

The logo for SEDA (Supportive care, Early Diagnosis and Advanced disease research group) features the letters 'SEDA' in a bold, dark blue, sans-serif font.

Supportive care, Early Diagnosis and
Advanced disease research group

The logo for the University of Hull features a crest with a crown and three lions, followed by the text 'UNIVERSITY OF Hull' in a serif font.The logo for the University of York features the text 'UNIVERSITY of York' in a serif font, with 'of' in a smaller, lowercase font.The logo for Yorkshire Cancer Research features a stylized blue rose above the text 'yorkshire cancer research' in a blue, sans-serif font.

Saving Yorkshire Lives

Understanding Cancer Presentation: the pathway study

A photograph of a person wearing a blue cap and a checkered shirt, standing with their back to the camera on a paved path that leads into a lush, green mountainous landscape under a cloudy sky.

Presented By: Osaretin Oviasu & Hong Chen

@ SEDA Conference 2017: Hull, UK

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Anderson, Miriam Johnson, Una Macleod...

Background and Project aim

- 👉 Cancer survival in the UK is lower than in many other European countries
- 👉 Late stage at diagnosis is a key reason
- 👉 Where delays happen, How and Why ?

The overall aim of the project:

*Better understanding of **the pathway from symptom to diagnosis**, using lung, head & neck cancers as exemplars*

A Mixed-method Study

- ✓ Survey (Researcher administered questionnaire)
- ✓ Medical records review (primary and secondary care records)
- ✓ In-depth interview



Recruitment and Data collection

- Patients with a recent (within 3 months) diagnosis of:
 - lung cancer (n=155)
 - head and neck cancers (n=80)
- From respiratory, ENT and maxillofacial clinics, Hull and East Yorkshire Trust

Data	Surveys	Hospital records	GP records	Interviews
Head & neck cancers	80	74	72	15
Lung cancer	155	155	135 (20 to collect)	15

Data Analysis

- 😊 Lung cancer (surveys, hospital records, GP records): analysis ongoing
- 😊 Head & neck cancers (surveys, hospital records, GP records): findings presented by Osaretin Oviasu
- 😊 Qualitative interviews (lung, head & neck cancers): findings presented by Hong Chen

Quantitative Findings

An analysis from first symptom to diagnosis for Head and Neck Cancers (HNC): A study based on patients survey and linkage to primary care and hospital medical records.

Research objectives

- To quantify the time intervals between first symptom recognition and diagnosis for patients with head and neck cancer (HNC)
- Explore the relationship between the time intervals and patient demographic, socio-economic status (SES) and clinical characteristics.

Key variables

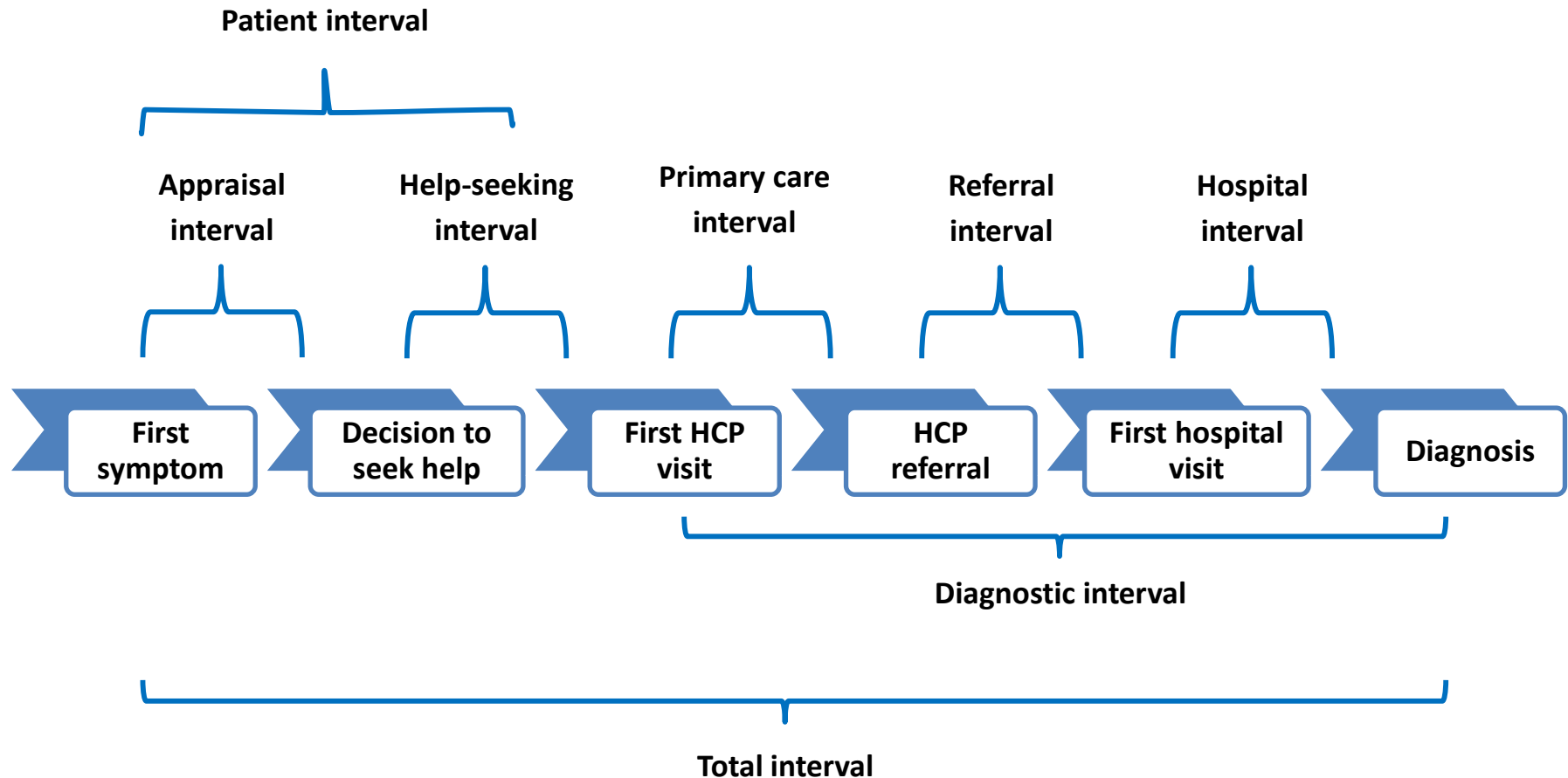
Patient questionnaire:

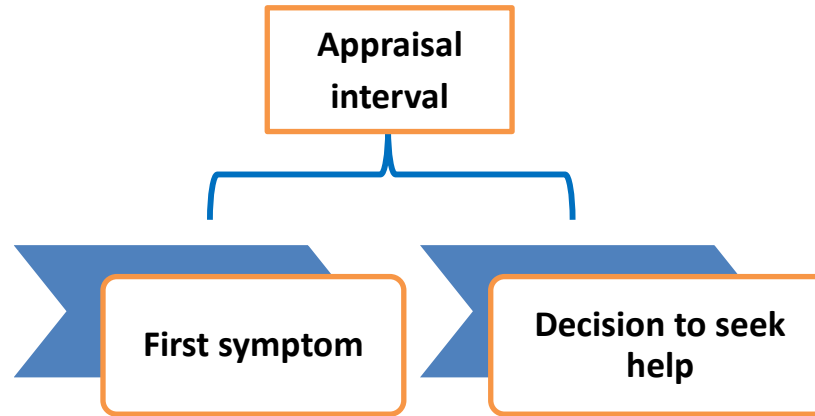
- Date of first symptom recognition, date decided to seek help for a health care professional and date of first contact with a health care professional
- Symptoms the participants had experienced
- Demographic characteristics (age, gender and relationship status)
- Socio-economic status (education, living status, employment status, Index of Multiple Deprivation [IMD])
- Smoking status and alcohol consumption.

Medical records:

- Date of first contact with a health care professional, date of referral to specialist, date of contact with specialist and date of diagnosis
- The number of co-morbidities
- Number of consultations following first consultation with a HNC symptom prior to referral or emergency presentation.
- The type cancer at diagnosis.

Overview of time points and calculated time intervals





Overall median appraisal interval was 24 (0-55.5) days

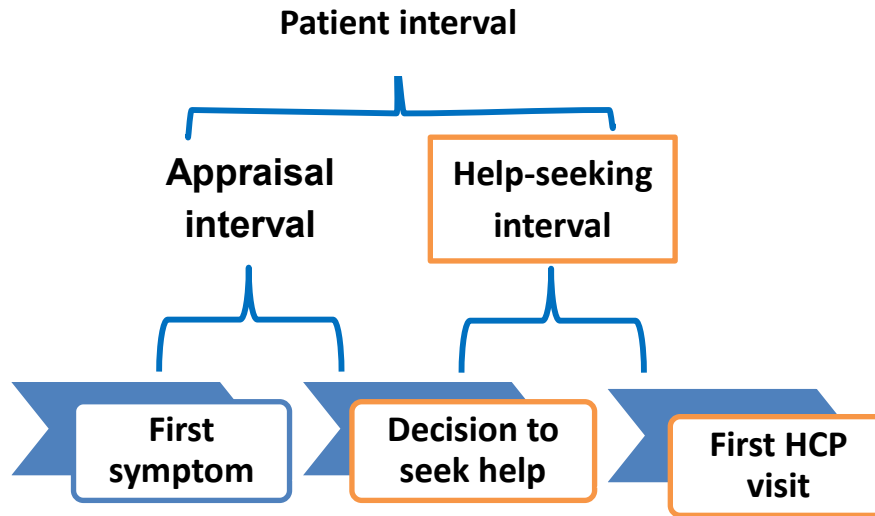
- An appraisal interval of > 1 month = 20/76 (**26%**).

“How long did you feel that something was wrong (with you) before you realised this was something which you might need help with?”

- 31/80 (**39%**): Appraisal interval > 1 month.

Statistically significant difference by:

- **Gender** (p=0.030): males **3.1 times more likely** to report an interval of > 1 month than females
- **Ulceration of mouth and throat** (p=0.021): > 1 month
- **Persistent, pain in the throat for more than four weeks** (p=0.048): > 1 month

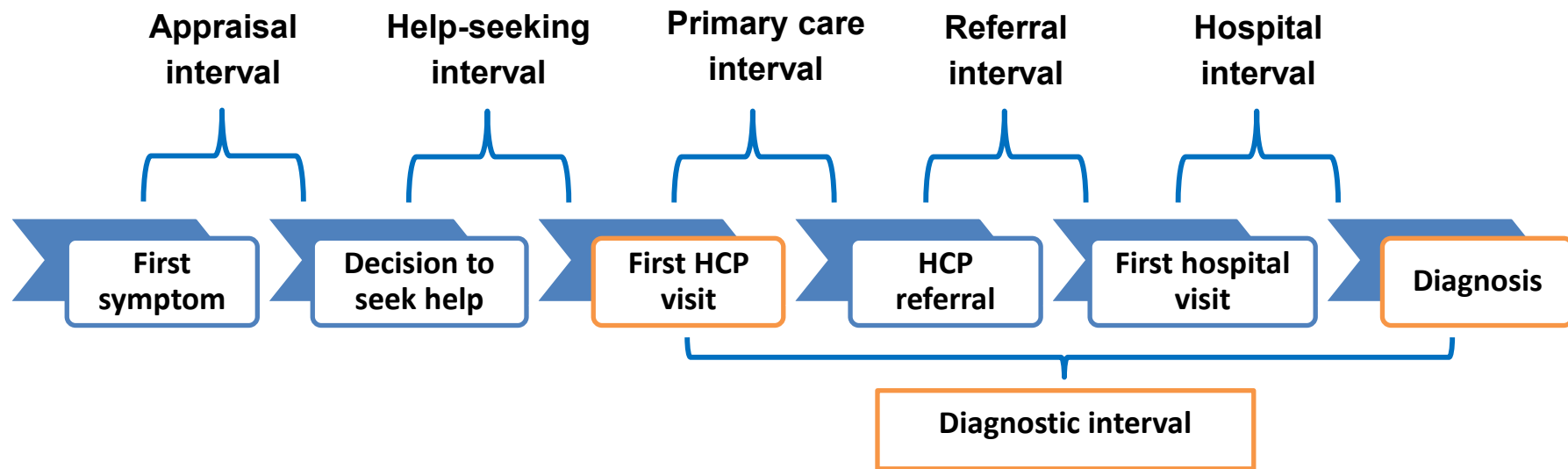


“How long after that was it before you decided to go and see your doctor?”

- 10/78 (**13%**): Help-seeking interval > 1month.

Statistically significant difference for **Ulceration of mouth and throat** ($p=0.020$):

- more likely to have an interval > 1 month than those without that symptom.

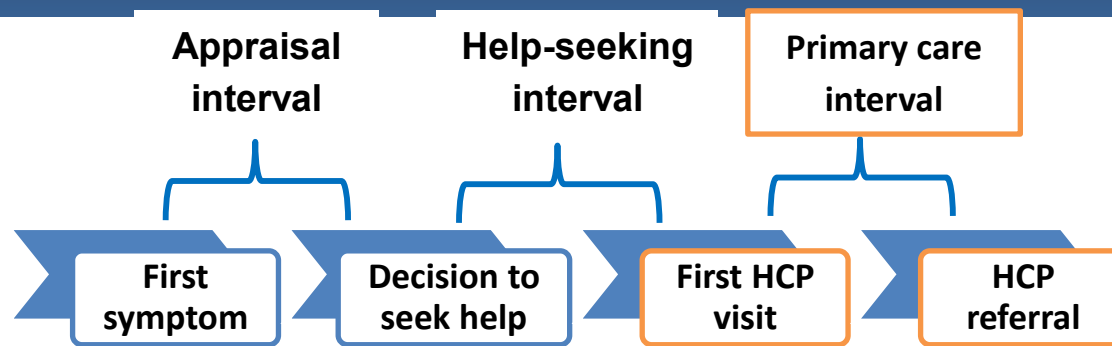


When asked which HCP the respondent first sought help from

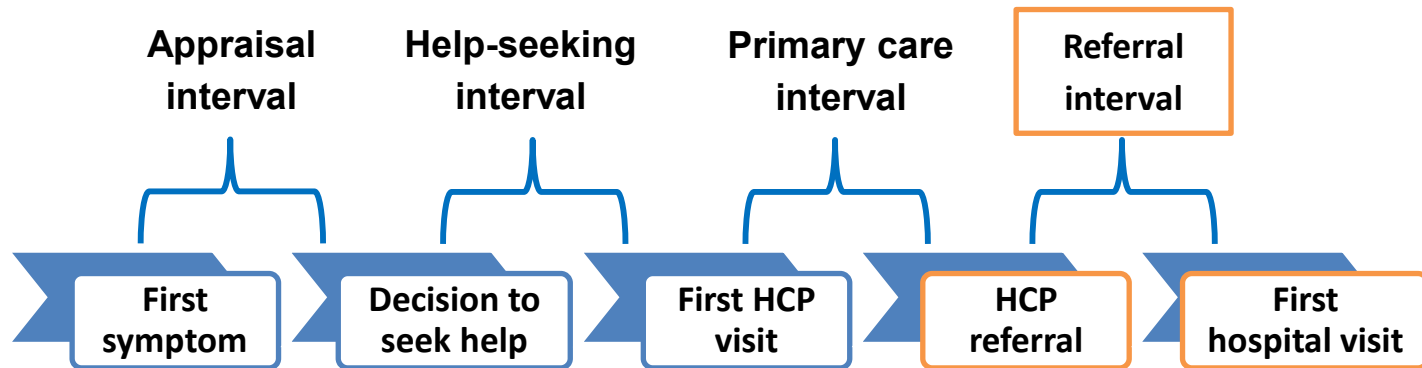
- 72 (90%) said their GP or practice nurse,
- 6 (7%) from a dentist and
- 2 (3%) a hospital doctor.

Table 1: Median days (IQR) for the diagnostic intervals

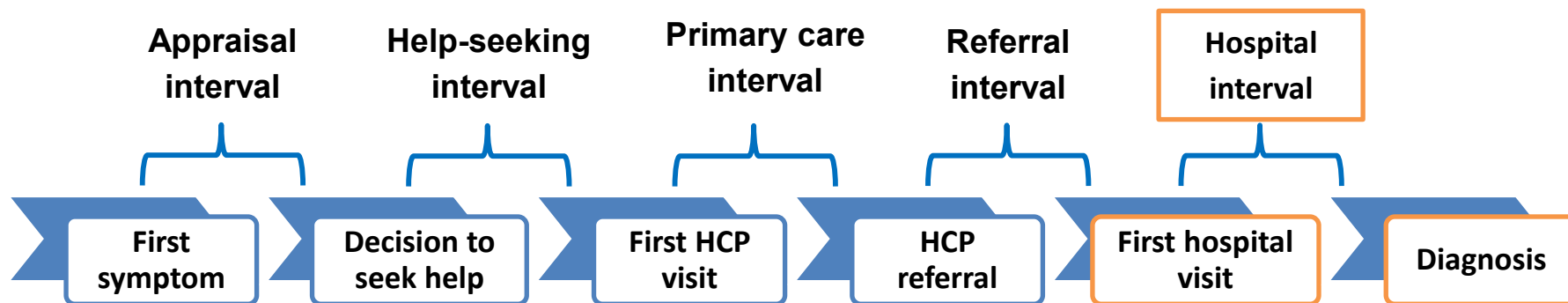
TIME INTERVALS	Median (IQR)
Primary care interval	46 (6-127)
Referral interval	9 (5-14)
Hospital interval	17 (8-36)
Diagnostic interval (1 st HCP visit to diagnosis)	91 (33-174)



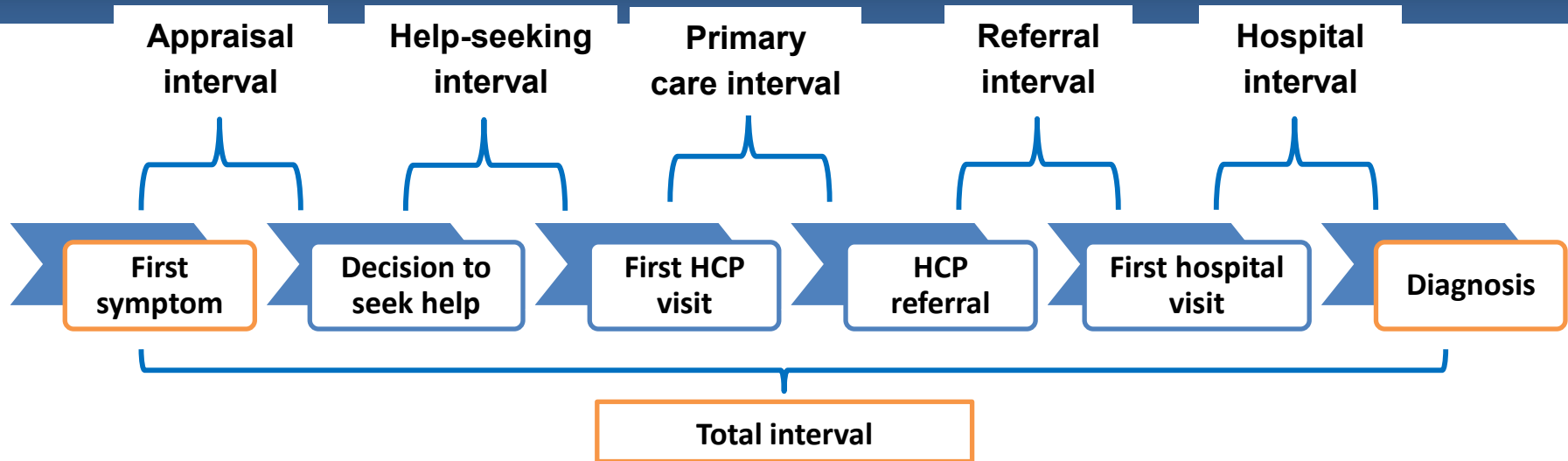
- Median interval of 46 (6-127) days.
- **Key findings:**
 - Longer intervals seen in those in rented accommodation compared to home owners (p=0.023)
 - Symptoms:
 - ✦ **Shorter** intervals: Lump in the neck, red/white patches in the mouth, ulceration, mouth swelling and tooth mobility
 - ✦ **Longer** intervals: Pain, difficulty swallowing, ear problems, breathlessness and hoarseness
 - Multiple consultations (p<0.001):
 - 41/66 (62%) had 3 or more consultations
 - 3 or more consultations: **longer** intervals
 - Different HNCs (p=0.015)
 - ✦ **Shortest** intervals: Oropharyngeal cancer
 - ✦ **Longest** intervals: Hypopharyngeal and Laryngeal



- The median referral interval was 9 (5-14) days.
- From the hospital records,
 - 43/69 (62%) were referred as a GP urgent referral,
 - 16 (23%) as a GP non-urgent referral,
 - 7 (10%) by a dentist and
 - 3 (4%) as an emergency at hospital.



- The median hospital interval was 17 (8-36) days.
- There was a statistically significant difference for education level and hospital interval ($p=0.007$)
 - **Longer** intervals seen in those with no formal qualifications (21 days (14-41))
 - **Shortest** interval seen in those with a degree or higher qualification (7 days (0-14))



- Median total interval was 111 days from first symptom to diagnosis:
 - A quarter (25%) had a total interval of more than 209 days.
 - A quarter of those in most deprived IMD groups had a total interval of more than 223 days, compared to 187 days in the most affluent groups,
 - Not statistically significant.
 - Smokers had longer intervals than non-smokers and ex-smokers,
 - Not statistically significant.

Impact on clinical outcome (stage at diagnosis)

- There was no statistically significant differences by stage for the appraisal ($p=0.629$) and help-seeking ($p=0.354$) intervals.
- There was a statistically significant difference by stage for the primary care interval ($p=0.030$):
 - with those diagnosed with advance disease having longer primary care intervals (**65 [14-155]**) than those diagnosed with limited disease (**16 [0-69]**).
- There was no difference for referral ($p=0.274$), hospital ($p=0.464$) or total interval (0.706).

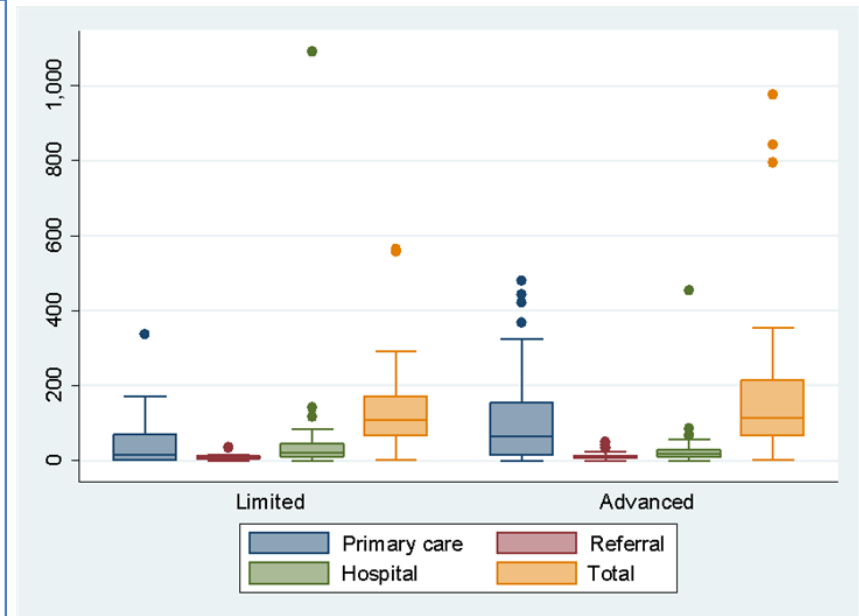


Figure 2: Boxplot of primary, referral, hospital and total intervals by stage at diagnosis

Patients' presentations within primary care and stage at presentation

The number of consultations before referral was the only variable significantly associated with stage at presentation (Table 2)

- Both patients that saw their GP once or twice were **less likely** to present with advanced disease
- Those that never saw their GP before diagnosis were **more likely** to present with advanced disease than those who saw their GP three or more times

Presentations at GP visit	Total (%)	Stage at diagnosis ^a		OR (95% CI)	p-value ^b
		Limited n=21 (%)	Advanced n=57 (%)		
<i>How often do you visit your doctor (GP) normally?</i> ^a					
About once a year	22 (28)	7 (32)	15 (68)	0.69 (0.03-19.0)	0.486 ^b
Less often than once a year	14 (18)	6 (46)	7 (54)	0.38 (0.01-11.17)	
About every 6 months	18 (23)	3 (18)	14 (82)	1.38 (0.05-41.66)	
About every 3 months	21 (27)	5 (24)	16 (76)	1.0 (0.04-28.30)	
At least once a month	3 (4)	0	3 (100)	2.33 (0.03-182.92)	
Most weeks	1 (1)	0	1 (100)	REF	
<i>How well do you think your doctor (GP) knows you?</i> ^a					
Very well	24 (30)	4 (17)	19 (83)	3.29 (0.83-12.98)	0.288 ^b
Quite well	25 (32)	7 (29)	17 (71)	1.68 (0.5-5.72)	
A little	8 (10)	1 (13)	7 (87.5)	4.85 (0.51-46.49)	
Not at all	22 (28)	9 (41)	13 (59)	REF	
<i>How many times did you see your GP (family doctor)/dentist about the health problem later diagnosed as cancer?</i>					
None, did not see GP before going to hospital	5 (6)	0	5 (100)	2.04 (0.08-49.68)	0.045*
saw GP/dentist once	32 (40)	14 (44)	18 (56)	0.2 (0.04-1.02)	
saw GP twice	28 (35)	5 (19)	21 (81)	0.65 (0.11-3.83)	
saw GP 3 or more times	15 (19)	2 (13)	13 (87)	REF	

^a Number do not add up to 80 cases because of missing data; ^b Fisher's exact test due to small numbers in categories

Table 2: Patients' experience at Primary care

Summary of findings from quantitative study

- **Appraisal interval >1 month: 39%**
 - Likely to report >1 month:
 - ✦ Male respondents
 - ✦ Ulceration of mouth and throat
 - ✦ Pain in the throat for more than four weeks
- **Help-seeking interval >1 month: 13%.**
 - Ulceration of mouth and throat ($p=0.020$): **more likely** to have a help-seeking interval of > 1 month than those without that symptom
- **Total median diagnostic interval: 91 (33-174) days.**
 - The **longest** interval: Primary care interval (46 days (6-127)).
 - Statistically significant associated with:
 - ✦ **living status**
 - ✦ **multiple consultations**
 - ✦ **type of HNCs**
- **The median total interval: 111 days**
 - 25% had a time interval of more than 209 days.

Qualitative Findings

**Health System Factors Influencing
Cancer Symptom Presentation and
Diagnostic Management in Primary Care**

Symptom discovery to Referral

Self- care

Normalised self-care practice

Symptom misattribution

Worry about wasting the doctor's time

Difficulty booking appointments

Consultations, treatments, investigations, referrals

Access

Continuity of care

Organisation of investigation and referral

Normalised Self-care Practice & Symptom Misattribution

“So as time went by I noticed something was there so what I decided to do was *try things like Bonjela* and, *thinking it might just be an ulcer* or something and it’ll go away, and so on and so on. But then it started hurting, hurting, where I got to the point where I *had to have painkillers* it was that bad. Eventually it started affecting my eating and it split open is how I would describe it, and when it split open *it got that bad it was more or less unbearable* ...This was *over a period of a year or more*, what I’ve just described.”

(Martin, H&N, 41)



"You got here just in time -
By tomorrow you'd have
been better."

I try not to waste the doctors' time cos I think they're very important people and they've got a lot of people that are, you know, so unless I'm really ill I don't bother. (Daisy, H&N, 63)

Worry about wasting doctor's time

That's why it took him so long to go to doctors because he "oh no, it's only a little ulcer on my tongue." "Well it might be serious [name removed]." "No, no, I'm fine, there's old, old people who need the doctor more than me.

(Wife of Martin, H&N, 41)

Difficulty booking appointments

See nine times out of ten I couldn't get an appointment at my doctors for a few weeks anyway and I thought well you could be dead by then.

(Tracey, H&N, 62)

*Well it [the symptom] did [concern me], but **trying to get an appointment with the doctor was useless, couldn't get one.** . . . Then I had to go back again to see the kidney doctor, and I mentioned it to that lady and she got me an appointment with the Castle Hill.*

(Carol, lung, 70)

Patient journey *from presentation to referral*

He [1st GP] said "It's one of three things" he said "it's your heart, your lungs or old age" he said "so we'll try and eliminate them as we go along" you see, so.

(Victor, lung, 81)

The first [GP] said I had a sore throat. The second said I had thrush and gave me 14 days of antibiotics. And the chemist made me another appointment when a Dr [name removed] prescribed morphine.

(Fred, H&N, 49)

Access



Multiple consultations + Difficulty booking appointments

=

Multiplied waiting times

“Like October she went to a doctor, Dr [name removed] erm like ear drops for pain and said that she needs to come back after two weeks and if the pain will not be gone then they will send her to hospital specialist some kind, yeah. Erm, but the pain didn’t go after these drops and she went again to doctor, to different one I think, and the doctor said it’s nothing to worry about, just drink paracetamol, yeah, you don’t have a cancer just go home.”

Yana’s (H&N, 57) daughter

Continuity of Care

“Cos you know they’re always coming up on television: ‘first sign get there straight away, it can be treatable if you get there early.’ You get there as soon as you get a symptom but by time you’ve had all the tests it takes that long and it’s got you...That’s my experience anyhow...And yet **they say ‘get in early and things can be done’ but obviously they can’t be done can they?**”

(Lucy, lung, 62)

Organisation of investigations and referrals

Implications for Practice and Research (1)

? How to promote self-care without discouraging prompt help-seeking?

- ✓ *Are we clear on what symptoms should be self-cared for, for how long, and what symptoms should get medical attention?*
- ✓ *How to solve the problem that cancer and non-cancer diseases share similar symptoms?*

Implications for Practice and Research (2)

? How to improve access to GP services?

- ✓ *Are we clear about the general definitions concerning conditions which qualify the patient for the services?*
- ✓ *How to reduce length of the queue for the services?*

Implications for Practice and Research (3)

? How to help GPs to reduce time needed to refer patients?

✓ *Access to diagnostics*

✓ *Process of referral*

...



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*Thank
you*

