Cancer Survivorship: Improving Quality of care for Patients with Lung Cancer

SCN NCIN Lung Workshop
Feb 2011
Sarah Doffman
Chair of Sussex Cancer Network Lung Tumour Group
Lead for Lung Cancer
Brighton and Sussex University Hospitals NHS Trust

Background

- BSUH NHS Trust:
  - Royal Sussex County Hospital
  - Princess Royal Hospital (Haywards Heath)
  - (Lewes Victoria Hospital)
  - (Brighton General Hospital)
- Catchment population ~ 500 000
- ~250 new cases per year of lung cancer (75% RSCH/25% PRH)

Lung Cancer in Sussex Cancer Network

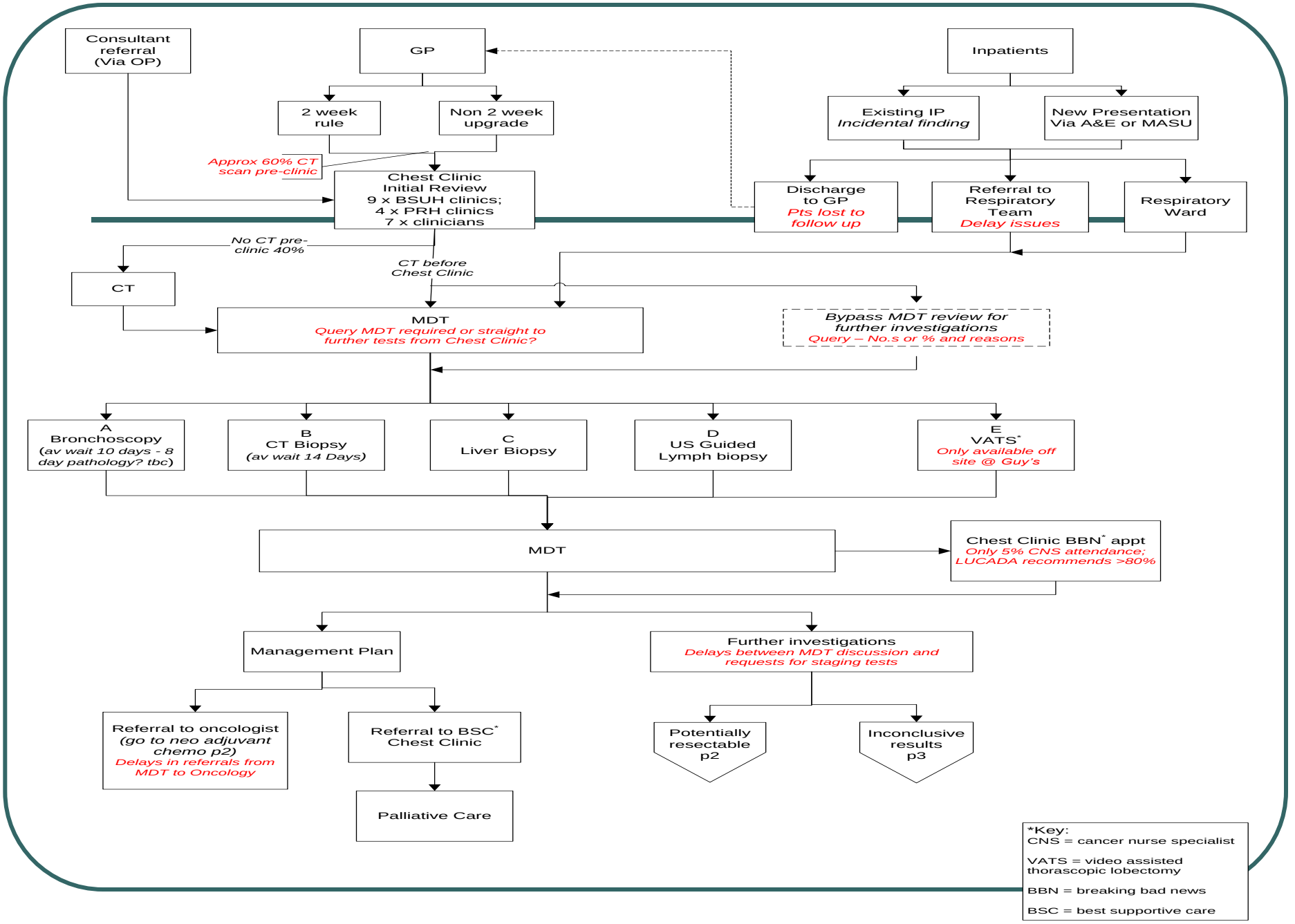
- ~220-250 new cases per year at BSUH

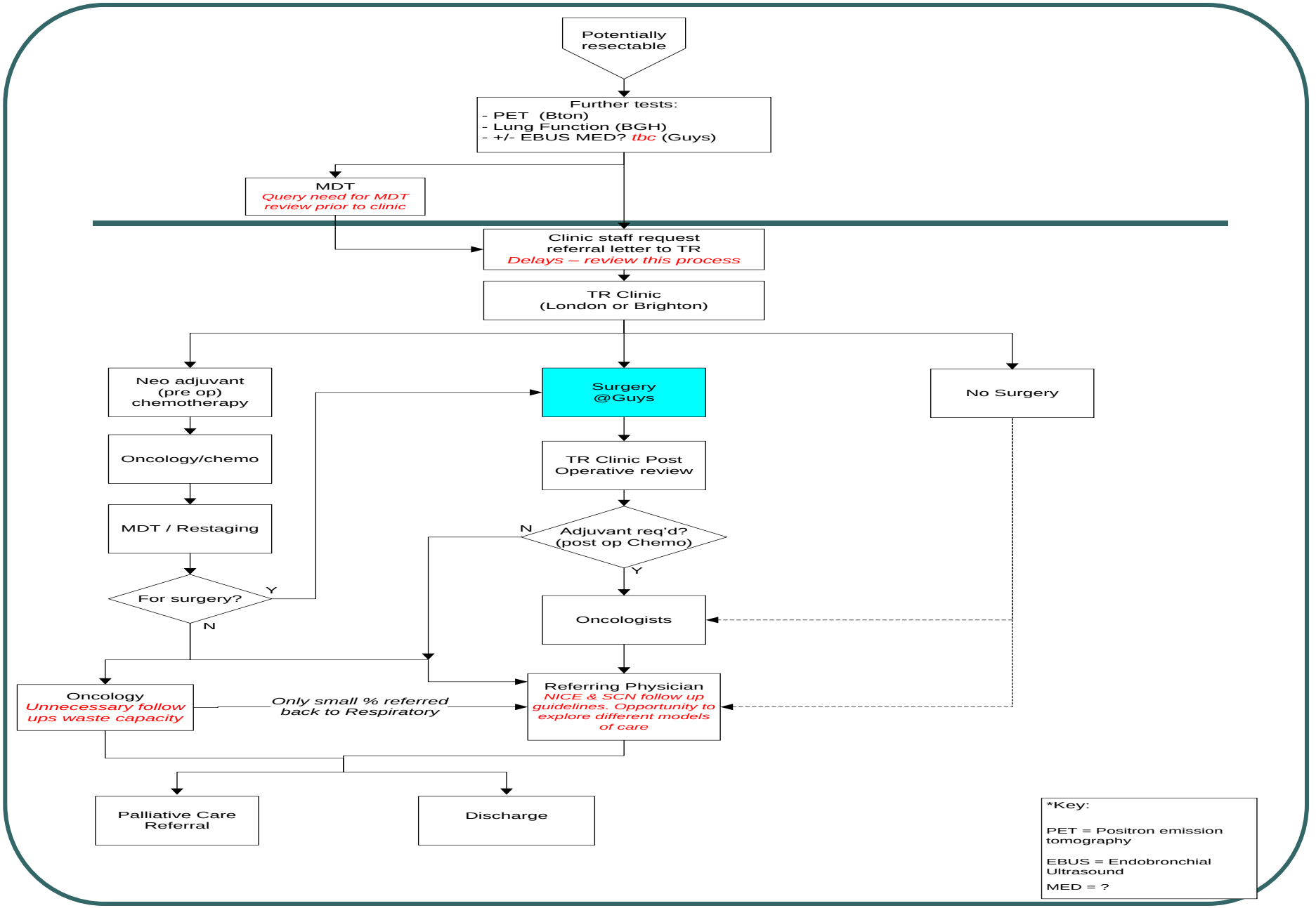
Trust	Primaries	Recurrences	Metastases	Benign	All Cases
BSUH	225			3	**228**
EDGH	126				**126**
CONQ	150				**150**
Worthing	169	3	6		**178**
Network	**670**	**3**	**6**	**3**	**682**

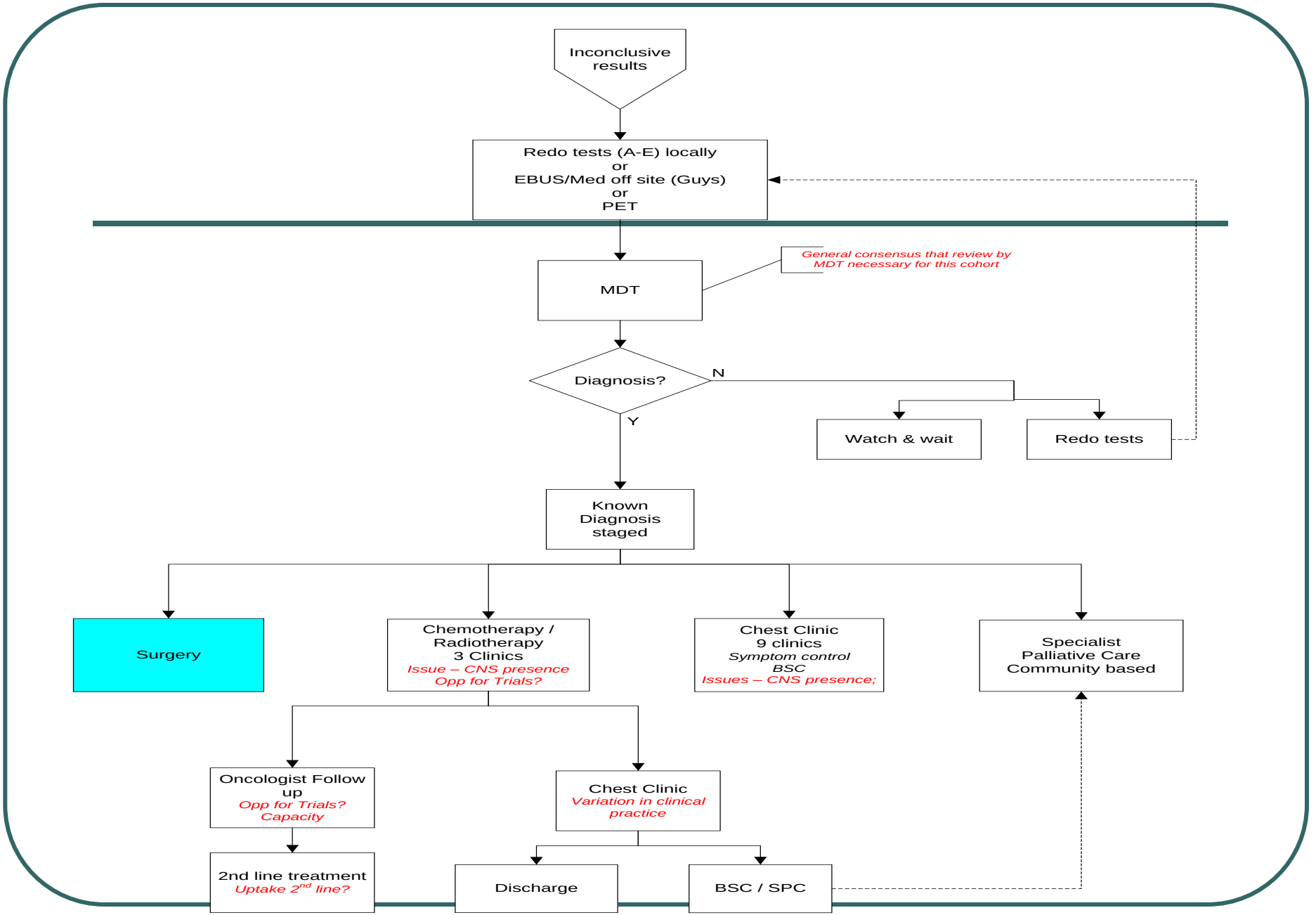
The Cancer Pathway - BSUH

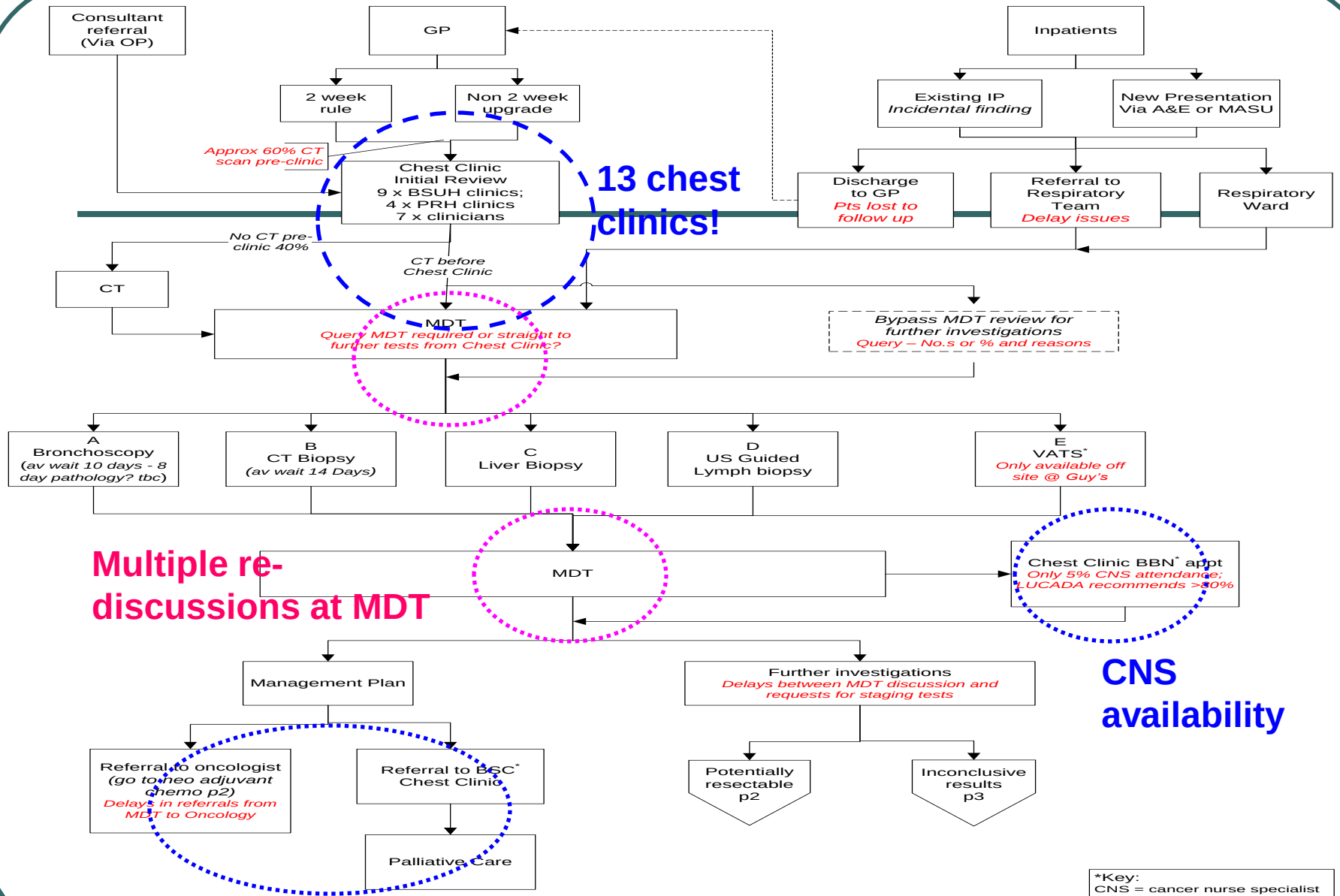
Local Issues

- Process mapping exercise, January 2010
  - All members of the team involved in care of patients with lung cancer
    - Clinicians (MDT)
    - Nurse specialists
    - Admin support – secretarial/clinic clerk/outpatient team
    - Pathway coordinator
    - Trust Management
    - Sussex Cancer Network Service Improvement Team


Consultant referral (Via OP)
GP
Inpatients
2 week rule
Non 2 week upgrade
Existing IP
Incidental finding
New Presentation Via A&E or MASU
Approx 60% CT scan pre-clinic
Chest Clinic Initial Review
9 x BSUH clinics;
4 x PRH clinics
7 x clinicians
Discharge to GP
Pts lost to follow up
Referral to Respiratory Team
Delay issues
Respiratory Ward
No CT pre-clinic 40%
CT before Chest Clinic
CT
MDT
Query MDT required or straight to further tests from Chest Clinic?
Bypass MDT review for further investigations
Query – No.s or % and reasons
A
Bronchoscopy
(av wait 10 days - 8 day pathology? tbc)
B
CT Biopsy
(av wait 14 Days)
C
Liver Biopsy
D
US Guided
Lymph biopsy
E
VATS*
Only available off site @ Guy's
MDT
Chest Clinic BBN* appt
Only 5% CNS attendance;
LUCADA recommends >80%
Management Plan
Further investigations
Delays between MDT discussion and requests for staging tests
Referral to oncologist
(go to neo adjuvant chemo p2)
Delays in referrals from MDT to Oncology
Referral to BSC* Chest Clinic
Palliative Care
Potentially resectable p2
Inconclusive results p3
*Key:
CNS = cancer nurse specialist
VATS = video assisted thorascopic lobectomy
BBN = breaking bad news
BSC = best supportive care


Potentially resectable
Further tests:
- PET (Bton)
- Lung Function (BGH)
- +/- EBUS MED? tbc (Guys)
MDT
Query need for MDT review prior to clinic
Clinic staff request referral letter to TR
Delays – review this process
TR Clinic
(London or Brighton)
Neo adjuvant (pre op) chemotherapy
Oncology/chemo
MDT / Restaging
For surgery?
Y
N
Surgery @Guys
TR Clinic Post Operative review
Adjuvant req'd? (post op Chemo)
N
Y
Oncologists
No Surgery
Oncology
Unnecessary follow ups waste capacity
Only small % referred back to Respiratory
Referring Physician
NICE & SCN follow up guidelines. Opportunity to explore different models of care
Palliative Care Referral
Discharge
*Key:
PET = Positron emission tomography
EBUS = Endobronchial Ultrasound
MED = ?


Inconclusive results
Redo tests (A-E) locally
or
EBUS/Med off site (Guys)
or
PET
MDT
General consensus that review by MDT necessary for this cohort
Diagnosis?
N
Y
Watch & wait
Redo tests
Known Diagnosis staged
Surgery
Chemotherapy / Radiotherapy
3 Clinics
Issue – CNS presence
Opp for Trials?
Chest Clinic
9 clinics
Symptom control
BSC
Issues – CNS presence;
Specialist Palliative Care
Community based
Oncologist Follow up
Opp for Trials?
Capacity
Chest Clinic
Variation in clinical practice
2nd line treatment
Uptake 2nd line?
Discharge
BSC / SPC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13 chest clinics!
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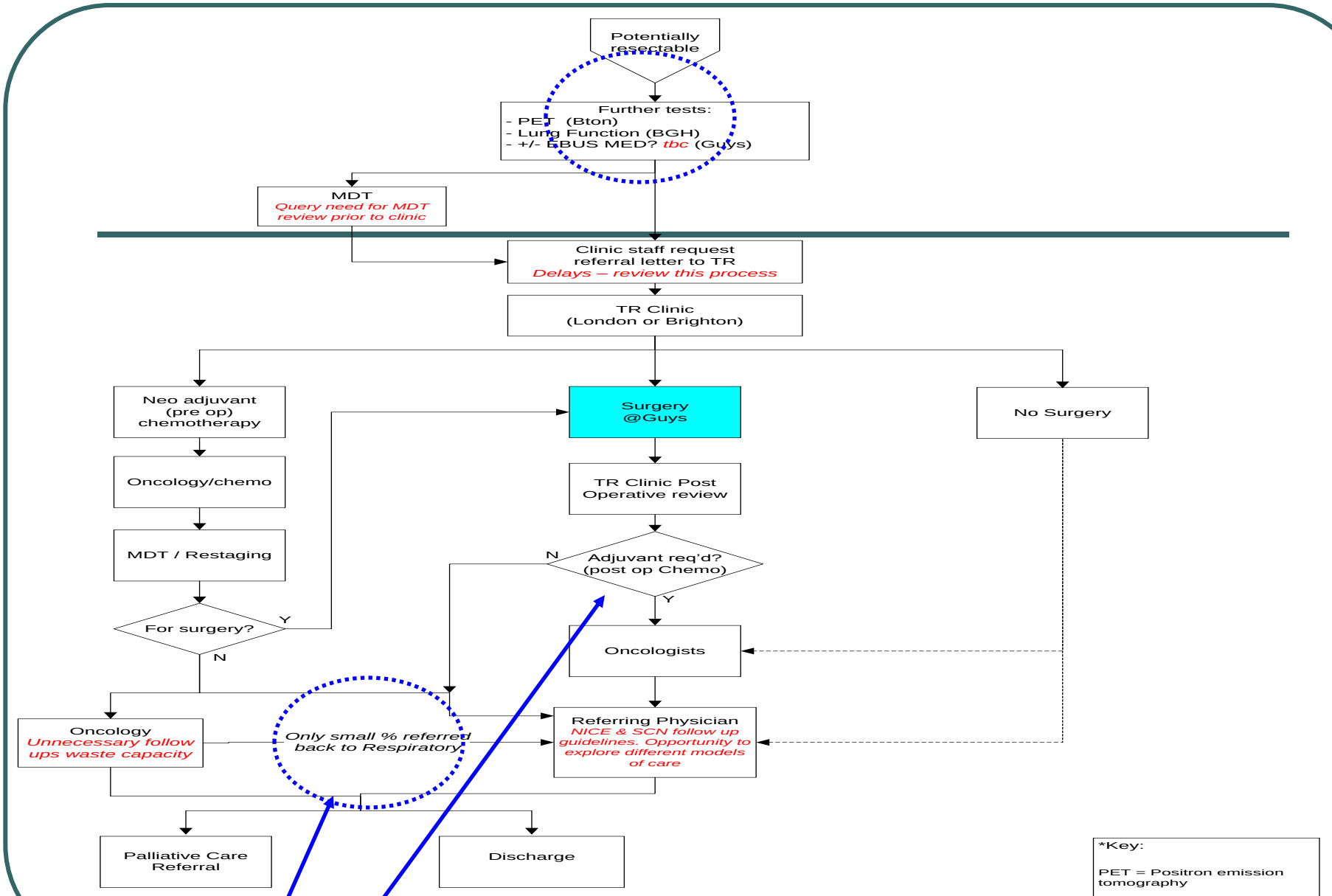

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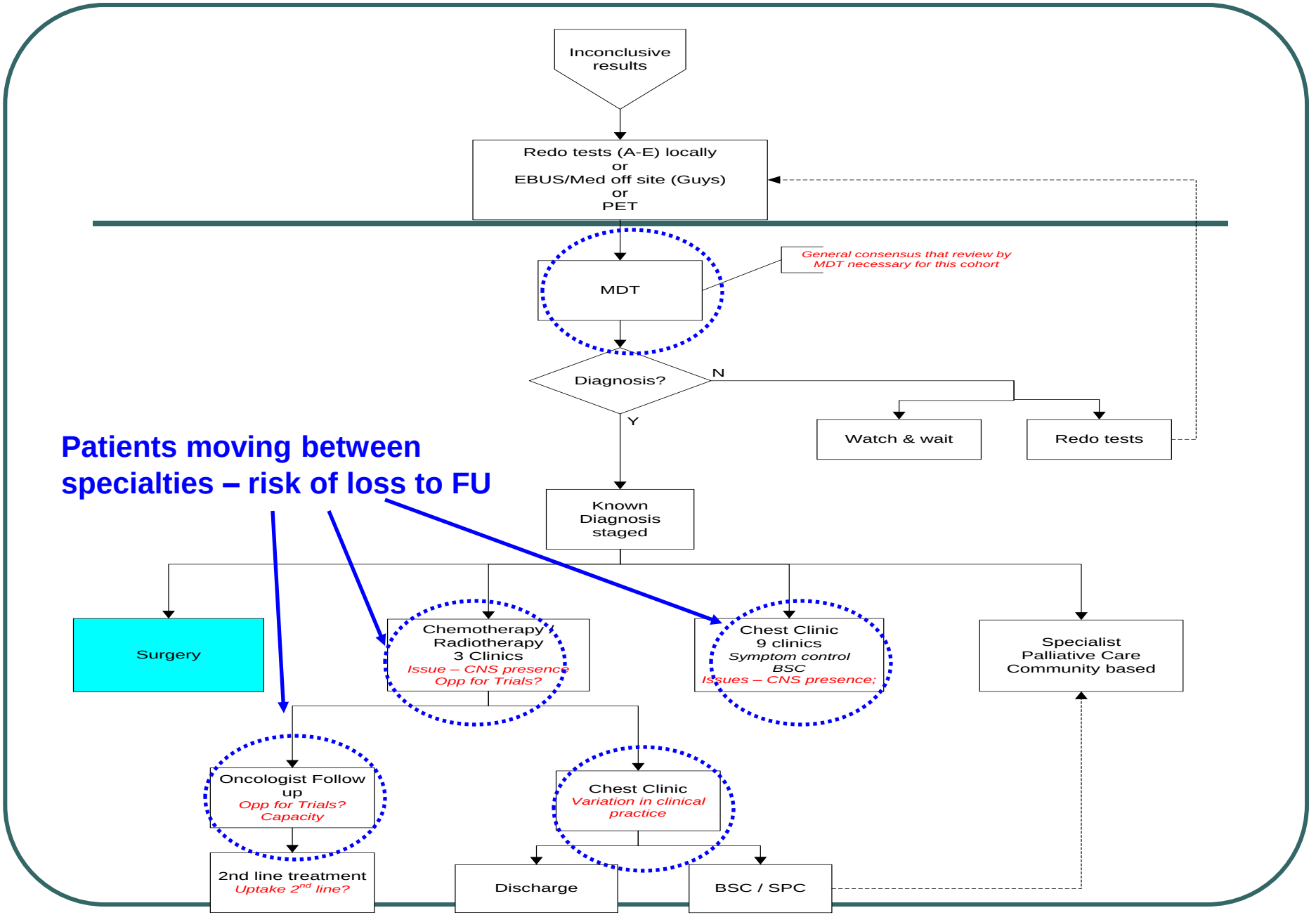
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Discharge
BSC / SPC

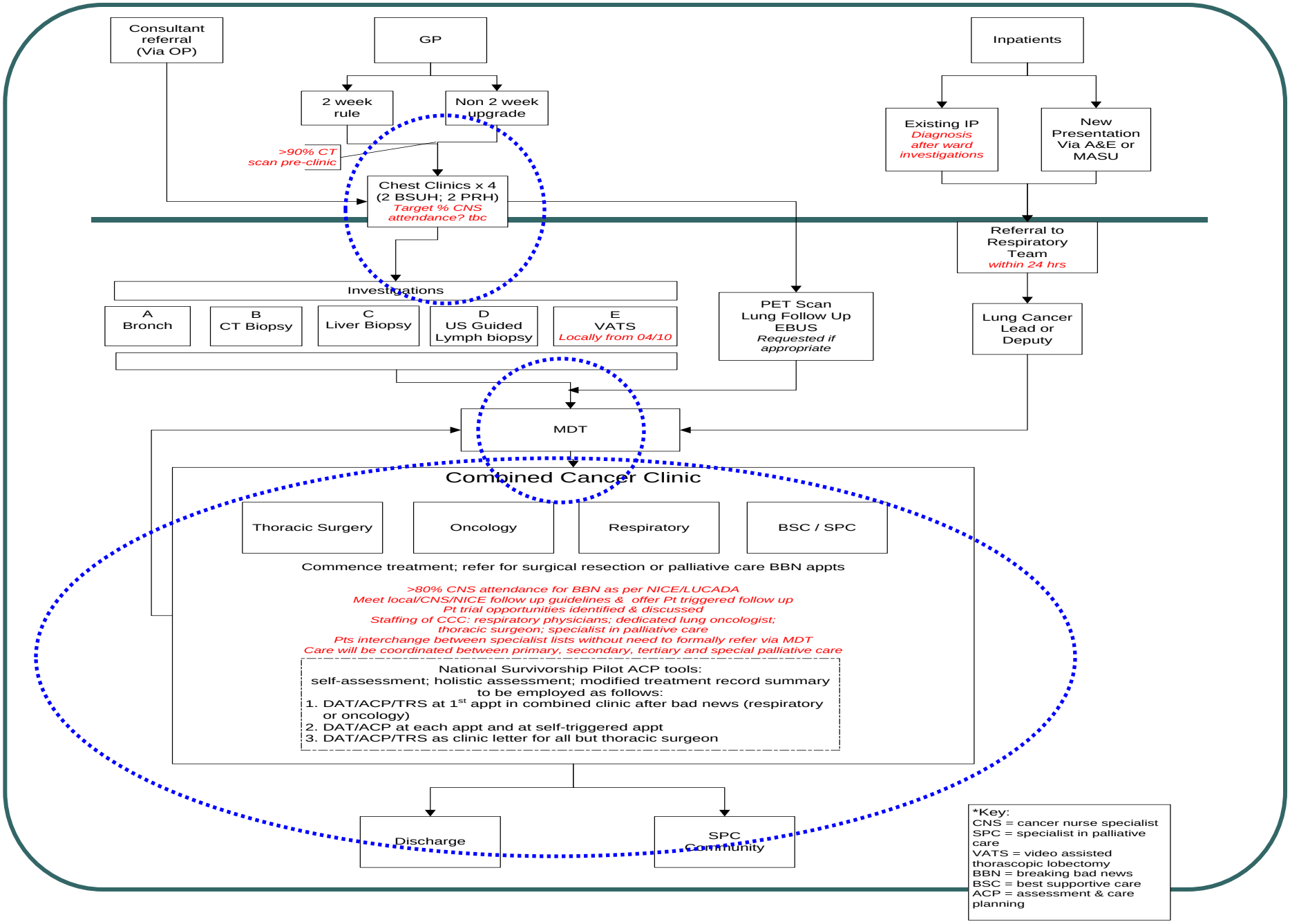
Local Issues

- Lack of Macmillan CNS presence at clinic (first OPA and BBN)
  - BBN < 5% attendance – 7 clinicians, 9 clinics at RSCH, 4 at PRH!)
- Delays in referral between specialties (e.g. resp to oncology)
- Lost to follow up – referral back to resp after active treatment complete
- Patient uncertainty re who is looking after them
- Lack of available capacity in oncology clinics (patients not having active therapy)
- Potentially avoidable “routine” follow-ups

Local Issues
(outside the remit of this project)

- Patients having to travel off-site for diagnostic tests and treatment
- Need for psychological input plus other ancillary services (physio/dietician etc) to lung cancer service not part of core MDT

Redesign of patient pathway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GP
2 week rule
Non 2 week upgrade
>90% CT scan pre-clinic
Chest Clinics x 4 (2 BSUH; 2 PRH)
Target % CNS attendance? tbc
Inpatients
Existing IP
Diagnosis after ward investigations
New Presentation Via A&E or MASU
Referral to Respiratory Team
within 24 hrs
Investigations
A Bronch
B CT Biopsy
C Liver Biopsy
D US Guided Lymph biopsy
E VATS
Locally from 04/10
PET Scan Lung Follow Up EBUS
Requested if appropriate
Lung Cancer Lead or Deputy
MDT
Combined Cancer Clinic
Thoracic Surgery
Oncology
Respiratory
BSC / SPC
Commence treatment; refer for surgical resection or palliative care BBN appts
>80% CNS attendance for BBN as per NICE/LUCADA
Meet local/CNS/NICE follow up guidelines & offer Pt triggered follow up
Pt trial opportunities identified & discussed
Staffing of CCC: respiratory physicians; dedicated lung oncologist; thoracic surgeon; specialist in palliative care
Pts interchange between specialist lists without need to formally refer via MDT
Care will be coordinated between primary, secondary, tertiary and special palliative care
National Survivorship Pilot ACP tools:
self-assessment; holistic assessment; modified treatment record summary to be employed as follows:
1. DAT/ACP/TRS at 1st appt in combined clinic after bad news (respiratory or oncology)
2. DAT/ACP at each appt and at self-triggered appt
3. DAT/ACP/TRS as clinic letter for all but thoracic surgeon
Discharge
SPC Community
*Key:
CNS = cancer nurse specialist
SPC = specialist in palliative care
VATS = video assisted thorascopic lobectomy
BBN = breaking bad news
BSC = best supportive care
ACP = assessment & care planning

The Project at BSUH

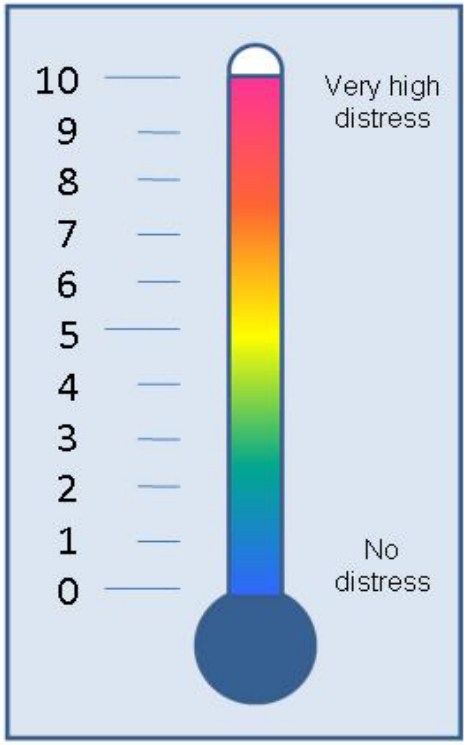
- Combined cancer clinic (CCC)
  - 2 respiratory physicians +/- SpR
  - 1 specialist palliative medicine consultant
  - 2 Macmillan lung CNS
  - some input from oncology
- Treatment Record Summary (TRS) and Assessment and Care Plan (ACP) at each appointment subsequent to breaking bad news
  - Electronic TRS and ACP developed (Access® database able to generate reports)
  - Clinic letter generated from database – printed off in clinic and given to patient/faxed to GP/community teams
  - Distress Assessment Thermometer (DAT) completed at each attendance – validated and well-used holistic assessment tool

Brighton and Sussex University Hospitals NHS Trust

Distress Thermometer

Patient details
(or space for label)

1. Please mark on the thermometer the number (between 0 and 10) that best shows how much distress you have felt in the past week overall, including today:



2. Please tick any of the following that has been a problem for you over the past week, including today:

Practical problems
- ❑ Care of children and/or relative
- ❑ Housing
- ❑ Money
- ❑ Transport
- ❑ Work and/or school

Family problems
- ❑ Relationship with partner
- ❑ Relationships with children

Emotional problems
- ❑ Worry
- ❑ Sadness
- ❑ Anger
- ❑ Guilt
- ❑ Depression
- ❑ Nervousness

Spiritual or religious concerns
- ❑ Loss of faith
- ❑ Loss of meaning or purpose in life

Physical problems
- ❑ Appearance
- ❑ Bathing/dressing
- ❑ Breathing
- ❑ Changes in urination
- ❑ Constipation
- ❑ Diarrhoea
- ❑ Eating
- ❑ Fatigue/tiredness
- ❑ Feeling swollen/lymphoedema
- ❑ Fever
- ❑ Getting around/restricted movement
- ❑ Indigestion
- ❑ Memory/concentration
- ❑ Mouth sores
- ❑ Nausea
- ❑ Nose dry/congested
- ❑ Pain
- ❑ Sexual
- ❑ Skin dry/itchy
- ❑ Sleep
- ❑ Tingling in hands/feet
- ❑ Taste in mouth

3. Please list your overall top three problems from the selection above:

a) _____ b) _____ c) _____

September 2009

Treatment Record Summary

- Standard template generated from Access database
- Summary page 1:
  - Current disease stage/histology/date of diagnosis
  - Treatment received, treatment intent, response to Rx
  - Performance status, DAT score
  - Actions required by GP
- Page 2
  - Alert symptoms
  - Contact numbers
  - Follow up plans and Gold Standards Framework
- Include READ codes?

Assessment and Care Plan

- Summary diagnosis/treatment etc populated from TRS
- Psychological/spiritual – QOL, fears, hopes
- Social – needs, financial/benefits, carers
- Self-management programmes, resus decision, referrals made

The Project at BSUH

- Patients able to self-trigger into clinic as needed and be seen within 1 week
- Patients on >2nd OPA in CCC contacted by Macmillan nurses week prior to appt to see if need to attend.
- Appt cancelled if not and rearranged – frees up capacity for self/professional triggered slots
- Clinic slots lengthened to enable time for ACP to be completed

National Measures

- Tribal
  - GP satisfaction with TRS
  - Patient satisfaction with TRS/ACP
  - Impact on communication with community teams
  - Patient focus group
- >100 patients enrolled

Local Measures

- Impact of CCC on satisfaction
  - Baseline satisfaction survey of sample of patients seen in old style clinics
  - To repeat satisfaction survey with sample from CCC

Local Measures

- Impact of ACP framework on unscheduled emergency admissions to hospital
  - Baseline data on lung cancer-related admissions Jan-Jun 2008/Jan-Jun 2009
  - Prospective data collection on similar for Jan-Jun 2010 (note made of whether patients within CCC)

Local Measures

- Number of referrals made outside the MDT and time from referral to review
  - Date referral made captured in electronic TRS
  - Total referrals outside MDT collected

Local Measures

- Changes to Distress Thermometer scores over time during participation in project (impact of use of ACP and CCC on distress)
  - DAT scores recorded at each attendance (scheduled/unscheduled) at hospital

Local Measures

- Impact of self-triggered assessment on routine clinic attendance
  - Nature of appt recorded (routine/self-triggered/cancelled)
  - If self-triggered/cancelled, reason documented
  - (Economic appraisal work)

Local Measures

- DNA rate in clinic
  - Impact on cost of care
    - Trust management team keen to monitor impact on costs – need to renegotiate tariff
    - (clinic slots extended to 30 mins for new 2WW/follow-up, protected slots (not overbooked)

Baseline Patient Satisfaction Survey

- Generally a high level of satisfaction with the service
- Room for improvement:
  - 25% patients felt that their worries about their condition were not discussed
  - 30% felt that they/their carers were not given enough info

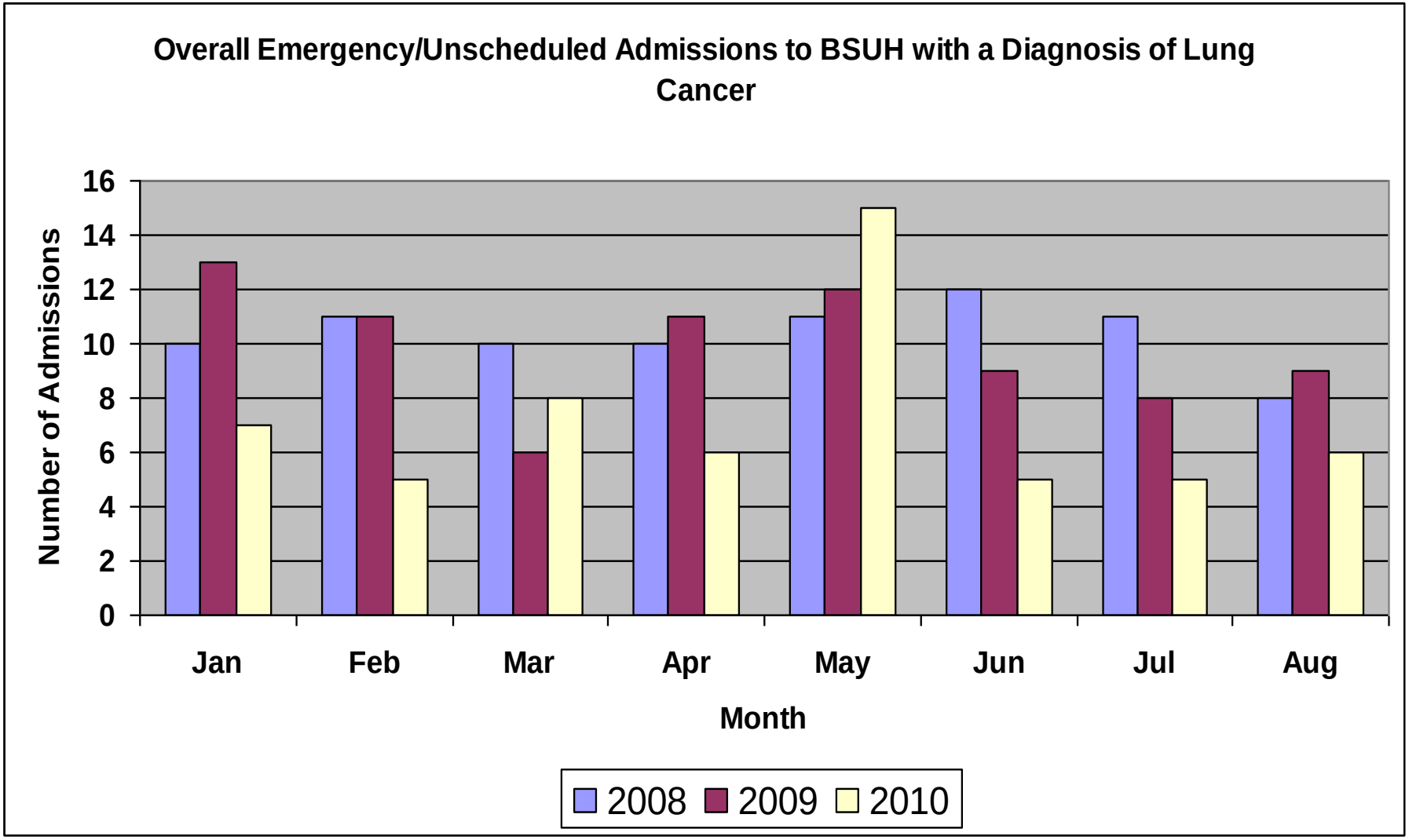
Results
Patient Satisfaction Survey

Question	Answer	Response Round 1 Number (%)	Response Round 2 Number (%)
If you had important questions to ask the doctor, did you get answers that you could understand?	**Yes, definitely**	**5 (42)**	**12 (67)**
	Yes, to some extent	3 (25)	1 (6)
	No	0	0
	I did not need to ask	1 (8)	2 (11)
	I did not have an opportunity to ask	0	0
	Missing/N/A	2 (17)	3 (17)
While you were in the Outpatients Department, how much information about your condition or treatment was given to you?	**Not enough**	**4 (33)**	**0**
	Right amount	**7 (58)**	**17 (94)**
	Too much	0	0
	I was not given any information	0	0
	Missing/N/A	1 (8)	1
How much information about your condition or treatment was given to your family, carer or someone close to you?	**Not enough**	**3 (25)**	**0**
	Right amount	**5 (42)**	**14 (78)**
	Too much	0	0
	No family/carer/friends were involved	3 (25)	3 (17)
	They didn't want/need information	0	0
	I didn't want them to have any information	0	0
	Don't know/can't say/missing	1 (8)	1 (6)
If you had any worries or fears about your condition or treatment, did a doctor discuss them with you?	**Yes, completely**	**5 (42)**	**12 (67)**
	Yes, to some extent	1 (8)	2 (11)
	No	**3 (25)**	**1 (6)**
	I did not have any worries	1 (8)	0
	Missing/N/A	2 (17)	3 (17)

Were you involved as much as you wanted to be in decisions about your care and treatment?	**Yes, definitely** Yes, to some extent No Missing	**7 (58)** 2 (17) 2 (17) 1 (8)	**16 (89)** 1 (6) 0 1 (6)
Did you receive copies of letters sent between hospital doctors and your family doctor (GP)?	**Yes, as far as I know I received copies of all letters** I received copies of some but not all letters No, I did not receive copies of any letters I do not know if any letters were sent I asked not to receive copies of letters	**3 (25)** 5 (42) 3 (25) 1 (8) 0	**14 (78)** 1 (6) 1 (6) 2 (11) 0
Was the main reason you went to the Outpatients Department dealt with to your satisfaction?	**Yes, completely** Yes, to some extent No	**7 (58)** 4 (33) 1 (8)	**17 (94)** 1 (6) 0
How well organised was the Outpatients Department you visited?	Not at all organised Fairly well organised **Very well organised**	1 (8) 5 (42) **6 (50)**	0 3 (17) **15 (83)**
Overall, how would you rate the care you received at the Outpatients Department?	**Excellent** **Very good** Good Fair Poor Very poor	**5 (42)** **3 (25)** **2 (17)** **1 (8)** **1 (8)** 0	**11 (61)** **7 (39)** 0 0 0 0

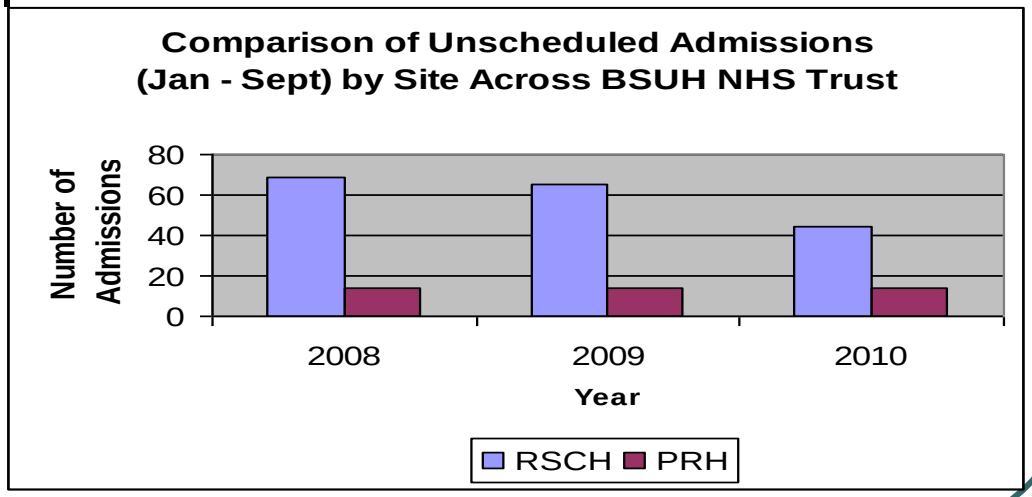
Impact of CCC on unscheduled admissions

	Total bed days used (LOS x number of admissions) 2008+2009 (average)	Total bed days used (LOS x number of admissions) 2010
Jan	74.75	49
Feb	82.5	60
Mar	156	48
Apr	162.75	78
May	103.5	180
Jun	120.75	60
Jul	114	45
Aug	80.75	48
Total	895	568

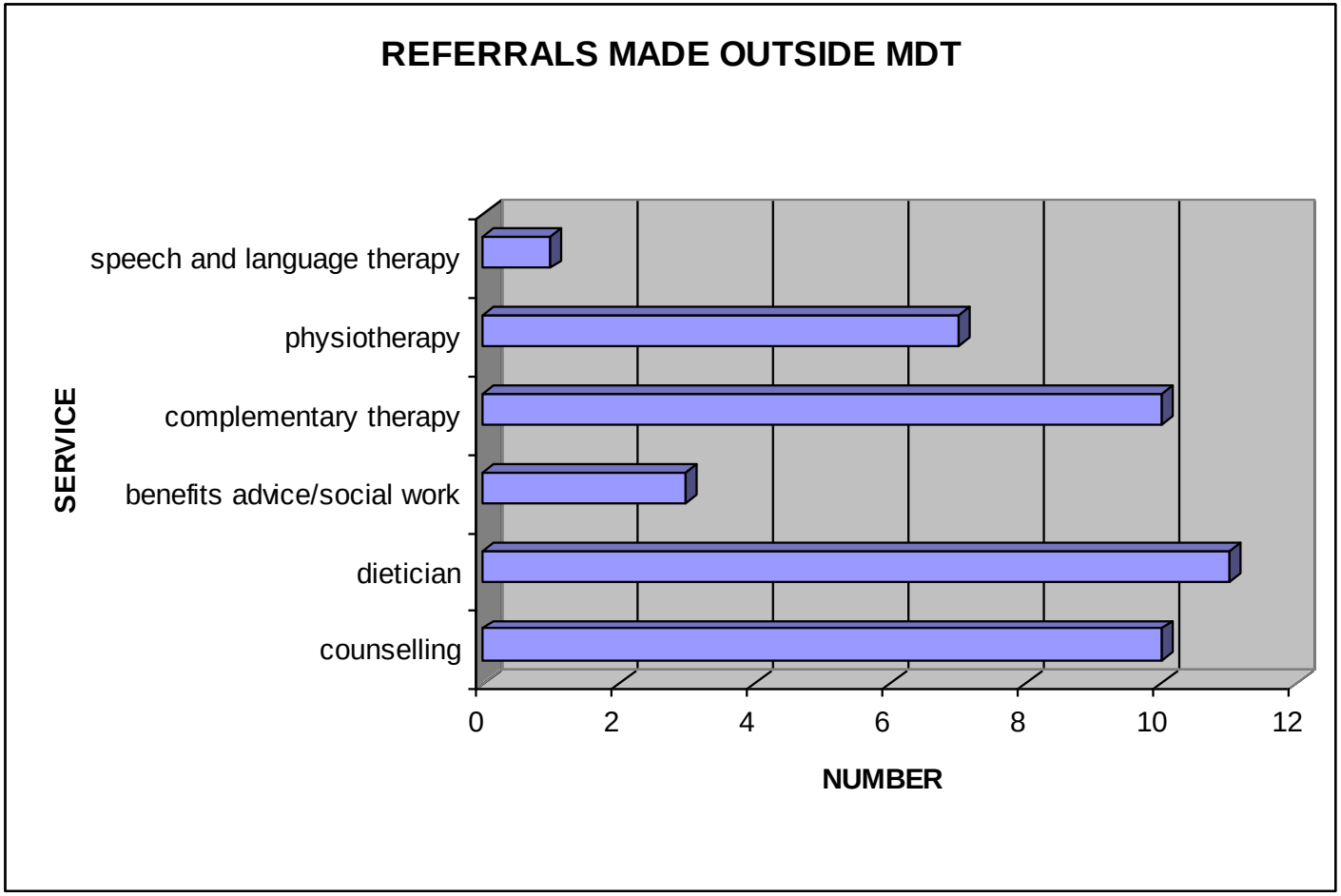

Overall Emergency/Unscheduled Admissions to BSUH with a Diagnosis of Lung Cancer
Number of Admissions
16
14
12
10
8
6
4
2
0
Jan
Feb
Mar
Apr
May
Jun
Jul
Aug
Month
2008
2009
2010

Impact of CCC on unscheduled admissions

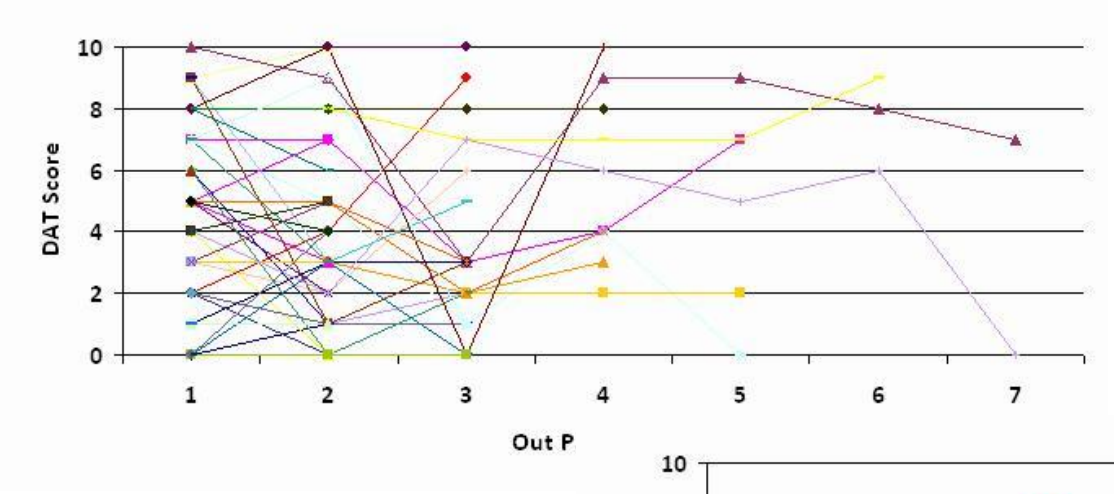
- Total admissions for Jan – Sept 2010 – **57**
- Total admissions for Jan – Sept 2008 – 83
- Total admissions for Jan – Sept 2009 – 79
- Looking at average monthly length of stay – saving of **327 bed days** overall

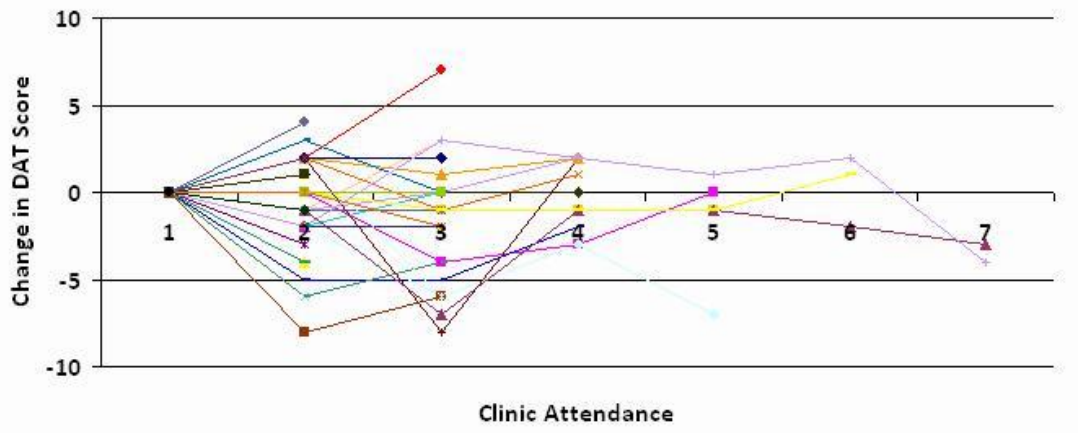


Referrals made outside MDT



Changes to Distress Assessment Thermometer (DAT) score (Jan 10- Jan 11)





Change in DAT Score

- Overall trend to reduced distress
  - Function of ability of patient to access service as needed and not attend if not required
  - Greater time and better quality care delivered
  - Feedback from focus group:
    - Patients able to self-manage yet feel supported by team at CCC
    - Improved communication led to feeling more empowered and informed about own condition and when to seek help
    - Familiarity and trust in team

Impact of CCC on clinic rates
Jan 2010 – Sep 2010

Nature of consultation:	**Number (%)** **n = 266**
Routine	**116 (44)**
Professionally triggered†	**32(12)**
Self triggered **(due to symptoms/distress)**	**14 (5)**
Number of cancellations (rate)	**86 (32)**
Asymptomatic/patient request	*77*
In hospital/died	*3*
Too unwell to attend	*6*
Number of "DNA" (rate)	**18 (7)**
Patient died	*1*
In hospital	*2*
Did not receive appointment	*2*
*Patient choice**	*10*
Reason unknown/not documented	*3*

Summary

- ***Prevention:***
- The flexible clinic resulted in a decrease in emergency admissions, saving 327 bed days over the period Jan-Sept 2010 (saving ~£100K)
- There were 14 urgent patient-triggered appointments, potentially avoiding emergency admission/attendance at A&E
- ***Efficiency:***
- Low DNA rates (7% versus 12% standard respiratory clinic DNA rate)
- One third of outpatient appointments cancelled by the implementation of CNS telephone contact prior to the clinic
- Facilitation of urgent clinic slots by increased efficiency and planning
- ***Quality:***
- Substantial increase in patient satisfaction through implementation of ACP, TRS, longer consultation length, greater patient involvement in decisions regarding treatment and increased clinic efficiency

Acknowledgements

- Lung cancer team:
  - Eileen Baldock (CNS)
  - Gill Hilton (CNS locum)
  - Leanne Picco (CNS)
  - Jenny Messenger (Physician)
  - Louise Mason (Palliative Med Consultant)
  - Madalyn Betsworth (Pathway coordinator)
  - Natalie Taylor (project manager)
- BSUH NHS Trust cancer service management team
- Sussex Cancer Network Service Improvement Team
  - Charlotte Marples
  - Joanna Gaddes
- NHS Improvement team
  - Anne Wilkinson
  - Noeline Young
  - Gilmour Frew
- TinIT (database creation)

For discussion….

- How does this work relate to your own pathway/service?
- What would best practice be in your Network/Trust?
- Is there an alternative to a traditional pathway of care?
- How can we increase links for patients' management between care settings?

Future work

- Risk-stratified pathway of care
  - Self-management
  - Shared care
  - Complex case management

Generic Lung Cancer Pathway for Prototype Testing