

# Insights from the Hospice UK Activity & Workforce Surveys Webinar

23 May 2024



# Big Conversations

We're excited to announce the launch of the Big Conversations which comprises of a series of webinars, workshops, and roundtables that will enable our members to:

- learn more about key issues
- share your knowledge and experience to inform our work
- discuss problems and solutions with your peers
- get practical guidance to move work forward.

We hope that you will join us over the coming weeks and months to find out more about topics such as complexity and cost, nursing career frameworks and racial equity.

## Agenda

14:00	Welcome	Annette Alcock, Director of Programmes, Hospice UK
14:05	Hospice Activity Data 2023	Annette Alcock, Director of Programmes, Hospice UK
14:15	Hospice Clinical Workforce Data 2023	Anita Hayes, Clinical Quality Lead, Hospice UK
14:25	Using the Data	Annette Alcock, Director of Programmes, Hospice UK
14:35	PopNAT	Ian Appleby, Gavurin
14:55	Prototyping demographic data comparisons	Richard Cooper, Data Manager, Hospice UK
15:10	Questions	All
15:25 – 15:30	Close	Annette Alcock, Director of Programmes, Hospice UK

# What data are we talking about?

## Population data

- [PopNAT tool](#) (adding hospice catchments)
- Future and unmet needs calculations

WHAT  
NEXT

## Service activity data

- Activity and patient demographic survey
- [Patient safety measures](#)

## Workforce data

- Clinical workforce survey

WHAT

## Financial data

- [Hospice accounts and financial benchmarking](#)
- [Financial sustainability index](#)

## Outcomes / impact data

- [PCOM360 tool](#) (patient outcome measures)
- [Making Data Count](#) (trends and outliers)

SO  
WHAT

# Hospice Activity Data 2023

Annette Alcock, Director of Programmes,  
Hospice UK

# Reach of UK hospice care

*There was an overall hospice response rate of 80% for the activity survey and 73% for the workforce survey. Data is for 2023 and for all UK hospices, unless stated.*

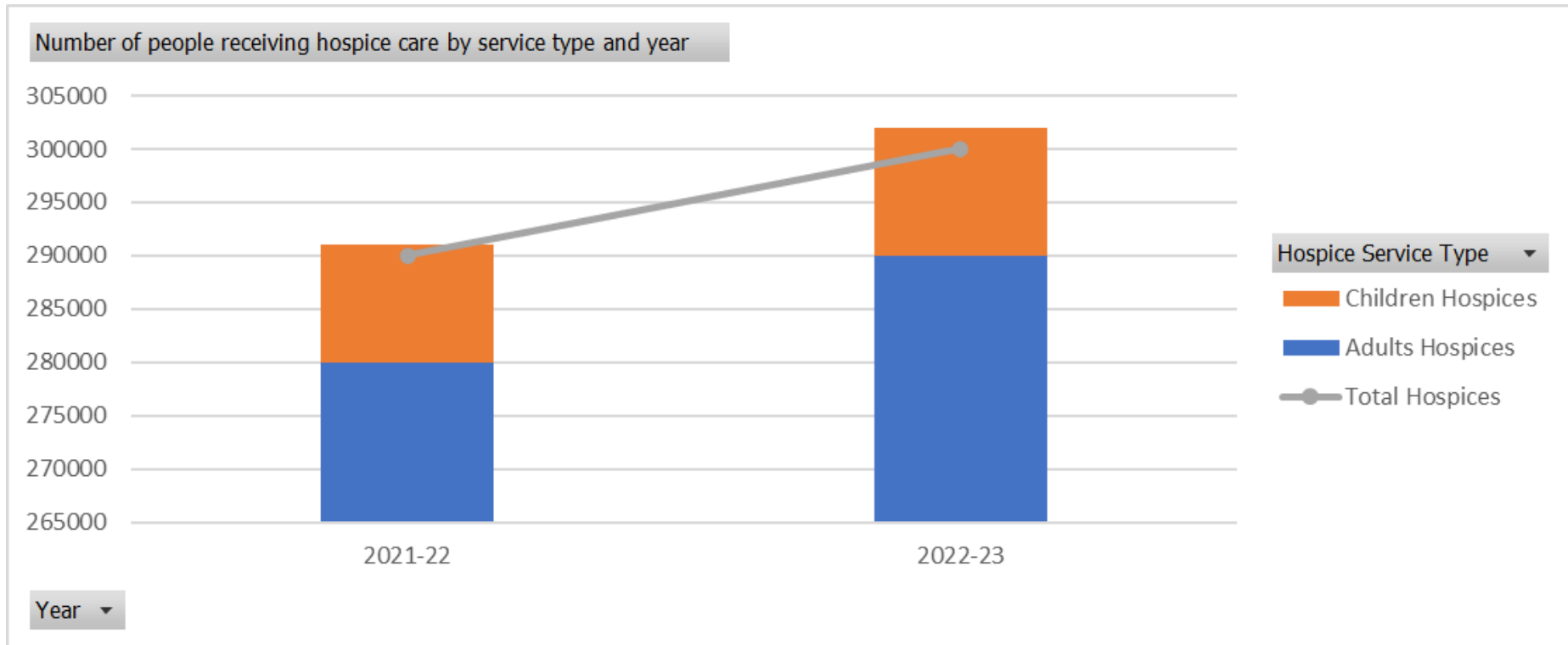
## Number of people receiving hospice care

UK hospices provide palliative and end of life care to **300,000 people** annually

UK hospices provide direct support services to **59,000 loved ones and carers** annually. 76 percent of these services are specifically bereavement care.

**Reflection:** *are we fully recording care to loved ones and carers*

# Starting to track reach over time



**Reflection:** *despite challenges, our reach is still increasing year on year*

# Comparison across the UK

Across the UK, you can look at the number of people receiving hospice care and the number of registered deaths. However, you cannot use the two figures to get a percentage as they do not directly correlate.

Country	Number of people receiving care 2022-23	Registered deaths in 2022
<i>UK Total</i>	<i>300,000</i>	<i>656,997</i>
England	260,000	540,333
Scotland	18,000	62,941
Wales	13,000	35,694
NI	11,000	17,159



# Inpatient activity data

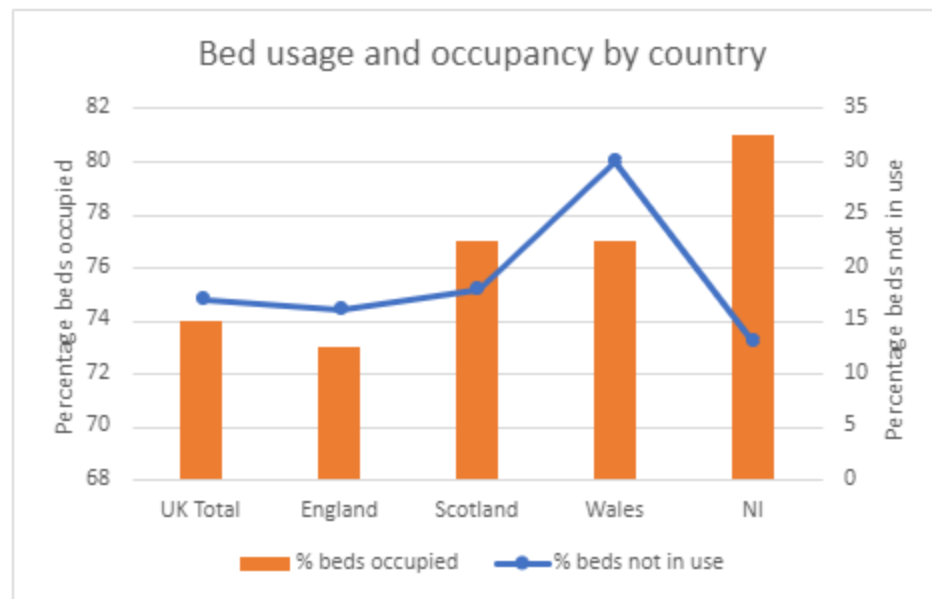
83 percent of hospice services provide inpatient beds

The registered capacity of hospice beds is 950,000 bed-days

**17 percent**, equating to 160,000 bed-days, **is not in use** due to systemic issues such as funding, staffing, estates

**74 percent of available bed-days are occupied**, equating to 600,000 occupied bed-days

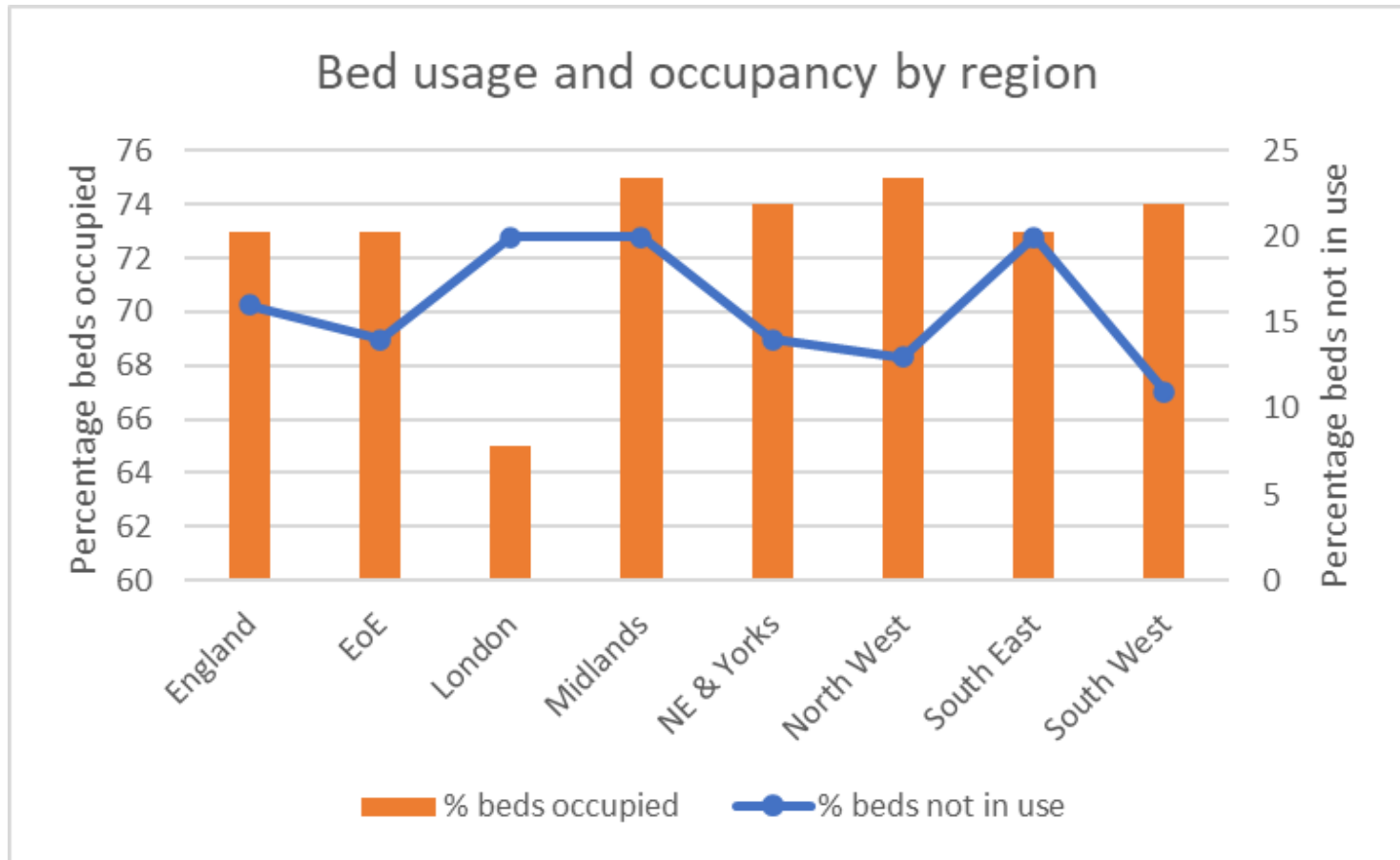
Comparison across the UK:



**Reflection:** *what is our message regarding both capacity and safety*

# Inpatient activity data

Comparison across the English regions:



# Community and outpatient activity data

82 percent of hospice services provide community services and 80 percent provide outpatient clinics and groups

There are 880,000 specialist palliative care community visits annually

There are 540,000 generalist palliative care community visits annually

There are 820,000 outpatient contacts annually

# Activity in the hospice or the community

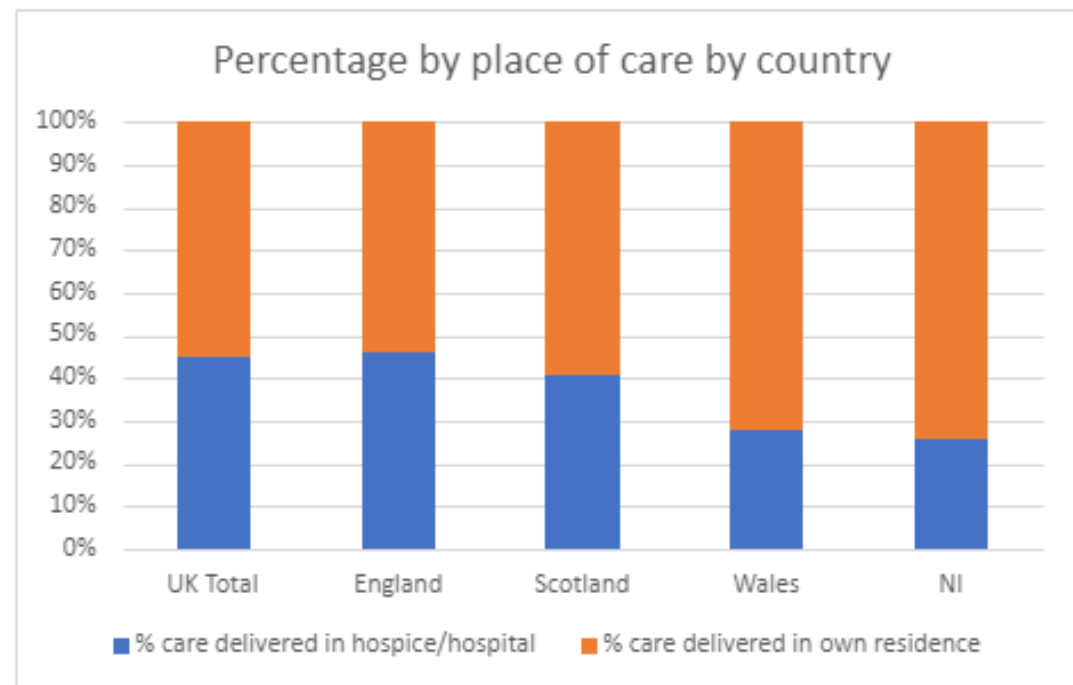
Care in the hospice includes inpatient and outpatient care

**18 percent** of total activity is delivered in a hospice **inpatient** unit

Scotland is an outlier at 28 percent

Children's hospices are 26 percent

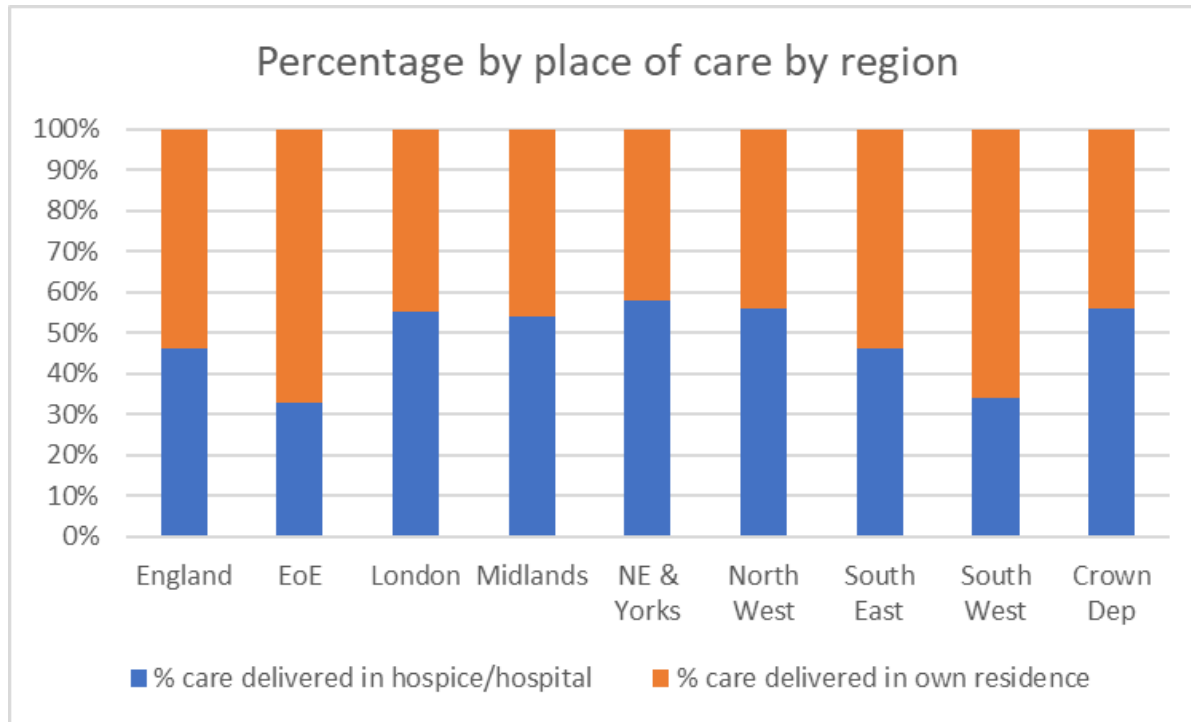
**55 percent** of total activity is delivered at the person's **place of residence**:



**Reflection:** *this underpins our policy message about hospices being not only a building; but what is the system need*

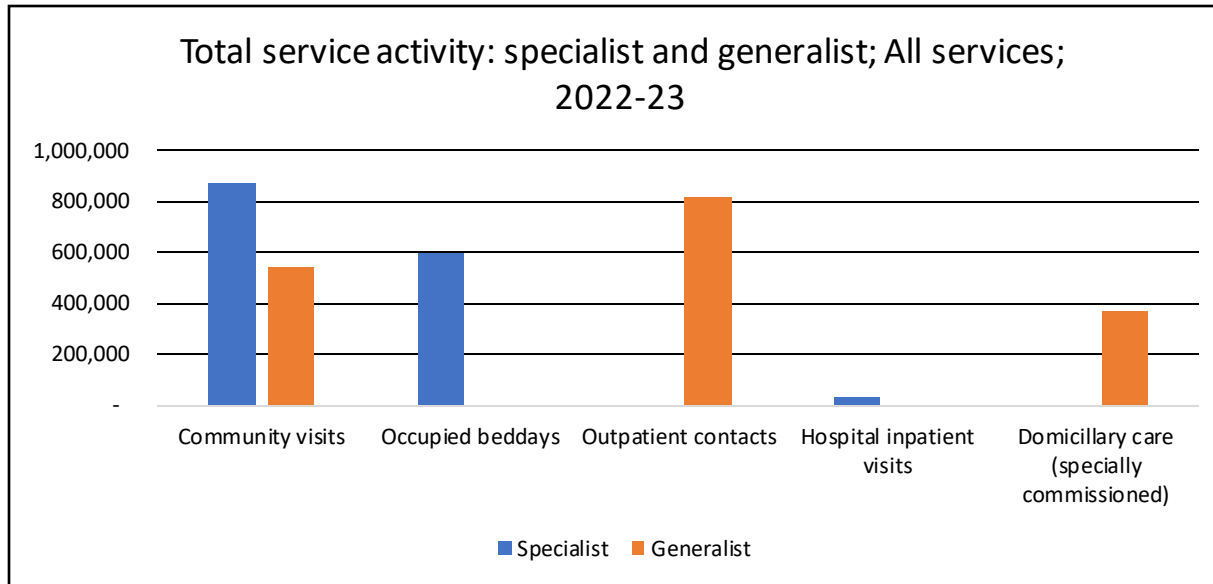
# Activity in the hospice or the community

Inpatient and outpatient care in the hospice vs community visits, comparison across the English regions:



Separately, the total activity delivered in a hospice **inpatient** unit ranges from 10 percent in the south-west to 32 percent in the north-west

# Activity broadly specialist or generalist



*Counting one unit of activity as a bed-day, an appointment, a visit*

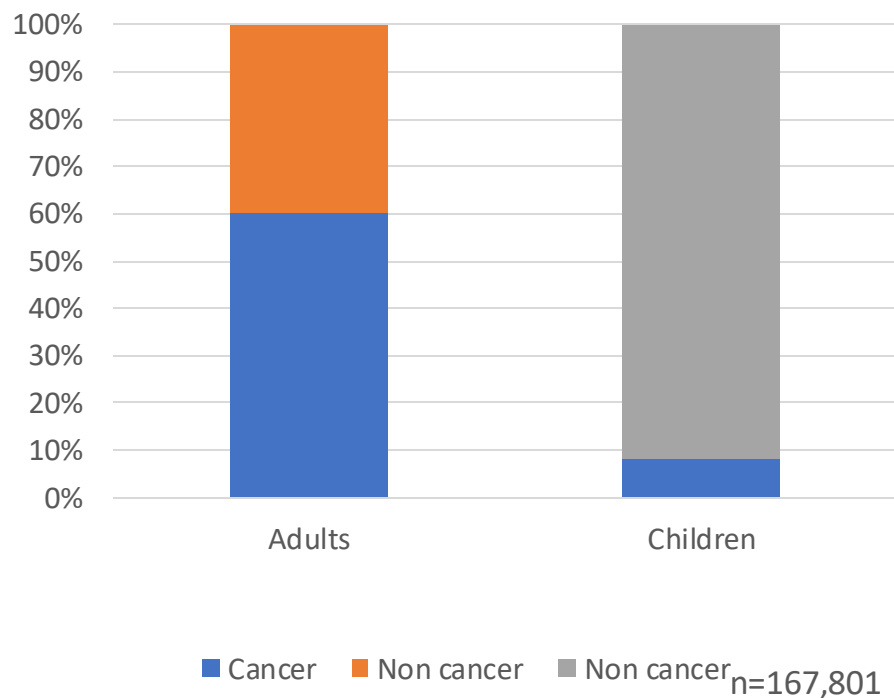
**47 percent** of total activity might be mostly **specialist** palliative care

**53 percent** of total activity might be more **generalist** palliative care

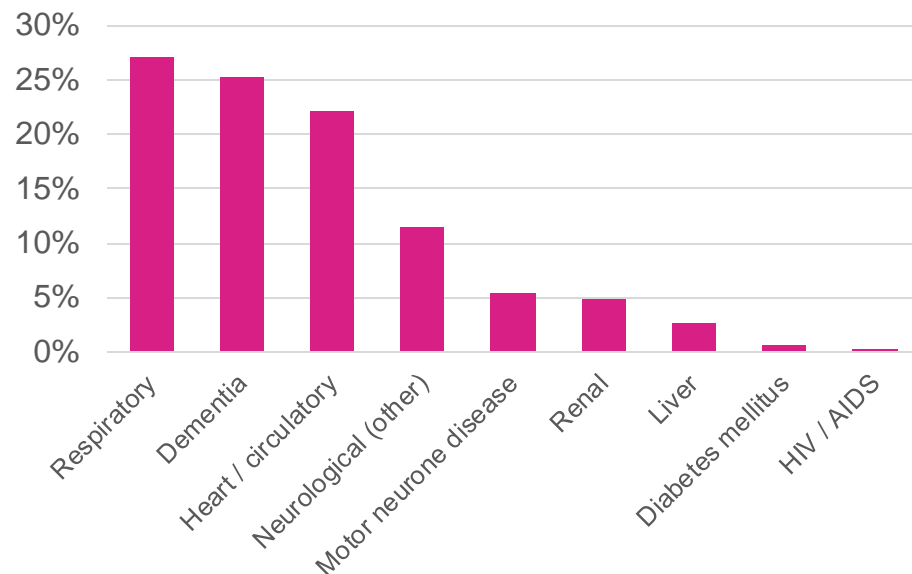
**Reflection:** *is this a useful classification; but what does it mean about our role in the system*

# Primary diagnosis

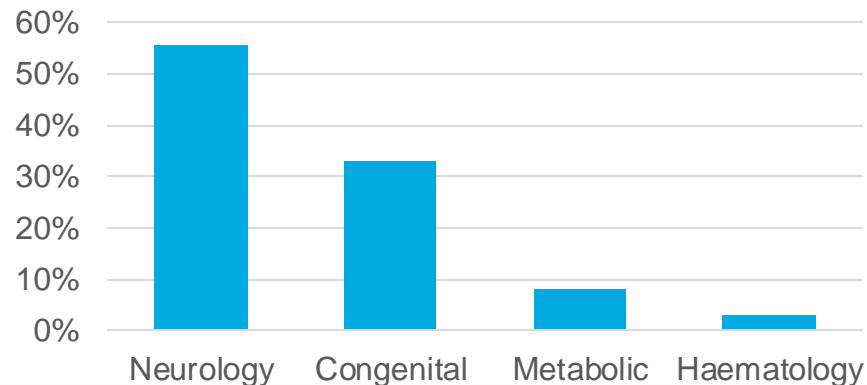
Primary diagnoses, UK hospices, 2022-23



Adult services: non-cancer main diagnoses, 2022-23

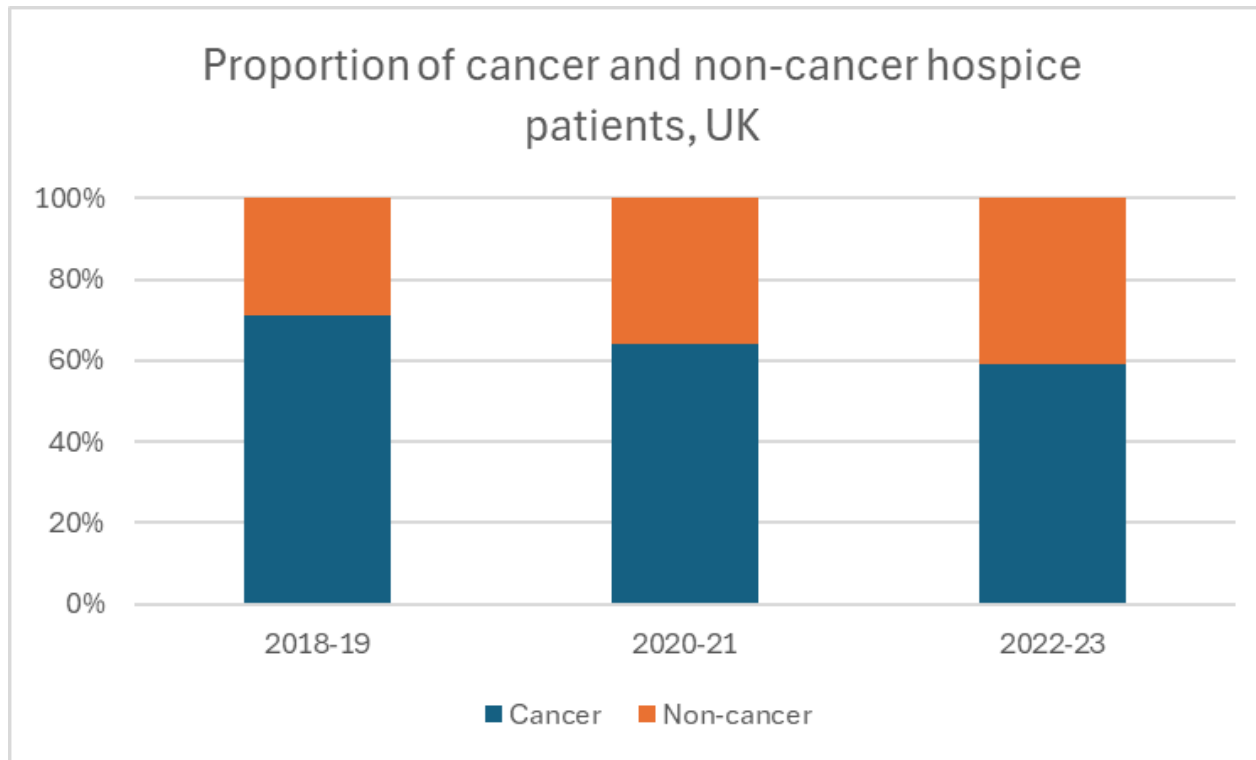


Children services: non-cancer main diagnoses, 2022-23



# Proportion of cancer and non-cancer patients

12 percent swing in primary diagnosis in four years:



**Reflection:** *this underpins our policy message about hospices being not only for people with cancer*



# Hospice Clinical Workforce Data 2023

Anita Hayes, Clinical Quality Lead, Hospice UK

# Clinical and care workforce data

## Head count

**16,000** Total clinical and care staff

### *Of which:*

12,200 Nurses and healthcare assistants

950 Doctors

2,850 Other health and care professionals

### *Of nurses:*

8,700 Hospice based nursing

3,500 Community based nursing

# Clinical and care workforce data

## Whole time equivalent

14,000 Total clinical and care staff establishment

*Of which:*

11,000 Whole time equivalent nurses / healthcare assistants

750 Whole time equivalent doctors

2,250 Whole time equivalent other health / care professionals

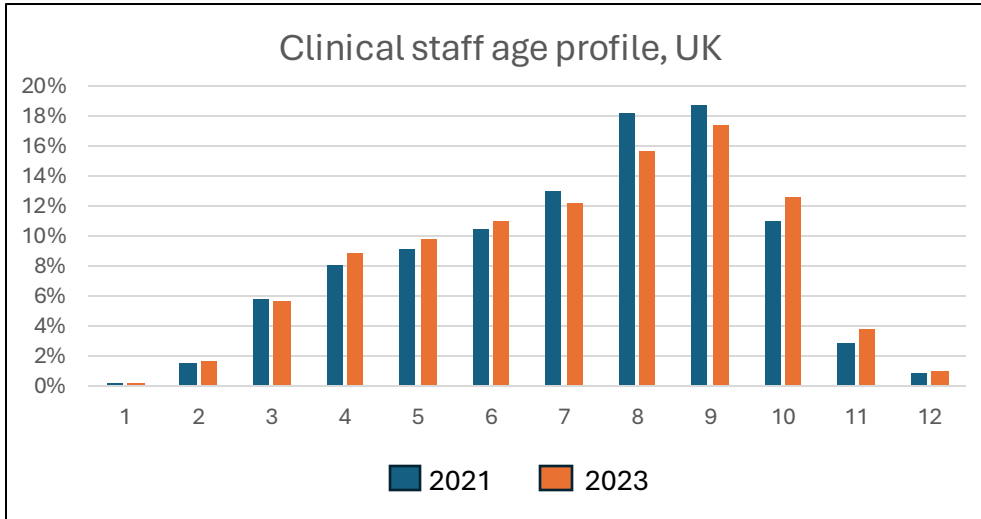
*Of nurses:*

7,785 Hospice based nursing

3,215 Community based nursing

**Reflection:** 17 percent increase in nursing establishment in two years, but vacancy rate has also increased to 9 percent (similar to NHS)

# Clinical workforce age and sex



**Reflection:** 5 percent decrease in 45-60 year-olds in two years, so who will provide experienced supervision

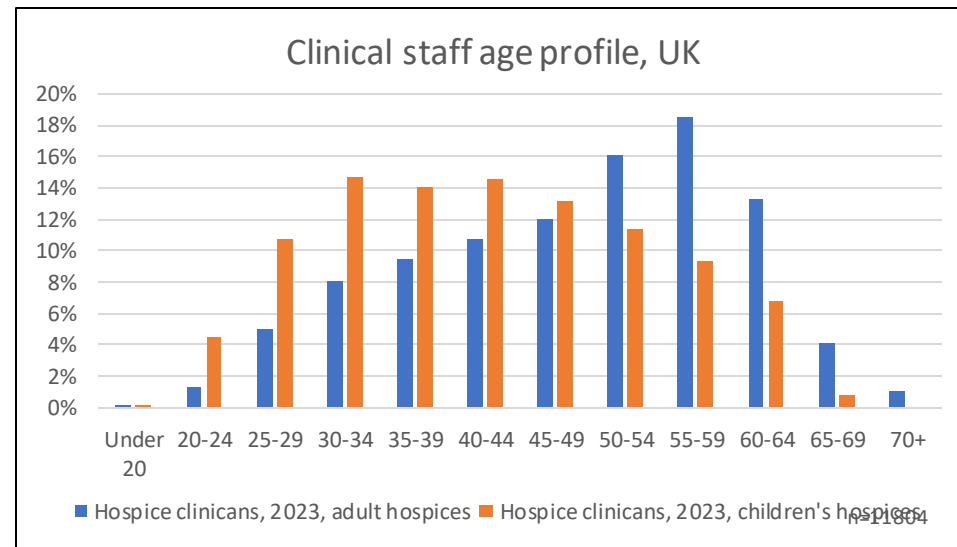
**35 percent** of clinical and care staff are **over 55** years of age

Wales is an outlier at 45 percent

Children's hospices is 17 percent

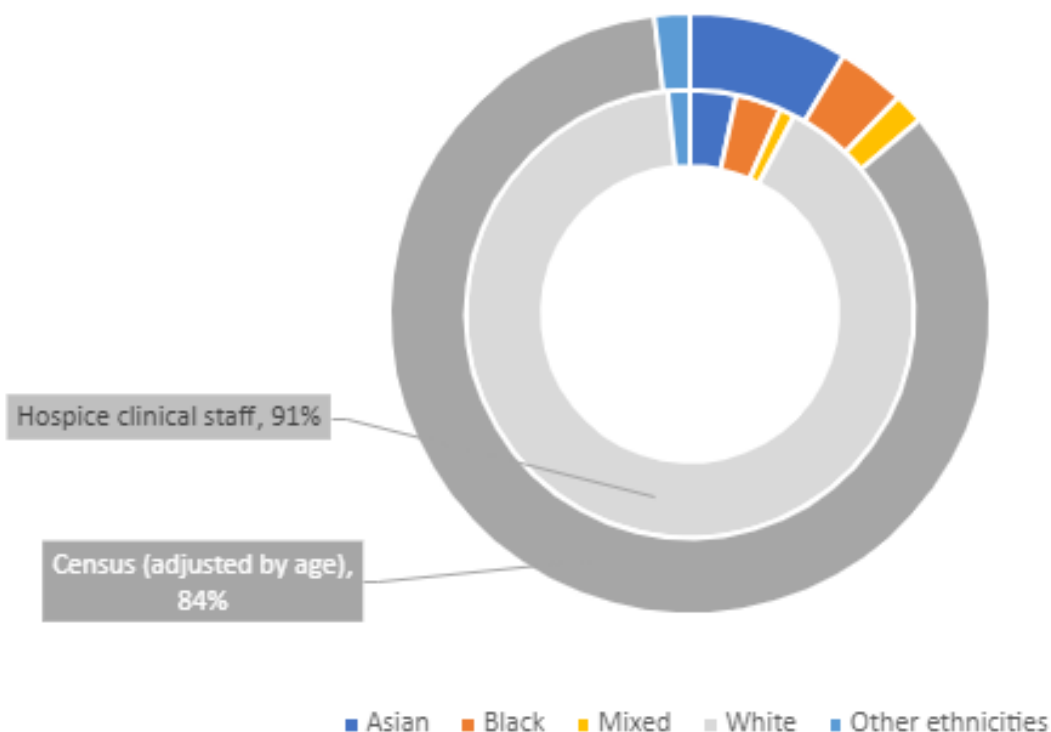
**91 percent** of the clinical and care workforce is **female**

Children's hospices is 77 percent



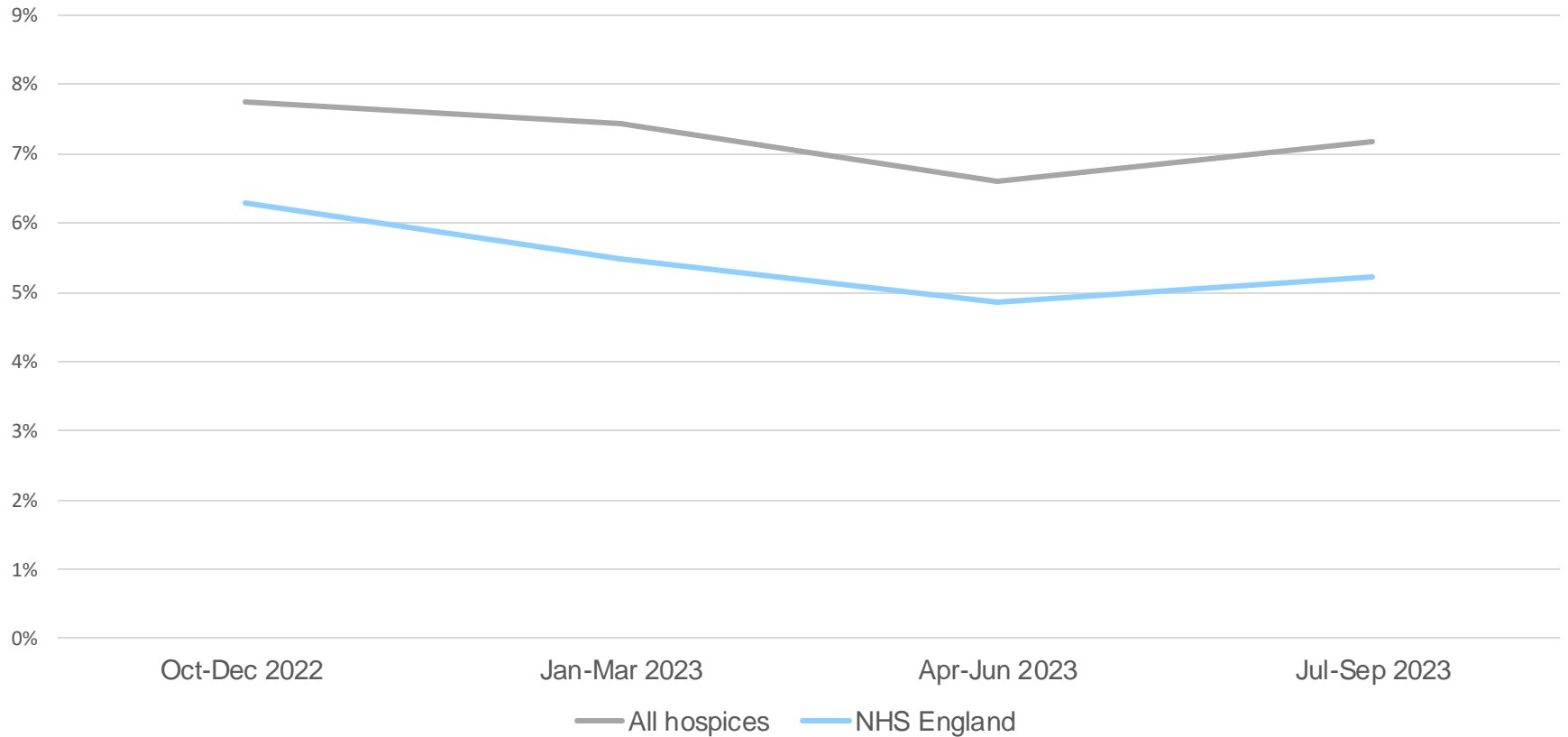
# Clinical workforce comparative ethnicity

Ethnicity of clinical staff compared to the age adjusted population census



# Staff sickness rates

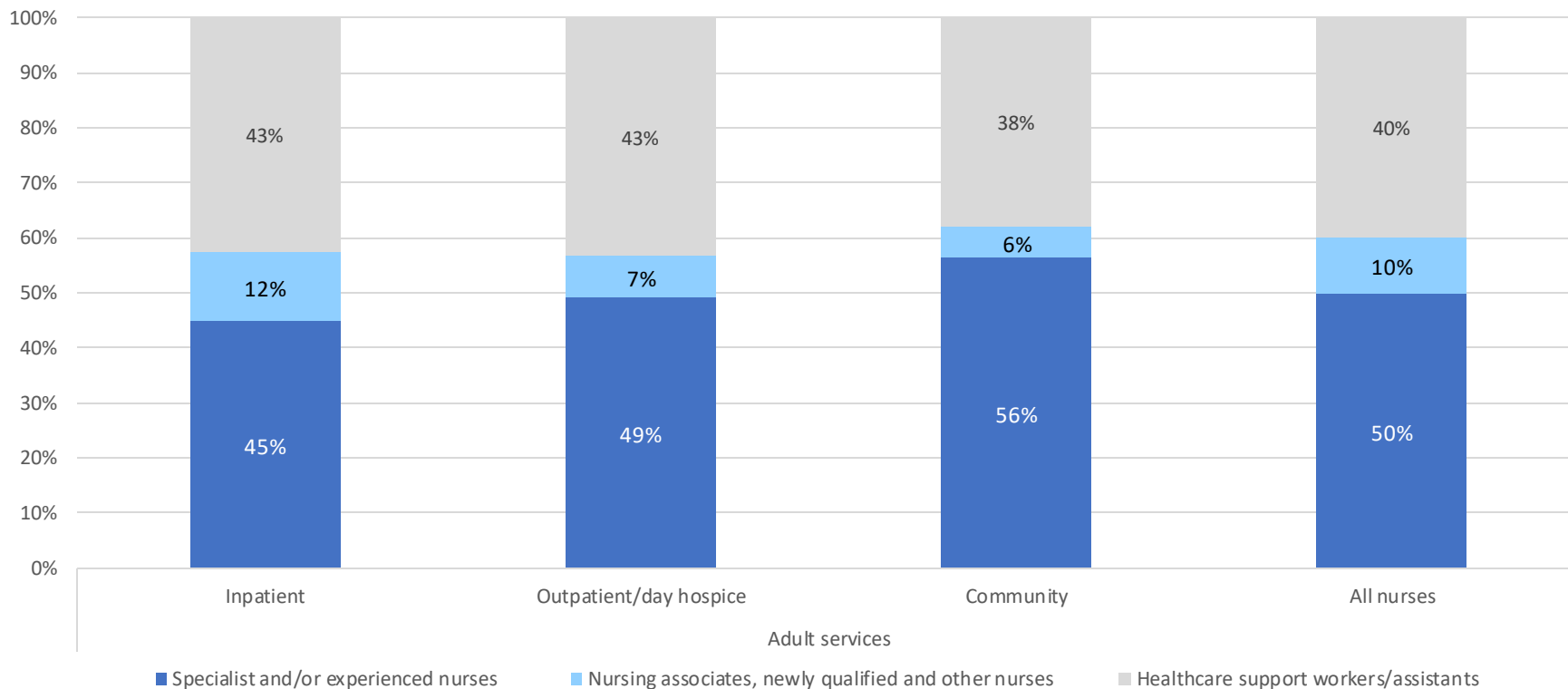
Clinical staff sickness rates



# Nursing skill mix

**Reflection:** *how does this link to our activity in terms of specialist palliative care*

Nursing skill mix



(N=66 hospices)

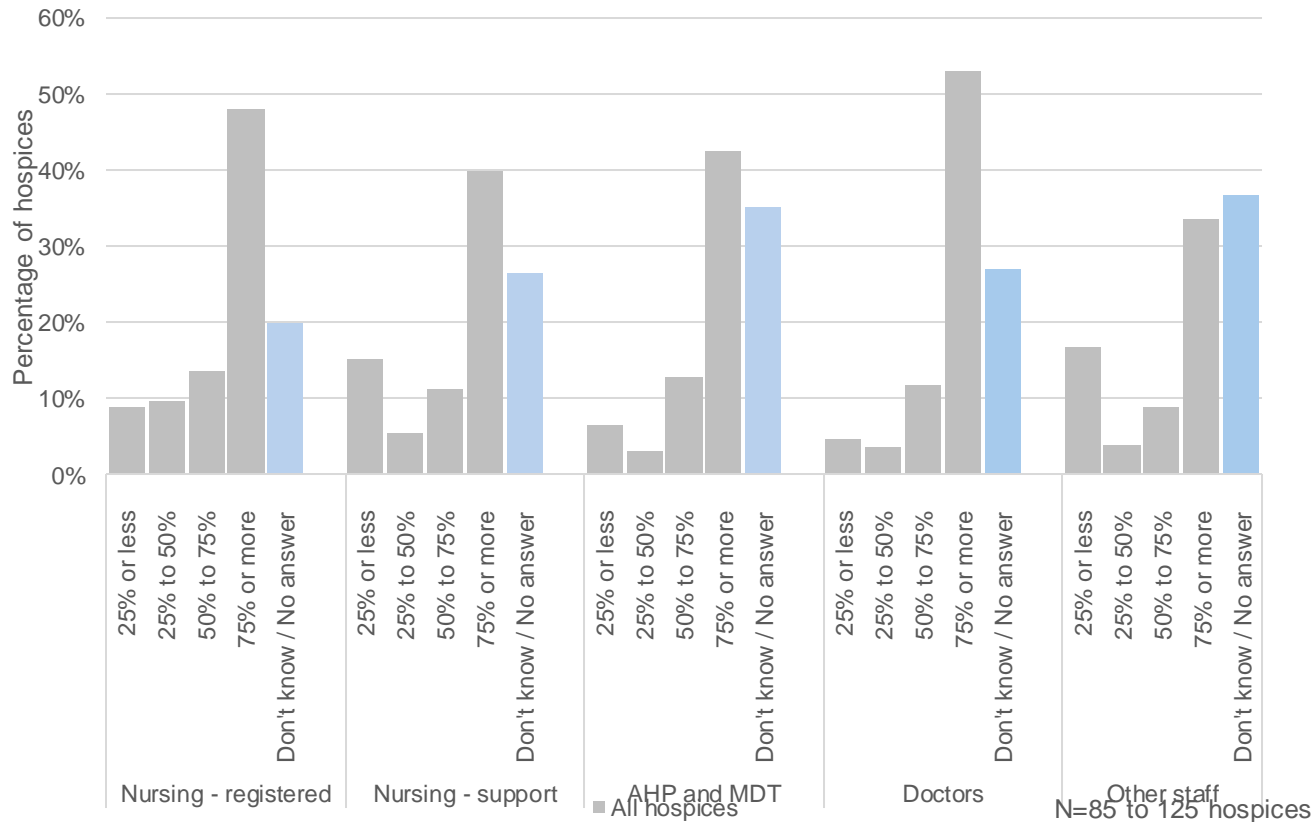
# Staff Support and Wellbeing

“The expectation that we can be immersed in suffering and loss daily and not be touched by it is as unrealistic as expecting to be able to walk through water without getting wet..”

Rachel Naomi Remen: “Kitchen Table Wisdom: Stories that Heal” Penguin, New York, 1996.



# Staff Support and Wellbeing



In half of hospices, 75% or more registered nurses received restorative supervision.

However, 20% were unable to provide a figure.

# Using the Data

Annette Alcock, Director of Programmes,  
Hospice UK

# What can we do with this data?

## Population data

denominator for comparison:  
catchment area or prevalence

equity of access by:  
need and patient characteristics and geography and diagnosis

## Workforce data

map functions to need

recruit and upskill for required capabilities

attractive T&Cs and succession planning

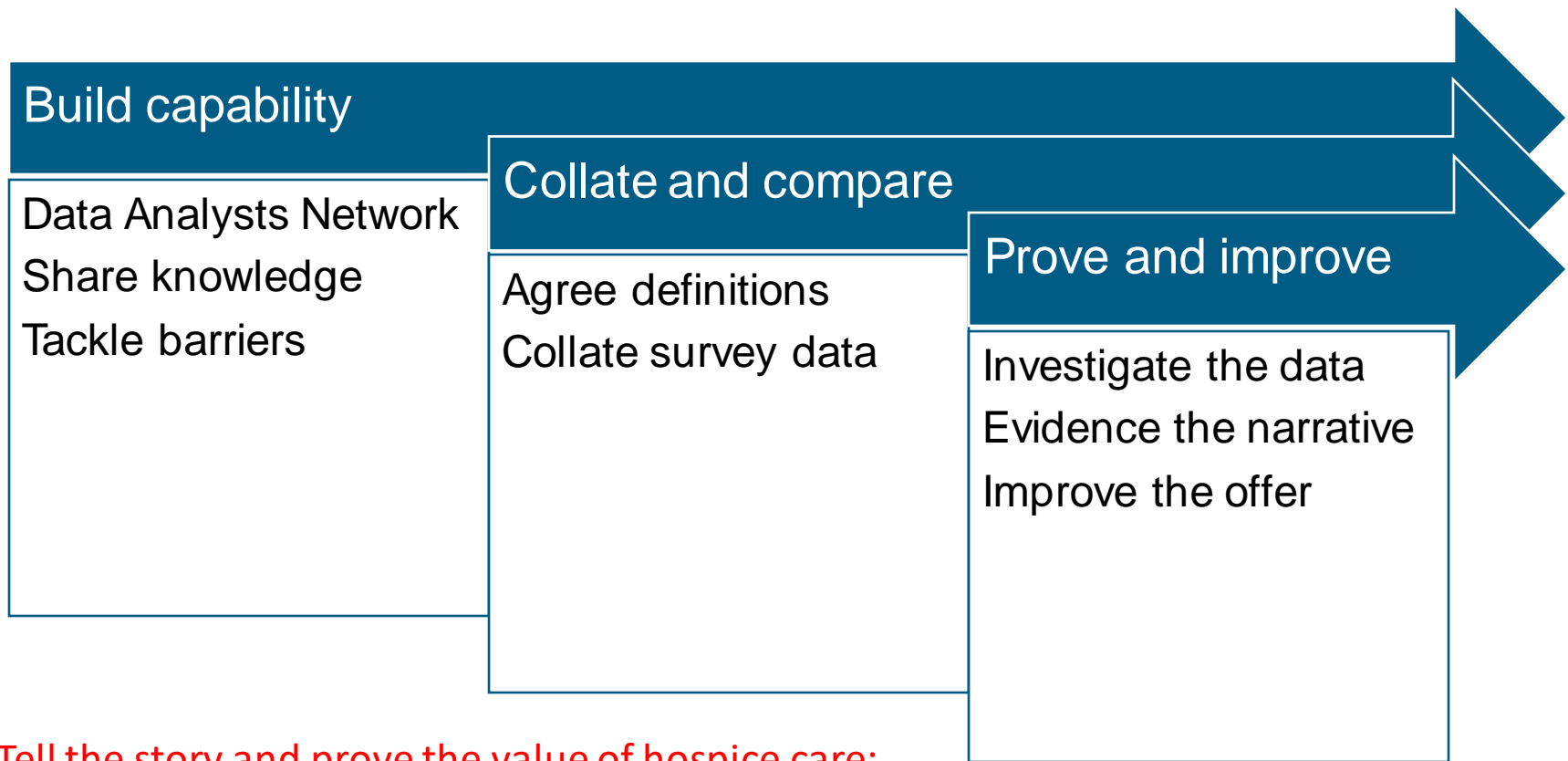
## Service data

clinically safe:  
regulatory compliance

financially sustainable:  
funding models

meeting patient needs:  
responsive, equitable, coordinated

# Why are we doing it together?



Tell the story and prove the value of hospice care:

Who needs  
palliative care?

Are there optimal  
service models?

What is the  
required skillmix?

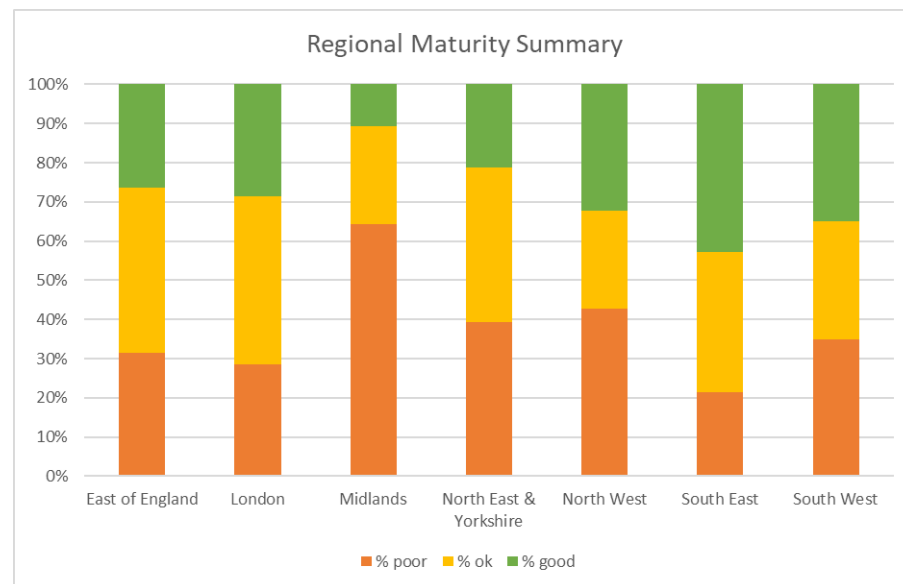
How do we  
describe value?

# Hospice data maturity mapping

Hospice UK has been working with hospice data analysts and data collections over the last year. We have mapped the maturity of hospices by the clinical patient systems they use, the analytical team they have in place and the completeness of the data (demographic in particular) they returned.

This is the summary by region:

Region	Hospices	poor	ok	good
EoE	19	6	8	5
London	14	4	6	4
Midlands	28	18	7	3
NE&Y	33	13	13	7
North West	28	12	7	9
South East	28	6	10	12
South West	20	7	6	7



# Data Orchard maturity framework



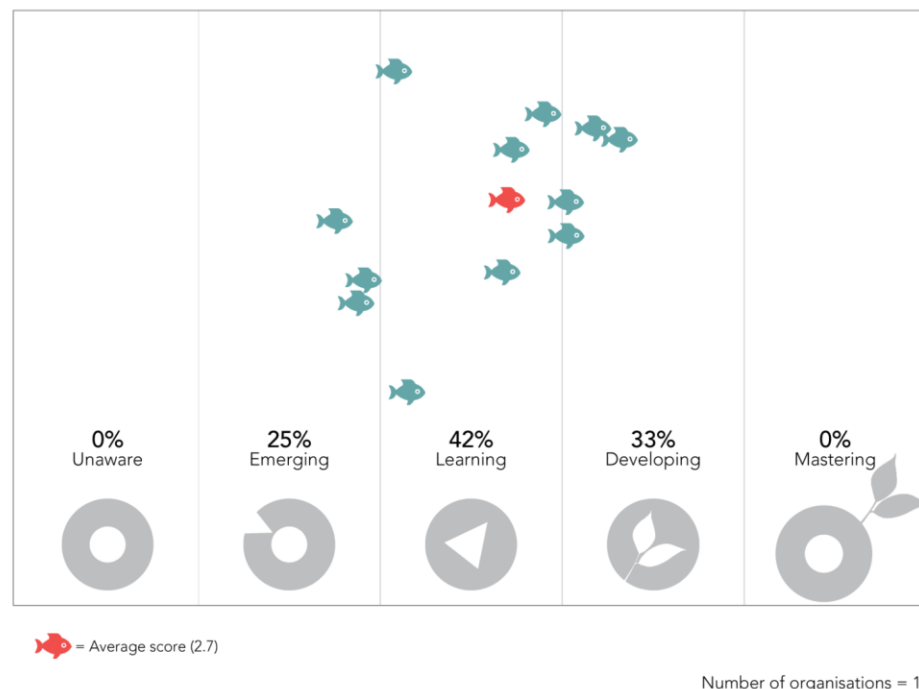
Data Orchard is an organisation that has developed a maturity framework for the not-for-profit sector. Individual organisation self-assessments are free.

12 of our hospices have completed a self-assessment and Data Orchard kindly shared the spread of results with Hospice UK.

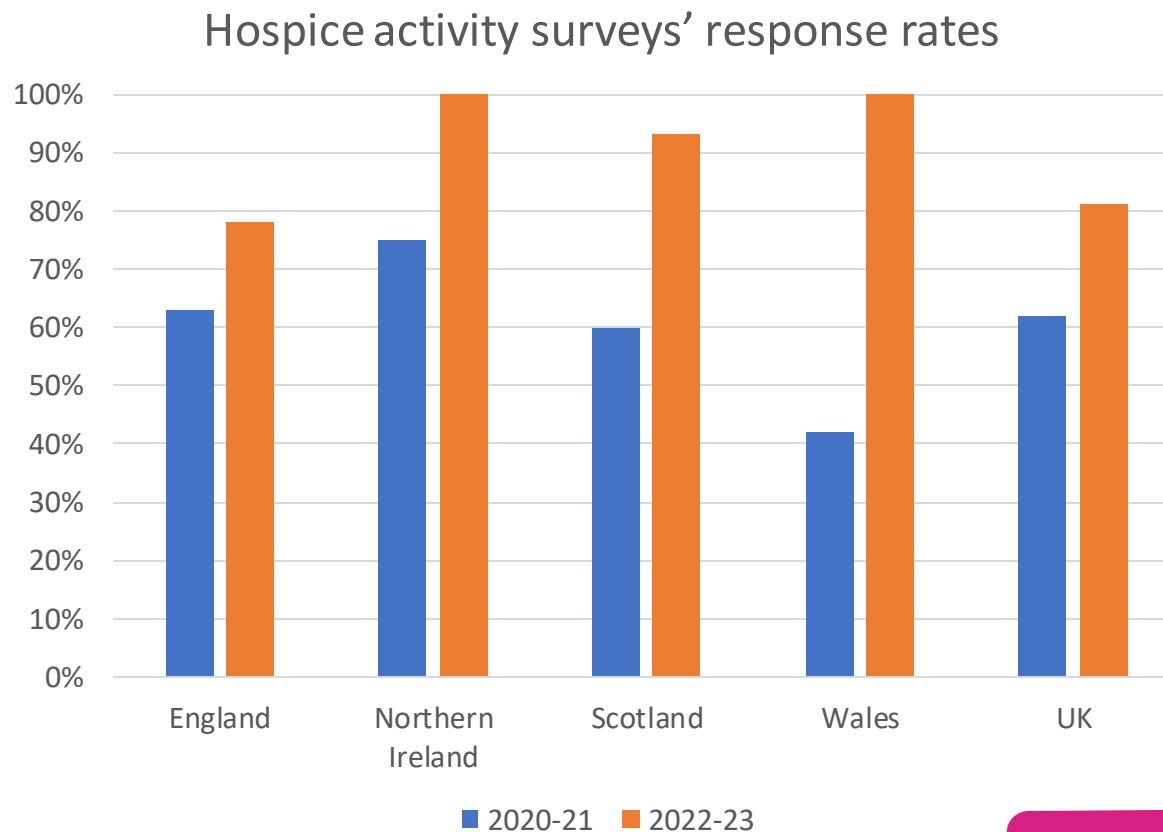
They scored, on average, 2.7 out of 5. Which puts them at 'learning' and slightly behind the NGO average of 2.8.

A next step would be for Hospice UK to promote more hospices to self-assess, then potentially seek funding for a sector comparison and support.

Data maturity of hospice organisations



# How representative is the data?

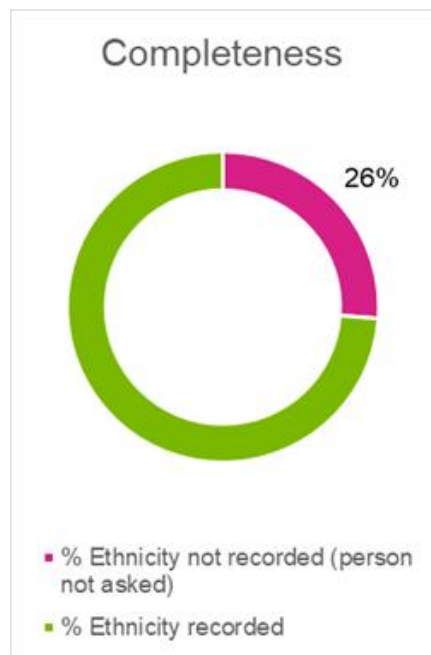


206 hospices  
127 replies 2020-21  
165 replies 2022-23

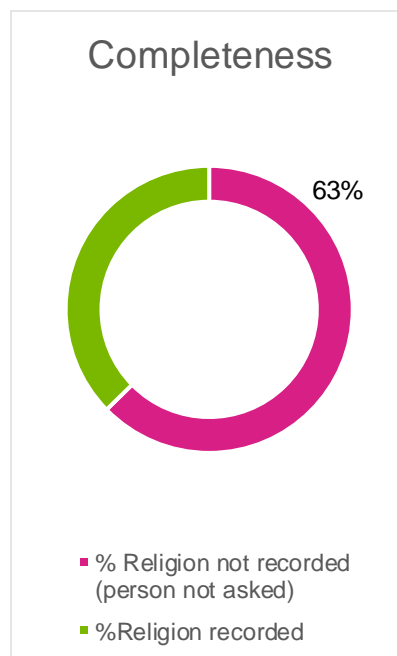
80% Response Rate

# How complete is the data?

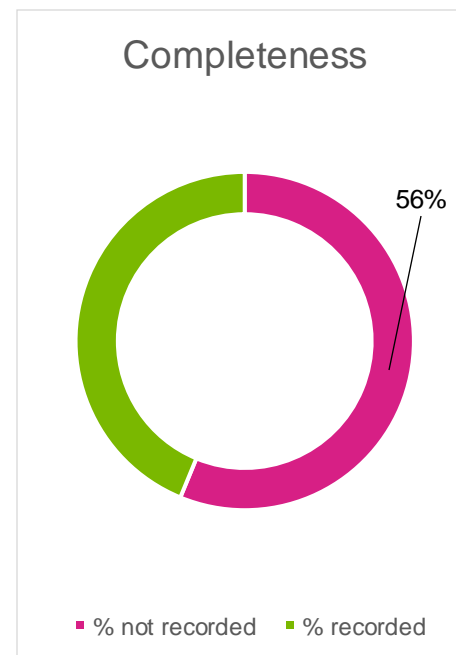
## Ethnicity data collected



## Religion data collected



## Sexuality data collected





# How can we use the catchment areas?

Hospice UK has collated all the hospice catchment areas.

These have been mapped onto [PopNAT](#) to:

- Allow hospices to see in one dataset the full demographics and health indices of the populations they serve
- Give a population denominator for the service and financial data we collect from hospices
- Enable a map of hospice service reach across the UK, indicating gaps in coverage and potentially under-served populations

This will assist with local service planning and development as well as add to the national data for understanding provision across the sector.

# PopNAT and hospice catchment areas

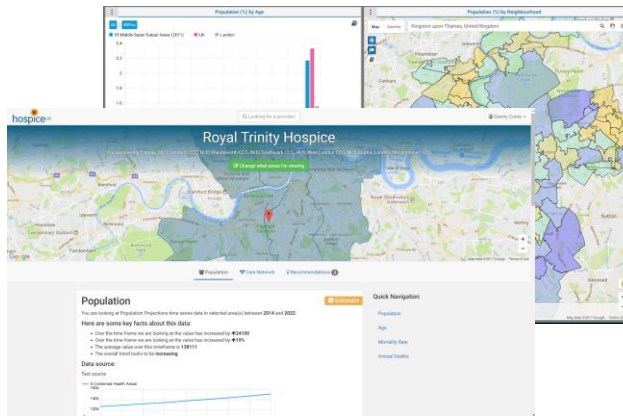
Ian Appleby, Gavurin

# What is PopNAT?

## Hospice UK's Population Needs Assessment Tool

- Aimed principally at people working in end of life care provision and/or commissioning.
- Intended to support strategy development and service planning.
- Designed to be useful yet accessible to users of varying technical expertise.

# PopNAT has grown out of user experience



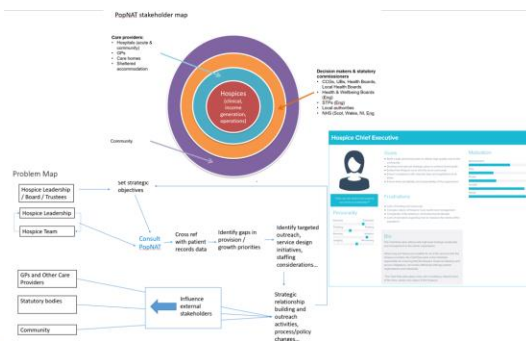
Field  
Research

V1 Launch  
(2017)

Recognised  
(2019)

V2 Launch  
(2022)

Next..  
(June 2024)



# Start by picking a path, then let PopNAT lead the way

As long as you know where you're assessing and why, you should be able to find your way..

## PopNAT

Hospice UK's population needs assessment tool. Created to bring together relevant and up to date population data for end of life care across the UK. For use by hospices and decision makers to understand and plan palliative and end of life care services for their local populations.



[Choose a Path](#) » [Create Your Study Area](#)

### Choose a Path

[Next >](#)

#### England Care System Level Needs

View data covering Population, Health, Deprivation, Demographics, and Care Network by pre-defined Health areas within England

#### England Local Needs

View data covering Population, Dementia, and Demographics for a custom study area within England

#### Northern Ireland Care System Level Needs

View data covering Population, Health, Deprivation, Demographics, and Care Network by pre-defined Health areas within Northern Ireland

#### Northern Ireland Local Needs

View data covering Population, Dementia, and Demographics for a custom study area within Northern Ireland

#### Scotland Care System Level Needs

View data covering Population, Health, Deprivation, Demographics, and Care Network by pre-defined Health areas within Scotland

#### Scottish Local Needs

View data covering Population, Dementia, and Demographics for a custom study area within Scotland

#### Wales Care System Level Needs

View data covering Population, Health, Deprivation, Demographics, and Care Network by pre-defined Health areas within Wales

#### Wales Local Needs

View data covering Population, Dementia, and Demographics for a custom study area within Wales

## Select a Level of Geography

### Hospice Catchment (Adults)

Catchment areas for Hospices serving Adults

This unique geography set, created by HospiceUK based on information supplied by Hospices, is constructed through the merging lower tier local authorities.

Note: This dashboard only shows a data for a single UK nation, so catchments which extend beyond that area may have incomplete or inaccurate data

### Integrated Care Board

Integrated Care Boards (ICBs), as part of the Integrated Care Systems (ICSs), are organisations focused on bringing NHS providers together to improve population health and establish shared strategic priorities.

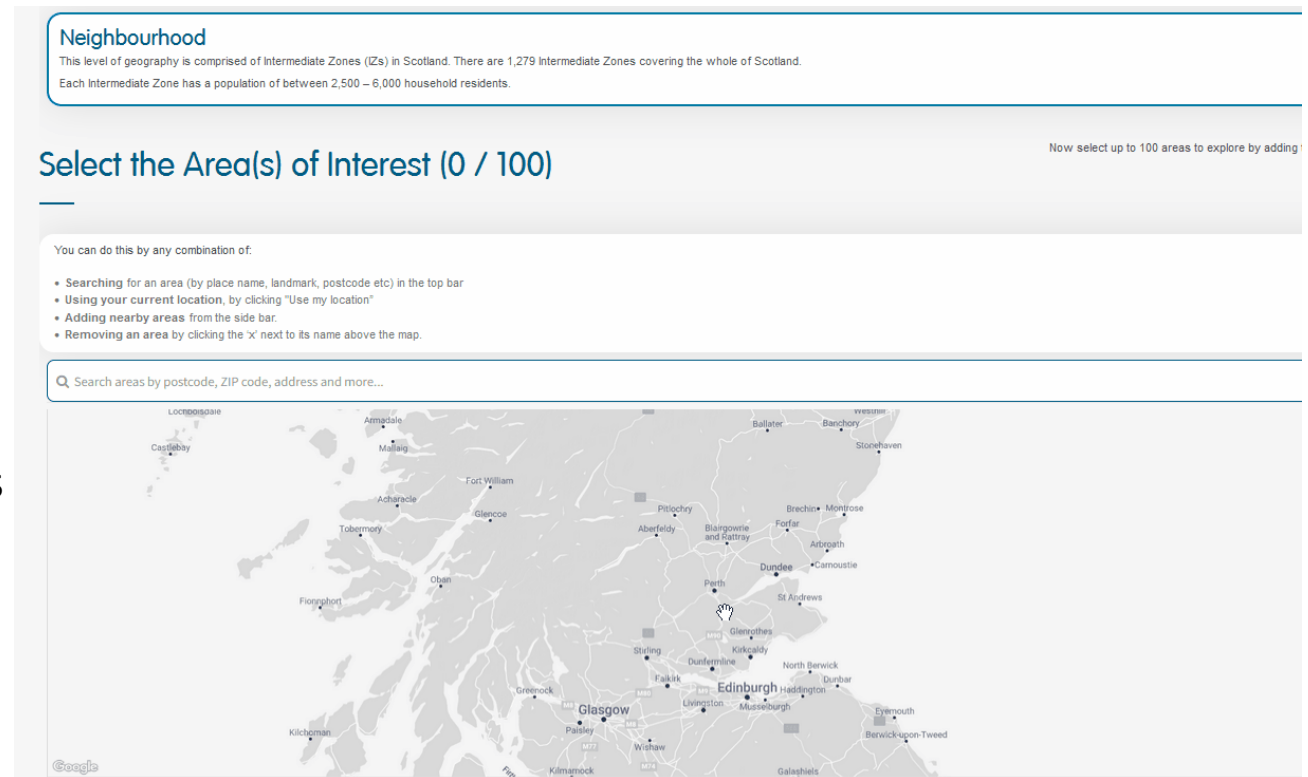
This level of geography is important for population needs assessments as ICBs are the primary entity involved in planning, commissioning and related decision making that affects NHS and local care providers in England.

### Place Level

This level of geography remains within the ICB structure. Place areas are designated by the name of the ICB with a code at the end denoting the Place. They are often the geographies covered by the old Clinical Commissioning Groups (CCGs).

This level of geography is important for more granular population needs assessments within an ICB. In many areas, NHS service planning and delivery is still done at this level.

# Intuitively find what you're looking for, using familiar experiences like Google Maps.



- Google Maps
- AI AutoComplete
- Multi-lingual Search
- Spatial Data Navigation
- Geospatial Relationships

# With visual searching, just looking around can be informative.

Before we even get to the outputs, people have found the selector useful to understand the spatial context – where things are and how they relate to one another.

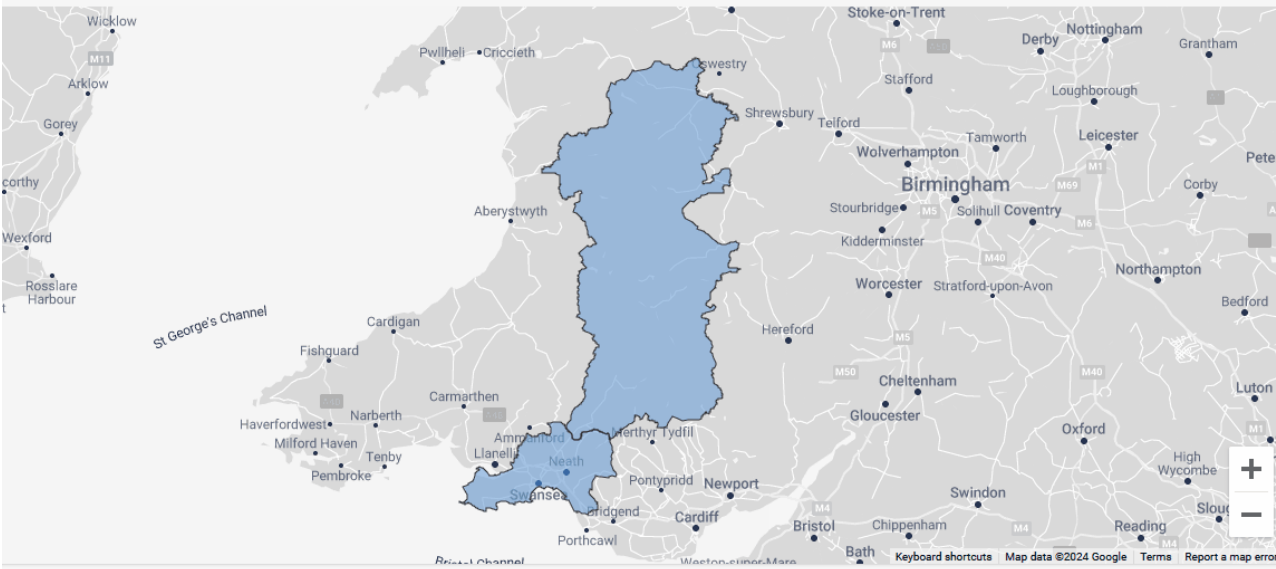
ing an area by clicking the 'x' next to its name above the map.

h areas by postcode, ZIP code, address and more...

Use my location

Preview and select nearby areas from the list below:

- North Wales**  
Adjacent to Powys
- West Wales**  
Adjacent to Powys, West Glamorgan
- Gwent**  
Adjacent to Powys
- Cwm Taf Morgannwg**  
Adjacent to Powys, West Glamorgan



Keyboard shortcuts Map data ©2024 Google Terms Report a map error

# Narrative provides structure and context to the process.

Highlights the steps where perspectives and data can contribute across a range of domains:

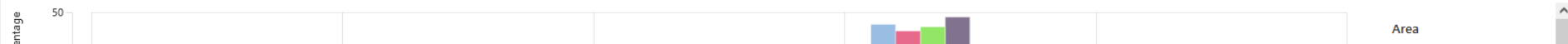
Population, Health, Deprivation, Demographics, Care Network

## 2: Health: Disease Prevalence and Causes of Death

This section focuses on the current health of the living local population across various domains, as a guide to future need. The Dementia Register data shows how many people are registered at a GP and have been added to the Dementia Register in a given year, where as the Dementia estimates try to also model those who haven't been diagnosed. The Cancer Incidence data shows how many people have been diagnosed with specific types of cancer in a given year. The Cause of Death data shows how many people have died of a specific cause in a given year. In all cases, data is derived from GP records, so should be of high accuracy, even at a very local level.

The core strengths of this approach are that it provides highly localised information, broken down by condition and adequately deals with changing demographics. The key challenge is estimating what proportion of these people require palliative care, and how far in the future. It is also limited in the forward range it can be used to forecast, as the data can only cover the timeframe from diagnosis to entering care.

### Health: Place of Death (%) (2022)





# Comparison is the most powerful analytical tool.

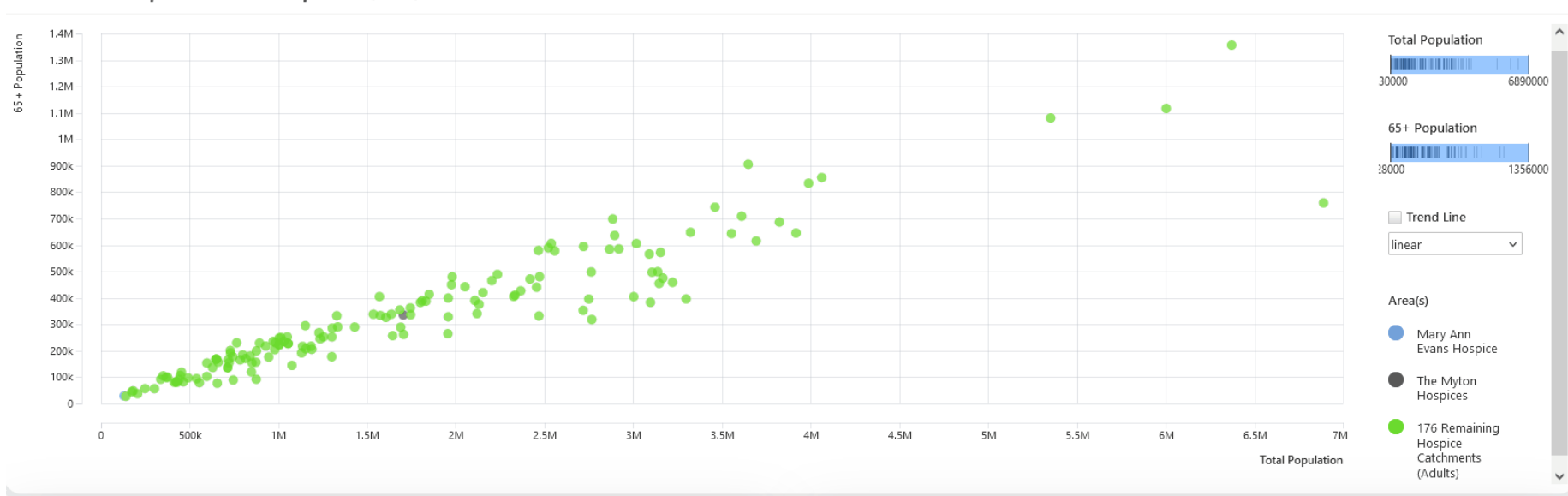
Compare with others like you.

Compare with the wider context.

Compare over time.

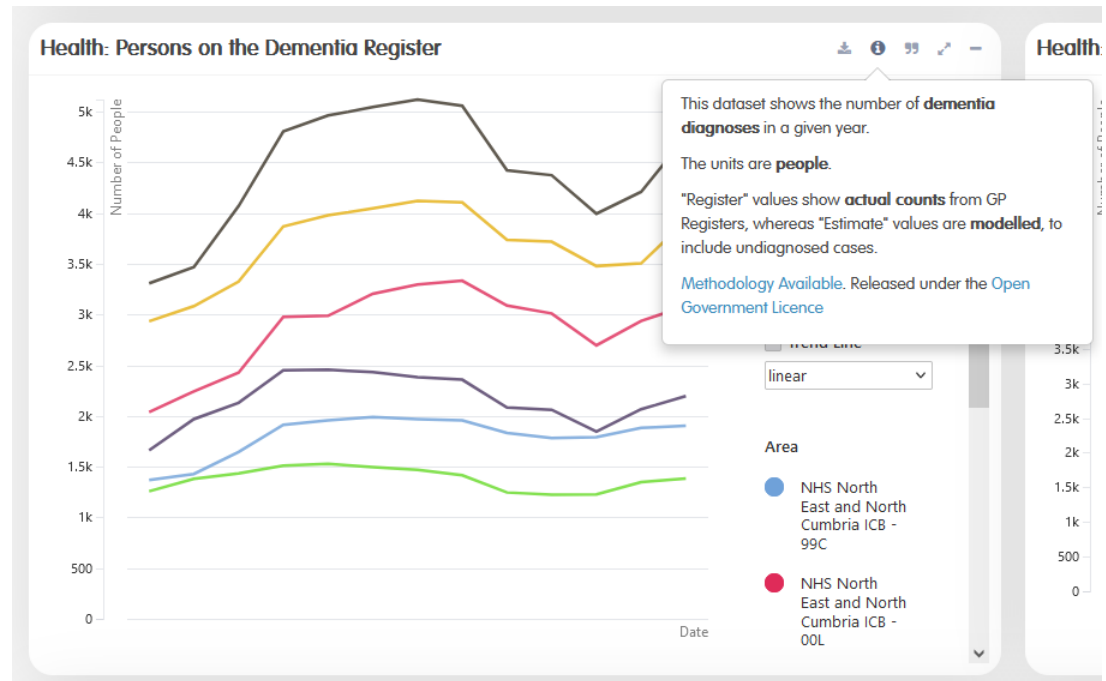
Focus on what's relevant.

Estimates: 65+ Population vs. Total Population (2022)



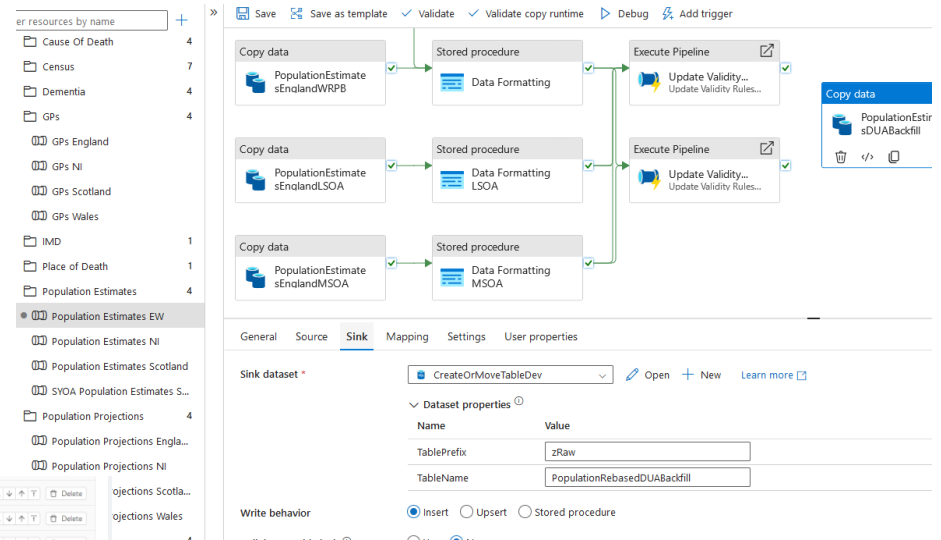
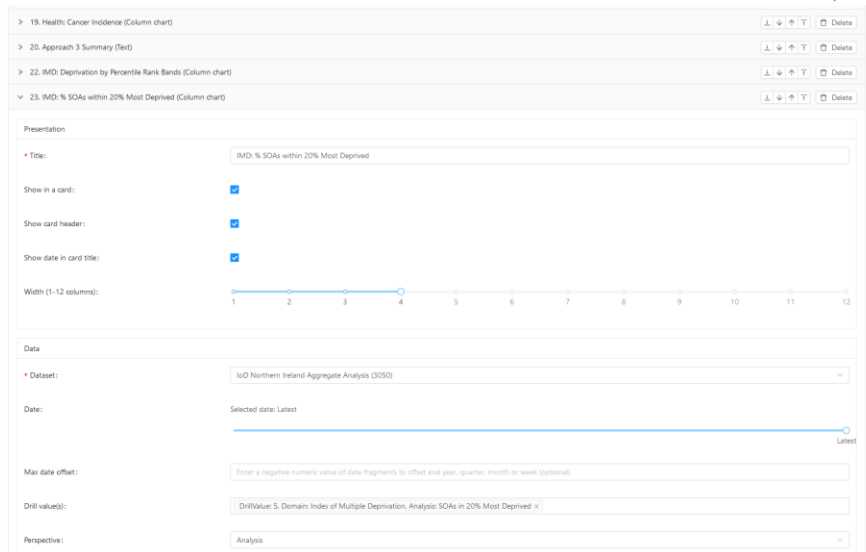
# Making good decisions requires confidence in the evidence base.

- Human friendly explanation
- Transparency by design
- Contextual access to export the data you're looking at.



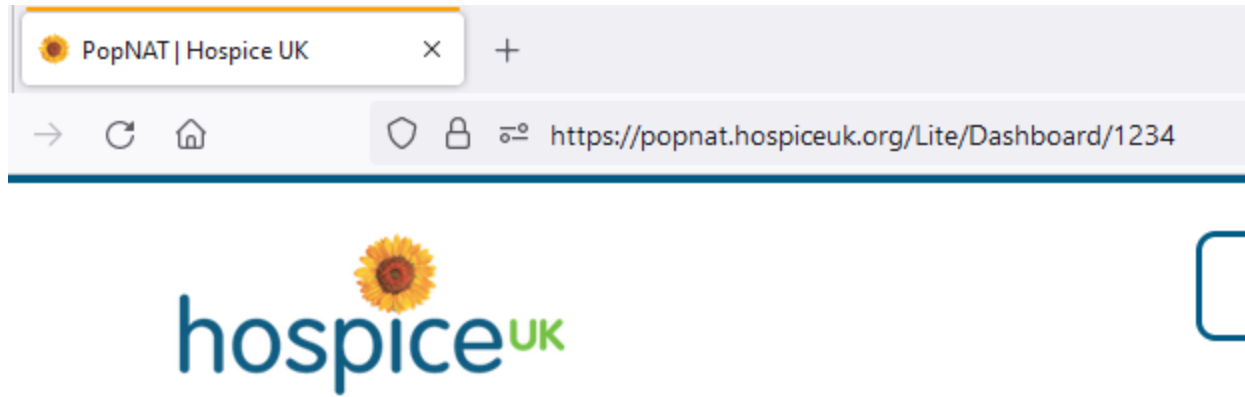
# Can't I just get this data myself?

- Curation
- Cost
- Completeness
- Consistency



# Collaboration is key. Repeating work is silly. Linking is easy (for you).

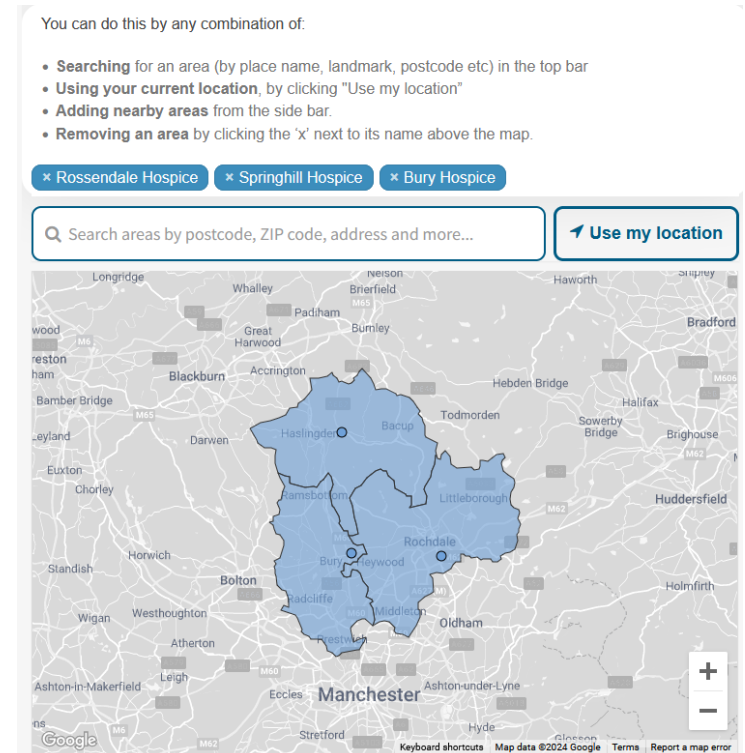
Saving and Sharing with links a bigger deal than it sounds



# Hospice Catchments are the next step in an easier, more tailored journey.

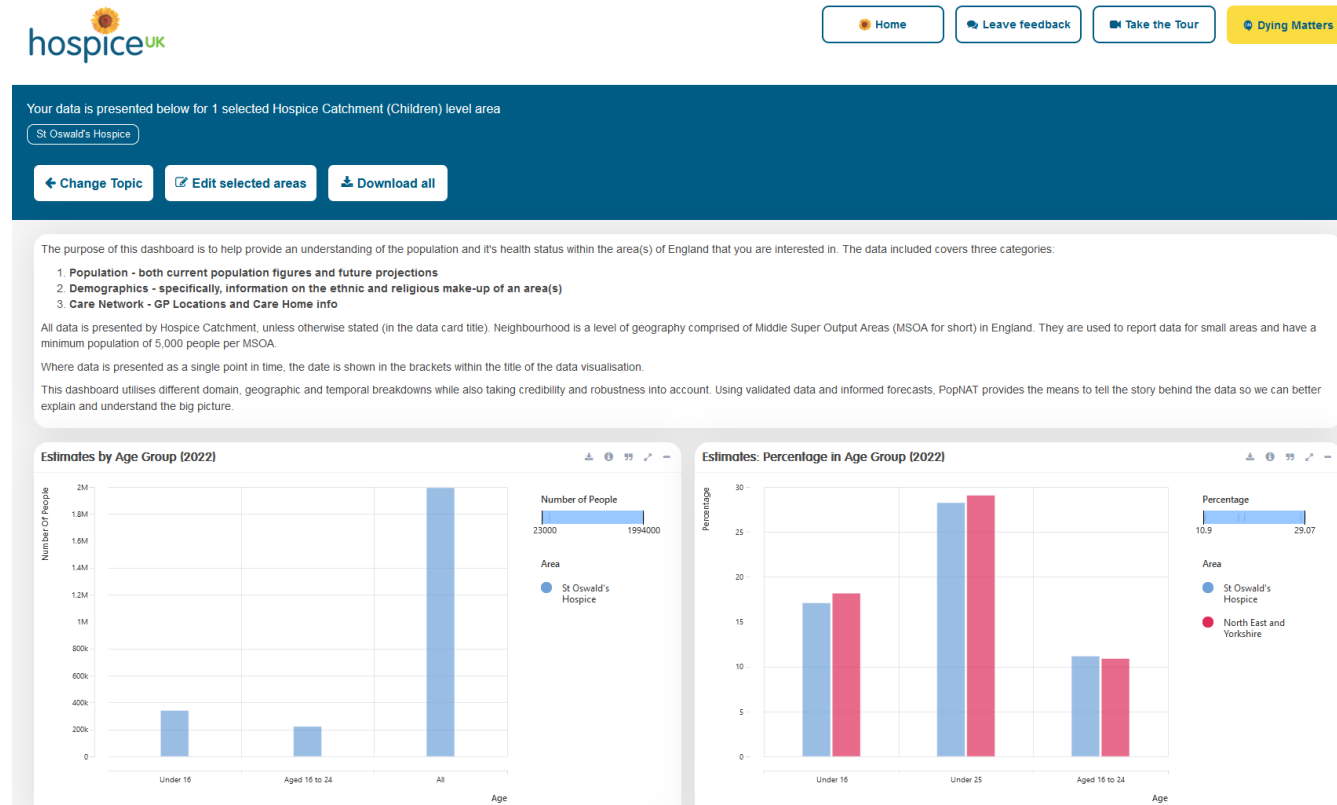
Support the full range of features

Derived aggregate data, not available anywhere else.



# PopNAT broadening scope with debut of support for Children's Hospices.

- New Path options tailored towards their unique population assessment needs
- Children's Hospice Catchments will be the principle geography
- Intention to build on this further in the future.



# Prototyping demographic data comparisons

Richard Cooper, Data Manager, Hospice UK

# Comparing service level population data

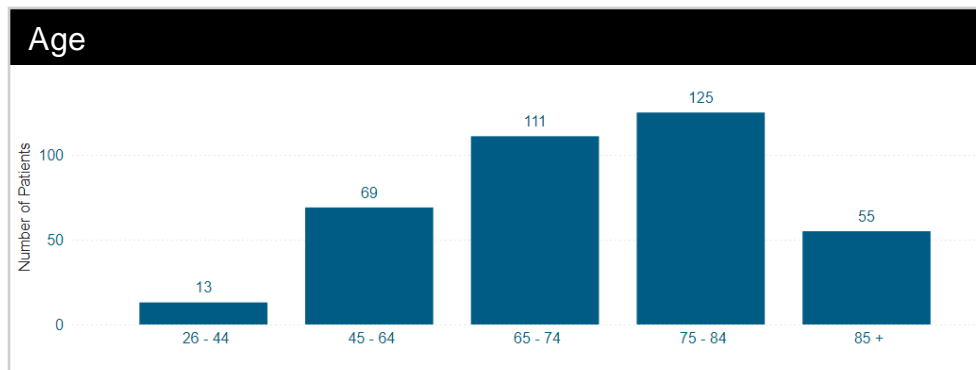
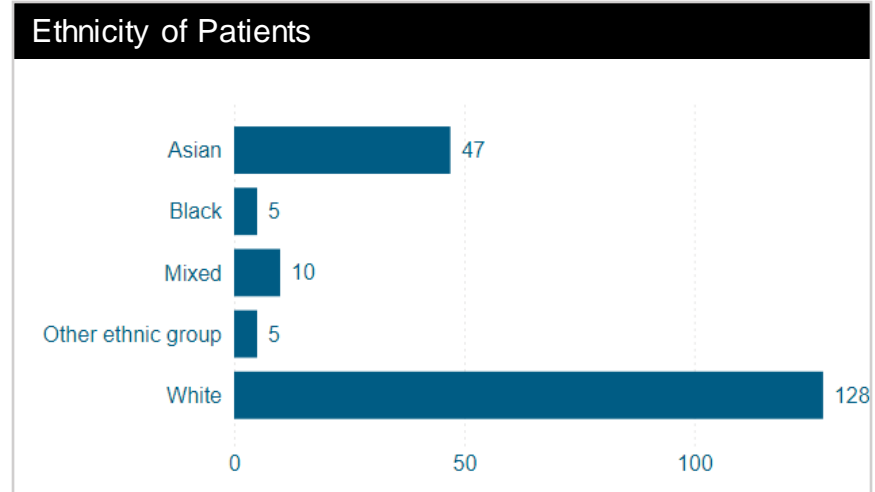
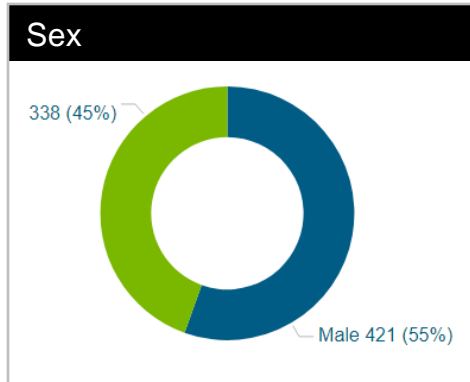
Hospice UK prototype tool to compare and visualise hospice service level patient demographics (from activity survey) with lower tier local authority ONS demographics (from PopNAT hospice catchment area data).

- Using catchment areas and LTLA areas was more accurate than using ICS areas
- Overlaying the ONS ethnicity data on the hospice sex and age distribution gave a more accurate ethnicity comparison
- The following case studies show the importance of utilising demographic data in a local context:
  - Urban vs rural populations are different
  - Children vs adult populations are different, on top of which the prevalence data shows a higher need in (a sub-category of) Asian children

There is the potential to use this tool both nationally and locally



# Collected Data





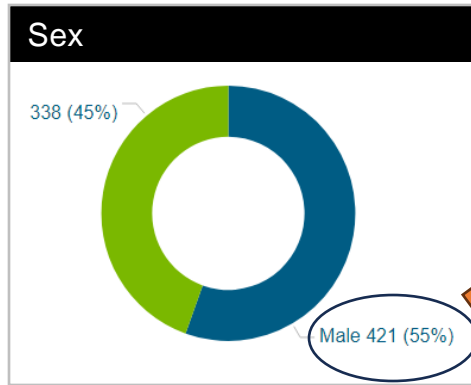
# ONS Demographic Data

Count, %

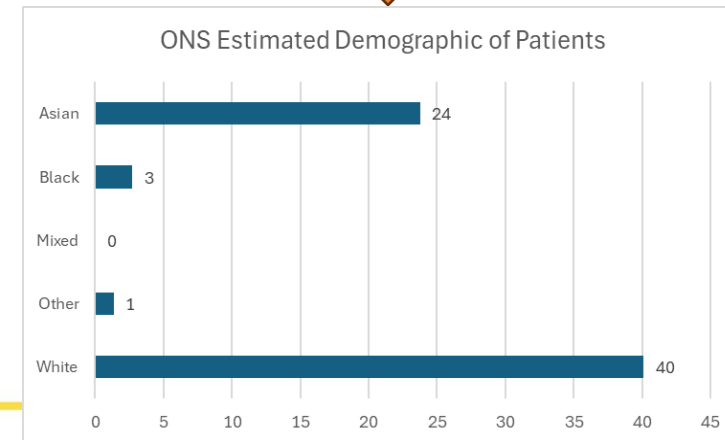
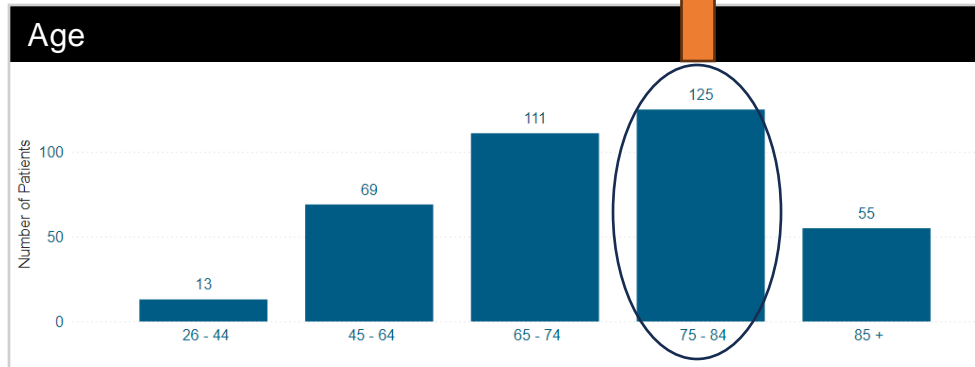
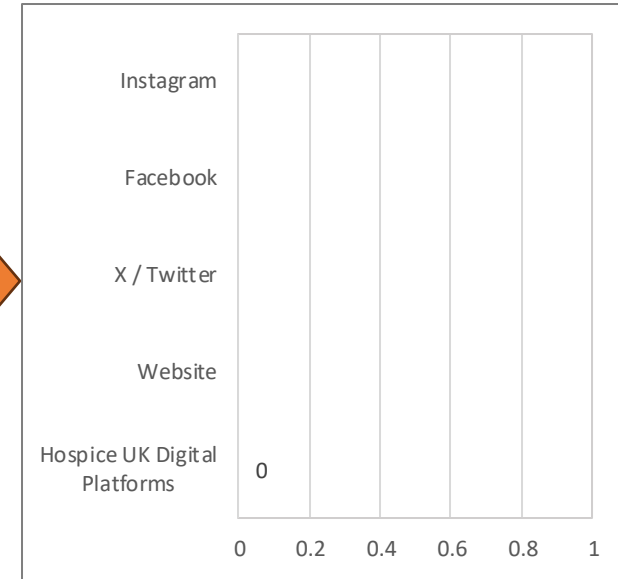
BY AGE, GENDER, ETHNICITY

Ethnicity	Asian		Black		Mixed		Other ethnic group		White		Total	
Gender	Count	%	Count	%	Count	%	Count	%	Count	%	Count	%
<b>Female</b>	<b>97,520</b>	<b>44%</b>	<b>17,594</b>	<b>8%</b>	<b>9,807</b>	<b>4%</b>	<b>10,290</b>	<b>5%</b>	<b>86,929</b>	<b>39%</b>	<b>222,140</b>	<b>100%</b>
0 - 15	35,830	45%	7,568	9%	6,092	8%	4,652	6%	25,922	32%	80,064	100%
16 - 18	3,458	44%	942	12%	467	6%	338	4%	2,618	33%	7,823	100%
19 - 25	9,623	40%	2,621	11%	1,099	5%	847	3%	10,059	41%	24,249	100%
26 - 44	23,082	47%	3,124	6%	1,425	3%	2,508	5%	19,470	39%	49,609	100%
45 - 64	17,786	44%	2,760	7%	626	2%	1,534	4%	17,703	44%	40,409	100%
65 - 74	5,285	43%	296	2%	60	0%	280	2%	6,458	52%	12,379	100%
75 - 84	1,911	34%	170	3%	29	1%	108	2%	3,412	61%	5,630	100%
85 +	545	28%	113	6%	9	0%	23	1%	1,287	65%	1,977	100%
<b>Male</b>	<b>97,155</b>	<b>43%</b>	<b>18,612</b>	<b>8%</b>	<b>10,177</b>	<b>5%</b>	<b>9,386</b>	<b>4%</b>	<b>88,654</b>	<b>40%</b>	<b>223,984</b>	<b>100%</b>
0 - 15	33,576	45%	7,300	10%	6,100	8%	4,168	6%	23,906	32%	75,050	100%
16 - 18	3,235	41%	964	12%	511	7%	289	4%	2,825	36%	7,824	100%
19 - 25	9,017	36%	2,961	12%	1,276	5%	780	3%	11,167	44%	25,201	100%
26 - 44	24,211	47%	3,678	7%	1,552	3%	2,462	5%	19,731	38%	51,634	100%
45 - 64	18,105	44%	2,997	7%	614	2%	1,209	3%	17,834	44%	40,759	100%
65 - 74	5,621	44%	353	3%	76	1%	298	2%	6,533	51%	12,881	100%
75 - 84	2,522	35%	253	4%	36	0%	129	2%	4,278	59%	7,218	100%
85 +	868	25%	106	3%	12	0%	51	1%	2,380	70%	3,417	100%
<b>Total</b>	<b>194,675</b>	<b>44%</b>	<b>36,206</b>	<b>8%</b>	<b>19,984</b>	<b>4%</b>	<b>19,676</b>	<b>4%</b>	<b>175,583</b>	<b>39%</b>	<b>446,124</b>	<b>100%</b>

# ONS Comparison



68 Male  
Aged 75-84





# Hospice 1 - A childrens's hospice in an urban area

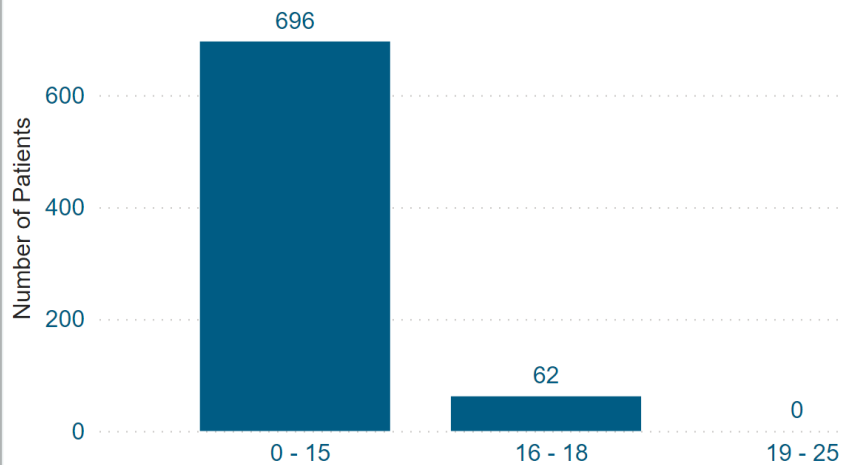


Comparison of the selected hospice ethnicity with the selected Lower Tier Local Authorities' ethnic distribution.

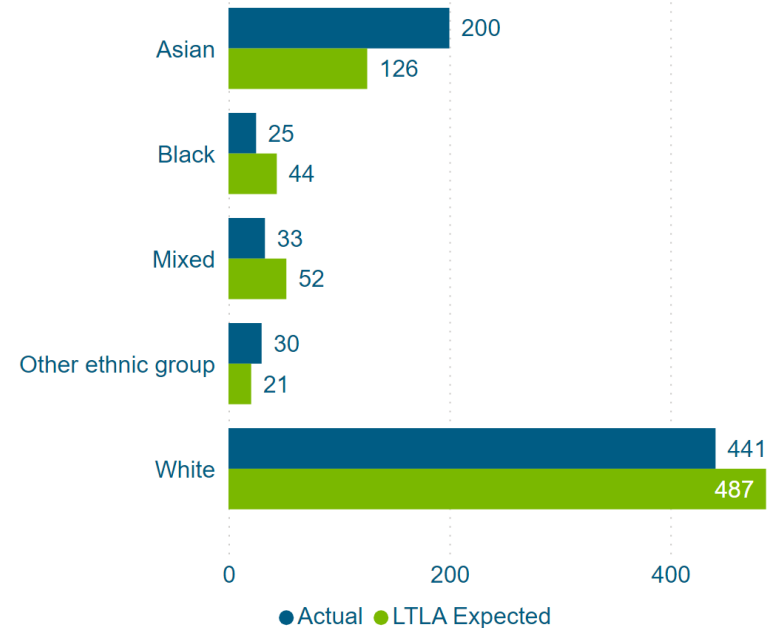
## Sex



## Age Distribution



## Ethnicity of Patients Actual versus ONS Predicted



[View ethnicity and age as percentages](#)





## Hospice 2 – An adult hospice in an urban area

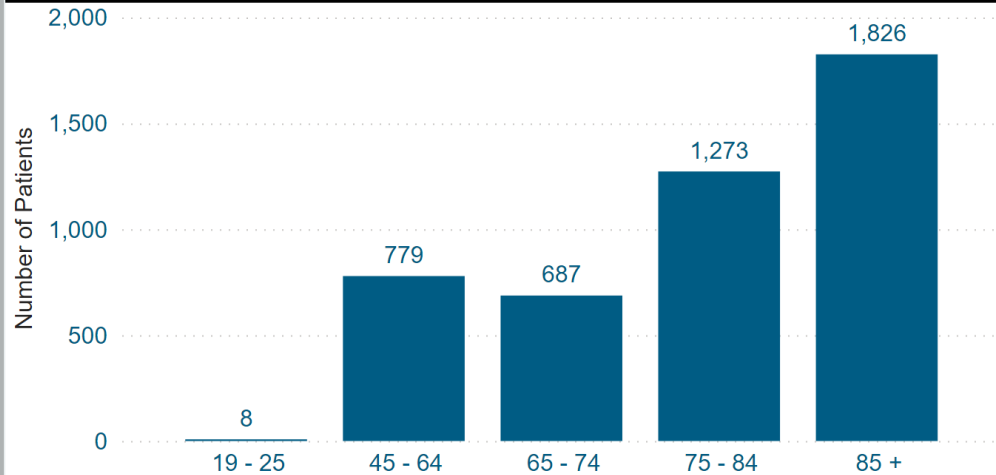


Comparison of the selected hospice ethnicity with the selected Lower Tier Local Authorities' ethnic distribution.

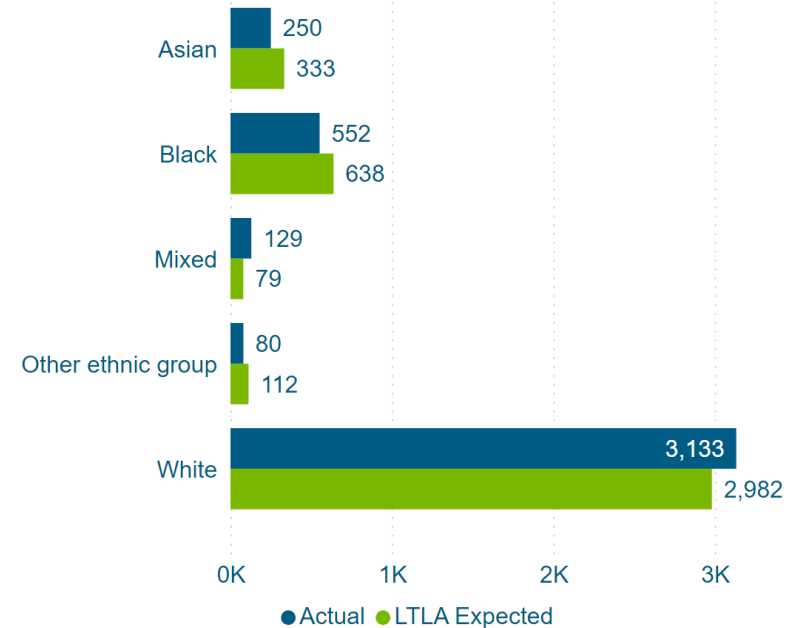
### Sex



### Age Distribution



### Ethnicity of Patients Actual versus ONS Predicted



[View ethnicity and age as percentages](#)





## Hospice 4 – An adult hospice in a coastal town

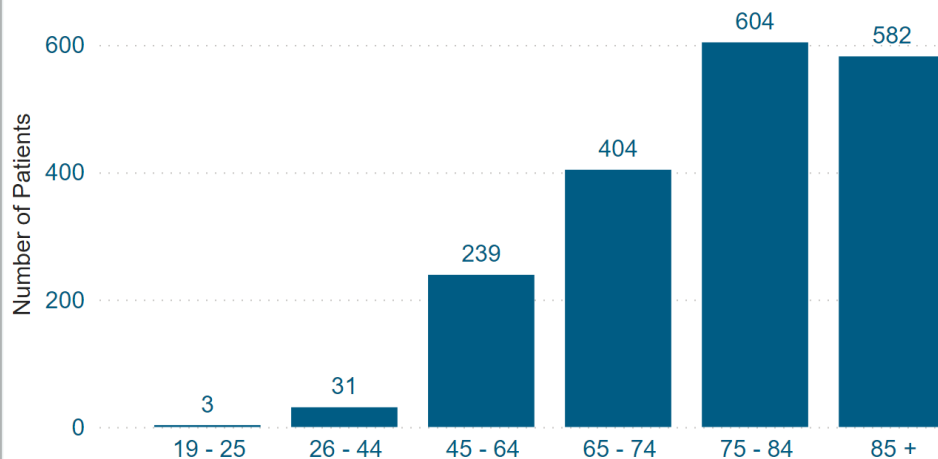


Comparison of the selected hospice ethnicity with the selected Lower Tier Local Authorities' ethnic distribution.

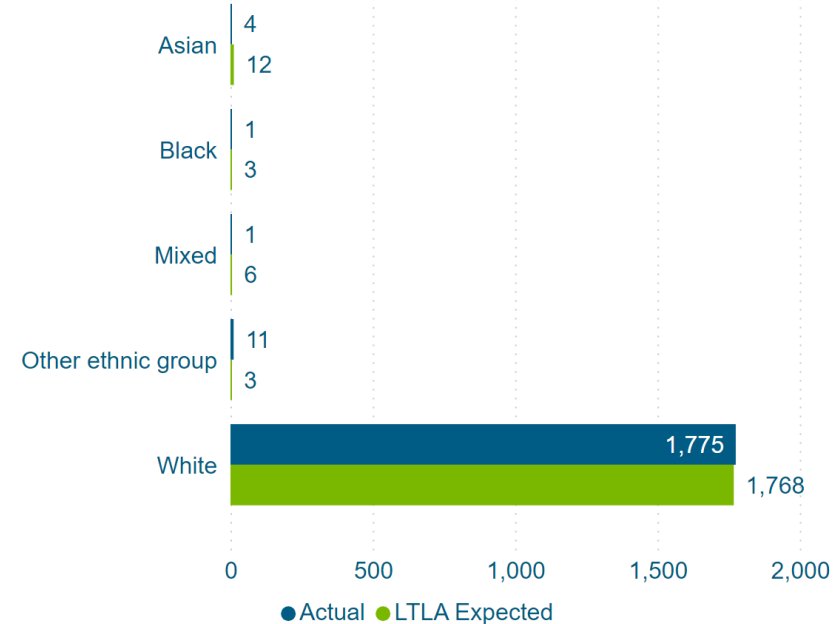
### Sex



### Age Distribution



### Ethnicity of Patients Actual versus ONS Predicted



[View ethnicity and age as percentages](#)



# Comparing patient level population data

London hospice (working with university students) prototype tool to compare and visualise hospice patient level demographics (from patient records) with local ONS demographics (from PopNAT).

- Patient level data enables direct comparisons of single and intersectional demographic data
- Some catchment population data can be downloaded from PopNAT
- The data is patient identifiable and therefore can only be extracted, held and compared within the hospice

This tool can be used at local level to interrogate the reach of hospice services

# Intersectionality of patient level data

Filter by other variables:

Gender

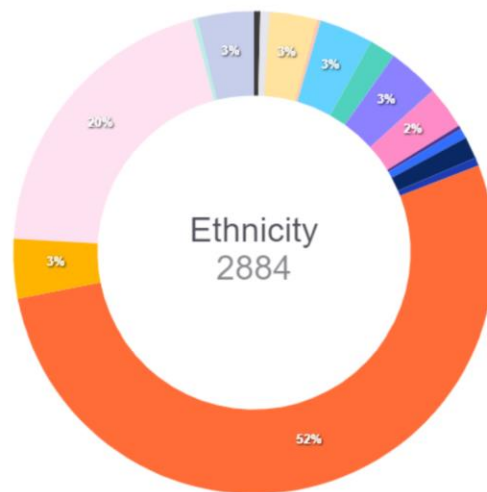
☒ Male ☒ Female

Age Group

☒ 19-24 years ☒ 25-64 years

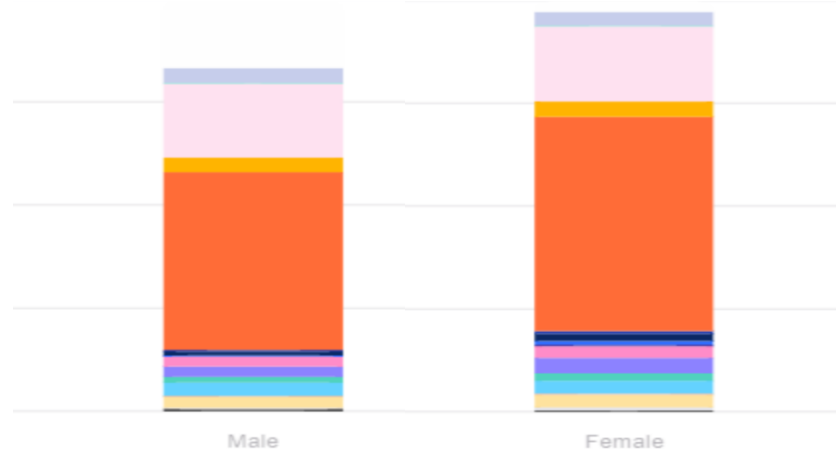
☒ 65-74 years ☒ 75-84 years

☒ 85+ years



- Asian, Asian British or Asian Welsh: Bangladeshi
- Asian, Asian British or Asian Welsh: Chinese
- Asian, Asian British or Asian Welsh: Indian
- Asian, Asian British or Asian Welsh: Pakistani
- Asian, Asian British or Asian Welsh: Other Asian
- Black, Black British, Black Welsh, Caribbean or African: African
- Black, Black British, Black Welsh, Caribbean or African: Caribbean
- Black, Black British, Black Welsh, Caribbean or African: Other Black
- Mixed or Multiple ethnic groups: White and Asian
- Mixed or Multiple ethnic groups: White and Black African
- Mixed or Multiple ethnic groups: White and Black Caribbean
- Mixed or Multiple ethnic groups: Other Mixed or Multiple ethnic groups
- White: English, Welsh, Scottish, Northern Irish or British
- White: Irish
- White: Gypsy or Irish Traveller
- White: Roma
- White: Other White
- Other ethnic group: Arab
- Other ethnic group: Any other ethnic group

Ethnicity can be compared eg by sex



Ethnicity can be filtered by sex and age, and compared over geography and time

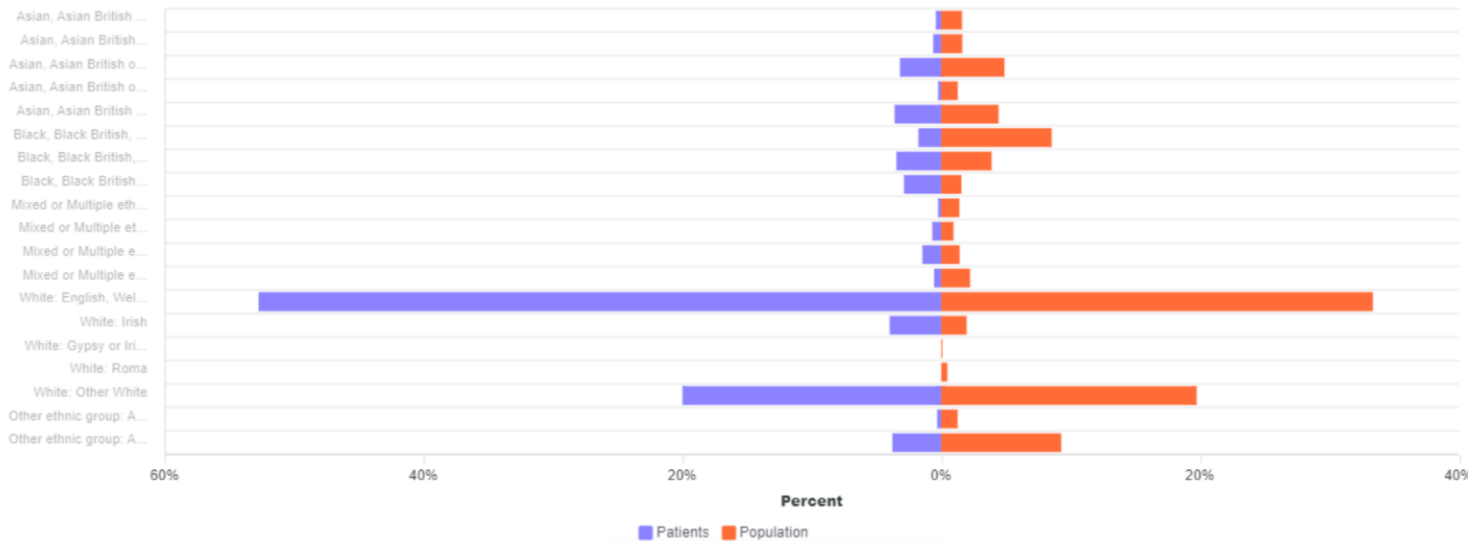


# Comparison with population data

Gender ☒ Male ☒ Female

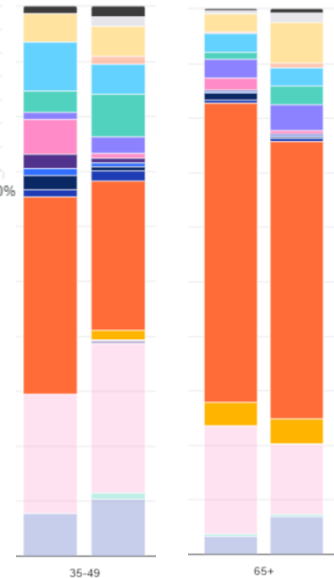
Age Group ☒ 24 years and under ☒ 25-34 years ☒ 35-49 years ☒ 50-64 years ☒ 65+ years

Patients vs Population by Ethnicity



Comparison can be filtered by sex and age

Ethnicity can be compared for different age ranges (hospice left; population right)



# Q&A