

# LPCN Data Update: 2015-24

Dr Adam Hurlow

July 24

# Leeds Adult Palliative and End of Life Care 2021-2026

*People will die well in their place of choice; carers and the bereaved will be well supported*

**What factors will enable us to achieve these outcomes?**

## 7 Outcomes that we aim to achieve

*People in Leeds who need palliative and /or end of life care*

Planning Ahead Dataset

% who died with digital ACP

% who achieved their preferred place of death

SUS Hospital Data

% with 3 or more unplanned hospital admissions in last 90 days of life

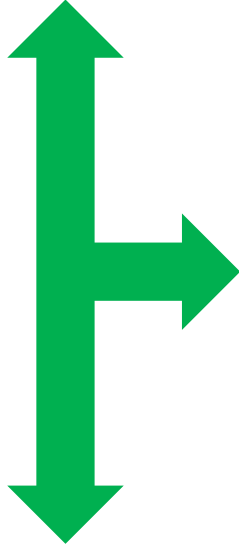
Bereaved Carers Survey

% satisfied/v. satisfied with symptom management

**Inequalities**

# Planning Ahead (nee EPaCCS) Dataset

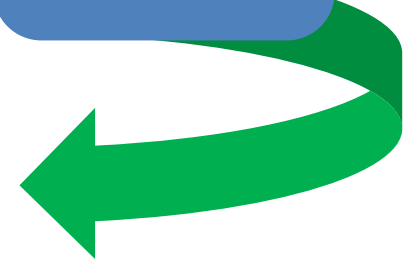
System1



EMIS

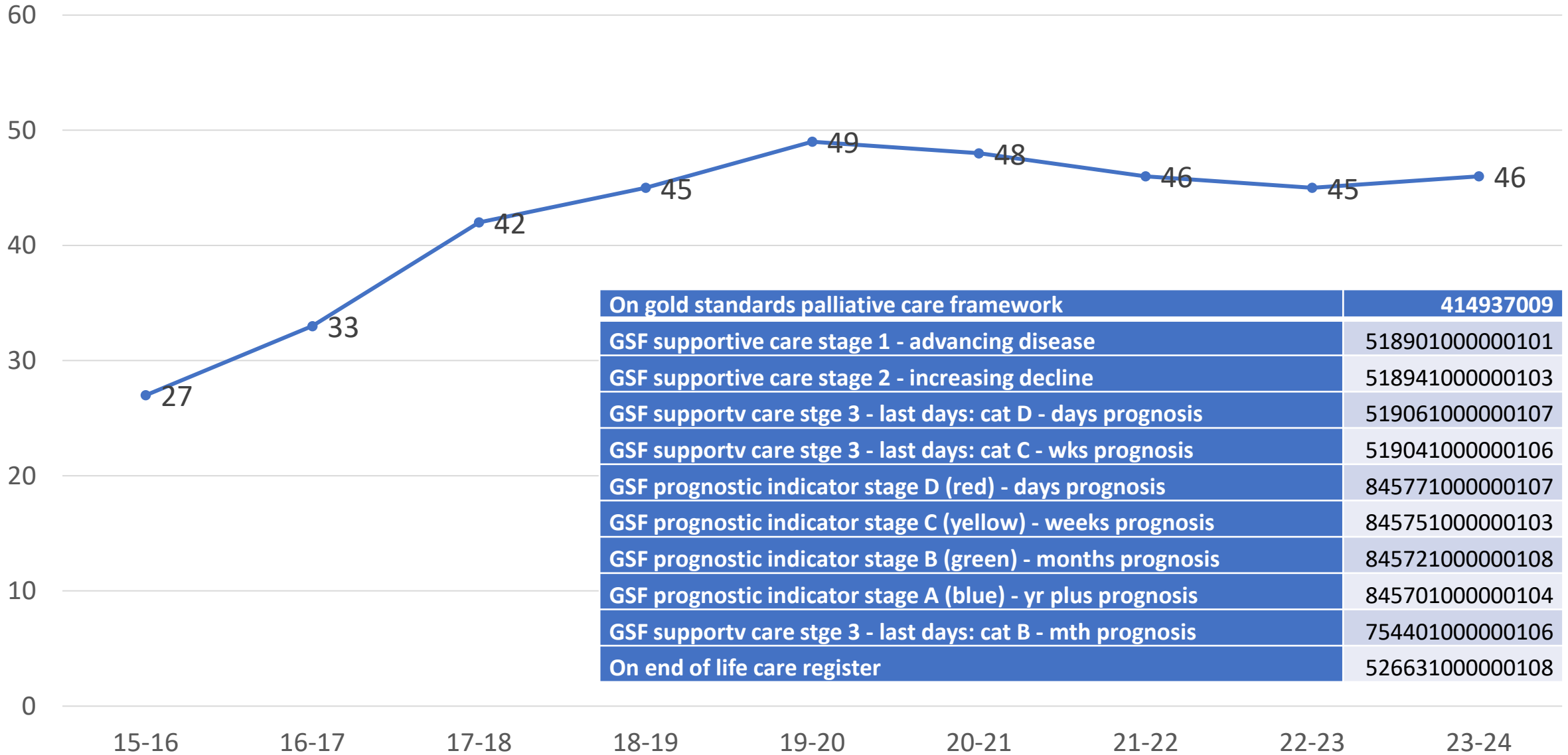
NHS number		
Age		
Sex		
Ethnicity	Code	Date
Postcode (translated to 4 digits for analysis)		
Practice population		
Palliative Care	Code	Date
EPaCCs	Code	Date
Carer assessment		
Long term conditions	Code	Date
Dementia	Code	Date
Parkinson's Disease	Code	Date
Frailty	Code	Date
Place of Care / Residential Status	Code	Date
Preferred Place of Care	Code	Date
Learning Disabilities	Code	Date
Severe Mental Illness	Code	Date
Patient involvement codes	Code	Date
What Matters to Me / Personalised Care Plan	Code	Date
Advance Care Plan	Code	Date
ReSPECT	Code	Date
DNACPR / CPR	Code	Date
Anticipatory Meds		
Preferred Place of Death	Code	Date
2 <sup>nd</sup> Preferred Place of Death	Code	Date
Date of death	Code	Date
Actual place of death	Code	Date
Cause of Death		
Time spent on Palliative Care Register	Code	Date
Gold Standards Framework	Code	Date
Cancer Diagnosis	Code	Date
Non Cancer Diagnosis	Code	Date
Referral to Specialised Palliative Care Team (SPCT)	Code	Date
IPOS (Hospice data)	Code	Date
Active population on EPaCCs register	Code	Date
Active population with ReSPECT	Code	Date

LTHT  
ReSPECT



All  
People  
who die in  
Leeds

## % Deaths in Leeds with Planning Ahead (EPaCCS/GSF code)



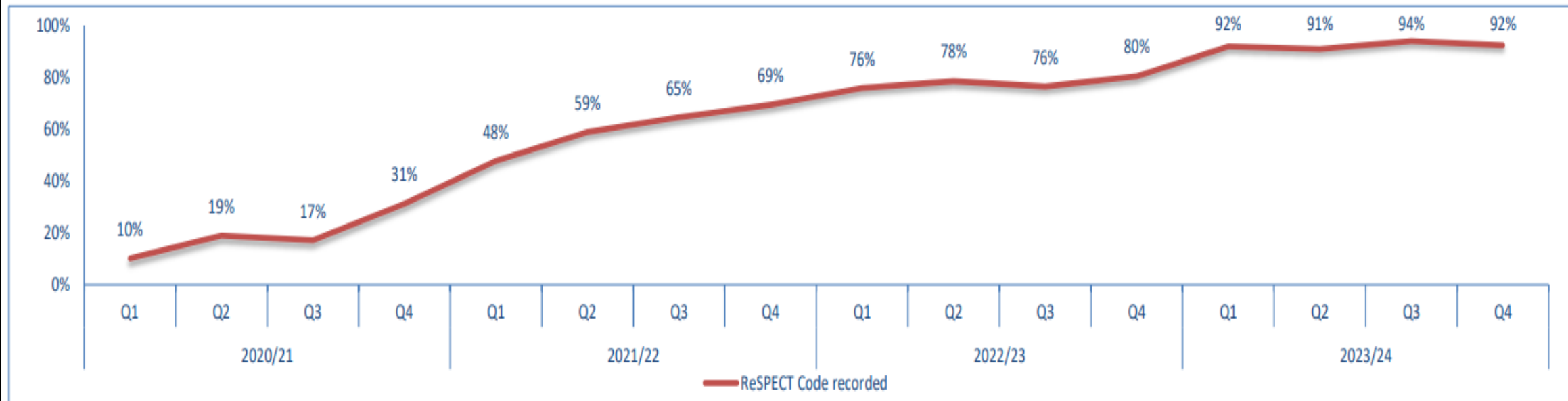
On gold standards palliative care framework	414937009
GSF supportive care stage 1 - advancing disease	518901000000101
GSF supportive care stage 2 - increasing decline	518941000000103
GSF supportv care stge 3 - last days: cat D - days prognosis	519061000000107
GSF supportv care stge 3 - last days: cat C - wks prognosis	519041000000106
GSF prognostic indicator stage D (red) - days prognosis	845771000000107
GSF prognostic indicator stage C (yellow) - weeks prognosis	845751000000103
GSF prognostic indicator stage B (green) - months prognosis	845721000000108
GSF prognostic indicator stage A (blue) - yr plus prognosis	845701000000104
GSF supportv care stge 3 - last days: cat B - mth prognosis	754401000000106
On end of life care register	526631000000108

## Part 2 - Leeds Health & Care Partnership EoL Data 2023-24 Report (Q1-Q4)

C2.7 Deceased EPaCCS patients who have ReSPECT (Recommended Summary Plan for Emergency Care and Treatment) Code recorded on the system.

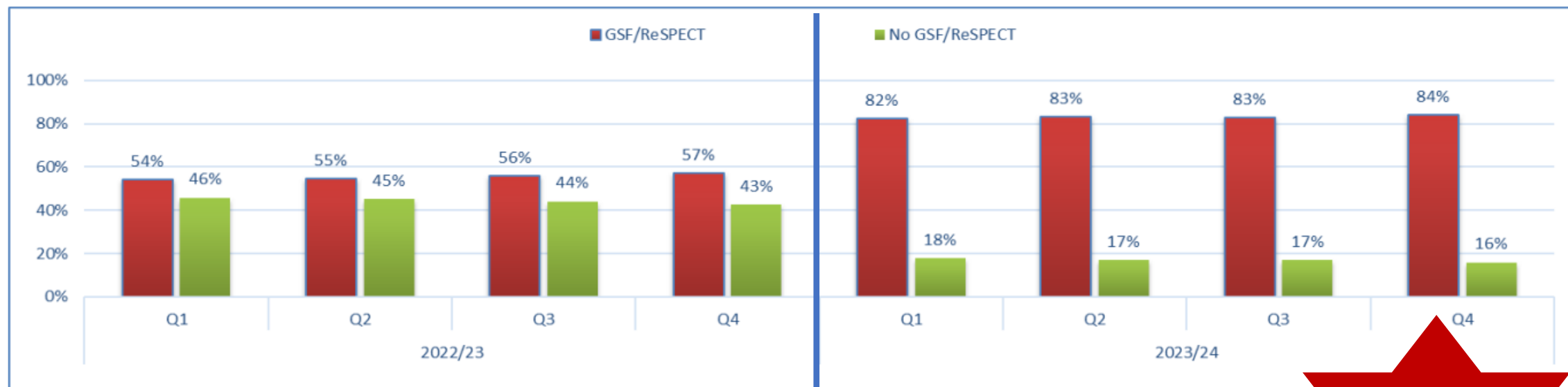
*Note: 2023-24 data has been enhanced using the ReSPECT data received from Leeds Teaching Hospital PPM+*

Patients with ReSPECT Code	Q1		Q2		Q3		Q4	
ReSPECT Code recorded	611	92%	636	91%	688	94%	638	92%
ReSPECT Code not recorded	54	8%	64	9%	44	6%	53	8%
<b>Total</b>	<b>665</b>		<b>700</b>		<b>732</b>		<b>691</b>	



# Planning Ahead (EPaCCS/GSF) and/or ReSPECT (community and/or LTHT)

Percentage of Patients who had either GSF codes or a ReSPECT code vs Patients who had neither GSF nor ReSPECT Code.



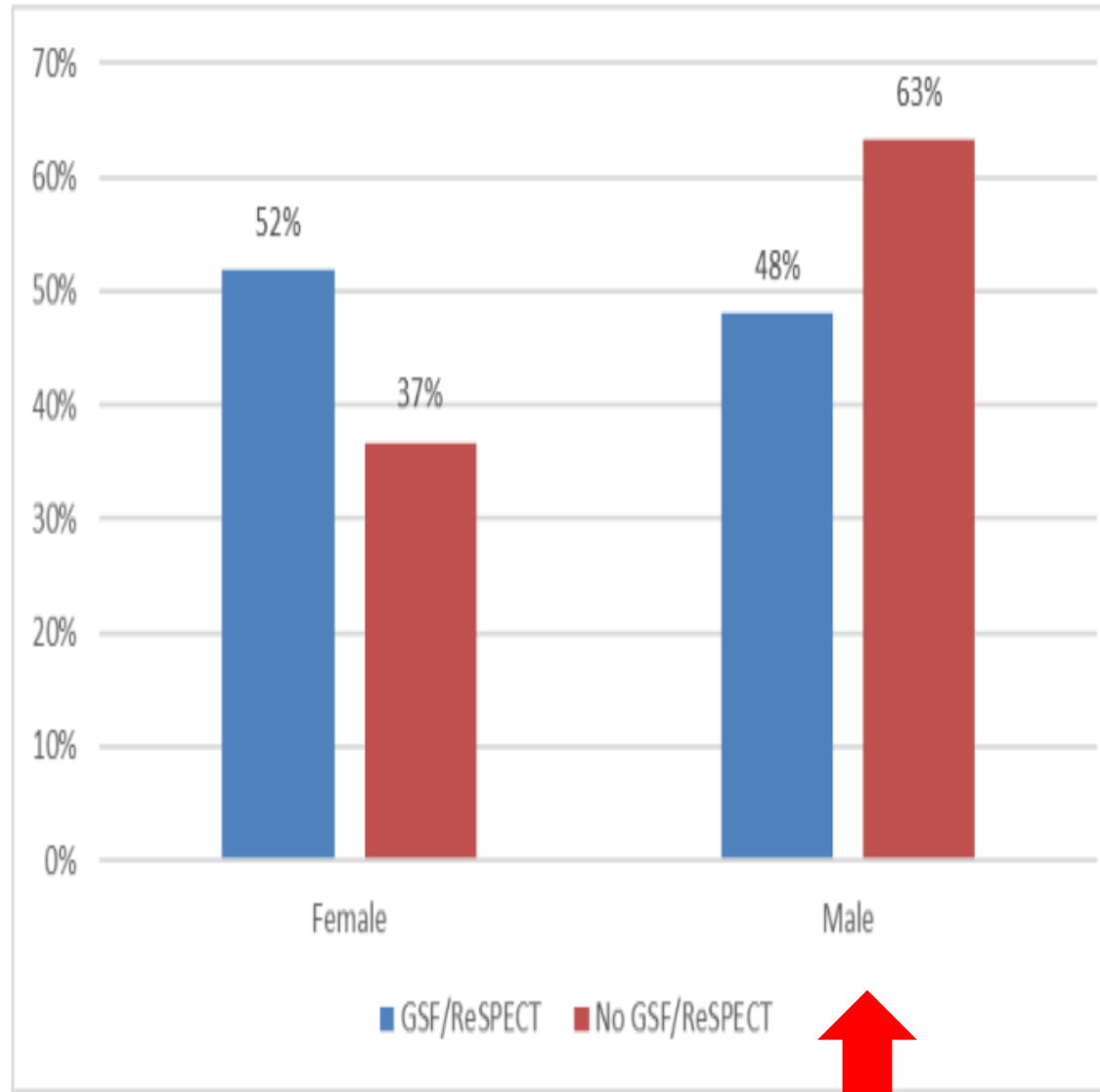
2023/24					
GSF/ReSPECT Status Final	Q1	Q2	Q3	Q4	Grand Total
GSF/ReSPECT	1188	1173	1304	1381	5046
No GSF/ReSPECT	256	239	270	261	1026
<b>Grand Total</b>	<b>1444</b>	<b>1412</b>	<b>1574</b>	<b>1642</b>	<b>6072</b>

**83%**

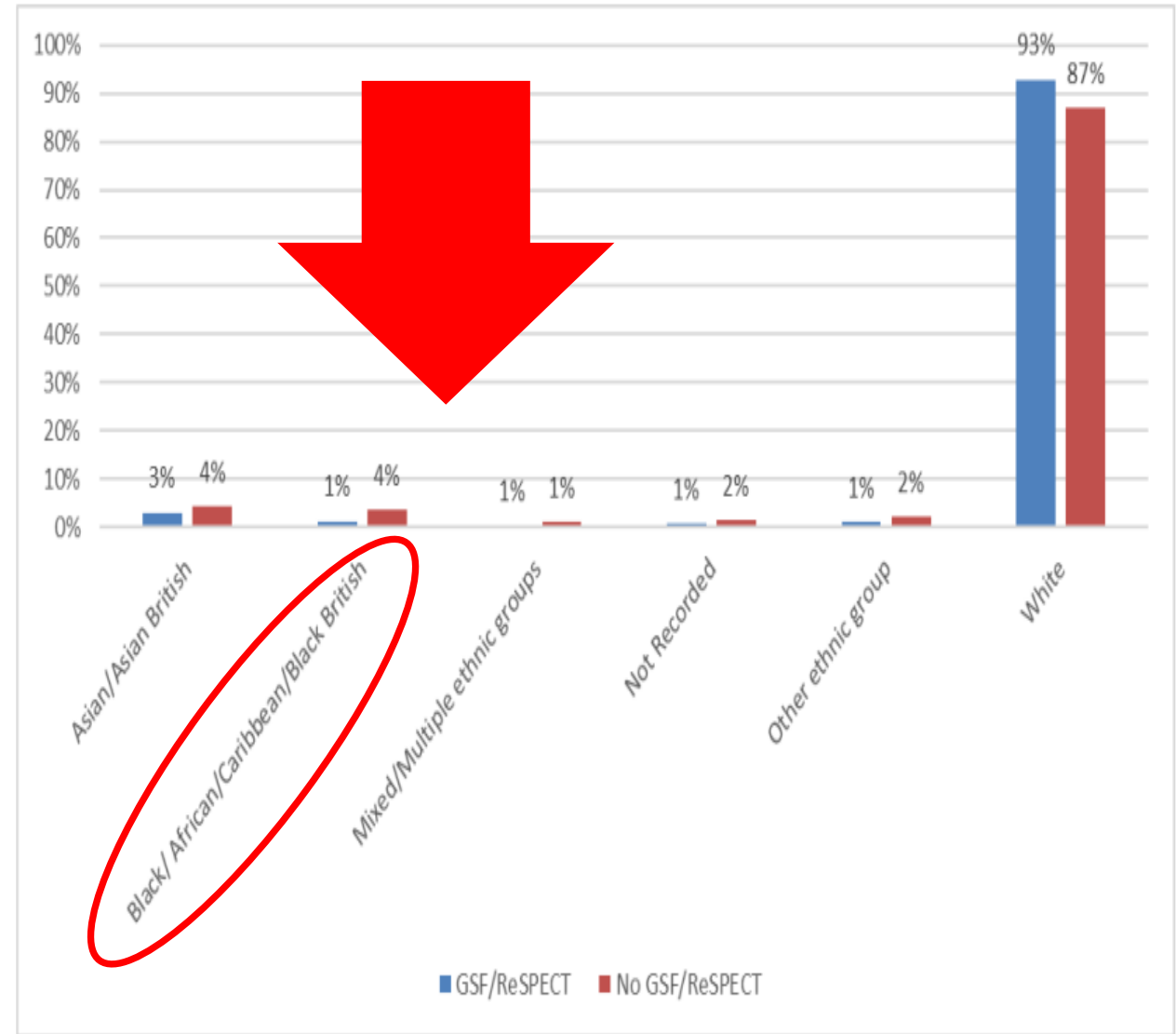
- Recognised
- ACP started

• Note: 2023-24 data has been enhanced using the ReSPECT data received from Leeds Teaching Hospital PPM+

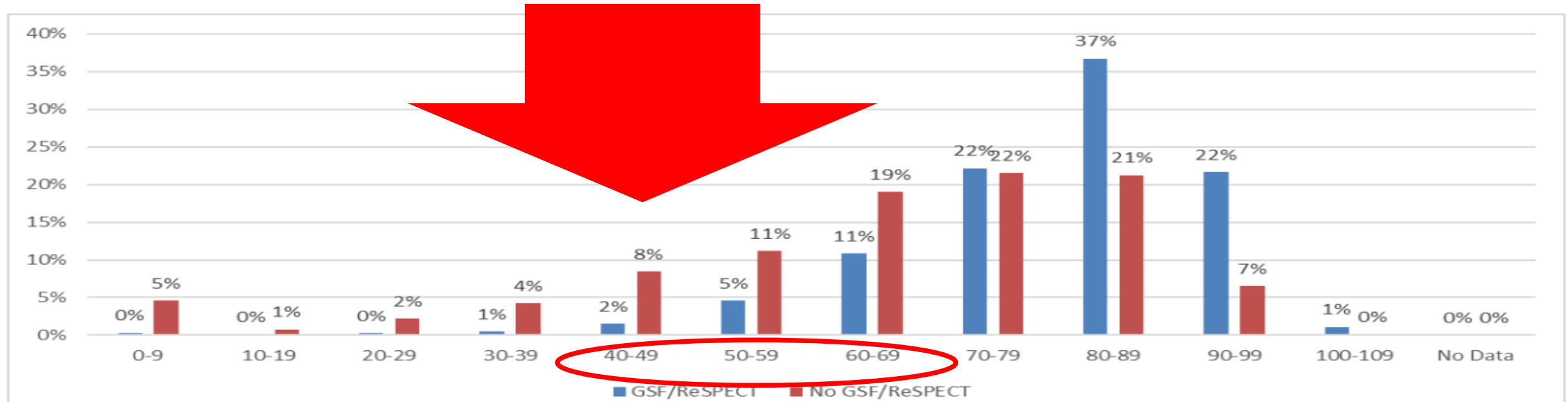
# Sex



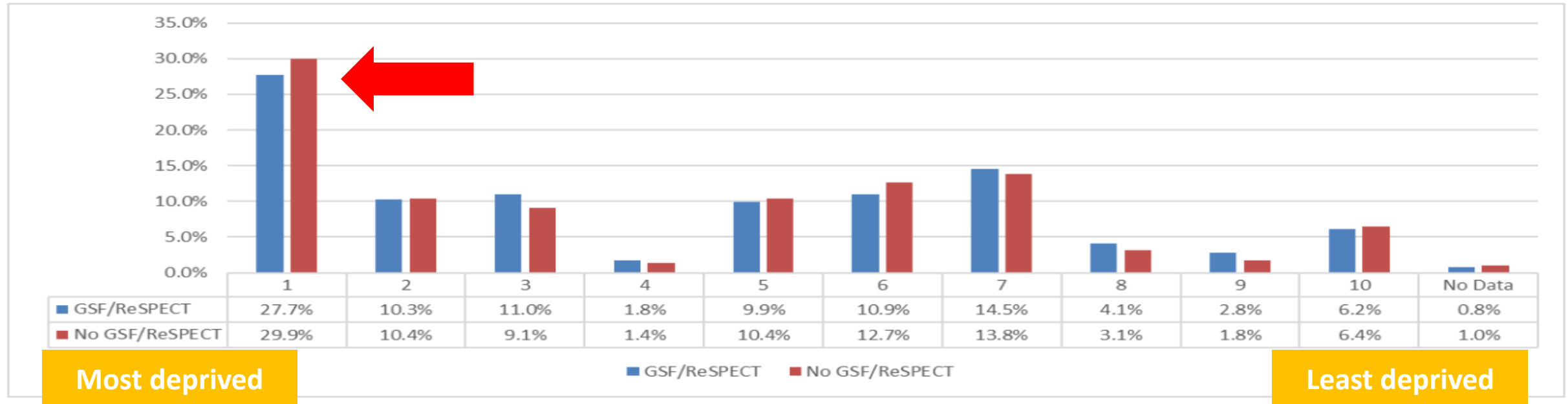
# Ethnicity



# Age Band

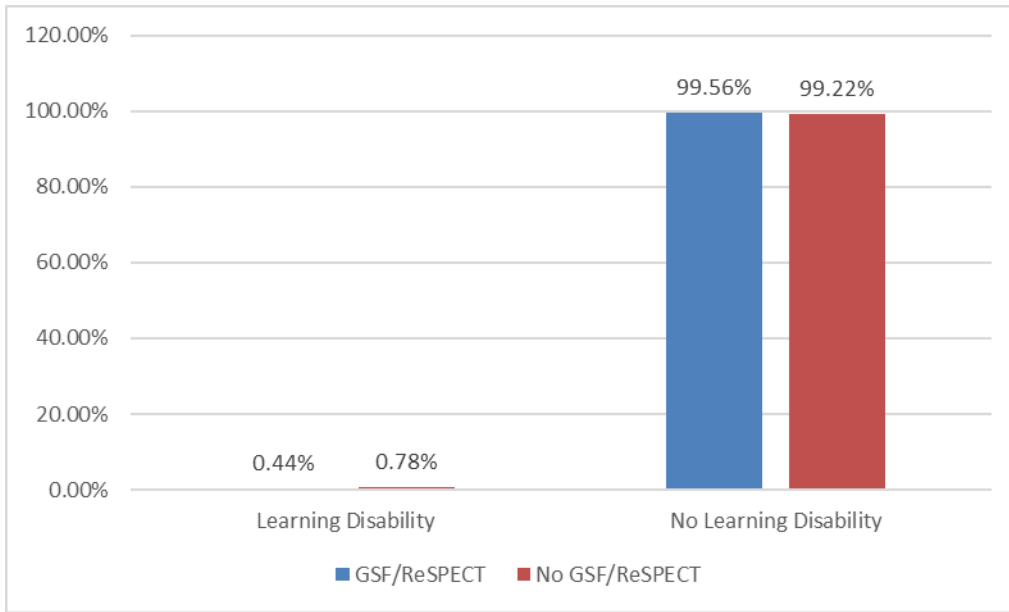


# IMD Decile

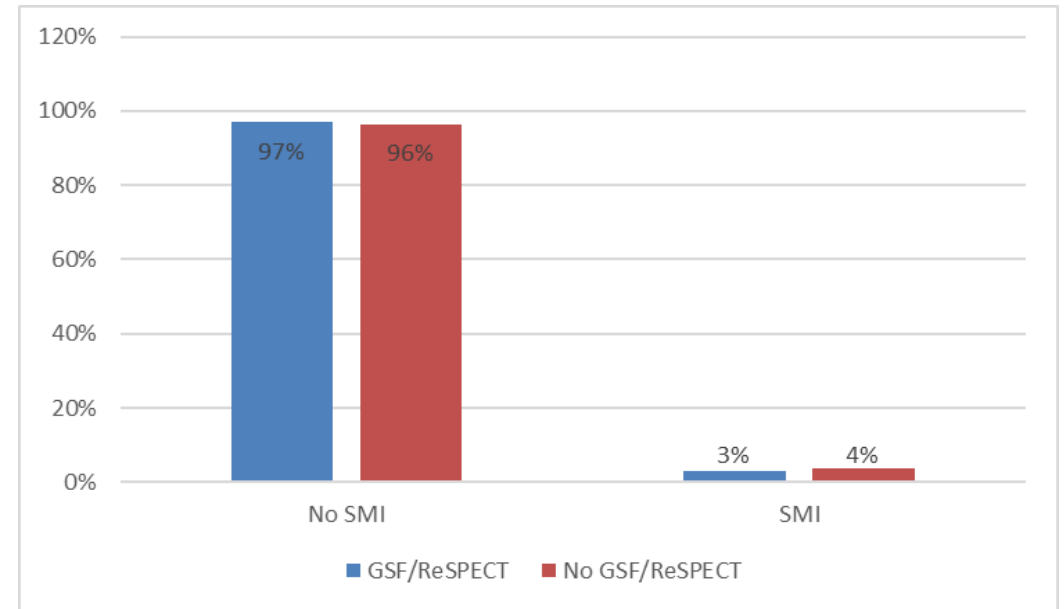




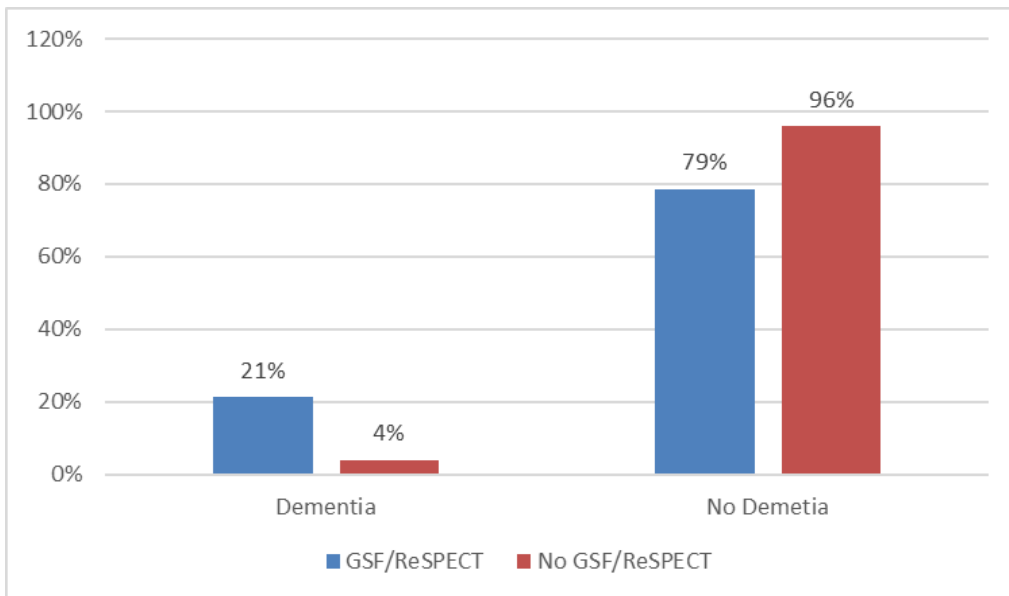
## Learning Disability



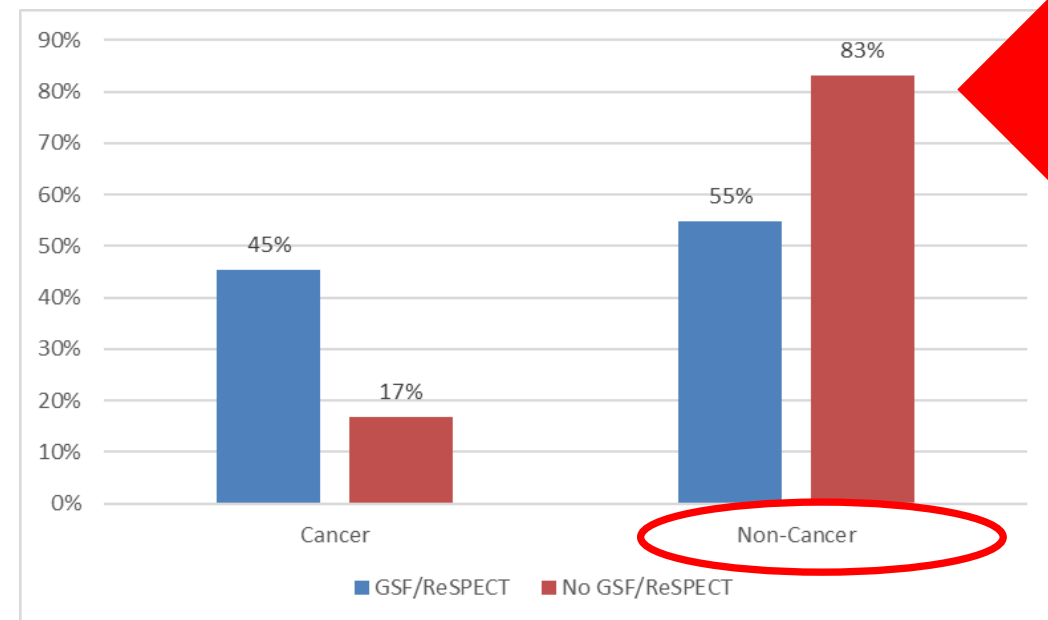
## Serious Mental Illness



## Dementia

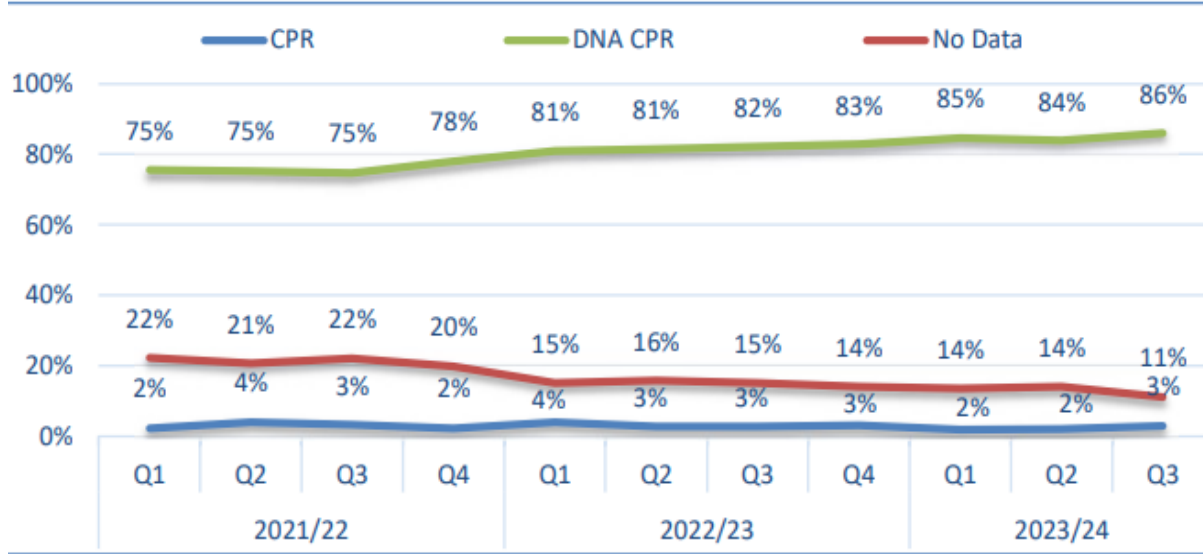


## Cancer (at any time)/Non-Cancer

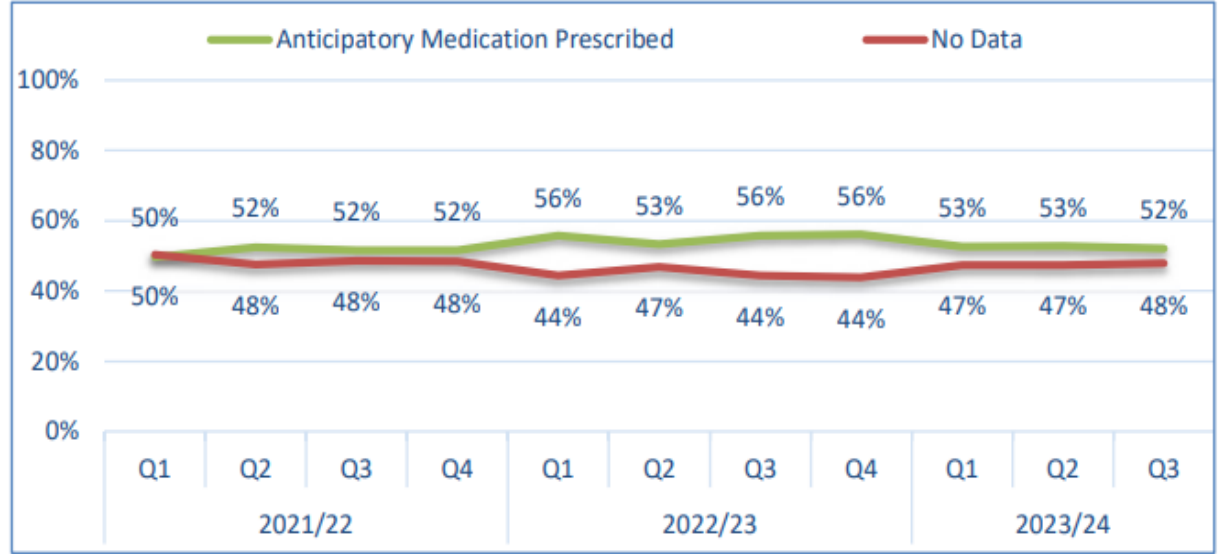


# Quality of ACP: Planning Ahead

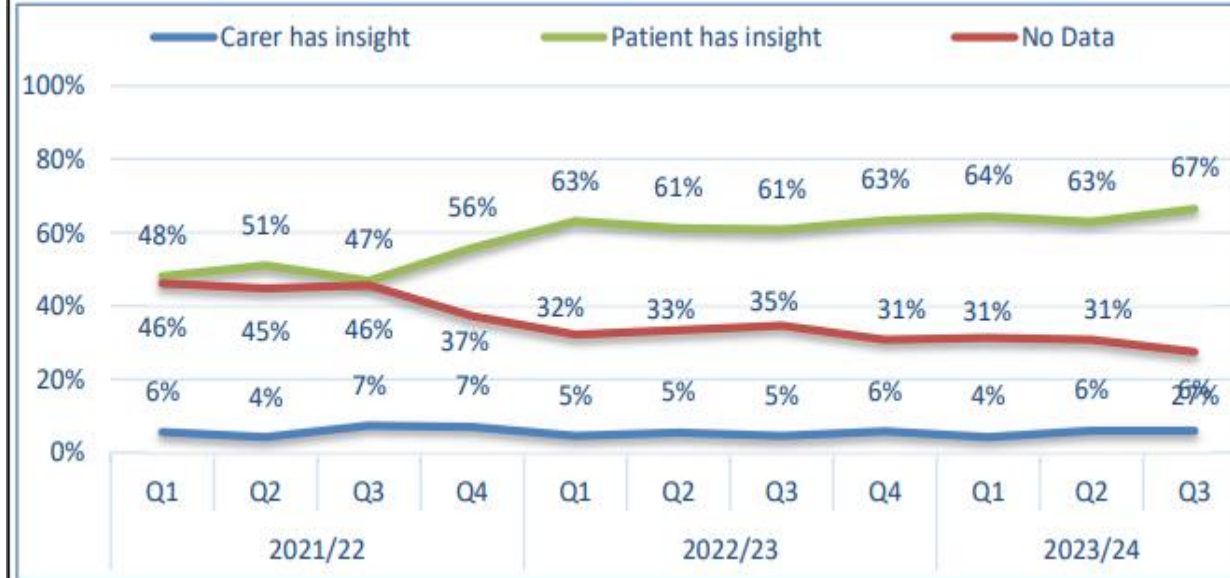
## CPR Recommendation



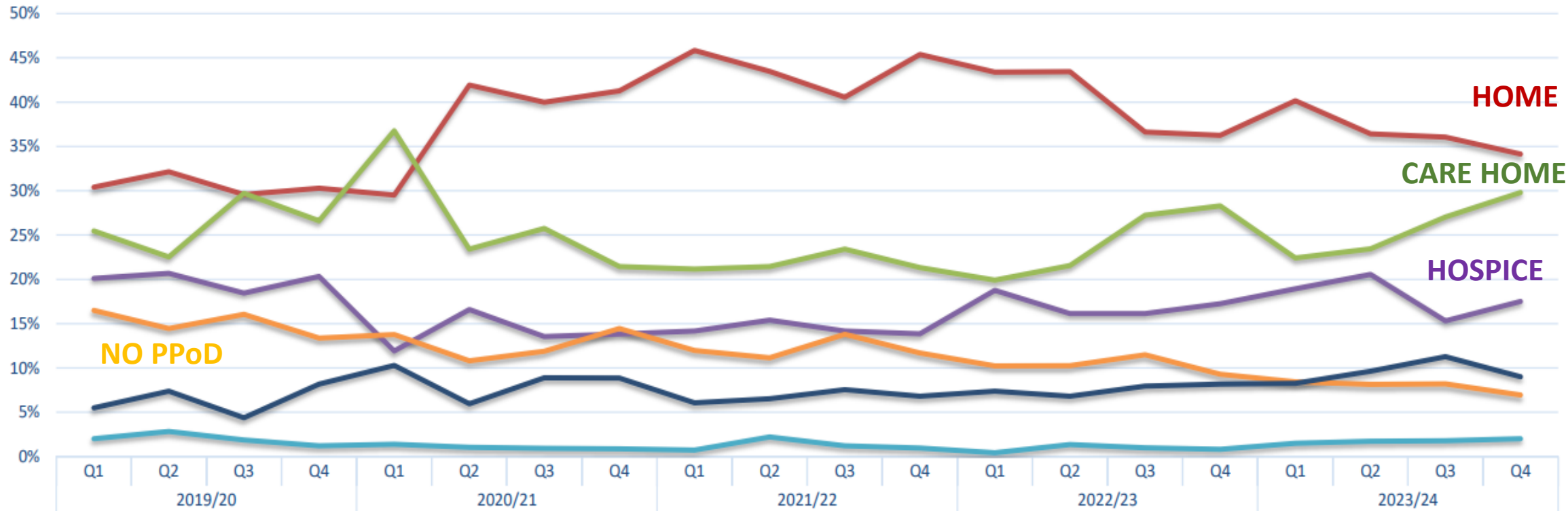
## Anticipatory Medication



## Insight



# Quality : PPOD



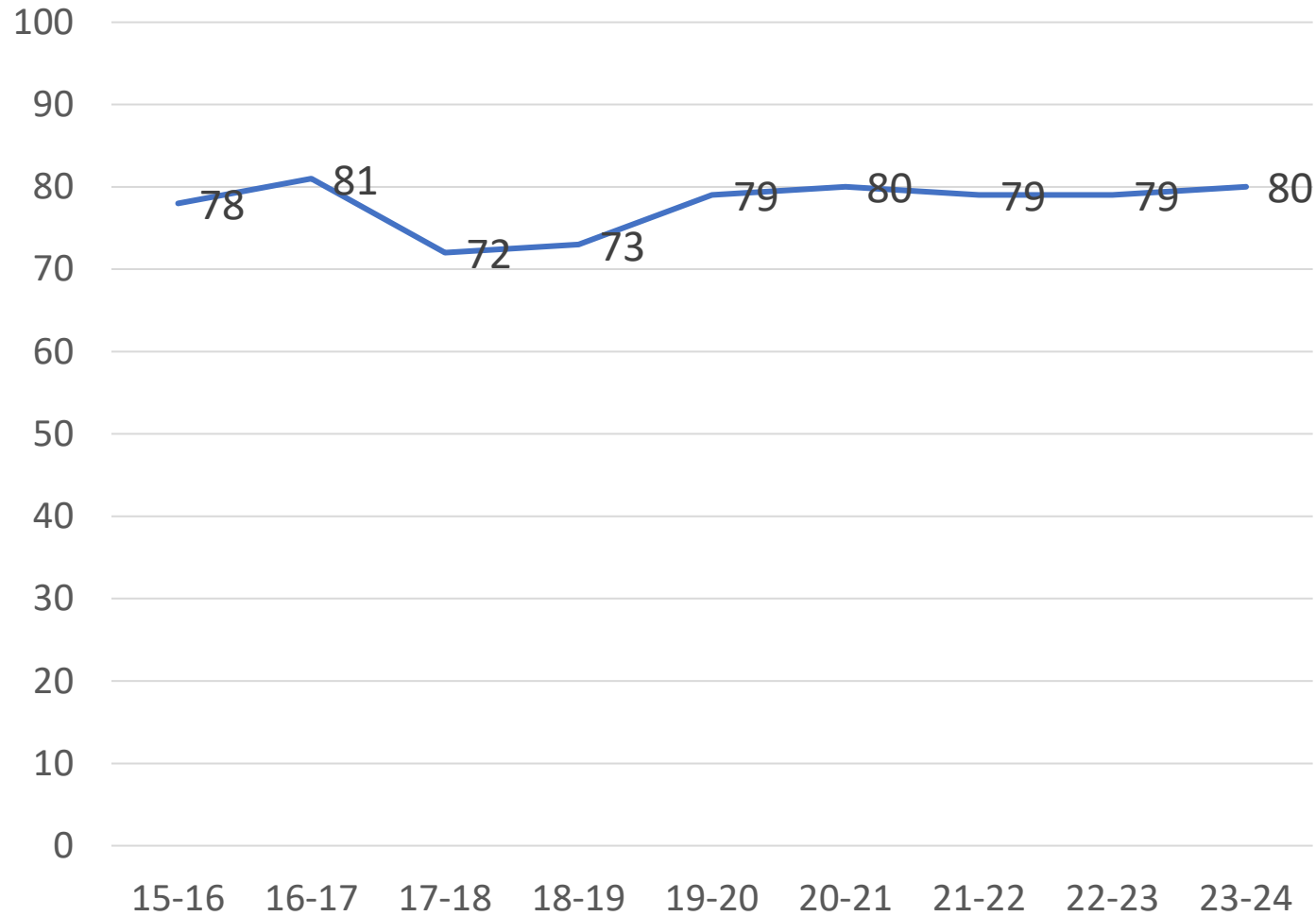
	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4
	2019/20				2020/21				2021/22				2022/23				2023/24			
Home	30%	32%	30%	30%	30%	42%	40%	41%	46%	43%	41%	45%	43%	43%	37%	36%	40%	36%	36%	34%
Care Home	25%	23%	30%	27%	37%	23%	26%	21%	21%	21%	23%	21%	20%	22%	27%	28%	22%	23%	27%	30%
Hospice	20%	21%	18%	20%	12%	17%	14%	14%	14%	15%	14%	14%	19%	16%	16%	17%	19%	21%	15%	18%
Hospital	2%	3%	2%	1%	1%	1%	1%	1%	1%	2%	1%	1%	0%	1%	1%	1%	2%	2%	2%	2%
No PPOD	16%	14%	16%	13%	14%	11%	12%	14%	12%	11%	14%	12%	10%	10%	12%	9%	8%	8%	8%	7%
Undecided/Declined	5%	7%	4%	8%	10%	6%	9%	9%	6%	7%	8%	7%	7%	7%	8%	8%	8%	10%	11%	9%

15% No PPOD

8% No PPOD

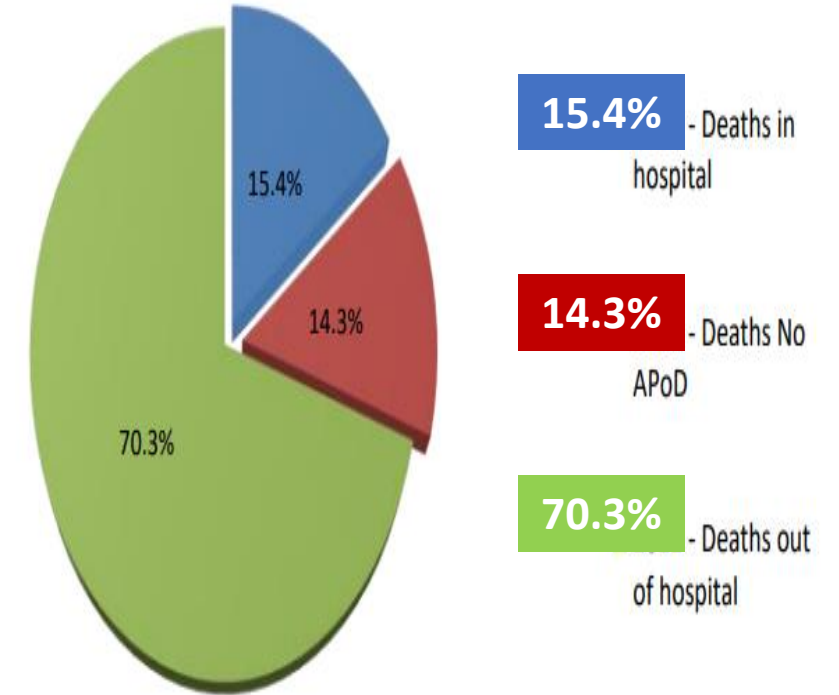
# Outcomes: PPOD Achieved

% Achieved preferred place of death



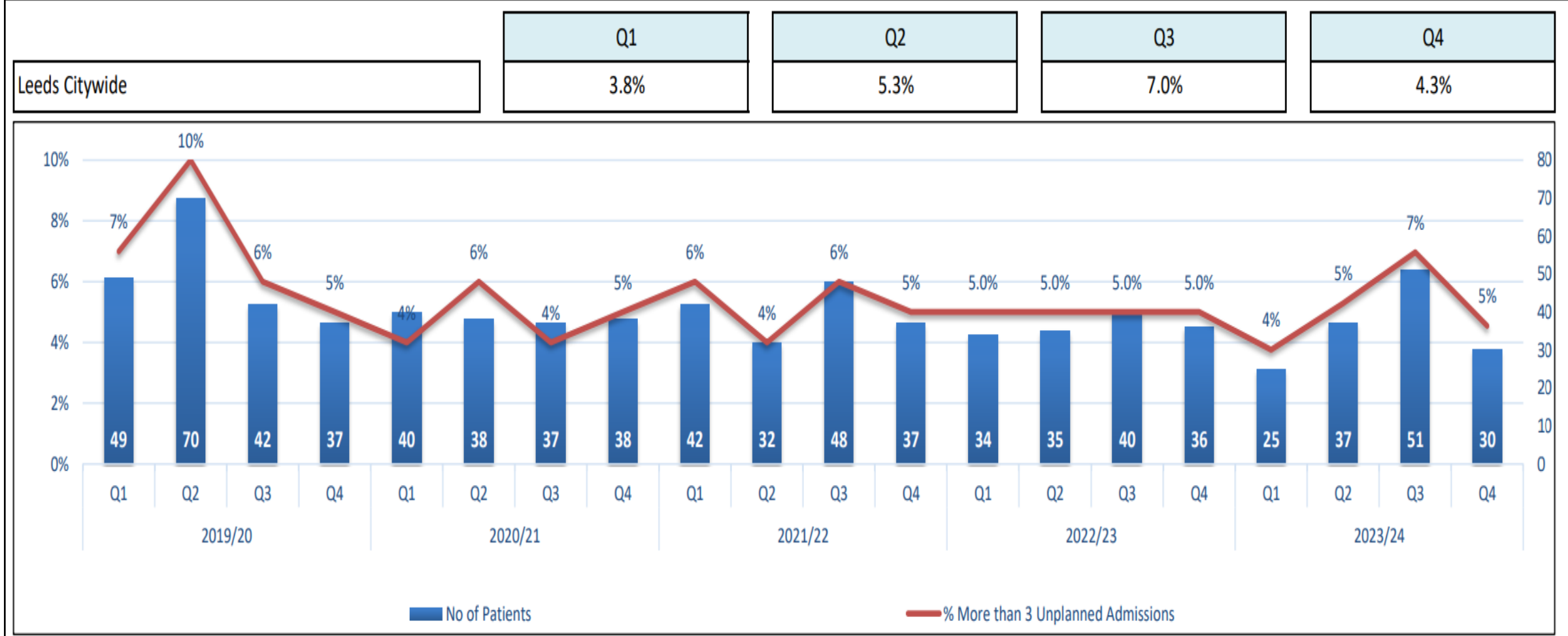
**44% OVERALL DIED IN HOSPITAL (2002)**

2023-24 - EPaCCS Deaths - In/Out of Hospitals



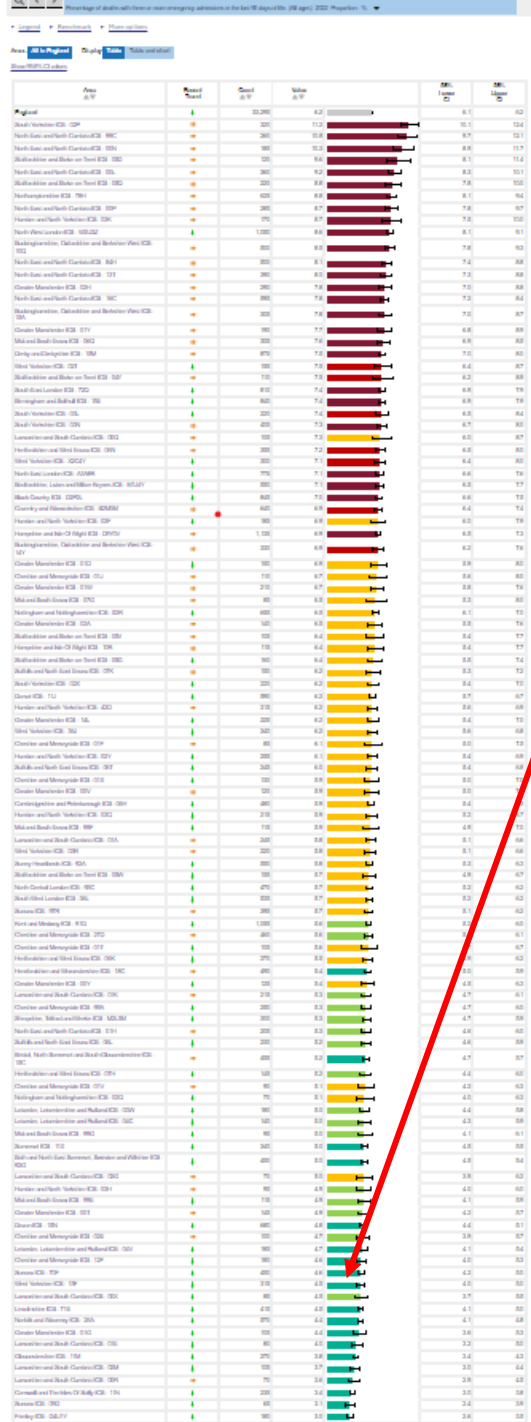
# Outcomes: 3 or more unplanned admissions last 90days

C2.9 Percentage of deceased EPaCCS patients with 3 or more Unplanned Admissions (Non-Elective Inpatient) in the last 90 days of their life.



% with 3 or more unplanned hospital admissions in last 90 days (2022): all deaths

Palliative and End of Life Care Profiles - Data - OHID (phe.org.uk)



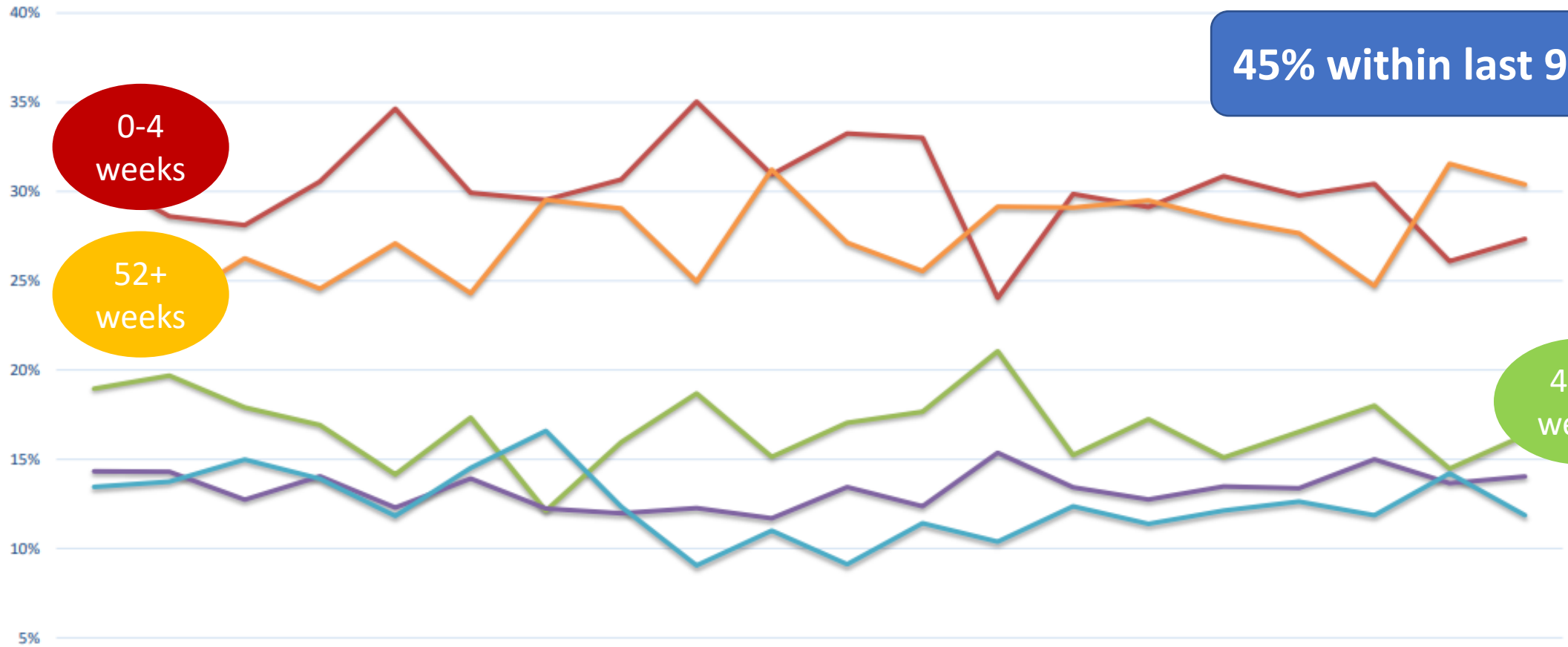
Leads 4.5%

Sussex ICB - 70F	↓	450	4.6
<b>West Yorkshire ICB - 15F</b>	↓	315	<b>4.5</b>
Lancashire and South Cumbria ICB - 00X	↓	85	4.5
Lincolnshire ICB - 71E	↓	415	4.5
Norfolk and Waveney ICB - 26A	↓	570	4.4
Greater Manchester ICB - 01G	↓	105	4.4
Lancashire and South Cumbria ICB - 01E	↓	80	4.0
Gloucestershire ICB - 11M	↓	270	3.8
Lancashire and South Cumbria ICB - 02M	↓	105	3.7
Lancashire and South Cumbria ICB - 00R	↔	70	3.6
Cornwall and The Isles Of Scilly ICB - 11N	↓	235	3.4
Sussex ICB - 09D	↓	65	3.1
Frimley ICB - D4U1Y	↓	180	3.0

Source: Hospital Episode Statistics (HES) data from NHS Digital linked to ONS Mortality database

[Indicator Definitions and Supporting Information](#)

# Time (weeks) with Planning Ahead: %



45% within last 90 days

0-4 weeks

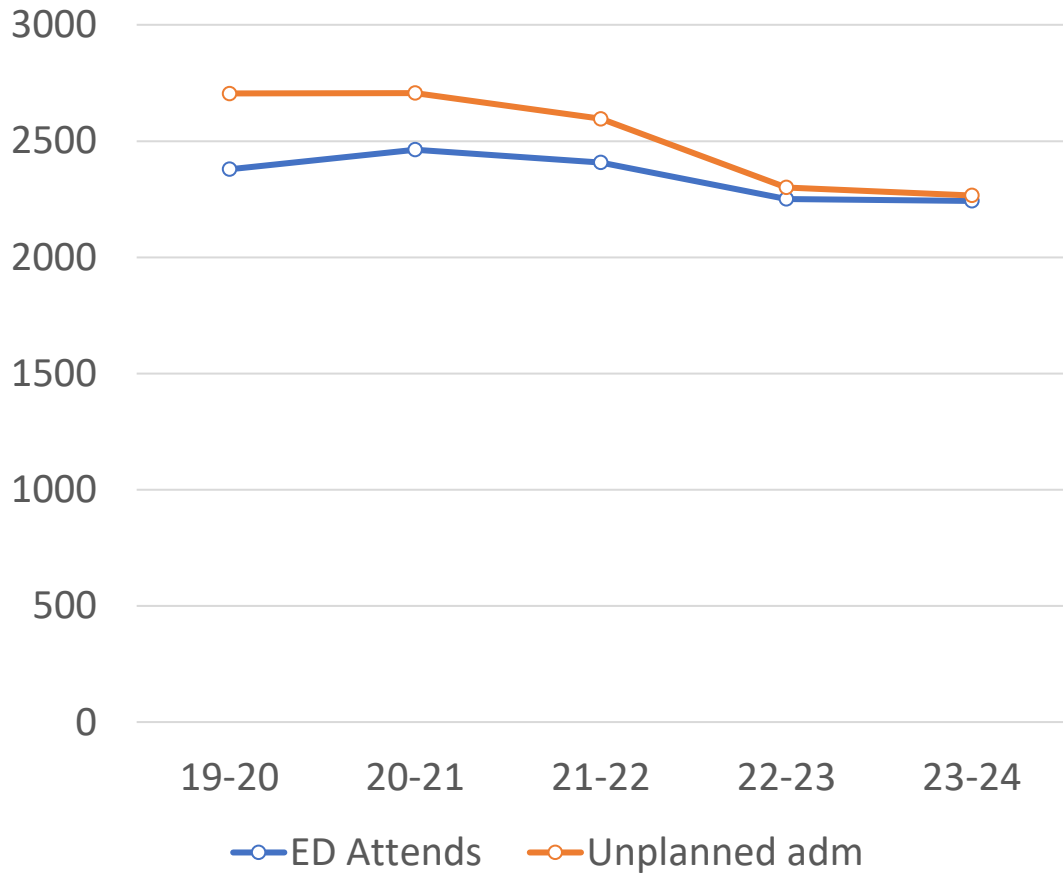
52+ weeks

4-12 weeks

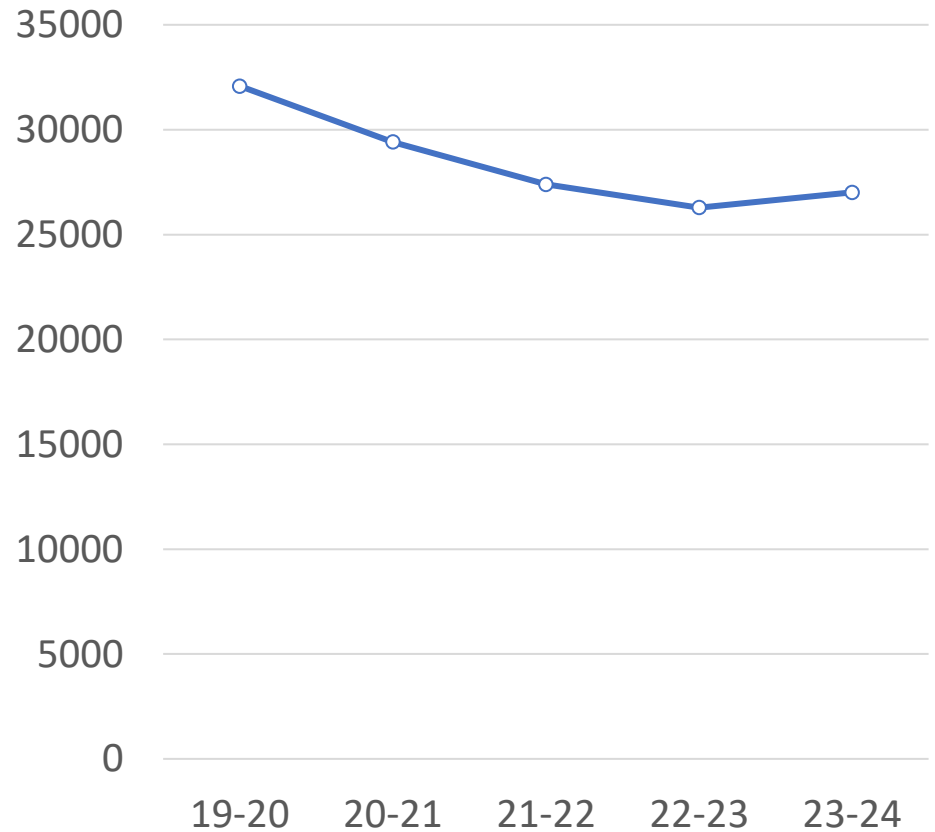
	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4
	2019/20				2020/21				2021/22				2022/23				2023/24			
0-4 weeks	31%	29%	28%	31%	35%	30%	30%	31%	35%	31%	33%	33%	24%	30%	29%	31%	30%	30%	26%	27%
4-12 weeks	19%	20%	18%	17%	14%	17%	12%	16%	19%	15%	17%	18%	21%	15%	17%	15%	17%	18%	14%	16%
12-26 weeks	14%	14%	13%	14%	12%	14%	12%	12%	12%	12%	13%	12%	15%	13%	13%	13%	13%	15%	14%	14%
26-52 weeks	13%	14%	15%	14%	12%	15%	17%	12%	9%	11%	9%	11%	10%	12%	11%	12%	13%	12%	14%	12%
52+ weeks	22%	24%	26%	25%	27%	24%	30%	29%	25%	31%	27%	26%	29%	29%	30%	28%	28%	25%	32%	30%

# Hospital Utilisation last 90 days: EPaCCS/GSF

No: ED attendances and unplanned admission last 90 days from EPaCCS population

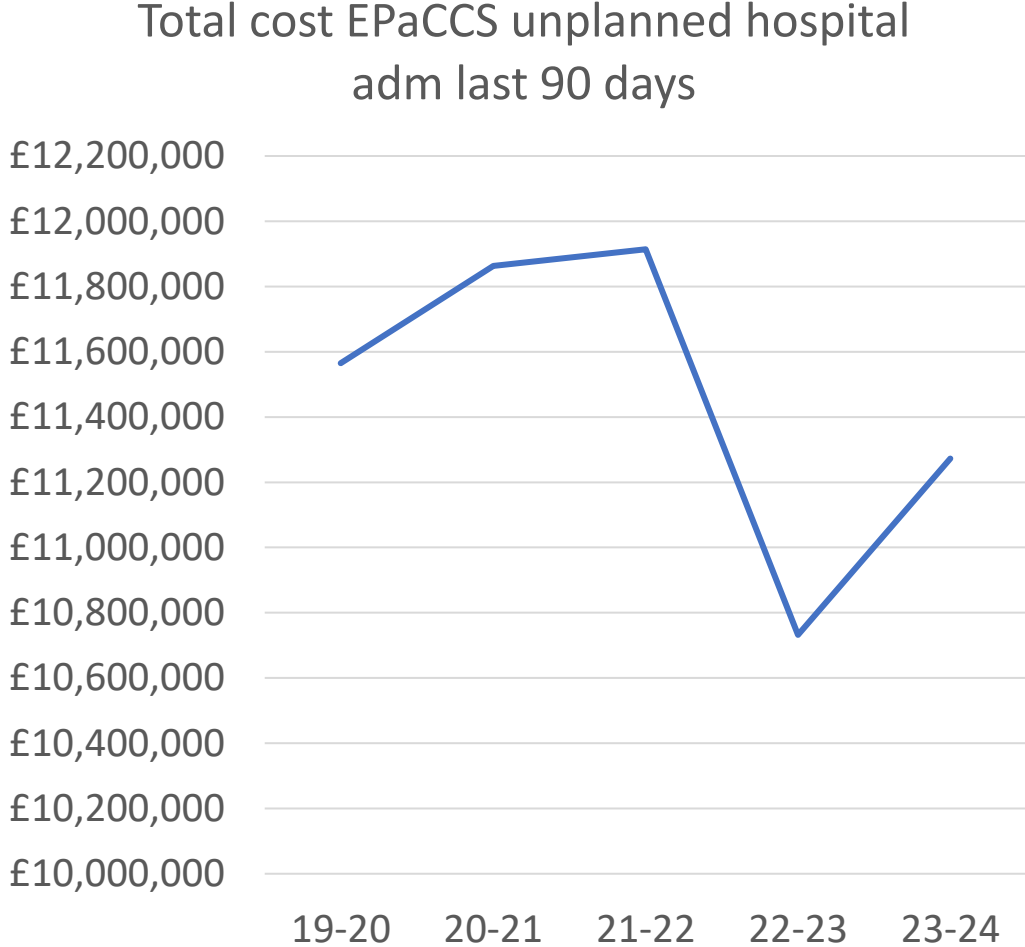
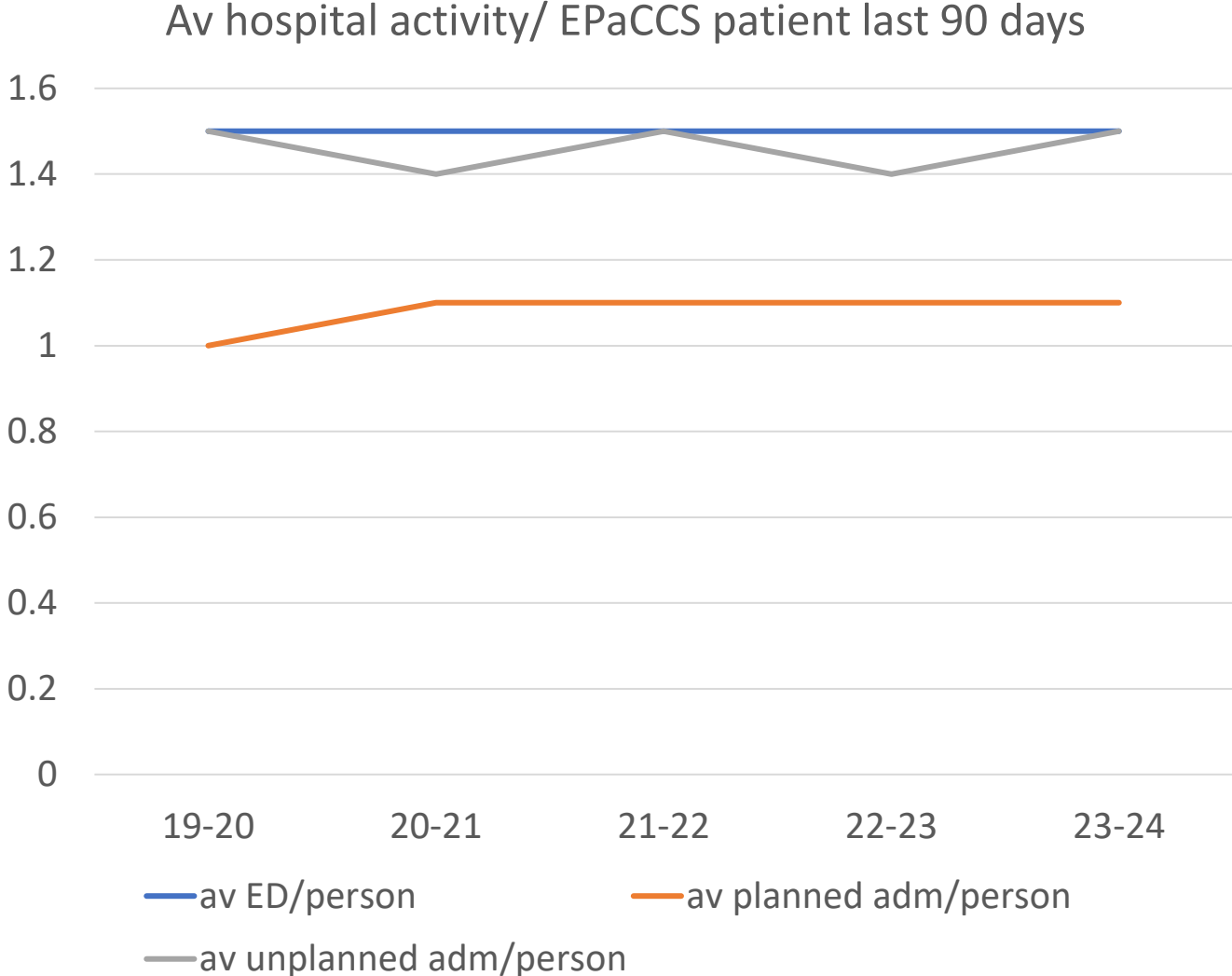


Total number of bed days EPaCCS patients last 90- days





# Hospital Utilisation last 90 days: EPaCCS/GSF



# Hospital Utilisation last 90 days: EPaCCS/GSF –cost/person

Hospital activity 23-34	Cost/person
ED attendance	£397
Planned admission	£3663
Unplanned admission	£7397

**Table 4: Summary costs of hospital care**

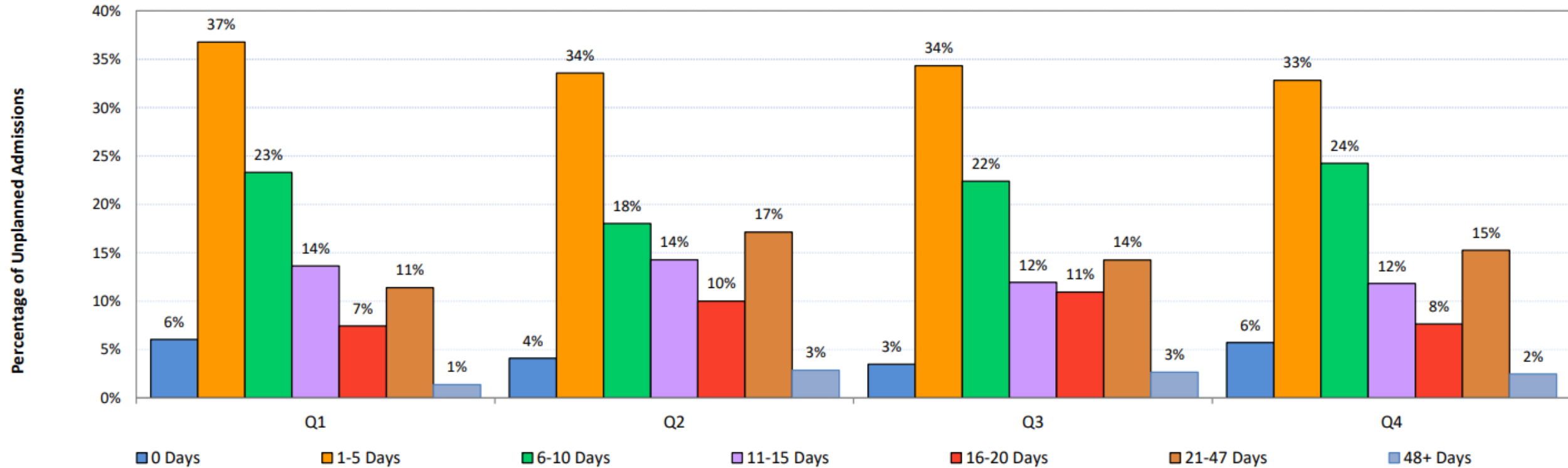
Group	No. deaths	Cost of care in final 90 days, per person (standard deviation)				
		Emergency inpatient admissions	Non-emergency inpatient admissions	Outpatient attendances	A&E visits	Total
All people	1,286,005	£3,465 (£3,912)	£822 (£2,730)	£211 (£511)	£82 (£94)	£4,580 (£4,915)
Cancer diagnosis final two years	485,847	£4,071 (£4,077)	£1,360 (£3,289)	£378 (£714)	£80 (£95)	£5,890 (£5,264)
No cancer diagnosis	800,158	£3,096 (£3,760)	£496 (£2,264)	£110 (£288)	£83 (£94)	£3,785 (£4,509)

x inflation	
Emergency	£5366
Non-emergency	£1273
ED	£127



Georghiou, T. and Bardsley, M., 2014. Exploring the cost of care at the end of life. *London: Nuffield Trust Research Report*. Hospital admissions April 2009 to March 2012

# Hospital Utilisation last 90 days: Duration unplanned admissions



# LPCN: work programme & priorities

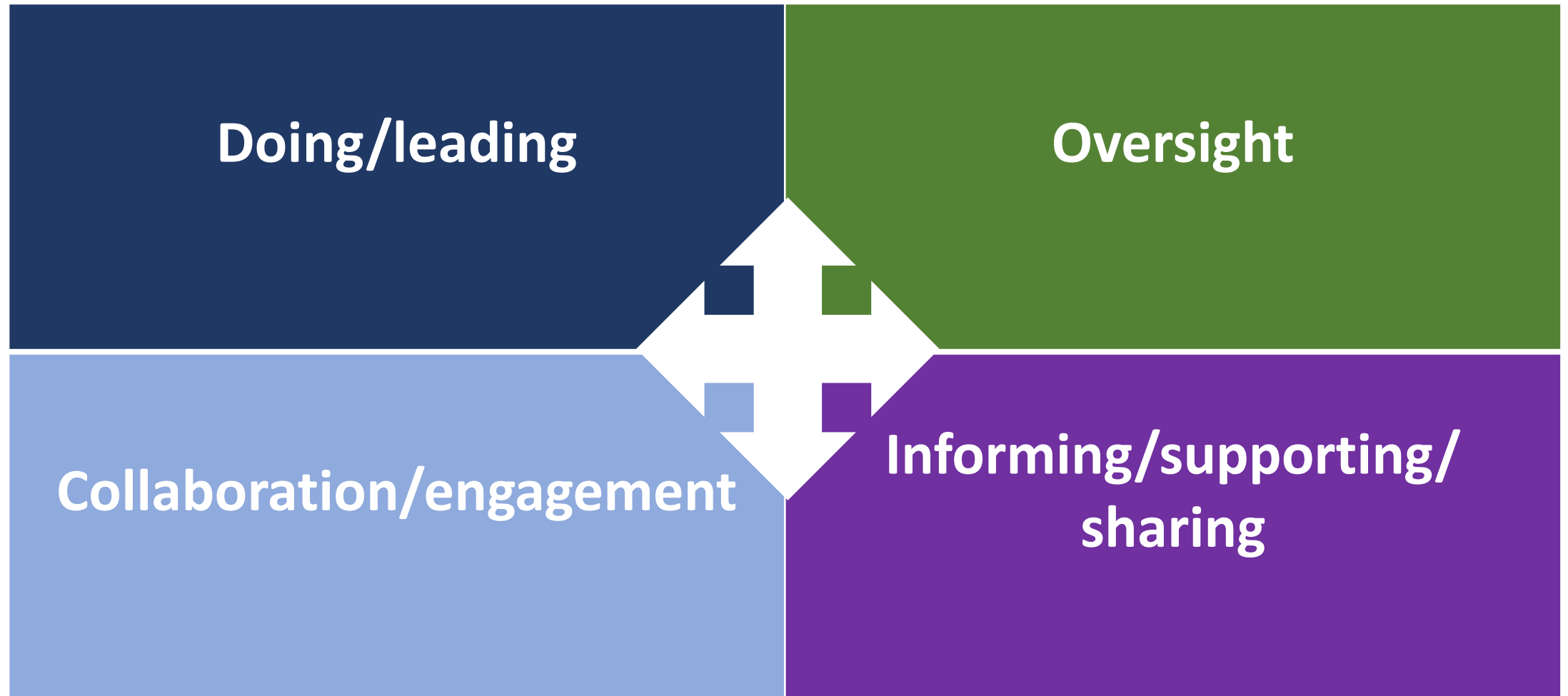
July 24

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# LPCN work programme: components

- Projects - task and finish (10)
- Groups/workstream – indefinite duration &/or overseeing T&F groups (9)
- Services - clinical/non-clinical (2)
- Education and training (7)

# LPCN: how does it work?



Project = 10	Group/Workstream = 9	Service = 2	Education = 7
<b>Community / Citywide ReSPECT Audit</b> - delayed, due 09/24	<b>Improving Planning Ahead (ReSPECT/EPaCCS)</b> - template maintenance, training/ l/w teams re sharing data	<b>5 Homelessness (Inclusion) Service</b>	<b>Communication Skills Training</b> (scoping)
<b>Timely Recognition of phase 2</b> - digital screening tool for patients approaching EoL	<b>Respiratory /Breathlessness Pathway</b> - reviewing patient experience and care pathways	<b>Website</b>	<b>Planning Ahead Training</b> (delivery)
<b>Leeds Dying Well in the Community Phase 2: Service Offer / Integration project</b> - sharing findings,(?Morley)	<b>Equality Diversity and Inclusion</b> - training, scoping, LD information	<b>Heart failure</b> - MDT to SGH, QI stopping	<b>ECHO System / Tele-education</b> (delivery)
<b>Anticipatory medication review: audit just out (EIP)</b>	<b>Leeds Palliative Care Ambulance</b> - support ops Group and service improvement		<b>Care Home Education Review</b> (next steps)
<b>Bereaved Carer's Survey:</b> - ? Future r/v Sept 24	<b>Dying Matters</b> - citywide programme of initiatives and activities		<b>Review Leeds ACP training</b> (next steps)
<b>Carers page in website</b> - to improve useful information available to the public	<b>Evidence into Practice / Research</b>		<b>Support Homelessness Citywide Training</b> (delivery inc. WY)
<b>Whole city EOL linked data</b>	<b>Transfer of Care - Hospital to Hospice</b> - optimise transfer of care from LTHT to Leeds hospices		<b>LTHT CSW Clinical Educator project</b> (delivery)
<b>EOLC Metrics</b>	<b>Informatics and Metrics Group</b>		
	<b>13b Leeds Dying Well in the Community Phase 2</b> • Service Offer / Integration project <span style="display:inline-block; width:10px; height:10px; background-color: #FF69B4; border: 1px solid black;"></span> • Scoping a P&EOL SPA for Leeds (?stop) <span style="display:inline-block; width:10px; height:10px; background-color: #A9A9A9; border: 1px solid black;"></span> • Adequate Resources (?stop) <span style="display:inline-block; width:10px; height:10px; background-color: #A9A9A9; border: 1px solid black;"></span>		
<b>Review &amp; agree possible training EOL &amp; EDI- May 24</b>	<b>West Yorkshire urgent supply of palliative care drugs service (completed)</b>		
<b>Review LD Resources and other supporting documents for people requiring PEOLC –May 24</b>	<b>Improving EOLC for people living with Dementia (closing)</b>	<b>Other:</b>  • <b>Supporting Leeds EoLC Board/ICB</b> • <b>Supporting WY ICB</b>	
<b>Improving EOLC Heart Failure – defunded</b>			
<b>LTHT ReSPECT Audit (completed)</b>			
<b>Electronic Prescribing in the Hospice Out Patient / Community setting (on hold)</b>			

# Priorities

- **Community / Citywide ReSPECT Audit**
  - no citywide evaluation since implemented, no other group over-seeing ReSPECT
- **Timely Recognition Phase 2**
  - externally funded, earlier/greater recognition of P&EoLC need
- **Leeds Dying Well in the Community Phase 2: Service Offer / Integration project**
  - dissemination of locality (Seacroft) findings, (? progress to Morley)
- **Improving Planning Ahead (ReSPECT/EPaCCS)**
  - single ReSPECT/person in Leeds, risk
- **Respiratory /Breathlessness Pathway**
  - pre-existing group, aligns with city priorities
- **Anticipatory medication review:**
  - audit just out (EIP) - ? Waste reduction



**Thank you for listening**

