The Christie
School of Oncology

NATIONAL LUNG CANCER FORUM FOR NURSES
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Ide**N**tification of **S**upport and **I**nformation needs alon**G** the care pat**H**way for patients with non-small cell lung cancer (NSCLC) receiving **T**reatment with curative intent chemo-radiotherapy: Emerging findings from the INSIGHT study

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Background

- Greater Manchester has a high incidence of lung cancer.
- Approx. 87% of lung cancers in the UK are NSCLC (e.g. Adenocarcinoma, Squamous Cell Carcinoma)
- Treatment with curative intent when surgery is not possible is concurrent chemo-radiotherapy.
- In 2017, Christie were referred 43 patients for concurrent treatment with 35 going on to receive it.

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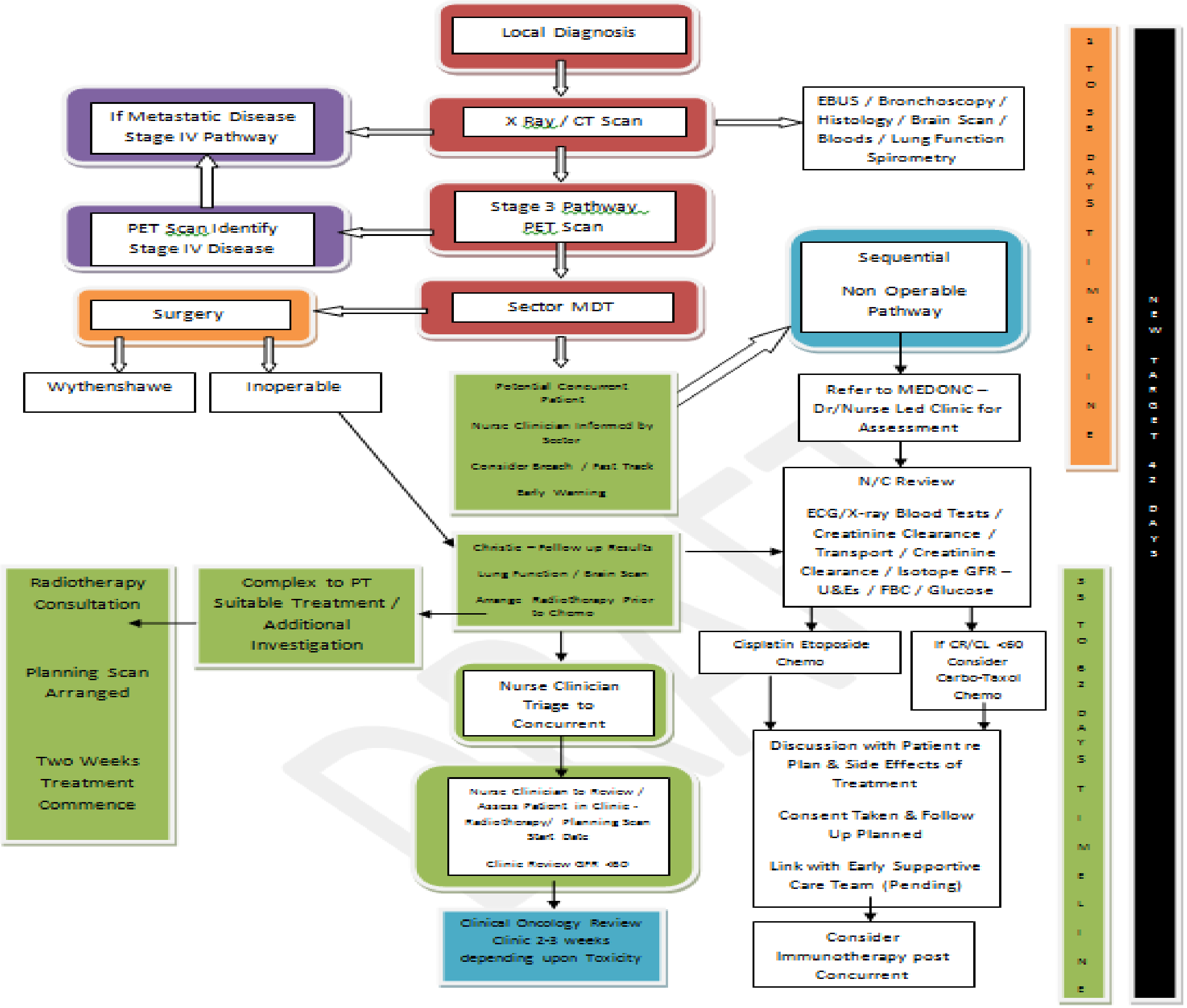
Pathway



Study Objectives

- Identify patient support and information needs at key points along the care pathway.
- Describe patient preferences for information provision at key points along the care pathway.
- Use the results to inform the development of an intervention for future testing.

Methodology

- Single centre, qualitative study
- Semi-structured interviews
- Approximately N = 20 participants (10-15 carer dyads)
- Recruiting patients pre-treatment, during treatment, during initial post treatment scans/reviews and at follow up
- Thematic analysis

Participants

- Recruited N = 20 participants (15 Patients, 5 Patient-Carer dyads)
- 3 Pre-treatment, 3 during treatment, 6 end of treatment, 3 in follow up.
- Age range 43 – 72 years

Treatment affecting quality of life

- Physical Symptoms
  - Breathlessness, fatigue, dysphagia (Painful swallowing), oesophagitis, night sweats, nausea, dysgeusia (loss of taste/metallic taste)
- Emotional Impact
  - Recurrence anxiety
  - Feeling overwhelmed and isolated (especially where no family or carers involved)
- Logistics of treatment
  - Frequency of visits
  - Long treatment waiting times

"They did tell me because the cancer was near my oesophagus that it may affect my swallowing and that. But I didn't know how severe that would be, and it's been really severe, I've been living Rice Krispies for about a week." I011, Patient

"Well I would have wanted them to actually say to me, this can make you really depressed. Because a few times I thought, I'm not going back there, I'm not having any more of this. I'm just going down to that big building in town, the Beetham Tower, going upstairs and jumping right off the roof, right onto the floor. I'm not living anymore. " I012, Patient

Ways of coping

- Accessing support
  - Maggie’s Centre
  - Macmillan Nurse
  - Clinical Nurse Specialist
- Motivations
  - Family
  - Maintaining positive attitude
  - Focus on completing treatment
  - Idea that there is “no alternative”

“I did feel lost then. I said, and I was so glad that I’d seen this about Maggie’s and I really wished that that day when the…I think it was a doctor we were talking to, had said I think you need to go over and just talk about moving on. ” I002, Carer

“Well, emotionally, see, it's been tough. It's been tough, but I'm a very positive person, me. This will not beat me, definitely not. It won't. I just won't have it. I won't have it.” I015, Patient

Information needs

- Ways of receiving information & when (verbal/written/internet)
- Specific information on concurrent treatment rather than separate information sheets
- Information on additional support
  - Claiming benefits due to not being able to work
  - Dietary information (soft diet)
  - Exercise (boundaries)

“Well, I was looking for a booklet on the chemo and the radiation together, because you get a radiation and you get a chemo, but you don’t get a radiation together. You don’t get a booklet that’s how you feel when it’s together like that. There was nothing out there that was specifically aimed at the treatment of the together.” I004, Carer

“The other thing is, what advice is available on things like diet, exercise, lifestyle, going out, mixing with people and all this sort of paraphernalia. I think that’s a vital part of it. Because what I find, there is a risk of sitting at home all day and not doing anything.” I013, Patient

Support needs

- Living with and beyond

- What happens next?

- Earlier links with Palliative/Supportive Care

“We got up on the Monday and we were sort of on our own. We knew that things were going to get worse and everything, and it started to get worse, but I didn’t really know what to do about it.” C04, Carer

Emerging Learning Outcomes

- Tailor information and support to the individual.
  - Where is treatment targeted? What side effects likely as a results? Will they need a mask?
  - Do we adjust information giving (verbal/written)?
  - Develop specific pathway information for concurrent treatment.

Thank You