



Earlier diagnosis.....

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NHS Cancer Plan 2000

Improve prevention, screening, early diagnosis and treatment



Cancer Reform Strategy 2007

Early diagnosis-one of the most significant challenges



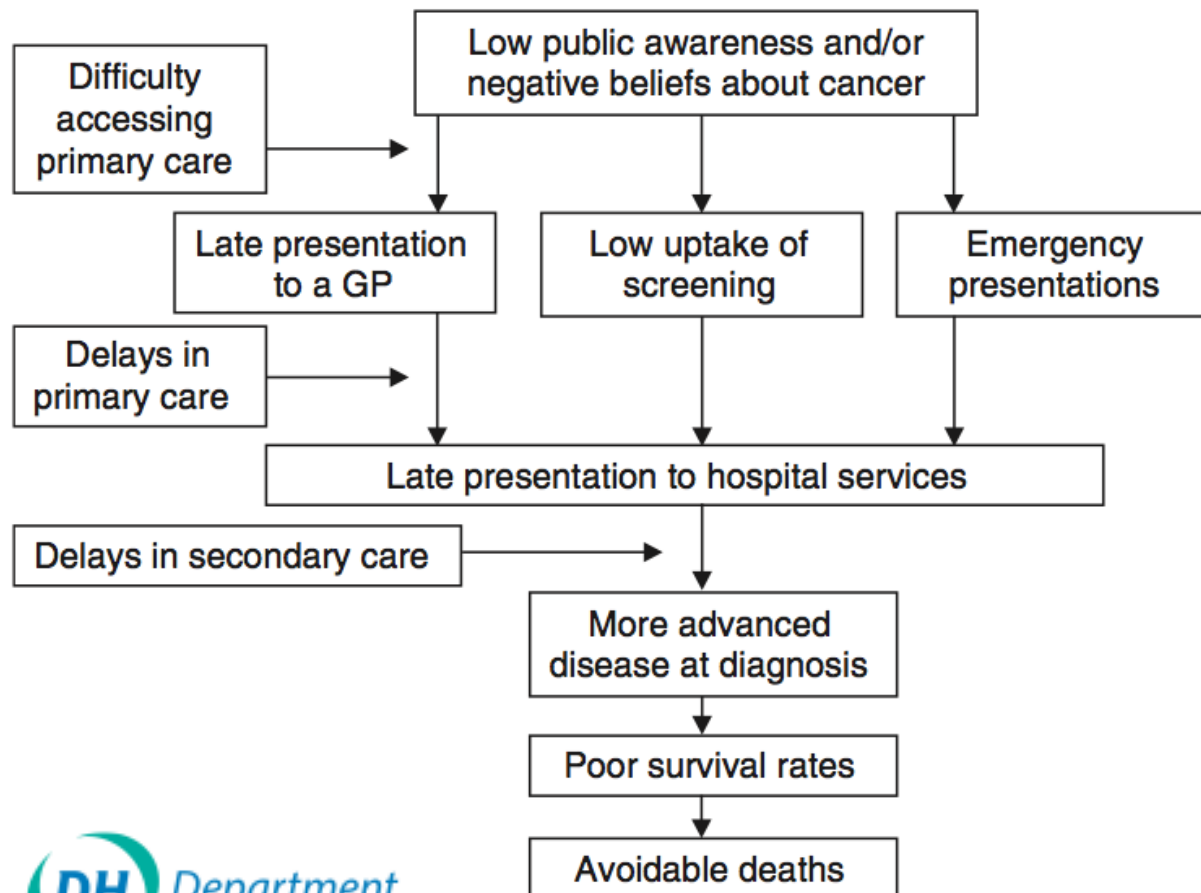
National awareness and early diagnosis initiative 2008



Improving Outcomes: A Strategy for Cancer 2011



National Awareness and Early Diagnosis Initiative (NAEDI)



What is the impact of delayed diagnosis for CTYA?

- Survival
- Morbidity
- Late effects



Wilms' tumour

	Incidental finding or Routine surveillance
Germany	27.4%
Royal Marsden	11%
Newcastle	4%

	Survival
Incidental finding/surveillance	90%
Symptomatic	84%

Craft & Pritchard-Jones 2007 Lancet Oncology
Graf et al 2003 MPO

Ewings Sarcoma

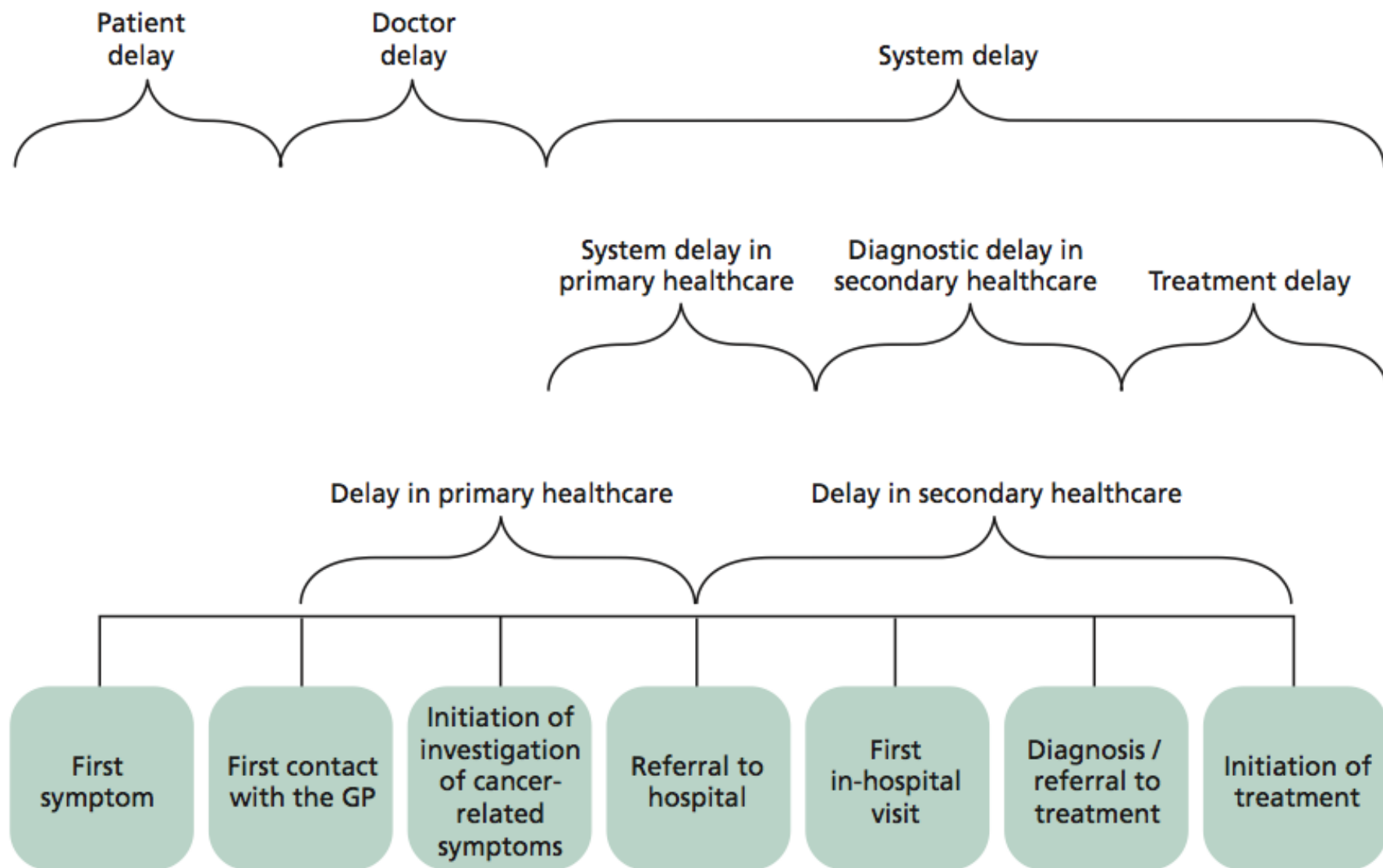
	n	Large tumour volume	Metastases
UK	506	54%	37%
France	631	42%	31%
Germany	1015	42%	31%

EuroEwings unpublished data
Personal communication

What is the impact of delayed diagnosis?

- Survival
- Morbidity
- Late effects
- Patient experience
- Future healthcare seeking behaviour of patient and carers





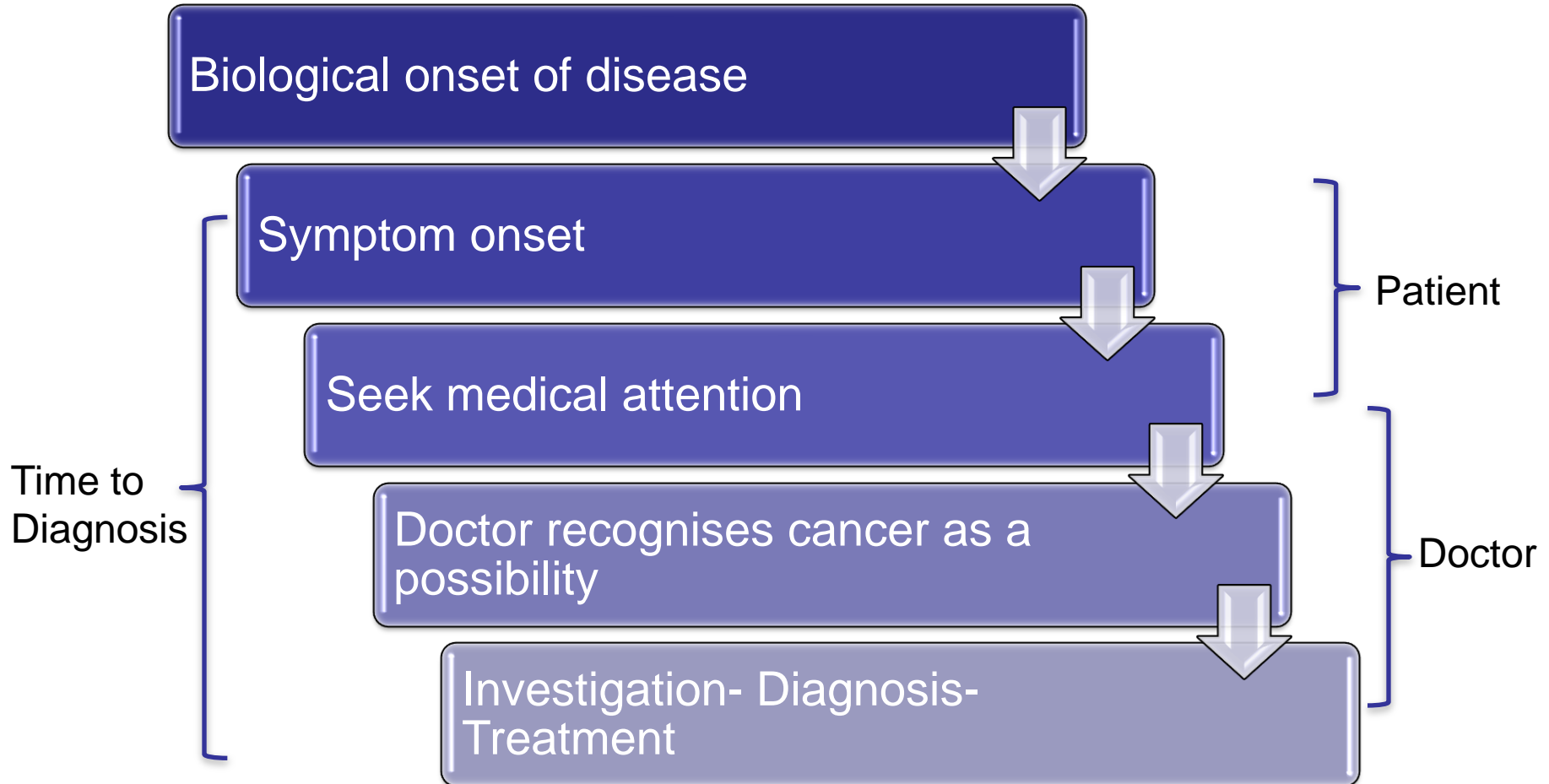
Olesen et al 2009 BJC

Methodology-Definitions and Data

- First symptom COSD
✓
- Symptom Interval
- Time to diagnosis (TTD)
- Delay
- Retrospective data



Diagnostic journey



Confounding factors

Patient

- Age
- Sex

Confounding factors

Patient

- Age
- Sex

Carer

- Carer-Doctor relationship
- Level of education



HEADSMART

be **brain tumour** aware



Under 5

Preschool

Brain tumours happen...
Symptoms include:

Persistent / recurrent vomiting
Abnormal balance / walking / co-ordination
Abnormal eye movements
Behaviour change, particularly lethargy
Fits or seizures (not with a fever)
Abnormal head position such as wry neck,
head tilt or stiff neck



5 - 11

Children

Brain tumours happen...
Symptoms include:

Persistent / recurrent vomiting
Persistent / recurrent headache
Abnormal balance / walking / co-ordination
Abnormal eye movements
Blurred or double vision
Behaviour change
Fits or seizures
Abnormal head position such as wry neck,
head tilt or stiff neck



12 - 18

Young People

Brain tumours happen...
Symptoms include:

Persistent / recurrent vomiting
Persistent / recurrent headache
Abnormal eye movements
Blurred or double vision
Abnormal balance / walking / co-ordination
Behaviour change
Fits or seizures
Delayed or arrested puberty

Additional symptoms
to be aware of

Reduced consciousness Diabetes insipidus (excessive drinking and urination) Abnormal growth



University of
BRISTOL

Don't gamble with your life.



Pain? Unusual lump? Fatigue? Weight loss?
Most of the time it's nothing, but *sometimes it's cancer*.
Check with your Doctor. Visit www.jimmyteenstv.com

The Christie NHS
NHS Foundation Trust

TEENAGE CANCER AWARENESS WEEK



WOULD YOU KNOW IF YOU HAD CANCER?

CANCER SYMPTOMS ARE:

UNEXPLAINED - you don't know what's causing them
AND **PERSISTENT** - may not go away or always come back, or gradually get worse.

The **FIVE COMMON SIGNS** of cancer in young people are:

- ⚠ **PAIN**
(that doesn't go away with painkillers)
- ⚠ **A LUMP, BUMP OR SWELLING**
- ⚠ **EXTREME TIREDNESS**
(meaning you find it hard to stay awake)
- ⚠ **SIGNIFICANT WEIGHT LOSS**
(more than a few pounds)
- ⚠ **CHANGES IN A MOLE**

Cancer in young people is rare, but it's important to know the warning signs, just in case.

Know the signs, know your body and be ready to act if something changes.

If you're worried about your health, see your GP.

**WE CAN CHALLENGE
CANCER TOGETHER.
PLEASE GET INVOLVED TODAY**

Find out more about Teenage Cancer Awareness Week and how you can support Teenage Cancer Trust at:

WWW.TEENAGECANCERTRUST.ORG

[FACEBOOK.COM/TEENAGECANCERTRUST](https://www.facebook.com/teenagecancertrust)

[TWITTER: @TEENAGECANCER](https://twitter.com/TEENAGECANCER)



Teenage Cancer Trust is a registered charity (102022) (Charities) (SC03307) (England)

Confounding factors

Patient

- Age
- Sex

Carer

- Carer-Doctor relationship
- Level of education

Disease

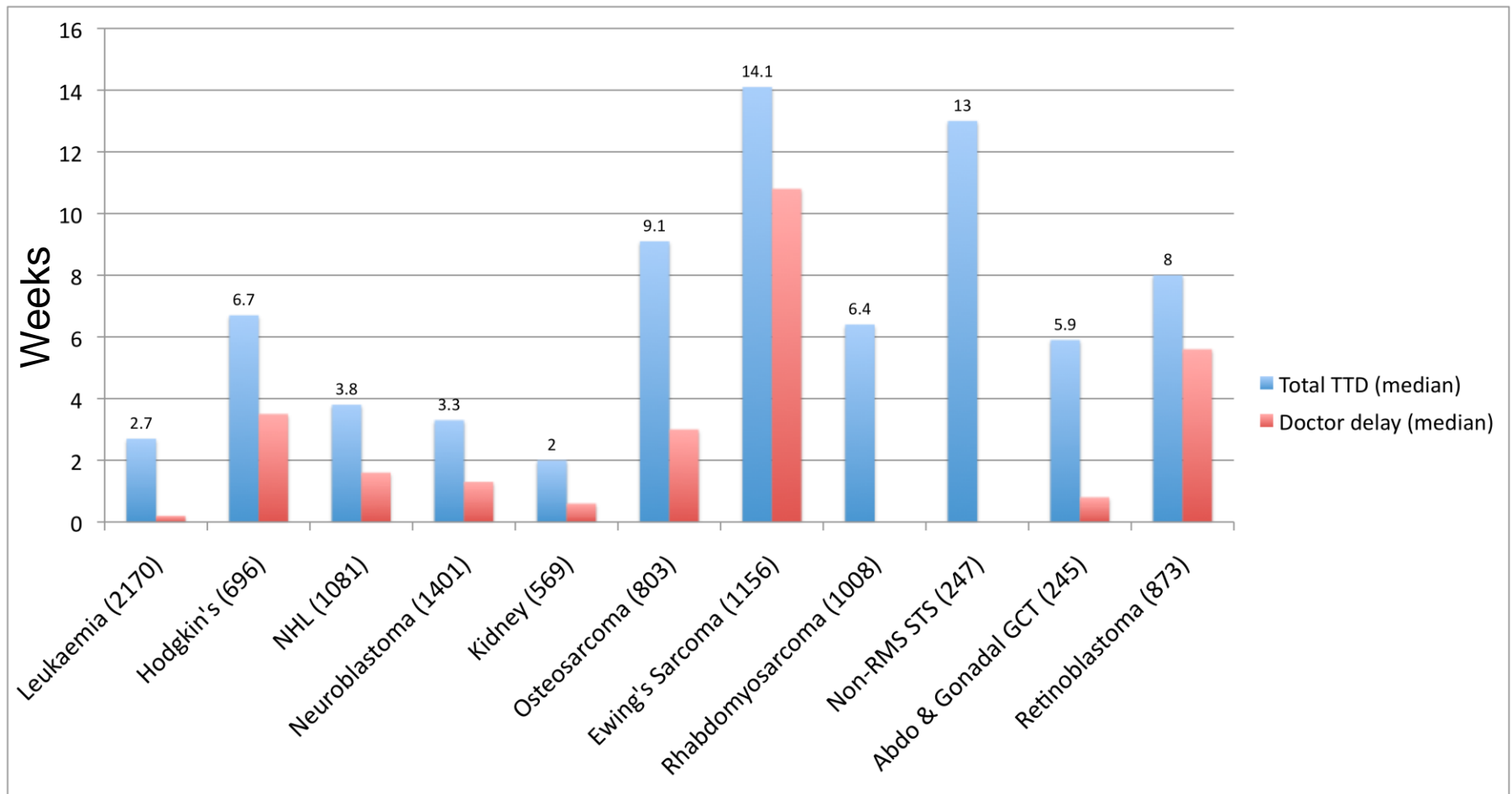
- Type
- Location

Disease

- Rare
- Diverse
 - Embryonal tumours → Carcinomas
- ‘Low risk but not no risk’ symptoms

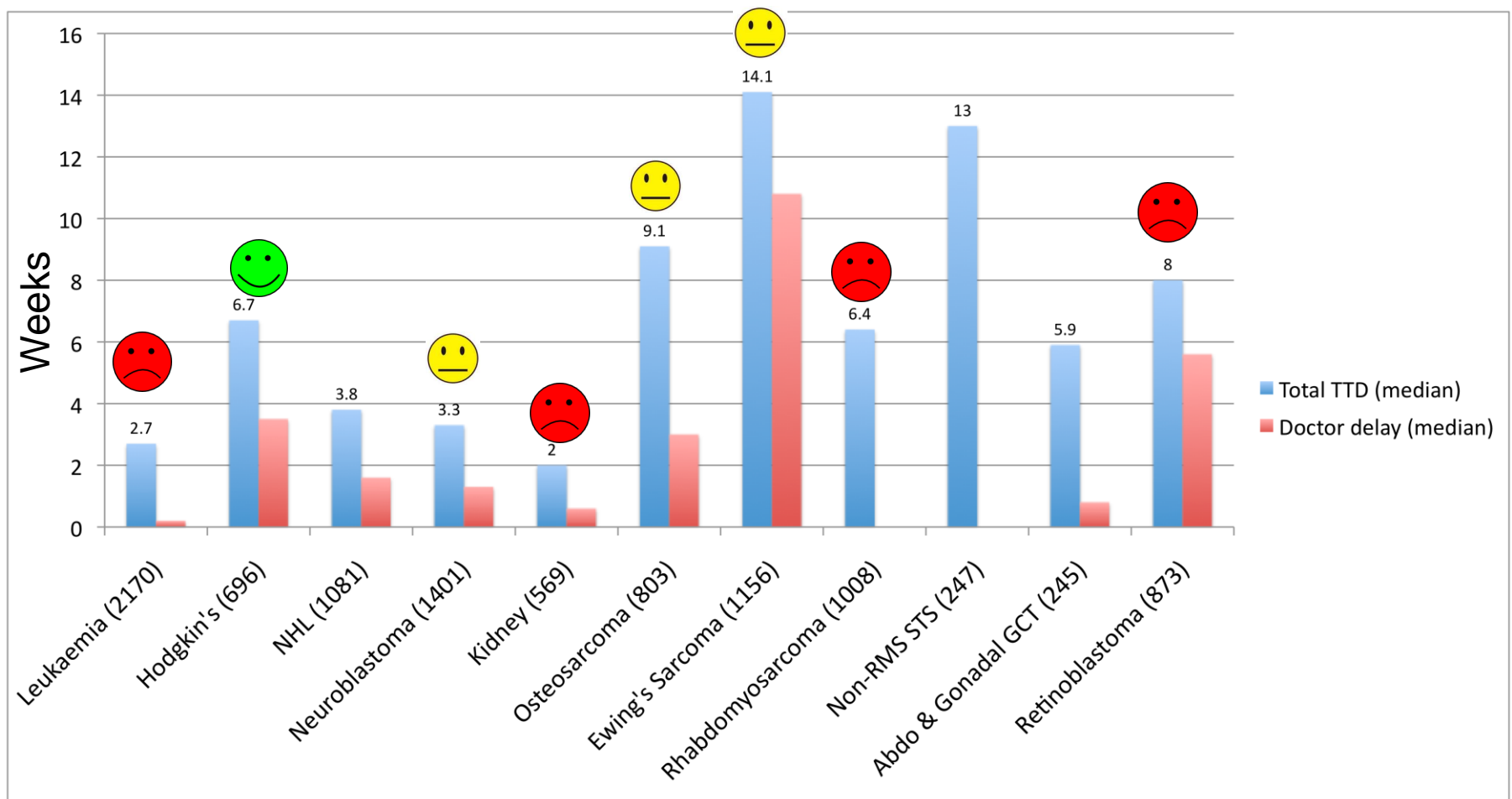


Time to diagnosis-Paediatric tumours



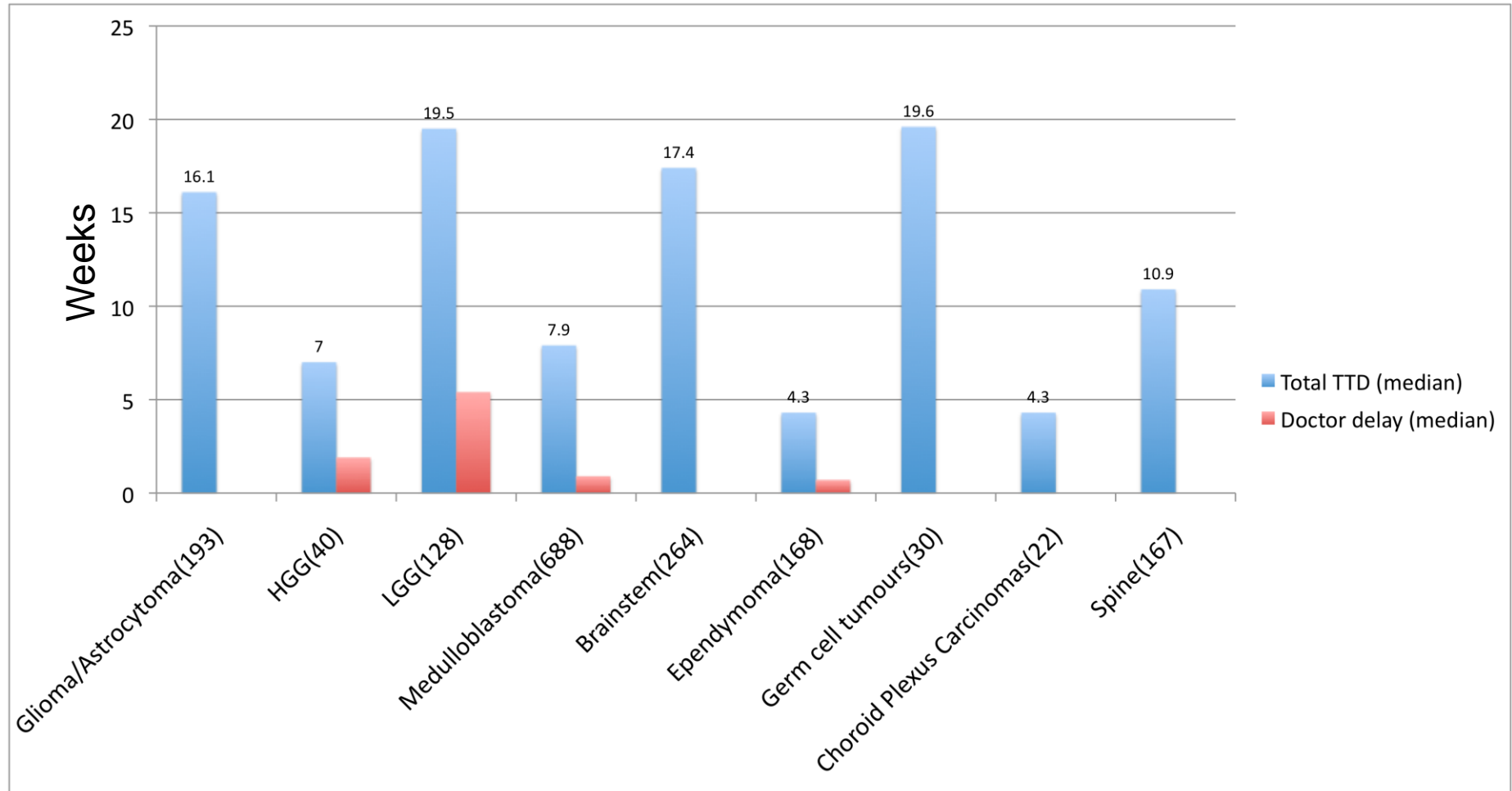
Brasme et al Lancet Oncology (2012) 13; e445-459

🔥 Time to diagnosis-Paediatric tumours



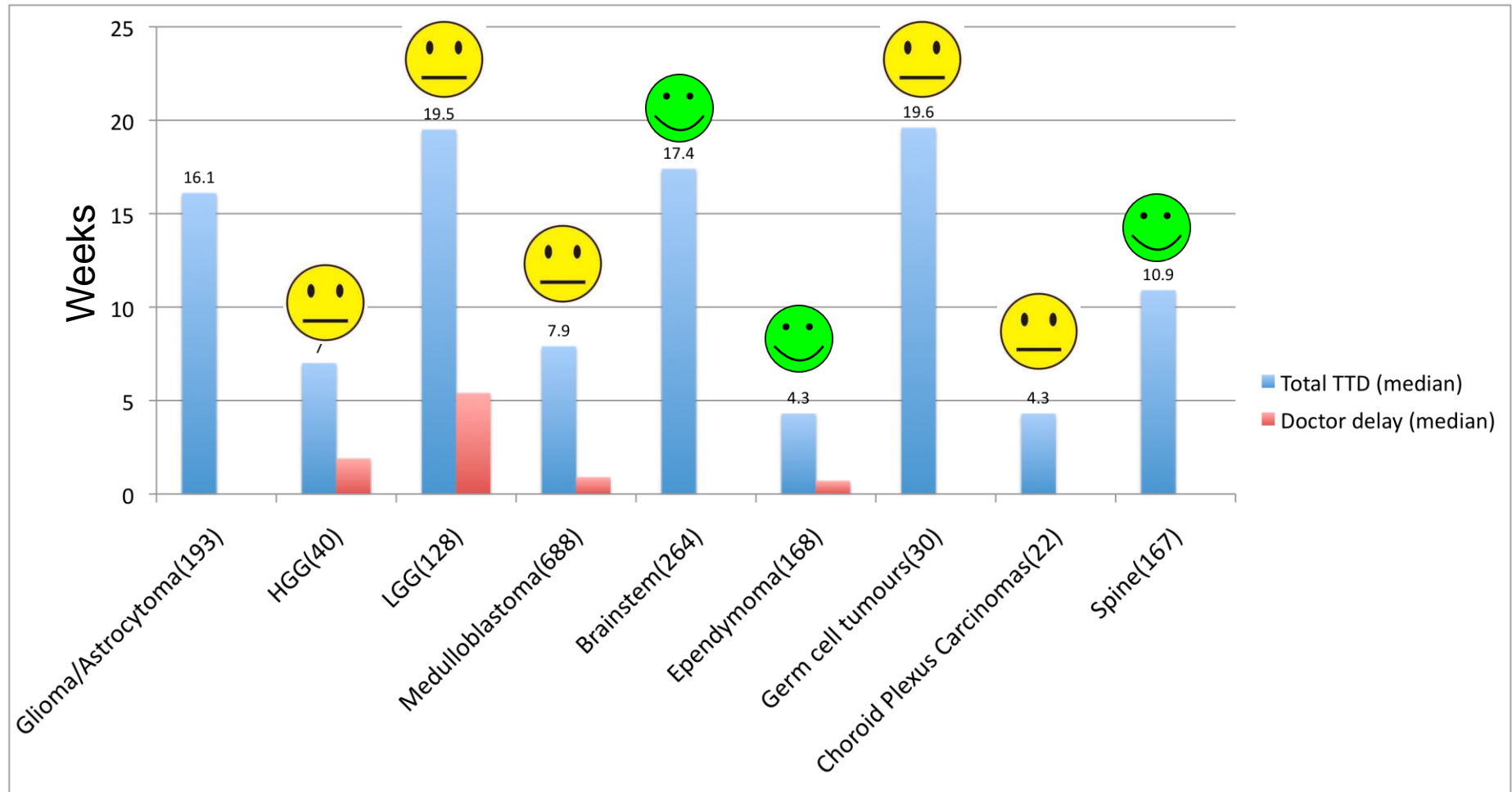
Brasme et al Lancet Oncology (2012) 13; e445-459

Time to Diagnosis Paediatric CNS tumours



Brasme et al Lancet Oncology (2012) 13; e445-459

🔥 Time to Diagnosis Paediatric CNS tumours



Brasme et al Lancet Oncology (2012) 13; e445-459

Delays in diagnosis of paediatric cancers: a systematic review and comparison with expert testimony in lawsuits

Jean-François Brasme, Michèle Morfouace*, Jacques Grill, Alain Martinot, René Amalberti, Catherine Bons-Letouzey, Martin Chalumeau*

‘The relations between delay in diagnosis and outcome are complex and probably depend more on tumour biology than on parental or medical factors’

Brasme et al Lancet Oncology (2012) 13; e445-459

Confounding factors

Patient

- Age
- Sex

Carer

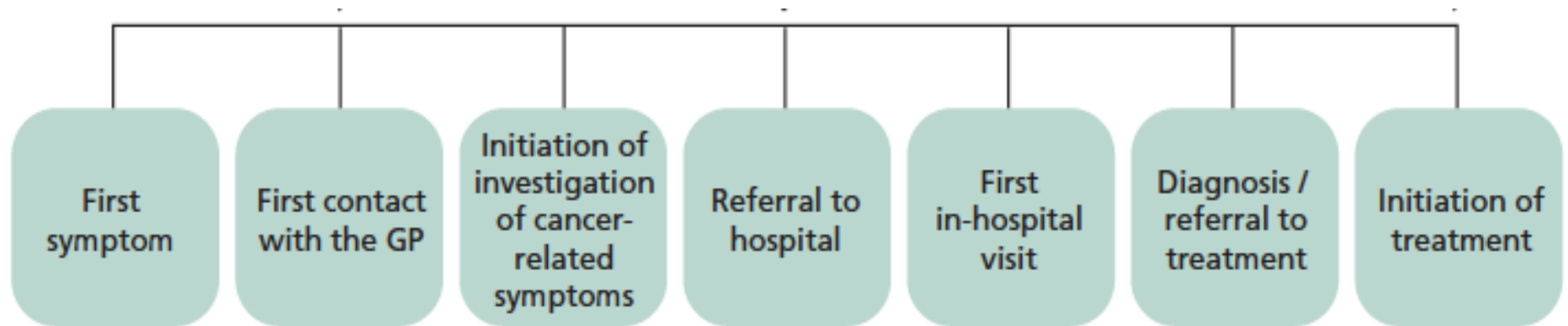
- Carer-Doctor relationship
- Level of education

Disease

- Type
- Location

Healthcare system

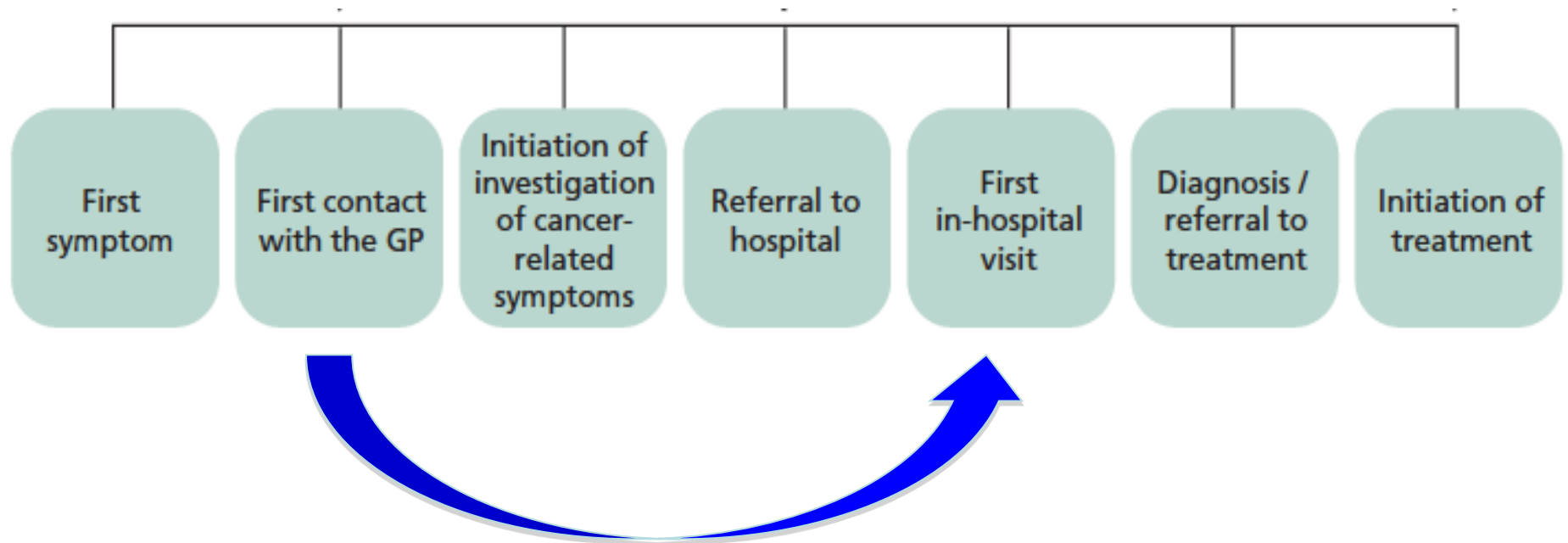
Timeline to diagnosis



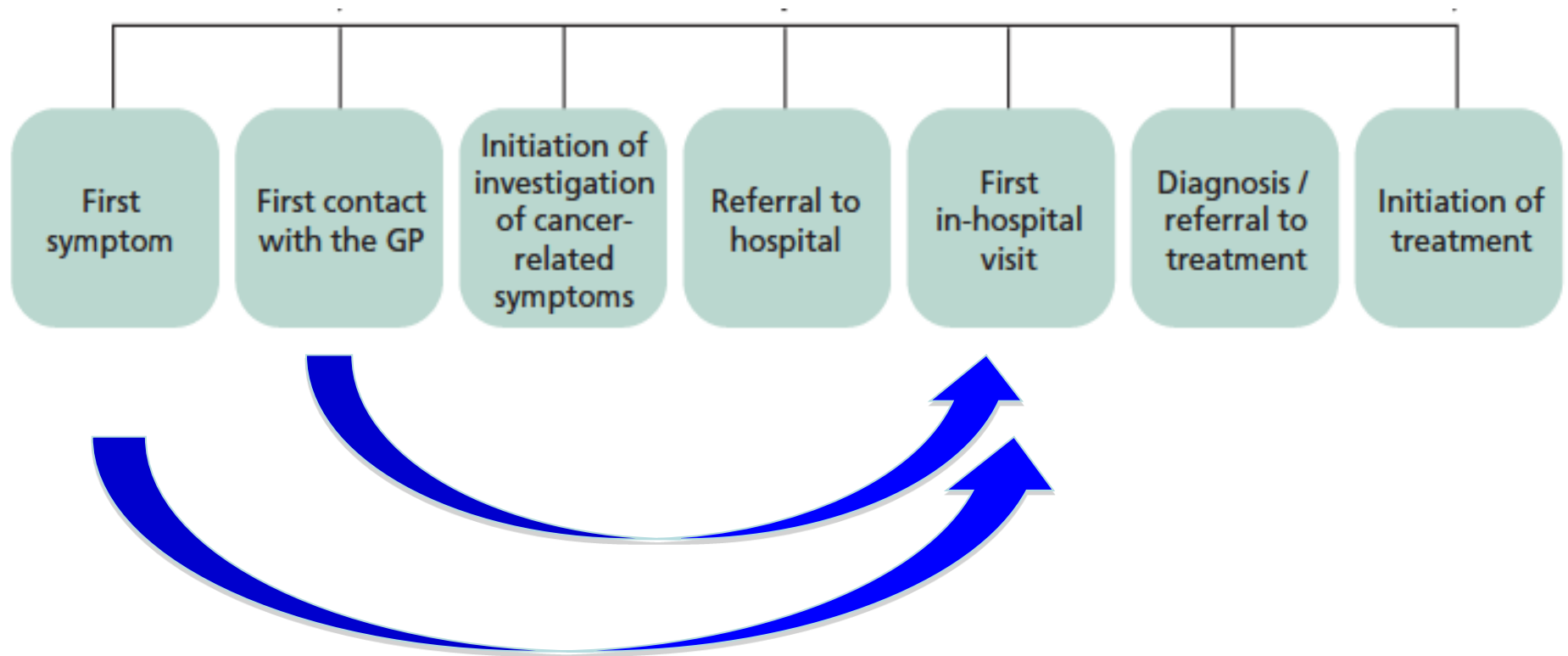
PRIMARY → SECONDARY → TERTIARY



Timeline to diagnosis



🔥 Timeline to diagnosis



Routes to Diagnosis

0-14yrs

- 54% Emergency presentations
- 2% Two week wait

15-24yrs

- 24% Emergency presentations
(57% Colorectal)

Elliss-Brookes et al
British Journal of Cancer (2012) 107, 1220–1226

Symptom interval in young people with bone cancer

Goyal et al. EJC 2004

Median symptom interval in months

First health
professional seen

Osteosarcoma			GP	A&E
	Total Symptom Interval		3.5	2.8
	Patient delay		1.3	0.9
	Professional delay		1.5	1.7

Ewings Sarcoma	Total Symptom Interval	6.3	3.0
	Patient delay	1.0	1.0
	Professional delay	2.8	1.3

GP

- Tolerate uncertainty
- Explore probability
- Marginalise danger

Hospital Specialist

- Reduce uncertainty
- Explore probability
- Marginalise error

National Patient Safety Agency

Delayed diagnosis of Cancer Thematic Review. March 2010

NICE referral guidelines for suspected cancer

- Published 2000
- Updated 2005
- Under revision

Lung cancer

Upper gastrointestinal cancer

Lower gastrointestinal cancer

Breast cancer

Gynaecological cancer

Urological cancer

Haematological cancer

Skin cancer

Head and neck cancer including thyroid cancer

Brain and CNS cancer

Bone cancer and sarcoma

Cancer in children and young people



The frequency of any NICE alert symptom 0-14yrs

Period prior to diagnosis	Cases (n=1267)		Controls (n=15318)	
	Freq	%	Freq	%
0-3 months	342	27.0	211	1.4
0-12 months	427	33.7	829	5.4

Dommett et al BJC (2012) 106(5) 982-7

The association of having a NICE alert symptom and a diagnosis of cancer

Period prior to diagnosis	Cases (n=1267)		Controls (n=15318)		OR	LR	PPV (per 10000)
	Freq	%	Freq	%			
0-3 months	342	27.0	211	1.4	28.8	19.6	5.5
0-12 months	427	33.7	829	5.4	9.8	6.2	7.0

Prior probability of cancer 0.35 / 10000 (3 months)
 1.4 / 10000 (12 months)

Significant Event Audit

Report for the National Awareness and Early Diagnosis Initiative

Cancer in Primary Care

AN ANALYSIS OF SIGNIFICANT EVENT
AUDITS (SEA) FOR DIAGNOSIS OF LUNG
CANCER AND CANCERS IN TEENAGERS
AND YOUNG ADULTS
2008 – 2009

- 35 cases of cancer in TYA



Secondary care

- Investigations?
- Who to refer to?
- HES data



Earlier diagnosis

- Patient expectation
- Major challenge
- Age - Disease - Biology



Strategies

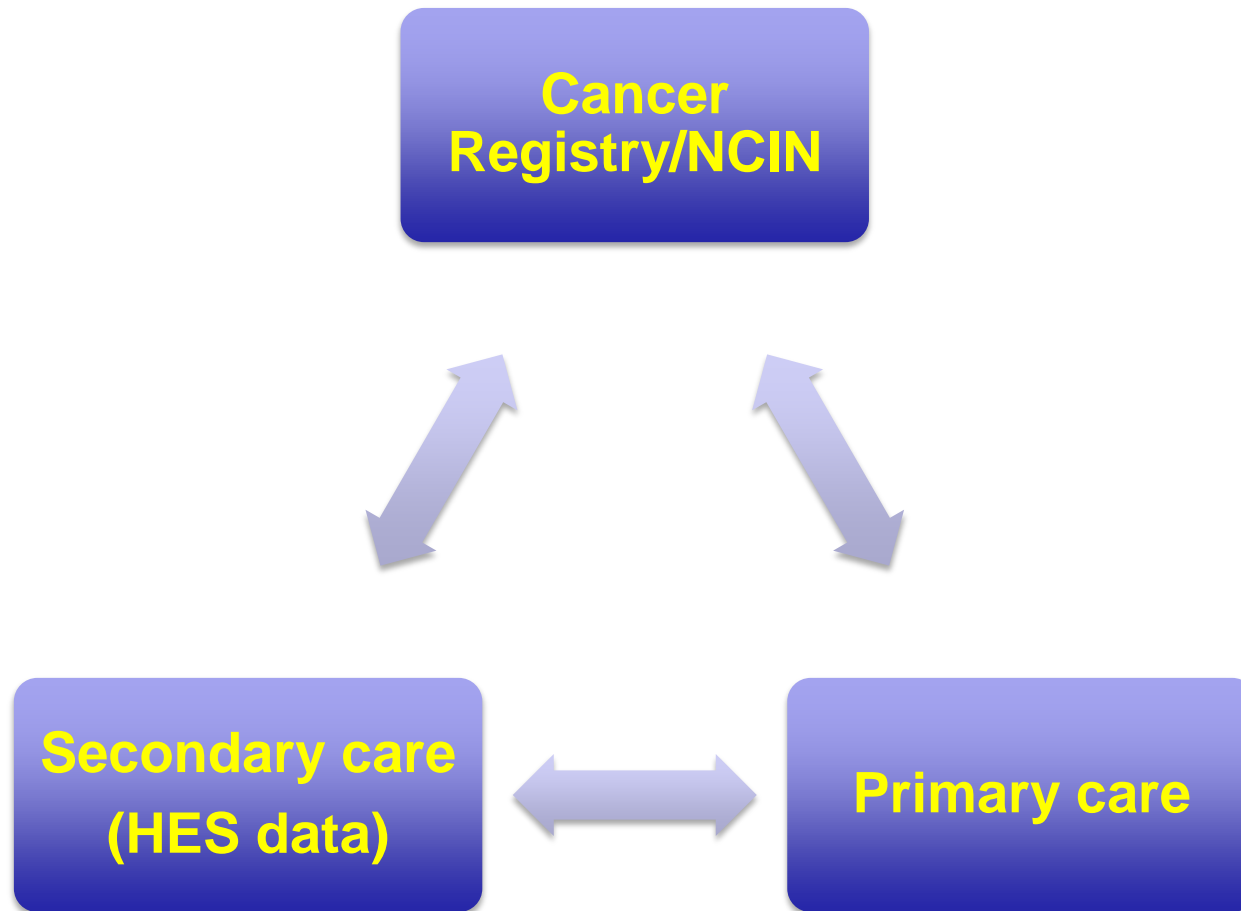
**Public
awareness**

**Primary
care**

**Secondary
care**



Integrated approach



Integrated approach

