CCG.

3. While the length of the consultation is clearly a much appreciated feature of the programme, it is worth exploring whether the consultation could be trimmed to 30 minutes, especially if the eligible population is to be expanded.
4. There is a need for highly targeted information and support for those undergoing CT scans. The CCG and the secondary care departments carrying out the scans should liaise to decide the best way to provide this.
5. There is also a need to revisit the protocol of delivery of results of the CT scans. It would free up specialist nurses' time if they were not charged with conveying normal scan results to participants by telephone. On the other hand, those with results requiring further investigation need appropriate support. A means of rationalisation needs to be found, which would ensure best use of resources while maintaining support of a potentially vulnerable patient population.
6. In relation to the above, the timing of results needs some thought. Experience in existing cancer screening programmes tells us that distress is kept to a minimum if patients are told when to expect results and when they receive results at the expected time. Means of achieving this should be explored.
7. Whatever the means of delivery of the results, it is likely that the specialist nurses will be called upon to support patients recalled for further investigation. It is worth some effort to establish whether a simpler pragmatic summary of findings, and immediate implications for the patient could be developed, in addition to the radiologist's report.
8. The second letter and third contact by telephone are clearly effective in increasing participation. While the participation rate is at least as good as one might have expected for the areas targeted, it is worth exploring whether this could be improved, possibly by means such as text message reminders or more general approaches, including publicity around the results so far, which are certainly favourable.

9. For evaluation, and production of the final report on the LHLP, additional data items would be helpful, including:
    a. More granularity of smoking data, including at least whether the subject is a current or ex-smoker. If possible, ages at starting and stopping (if relevant) are desirable.
    b. Secondary care data, including MDT pathway referral, further diagnostic investigations, diagnosis and if possible treatment of cancers, significant other findings.

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