

# Routes to Diagnosis

## *Haematology*

**NCIN Haematological Cancers Workshop**  
**27<sup>th</sup> September 2012**

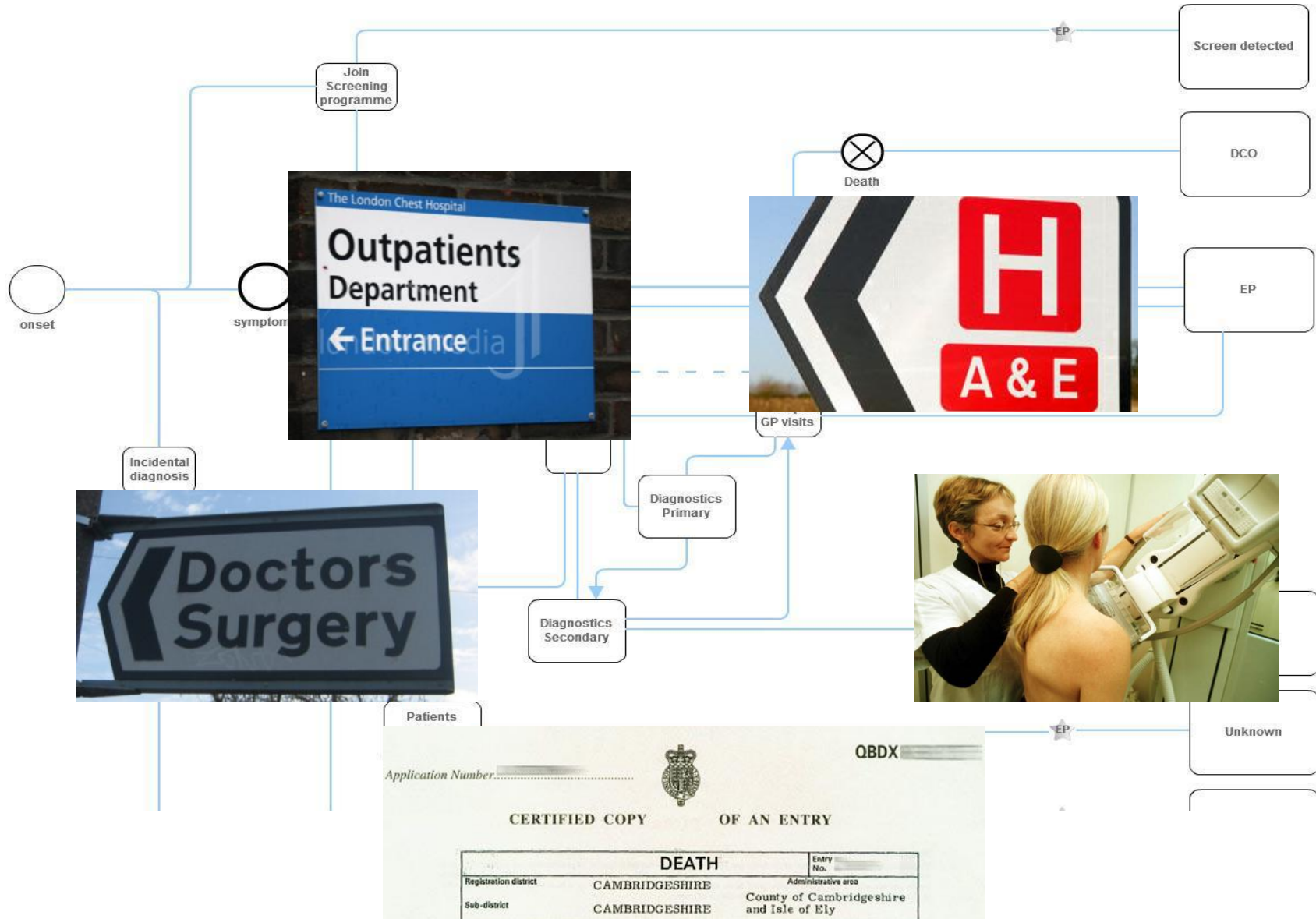
# Routes to Diagnosis

- What is Routes to Diagnosis?
- Description of Routes
- Cancer sites Routes have been calculated for
- Overall results
- Specific results (age, sex, deprivation, survival) for *haematology*
- Application of Routes to Diagnosis
- What next (outputs)?

# Background to Routes to Diagnosis

- Nationally, what didn't we know?
  - How people come to get diagnosed with cancer
  - Whether late diagnosis arises in cases where patients have not gone through the screening or suspected cancer route
  - What impact awareness and early diagnosis initiatives might have on the routes to diagnosis
- Nationally, what did we want to know?
  - Can we use routinely available datasets to define the route to diagnosis for patients diagnosed with cancer?
  - If so, how do routes differ by cancer site, age, sex, ethnicity, deprivation or Cancer Network?
  - Are there differences in outcomes (one year survival) for different routes?

# What is Routes to Diagnosis?



# Eight Routes assigned

- **Screen detected:** breast, bowel or cervical
- **Two week wait:** urgent GP referrals with a suspicion of cancer
- **GP referral:** includes routine and non-TWW GP referrals
- **Emergency presentation:** emergency route via A&E, emergency GP or consultant outpatient referral, emergency transfer etc
- **Other outpatient:** elective route starting with a consultant outpatient appointment
- **Inpatient elective:** elective route starting with an inpatient admission (no earlier information found)
- **DCO:** diagnosis by death certificate only
- **Unknown:** no data available from HES, CWT or screening

# Cancer sites included

- All cancers
- Bladder
- Breast
- Cervix
- CNS
- Colorectal
- Head and neck:
  - Hypopharynx\*
  - Larynx
  - oral cavity
  - oropharynx
  - other sites of the lip, oral cavity and pharynx\*
  - salivary glands\*
  - thyroid
- Hodgkin lymphoma
- Kidney and unspecified urinary organs
- Leukaemia:
  - acute lymphoblastic\*
  - acute myeloid
  - chronic lymphocytic
  - chronic myeloid\*
  - rarer types
- Liver
- Lung
- Melanoma
- Mesothelioma
- Multiple myeloma
- Non-Hodgkin lymphoma
- Oesophagus
- Ovary
- Pancreas
- Prostate
- Sarcoma:
  - Bone\*
  - connective and soft tissue
  - retroperitoneum and peritoneum\*
- Stomach
- Testis
- Uterus
- Vulva
- Other malignant neoplasms

\* No breakdowns by age, sex, DQ, etc. are available for these sites

# Sites with low proportion of emergencies

Percentage of diagnoses (2006-2008) by Route	Screen detected	Two Week Wait	GP referral	Other Outpatient	Inpatient Elective	Emergency presentation	Death Certificate Only	Unknown	Total	Number of patients
Melanoma		41%	27%	7%	3%	3%	0%	18%	100%	26,660
Breast	28%	43%	11%	3%	1%	5%	0%	9%	100%	110,173
Head and neck - Oral cavity		30%	22%	27%	5%	6%	0%	10%	100%	5,992
Head and neck – thyroid		12%	47%	18%	5%	8%	0%	11%	100%	5,304
Head and neck - Salivary glands		18%	42%	17%	4%	8%	0%	10%	100%	1,571
Vulva		32%	34%	12%	5%	8%	0%	9%	100%	2,733
Uterus		37%	31%	10%	5%	8%	0%	8%	100%	18,462
Head and neck - Oropharynx		39%	27%	12%	5%	9%	0%	8%	100%	3,859
Prostate		26%	32%	11%	8%	10%	0%	12%	100%	92,922

# Low to medium emergencies

Percentage of diagnoses (2006-2008) by Route	Screen detected	Two Week Wait	GP referral	Other Outpatient	Inpatient Elective	Emergency presentation	Death Certificate Only	Unknown	Total	Number of patients
Testis		48%	15%	8%	8%	10%	0%	11%	100%	5,070
Head and neck - Other sites		27%	31%	18%	5%	11%	0%	9%	100%	2,740
Head and neck – larynx		32%	34%	11%	6%	11%	0%	5%	100%	5,200
Cervix	15%	17%	28%	10%	5%	13%	0%	12%	100%	7,000
Head and neck - Hypopharynx		37%	28%	12%	5%	14%	0%	4%	100%	1,098
Sarcoma: connective and soft tissue		12%	37%	16%	7%	16%	0%	12%	100%	3,447
Hodgkin lymphoma		26%	28%	14%	6%	17%	0%	8%	100%	3,644
Bladder		30%	24%	13%	9%	19%	1%	5%	100%	25,639
Oesophagus		34%	16%	8%	14%	22%	1%	5%	100%	19,449
All cancers	5%	26%	21%	10%	6%	24%	1%	8%	100%	739,667



# Medium to high emergencies

Percentage of diagnoses (2006-2008) by Route	Screen detected	Two Week Wait	GP referral	Other Outpatient	Inpatient Elective	Emergency presentation	Death Certificate Only	Unknown	Total	Number of patients
Sarcoma: bone		10%	26%	19%	11%	25%	0%	9%	100%	1,378
Kidney and unspecified urinary organs		19%	26%	17%	6%	25%	1%	6%	100%	20,594
Leukaemia: chronic lymphocytic		11%	31%	11%	5%	25%	1%	17%	100%	6,835
Colorectal	2%	27%	20%	9%	9%	26%	1%	6%	100%	91,416
Non-Hodgkin lymphoma		18%	28%	12%	6%	27%	0%	9%	100%	25,413
Ovary		23%	20%	12%	5%	32%	1%	7%	100%	16,026
Stomach		23%	17%	8%	13%	33%	1%	5%	100%	18,613
Leukaemia: Chronic myeloid		8%	26%	12%	9%	35%	1%	9%	100%	1,518
Mesothelioma		18%	21%	15%	6%	36%	0%	4%	100%	6,179
Multiple myeloma		11%	27%	13%	6%	37%	1%	6%	100%	11,221

# High proportion of emergencies

Percentage of diagnoses (2006-2008) by Route	Screen detected	Two Week Wait	GP referral	Other Outpatient	Inpatient Elective	Emergency presentation	Death Certificate Only	Unknown	Total	Number of patients
Leukaemia: rarer types		7%	29%	10%	7%	38%	1%	8%	100%	2,567
Lung		24%	17%	10%	4%	39%	1%	5%	100%	96,735
Sarcoma: retroperitoneum and peritoneu		15%	20%	14%	5%	39%	0%	7%	100%	1,513
Other malignant neoplasms	0%	10%	19%	10%	5%	46%	2%	8%	100%	50,497
Liver		8%	18%	12%	5%	48%	2%	7%	100%	8,576
Pancreas		11%	16%	9%	6%	50%	1%	6%	100%	19,896
Leukaemia: acute myeloid		2%	18%	12%	7%	54%	0%	6%	100%	6,365
CNS		1%	13%	11%	7%	62%	1%	6%	100%	11,697
Leukaemia: acute lymphoblastic		2%	10%	8%	10%	63%	0%	7%	100%	1,665

# NICE Referral Guidelines

(Macmillan Rapid Referral Toolkit)

## Haematological cancer

### Information

- Be aware that haematological cancers can present with a variety of symptoms that may have a number of different clinical explanations.
- Combinations of the following symptoms and signs warrant full examination, further investigation (including a blood count and film) and possible referral:
  - fatigue
  - breathlessness
  - alcohol-induced pain
  - drenching night sweats
  - bruising
  - abdominal pain
  - fever
  - bleeding
  - lymphadenopathy
  - weight loss
  - recurrent infections
  - splenomegaly
  - generalised itching
  - bone pain

The urgency of referral depends on the symptom severity and findings of investigations.

### Immediate referral

Refer immediately patients:

- with a blood count/film reported as acute leukaemia
- with spinal cord compression or renal failure suspected of being caused by myeloma.

### Urgent referral

Refer urgently patients with persistent unexplained splenomegaly.

# Hodgkin lymphoma

## by sex and age

Hodgkin lymphoma		Screen detected	Two Week Wait	GP referral	Other Outpatient	Inpatient Elective	Emergency presentation	Death Certificate Only	Unknown	Total	Number of cases
2006-2008	Male		24%	28%	15%	6%	18%	0%	9%	100%	2,043
	Confidence interval		23% 26%	26% 30%	13% 16%	5% 7%	16% 19%	0% 1%	8% 11%		
	Female		29%	30%	13%	6%	17%		7%	100%	1,601
	Confidence interval		27% 31%	27% 32%	11% 14%	5% 7%	15% 19%		6% 9%		

2006-2008	Under 50		28%	27%	14%	7%	14%	0%	10%	100%	2,239
	Confidence interval		26% 30%	26% 29%	12% 15%	6% 8%	13% 16%	0% 0%	9% 11%		
	50-59		27%	31%	14%	5%	14%	0%	10%	100%	396
	Confidence interval		23% 31%	27% 36%	11% 18%	3% 7%	11% 17%	0% 1%	7% 13%		
	60-69		25%	30%	13%	5%	21%		6%	100%	415
	Confidence interval		21% 29%	26% 35%	10% 17%	4% 8%	18% 25%		4% 9%		
	70-79		22%	29%	15%	2%	27%	0%	6%	100%	406
Confidence interval		18% 26%	25% 34%	11% 18%	1% 4%	23% 31%	0% 1%	4% 8%			
80-84		23%	32%	12%	4%	26%		3%	100%	105	
Confidence interval		16% 32%	24% 42%	7% 20%	2% 9%	18% 35%		1% 8%			
85+		20%	25%	16%	4%	30%		5%	100%	83	
Confidence interval		13% 30%	17% 36%	9% 25%	1% 10%	21% 41%		2% 12%			

# Leukaemia: acute myeloid by sex and age

Leukaemia: acute myeloid		Screen detected	Two Week Wait	GP referral	Other Outpatient	Inpatient Elective	Emergency presentation	Death Certificate Only	Unknown	Total	Number of cases
2006-2008	Male		2%	19%	13%	7%	53%	0%	6%	100%	3,502
	Confidence interval		2% 3%	18% 20%	12% 14%	6% 8%	51% 55%	0% 1%	5% 6%		
	Female		2%	18%	11%	7%	54%	1%	7%	100%	2,863
	Confidence interval		2% 3%	16% 19%	10% 12%	7% 9%	52% 56%	0% 1%	6% 8%		

2006-2008	Under 50		1%	10%	9%	10%	61%		9%	100%	1,099
	Confidence interval		0% 2%	8% 11%	8% 11%	8% 12%	58% 64%		8% 11%		
	50-59		2%	18%	12%	10%	51%	0%	7%	100%	679
	Confidence interval		1% 3%	15% 21%	10% 14%	8% 13%	48% 55%	0% 1%	5% 9%		
	60-69		3%	21%	17%	7%	46%	0%	5%	100%	1,219
	Confidence interval		2% 4%	19% 24%	15% 19%	6% 9%	43% 48%	0% 1%	4% 7%		
	70-79		3%	21%	13%	7%	50%	1%	5%	100%	1,769
Confidence interval		2% 4%	19% 23%	12% 15%	6% 8%	48% 53%	0% 1%	4% 6%			
80-84		3%	23%	9%	5%	55%	0%	5%	100%	858	
Confidence interval		2% 4%	21% 26%	7% 11%	4% 7%	52% 58%	0% 1%	4% 7%			
85+		2%	16%	6%	5%	63%	1%	7%	100%	741	
Confidence interval		1% 3%	13% 18%	5% 8%	4% 7%	60% 67%	1% 2%	5% 9%			

# Leukaemia: chronic lymphocytic by sex and age

Leukaemia: chronic lymphocytic		Screen detected	Two Week Wait	GP referral	Other Outpatient	Inpatient Elective	Emergency presentation	Death Certificate Only	Unknown	Total	Number of cases
2006-2008	Male		12%	31%	11%	5%	24%	1%	16%	100%	4,158
	Confidence interval		11% 13%	30% 33%	10% 12%	4% 6%	23% 25%	1% 1%	15% 17%		
	Female		9%	30%	10%	4%	27%	1%	18%	100%	2,677
	Confidence interval		8% 10%	28% 32%	9% 12%	4% 5%	26% 29%	1% 2%	17% 20%		

2006-2008	Under 50		20%	28%	10%	4%	13%	0%	24%	100%	283
	Confidence interval		16% 25%	23% 33%	7% 14%	2% 7%	10% 18%	0% 2%	20% 30%		
	50-59		17%	32%	11%	7%	9%	0%	24%	100%	783
	Confidence interval		15% 20%	28% 35%	9% 13%	6% 9%	7% 11%	0% 1%	21% 27%		
	60-69		12%	36%	12%	5%	16%	0%	19%	100%	1,629
	Confidence interval		11% 14%	33% 38%	10% 13%	5% 7%	14% 17%	0% 1%	17% 21%		
	70-79		10%	33%	12%	4%	23%	1%	16%	100%	2,195
Confidence interval		9% 11%	31% 35%	11% 14%	4% 5%	21% 25%	0% 1%	15% 18%			
80-84		8%	28%	11%	4%	36%	1%	13%	100%	914	
Confidence interval		7% 10%	26% 31%	9% 13%	3% 5%	33% 39%	0% 2%	11% 15%			
85+		4%	20%	7%	3%	51%	4%	11%	100%	1,031	
Confidence interval		3% 6%	17% 22%	6% 9%	2% 4%	48% 54%	3% 5%	9% 13%			

# Multiple myeloma by sex and age

Multiple myeloma		Screen detected	Two Week Wait	GP referral	Other Outpatient	Inpatient Elective	Emergency presentation	Death Certificate Only	Unknown	Total	Number of cases
2006-2008	Male		12%	26%	13%	6%	37%	0%	6%	100%	6,190
	Confidence interval		11% 13%	25% 27%	13% 14%	5% 7%	36% 38%	0% 1%	5% 6%		
	Female		10%	27%	13%	6%	37%	1%	6%	100%	5,031
	Confidence interval		10% 11%	26% 29%	12% 14%	5% 7%	35% 38%	1% 1%	5% 7%		

2006-2008	Under 50		8%	24%	14%	9%	34%		10%	100%	540
	Confidence interval		6% 10%	21% 28%	12% 18%	7% 12%	31% 39%		8% 13%		
	50-59		13%	25%	15%	8%	31%	0%	8%	100%	1,297
	Confidence interval		11% 15%	23% 28%	13% 17%	6% 9%	29% 34%	0% 1%	7% 10%		
	60-69		13%	29%	14%	7%	31%	0%	7%	100%	2,677
	Confidence interval		12% 14%	27% 30%	13% 15%	6% 8%	30% 33%	0% 0%	6% 8%		
	70-79		13%	28%	14%	5%	36%	0%	5%	100%	3,614
Confidence interval		12% 14%	27% 30%	13% 15%	4% 6%	34% 37%	0% 0%	4% 5%			
80-84		10%	28%	12%	5%	42%	1%	3%	100%	1,671	
Confidence interval		9% 11%	25% 30%	11% 14%	4% 6%	39% 44%	0% 1%	3% 5%			
85+		6%	21%	10%	5%	50%	2%	6%	100%	1,422	
Confidence interval		5% 8%	19% 23%	8% 11%	4% 6%	48% 53%	2% 3%	5% 7%			

# Non-Hodgkin lymphoma by sex and age

Non-Hodgkin lymphoma		Screen detected	Two Week Wait	GP referral	Other Outpatient	Inpatient Elective	Emergency presentation	Death Certificate Only	Unknown	Total	Number of cases
2006-2008	Male		17%	27%	12%	6%	28%	0%	9%	100%	13,659
	Confidence interval		16% 18%	26% 28%	12% 13%	6% 7%	28% 29%	0% 1%	8% 9%		
	Female		18%	29%	12%	6%	26%	0%	8%	100%	11,754
	Confidence interval		18% 19%	28% 30%	11% 13%	5% 6%	26% 27%	0% 1%	8% 9%		

2006-2008	Under 50		14%	26%	12%	7%	27%	0%	13%	100%	3,610
	Confidence interval		13% 15%	24% 27%	11% 13%	6% 8%	26% 29%	0% 0%	12% 15%		
	50-59		19%	29%	13%	7%	22%	0%	11%	100%	3,709
	Confidence interval		17% 20%	28% 30%	12% 14%	6% 8%	20% 23%	0% 1%	10% 12%		
	60-69		19%	30%	13%	6%	24%	0%	8%	100%	6,060
	Confidence interval		18% 20%	29% 31%	12% 14%	6% 7%	23% 25%	0% 0%	8% 9%		
	70-79		19%	29%	12%	5%	28%	0%	6%	100%	6,967
Confidence interval		18% 20%	28% 30%	12% 13%	5% 6%	27% 29%	0% 1%	6% 7%			
80-84		18%	27%	12%	4%	33%	1%	6%	100%	2,748	
Confidence interval		16% 19%	25% 29%	10% 13%	4% 5%	31% 35%	0% 1%	5% 7%			
85+		15%	23%	8%	4%	39%	2%	8%	100%	2,319	
Confidence interval		14% 17%	22% 25%	7% 10%	4% 5%	37% 41%	1% 2%	7% 10%			



# Leukaemia: acute myeloid by deprivation

Leukaemia: acute myeloid		Screen detected	Two Week Wait	GP referral	Other Outpatient	Inpatient Elective	Emergency presentation	Death Certificate Only	Unknown	Total	Number of cases
2006-2008	1 (least deprived)		3%	20%	14%	7%	49%	1%	7%	100%	1,301
	Confidence interval		2% 4%	18% 22%	12% 16%	6% 8%	47% 52%	0% 1%	5% 8%		
	2		2%	19%	12%	8%	52%	0%	6%	100%	1,412
	Confidence interval		2% 3%	18% 22%	10% 14%	7% 10%	49% 54%	0% 1%	5% 7%		
	3		3%	19%	12%	7%	53%	0%	7%	100%	1,391
	Confidence interval		2% 4%	17% 21%	10% 13%	6% 8%	51% 56%	0% 1%	6% 8%		
	4		2%	16%	11%	7%	58%	0%	6%	100%	1,197
	Confidence interval		1% 3%	15% 19%	9% 13%	6% 9%	55% 60%	0% 1%	5% 7%		
	5 (most deprived)		2%	17%	10%	7%	57%	0%	6%	100%	1,064
	Confidence interval		1% 3%	15% 20%	8% 12%	6% 9%	54% 60%	0% 1%	5% 7%		

# Haematology

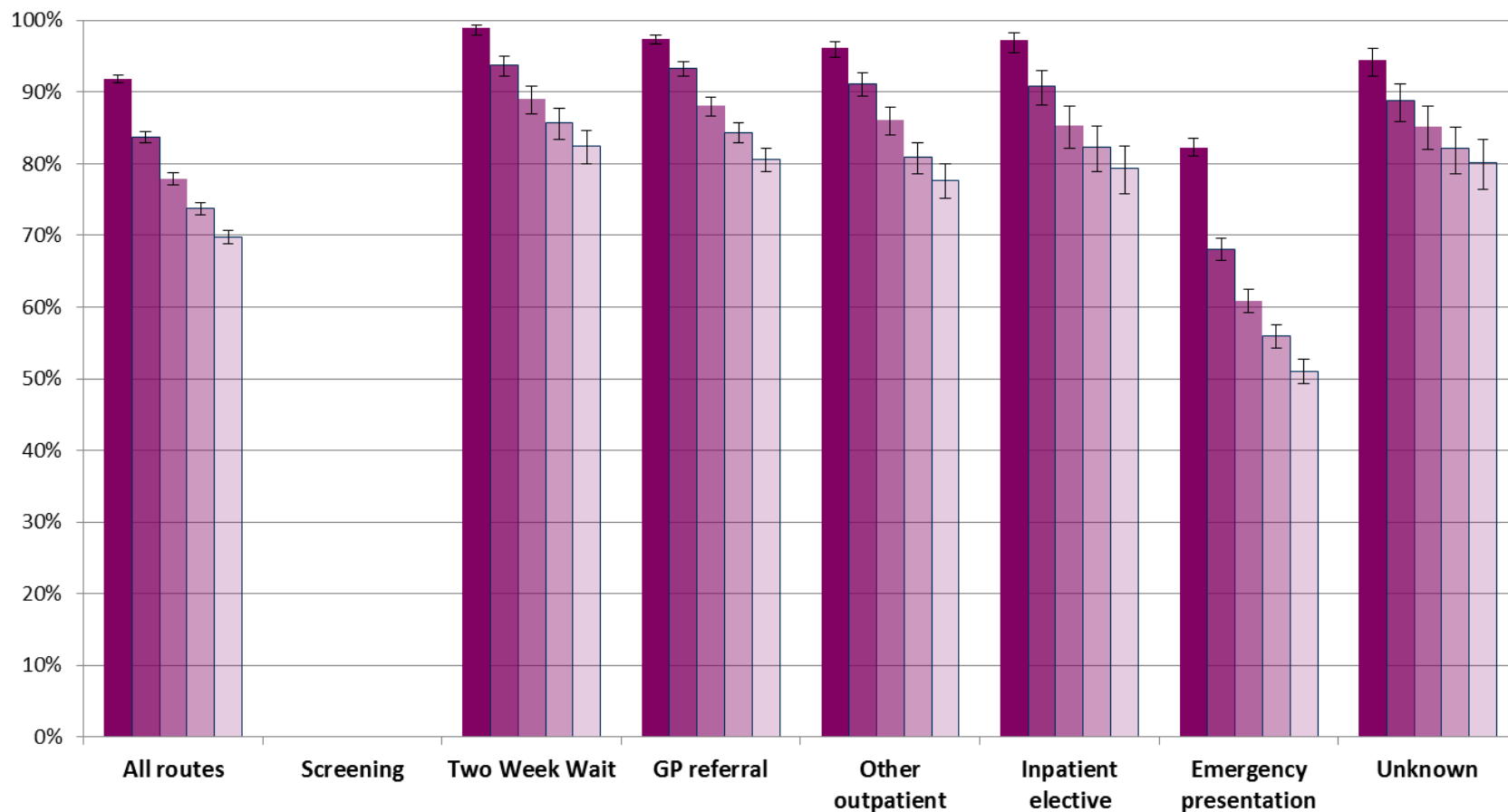
## relative survival estimates

12-month		All routes	Screening	Two Week Wait		GP referral		Other outpatient		Inpatient elective		Emergency presentation		Unknown	Number of cases
Persons	Hodgkin lymphoma	<b>90%</b>		<b>96%</b>	<b>91%</b>	<b>91%</b>	<b>97%</b>	<b>74%</b>	<b>94%</b>						3,630
	Confidence interval	89% 91%		94% 97%	89% 93%	88% 93%	91% 99%	71% 78%	90% 96%						
	Leukaemia: acute myeloid	<b>35%</b>		<b>49%</b>	<b>35%</b>	<b>34%</b>	<b>49%</b>	<b>31%</b>	<b>46%</b>						6,114
	Confidence interval	34% 36%		41% 57%	32% 38%	30% 38%	44% 53%	29% 32%	41% 51%						
	Leukaemia: chronic lymphocytic	<b>87%</b>		<b>96%</b>	<b>93%</b>	<b>87%</b>	<b>88%</b>	<b>64%</b>	<b>96%</b>						6,489
	Confidence interval	86% 88%		94% 98%	92% 95%	84% 90%	83% 92%	61% 67%	94% 97%						
	Leukaemia: other (all excluding AML and CLL)	<b>74%</b>		<b>87%</b>	<b>80%</b>	<b>74%</b>	<b>86%</b>	<b>65%</b>	<b>80%</b>						5,519
Confidence interval	73% 75%		83% 91%	77% 82%	70% 78%	82% 89%	63% 67%	75% 83%							
Multiple myeloma	<b>70%</b>		<b>82%</b>	<b>81%</b>	<b>78%</b>	<b>79%</b>	<b>51%</b>	<b>80%</b>						10,864	
Confidence interval	69% 71%		80% 85%	79% 82%	75% 80%	76% 83%	49% 53%	76% 83%							
Non-Hodgkin lymphoma	<b>75%</b>		<b>85%</b>	<b>86%</b>	<b>81%</b>	<b>84%</b>	<b>50%</b>	<b>86%</b>						25,014	
Confidence interval	75% 76%		84% 87%	85% 87%	79% 82%	81% 86%	49% 51%	84% 88%							

# Multiple Myeloma

## *by survival interval*

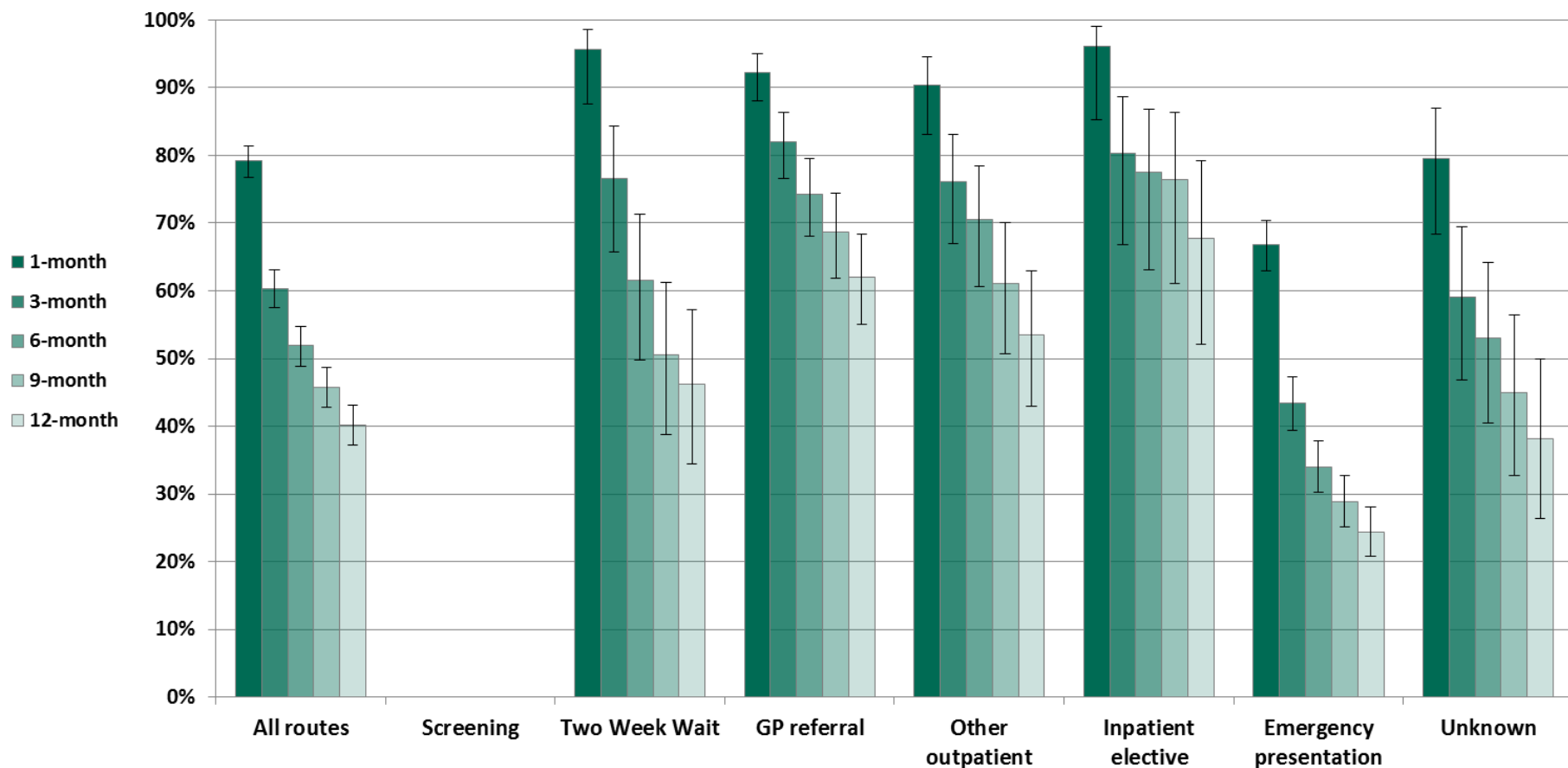
**Relative survival estimates by presentation route and survival time, Multiple myeloma, 2006-2008**



# Multiple Myeloma

## *by survival interval, age 85+*

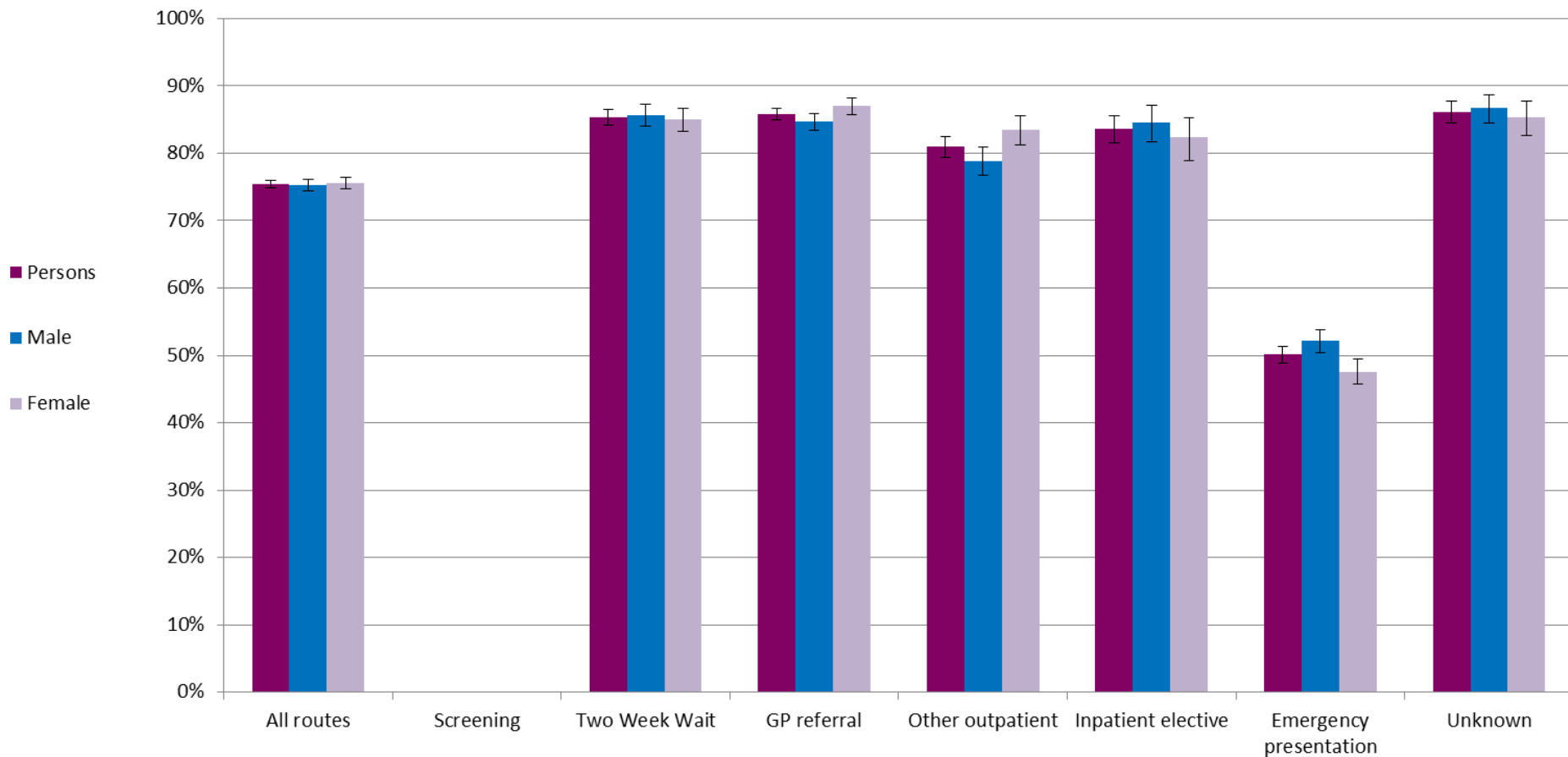
**Relative survival estimates by presentation route and survival time, Multiple myeloma, 2006-2008, aged 85+**



# Non-Hodgkin lymphoma

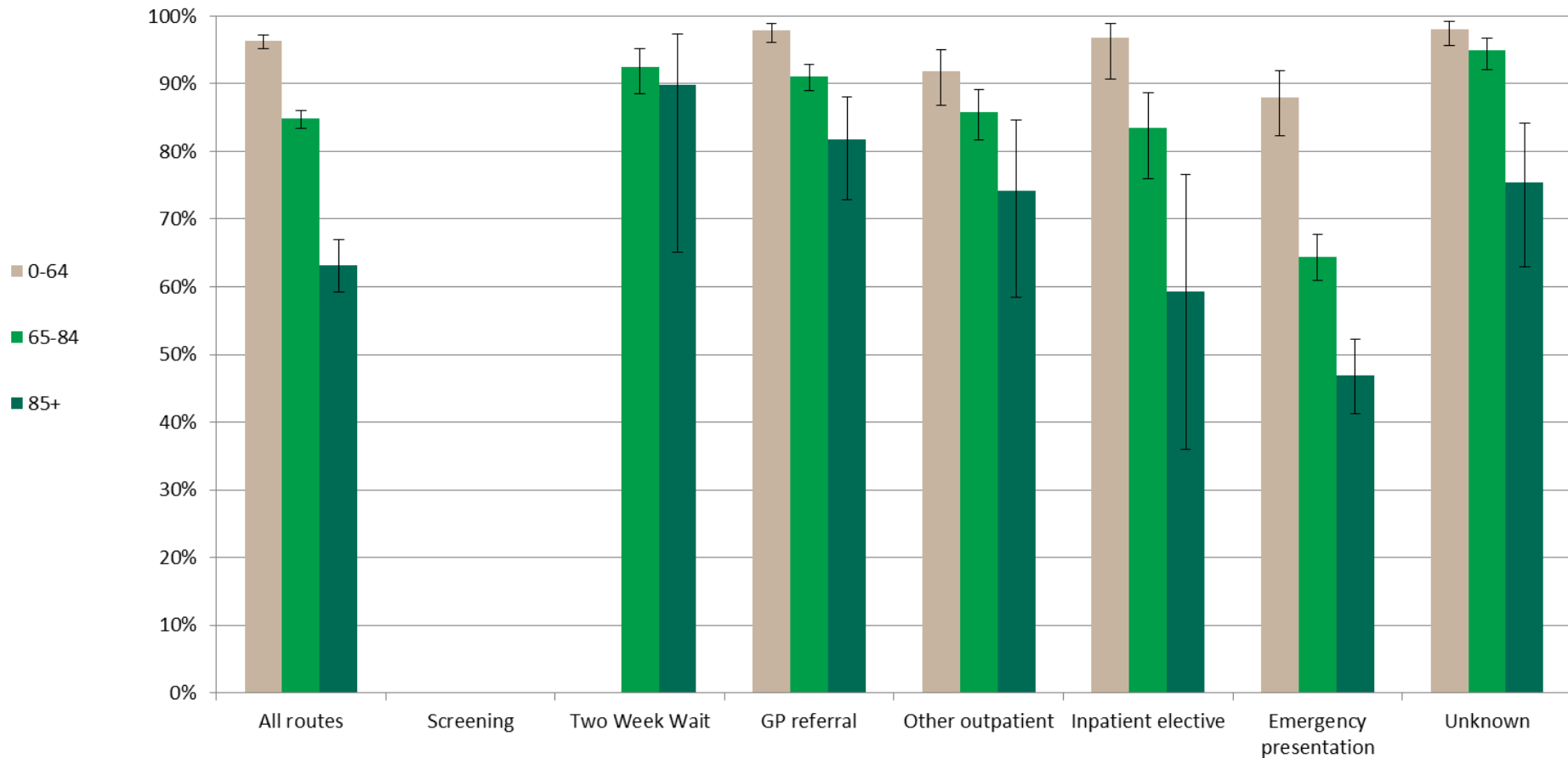
## *survival by sex*

**12-month relative survival estimates by presentation route,  
Non-Hodgkin lymphoma, 2006-2008, by sex**



# Leukaemia: chronic lymphocytic *survival by age*

**12-month relative survival estimates by presentation route,  
Leukaemia: chronic lymphocytic , 2006-2008, by age**



# Application of Routes to Diagnosis

- Understand the different routes for different cancer sites
- Build a picture for each cancer site
- Explore possible reasons for delayed diagnosis
- Direct the focus of early diagnosis initiatives
  - Awareness campaigns
  - Targeted interventions
  - Monitoring and evaluating impact
- Identify areas for further research
  - Link to GP audit and GP data
  - Routes from diagnosis
  - Exploring emergency presentations
- Patient-level Routes are available to registries for further investigation

# What next?

- Peer reviewed paper in British Journal of Cancer November 2012, advanced online publication 21<sup>st</sup> September 2012
- Full spreadsheet of results available to the public, containing:
  - proportion by Route by age, sex, deprivation quintile and cancer network by year and 06-08 combined
  - relative survival estimates by age, sex and deprivation quintile for 1, 3, 6, 9 and 12 month survival intervals
- Information supplement of results for selected sites, and a basic explanation of methodology available from the NCIN website
- PCT level results available with data presented as age-standardised funnel plots
- Updated results for 2010 to be produced in Spring 2013



For more information, please contact:

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