



# INSIGHT 2021

**Data for the head,  
stories for the heart**

Tuesday 12<sup>th</sup> October, 1:00-2:00



Midlands  
Decision Support  
Network

# Making the most of our time together

- Please keep your microphone muted
- Introduce yourselves in the chatbox
- Use chatbox to ask questions / raise technical issues
- Sessions are recorded and put on our website
- Tweet!

**#Insight2021 @MidlandsDSN @Strategy\_unit**

# Data for the head, stories for the heart



**Kathryn Mannix - @drkathrynmannix**

**Justine Wiltshire - @jillcowshire**

**Ollie Minton - @drol007**



# Data for the head, Stories for the heart

Communicating the insights that  
motivate actions

Fraser Battye, Kathryn Mannix,  
Justine Wiltshire, Ollie Minton



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# WAITING TO DIE IN OUR HOSPITALS



'Tragedy' as 86 pass away while stuck on list for care package

FULL STORY - SEE PAGE 6

■ **INQUEST:** Hearing told elderly woman died three days after arrival at hospital

## Daughter's surprise at mother's decline

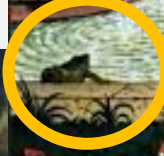
NHS discharge system failing too many elderly patients, says watchdog

## Elderly care cut despite demand

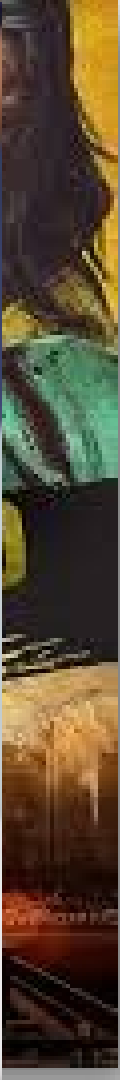
**EXCLUSIVE:** Council scraps 15% of care home places



Once upon a time....



M



# Health service use in the last two years of life

**1 October 2020**

Prepared by: Justine Wiltshire and Fraser Battye



**Midlands and Lancashire**  
Commissioning Support Unit





# Analysis - Healthcare use in the last two years of life



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# Introduction

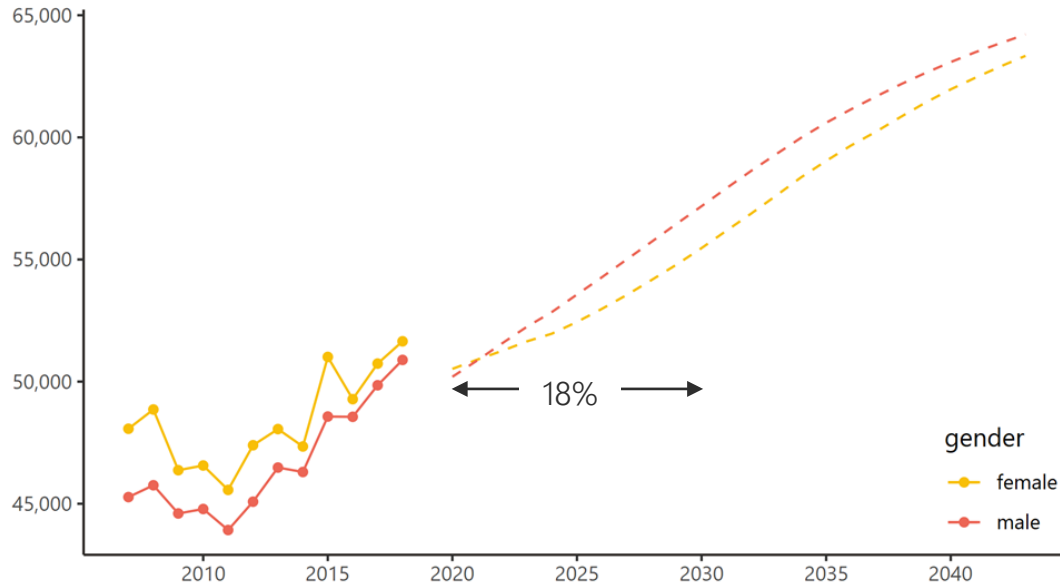
There were **93,580** adult deaths in the Midlands in 2018/19.

**(These findings predate the Covid-19 pandemic)**

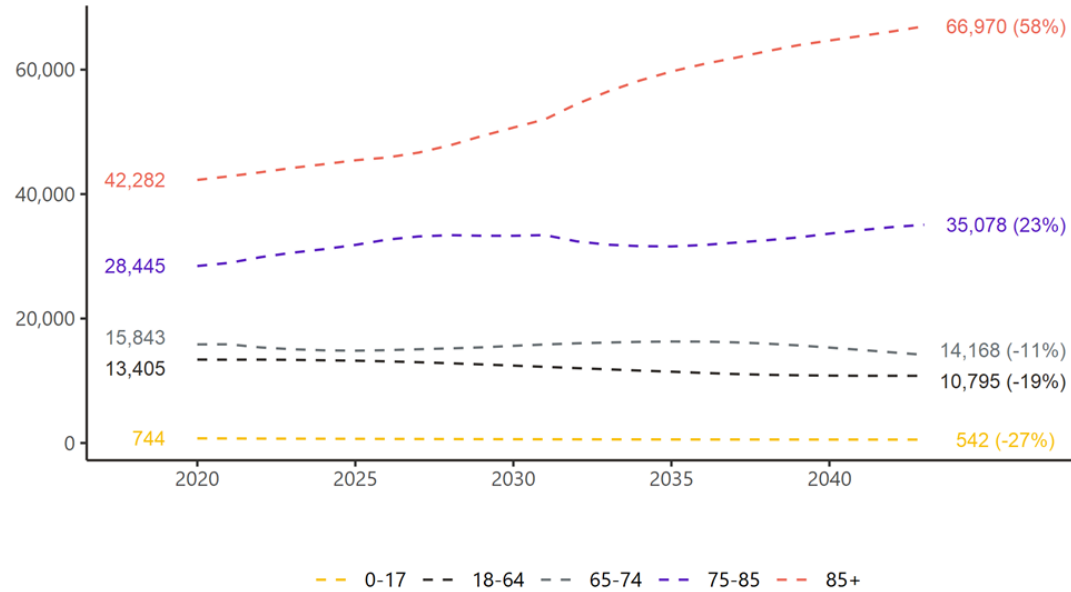
In our reports we utilise each of these deceased individuals' **mortality record**, collected when deaths are certified and registered, and link this to their retrospective **healthcare activity**, also sourced from national data, which take place in the two-year period prior to their death.

Linkage between a person's mortality record and their interactions with healthcare services, as collected by providers, form a potent population dataset. It can be used to reflect on the **manner of a person's death** and the **type, frequency and resource** of the activities allocated to this population over the two-year period before they die.

# Deaths predicted to increase, future shift to more males than females

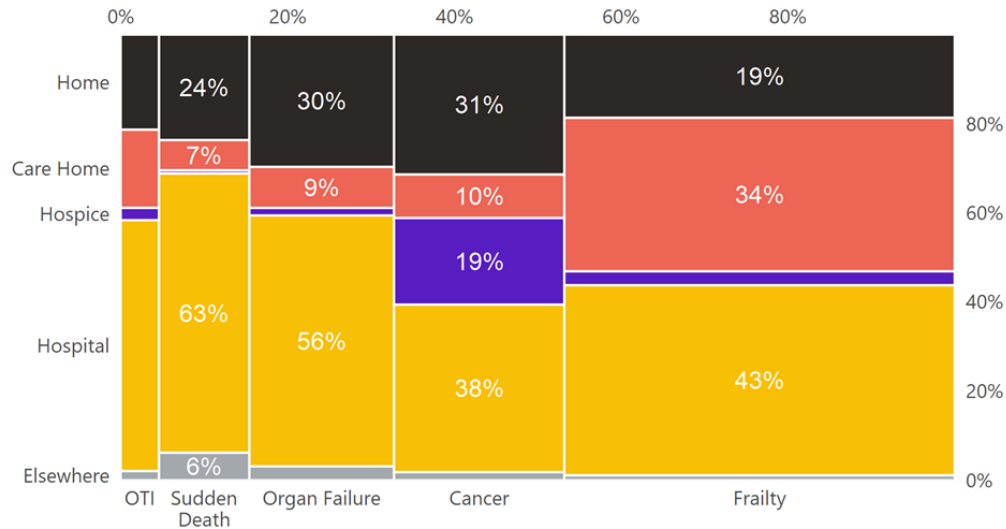


# Older age groups are where deaths are increasing



# Of all deaths 47% took place in hospital but place of death profile differs by cause of death

Place of death by cause of death group

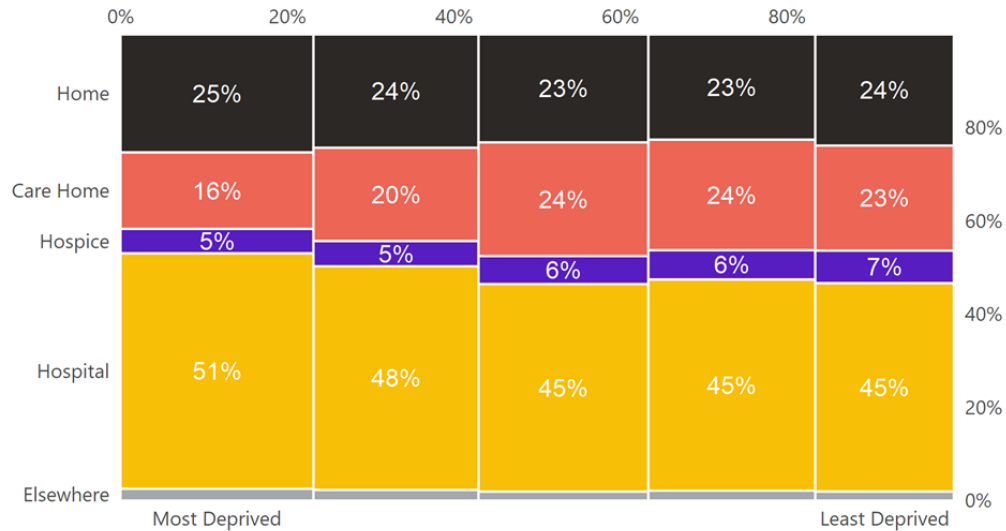


OTI = other terminal illness



# The most deprived had more deaths in hospital and fewer deaths in care homes

Place of death by quintile of deprivation



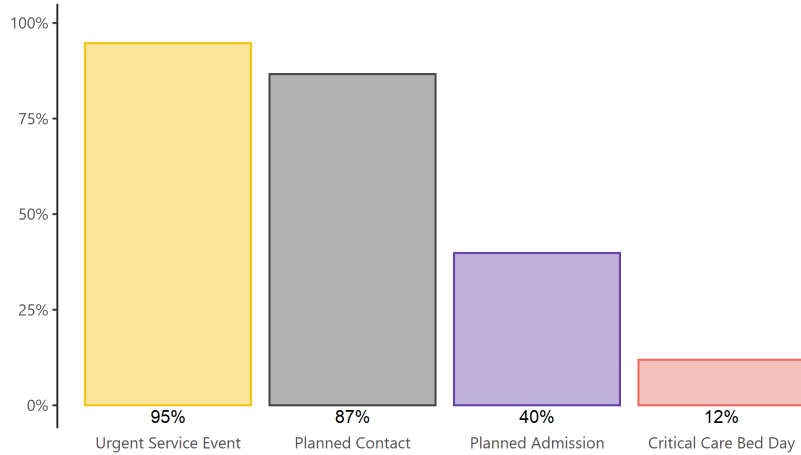
## Which people access what healthcare?...and how do we categorise them?

From the datasets used in this report services have been grouped into four different healthcare activity types, comprised of the following service groups.

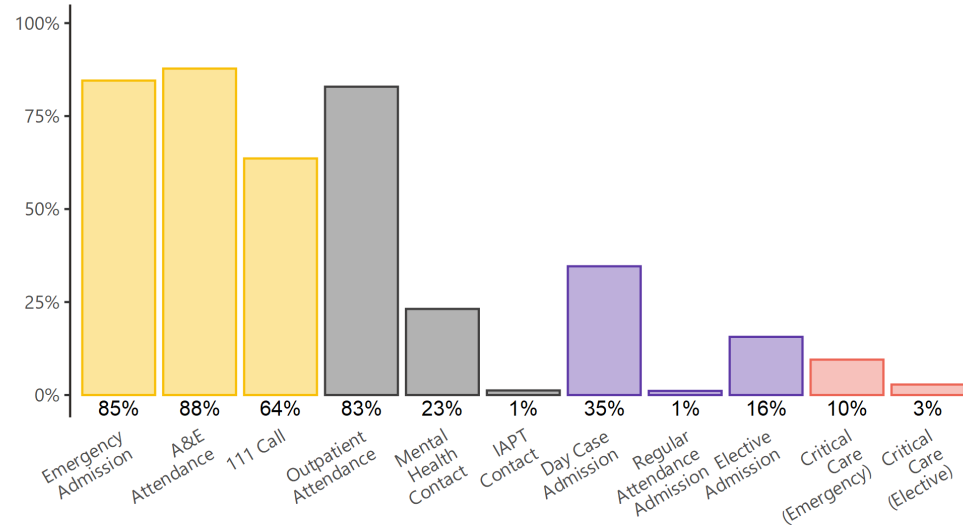
<b>ACTIVITY TYPE</b>	<b>SERVICE GROUP</b>
<b>Urgent service event</b>	Emergency Admissions A&E Attendances Calls to 111
<b>Planned contact</b>	Planned Outpatient Attendances Mental Health Contact IAPT Appointments
<b>Planned admission</b>	Daycases Elective Admissions Regular Day/Night Admissions
<b>Bed days</b>	Critical Care All Other Bed Types

# Most people have at least one urgent care interaction in the two years before they die

By activity type:

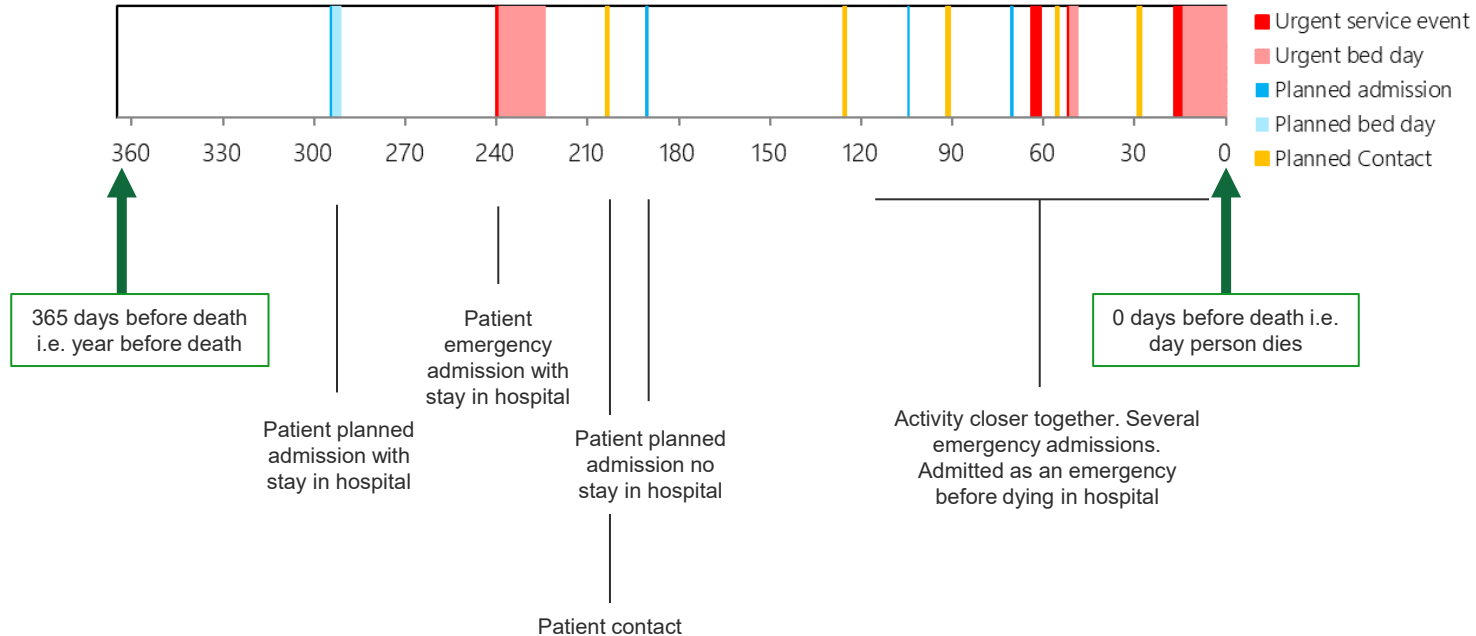


By service type:

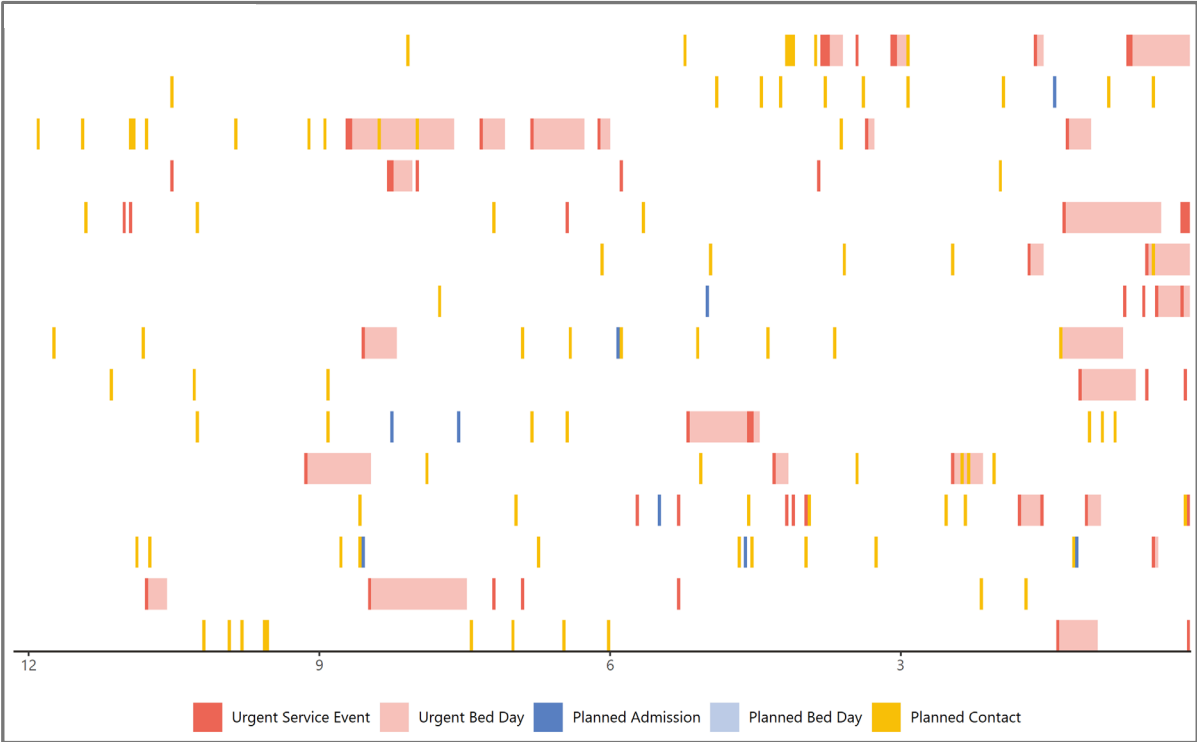


# What does a person's end of life care pathway look like?

Final year of life example:

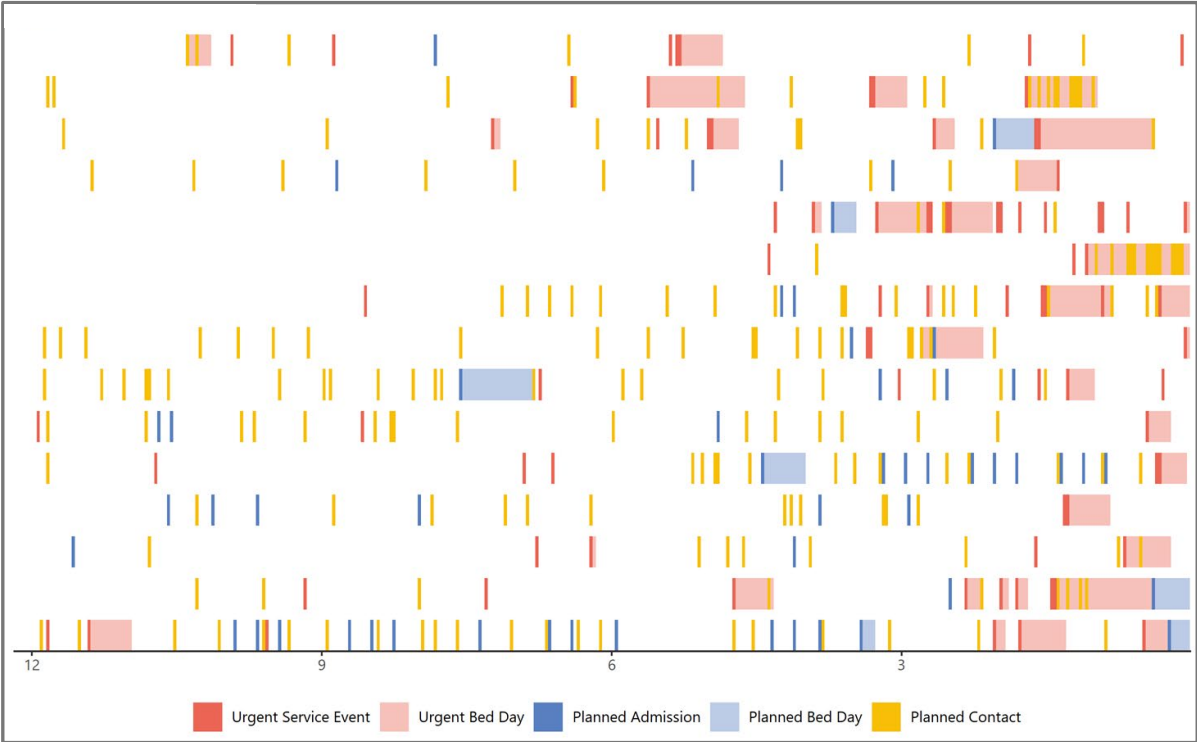


# What does pathway look like for patients who die because they are frail?

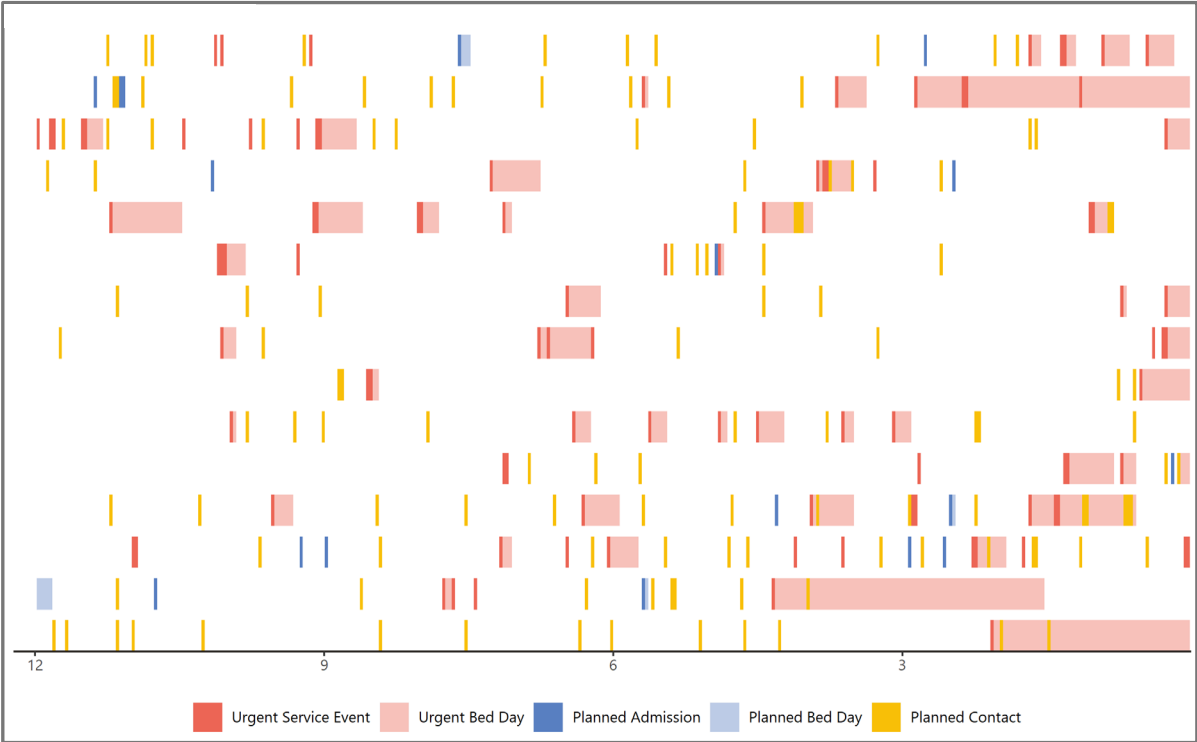




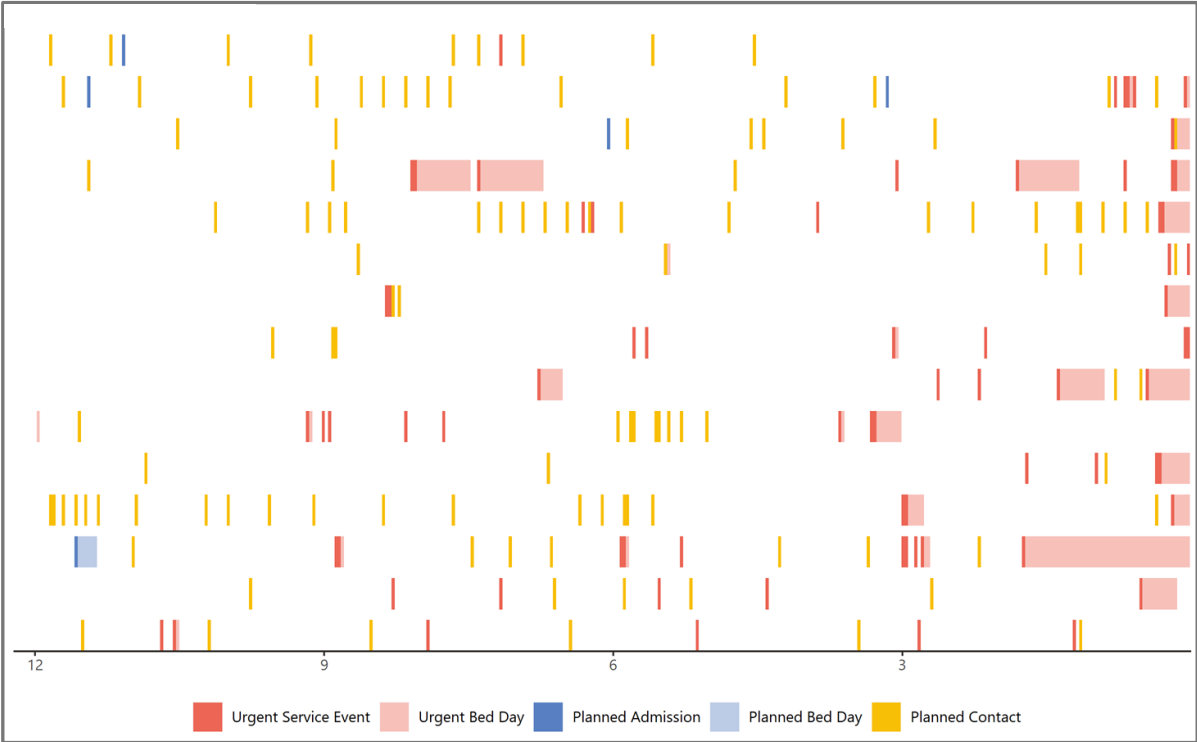
# What does pathway look like for someone dying from cancer?



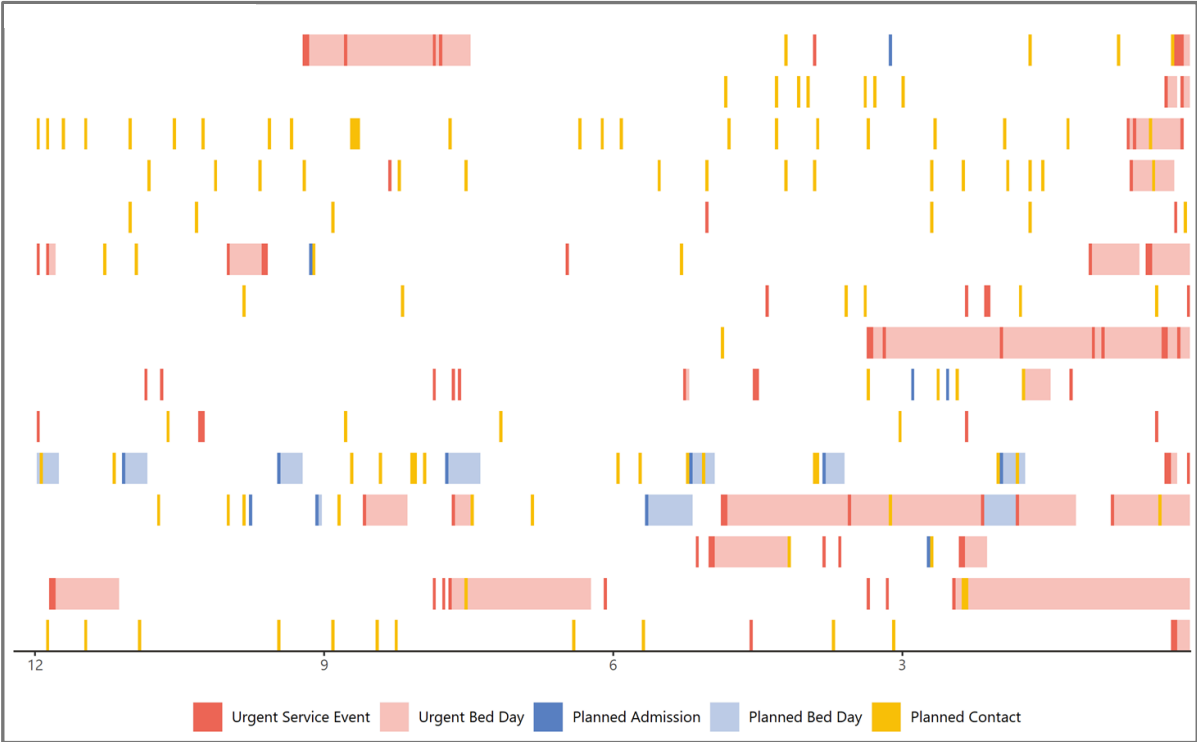
# What does pathway look like for someone dying from organ failure?



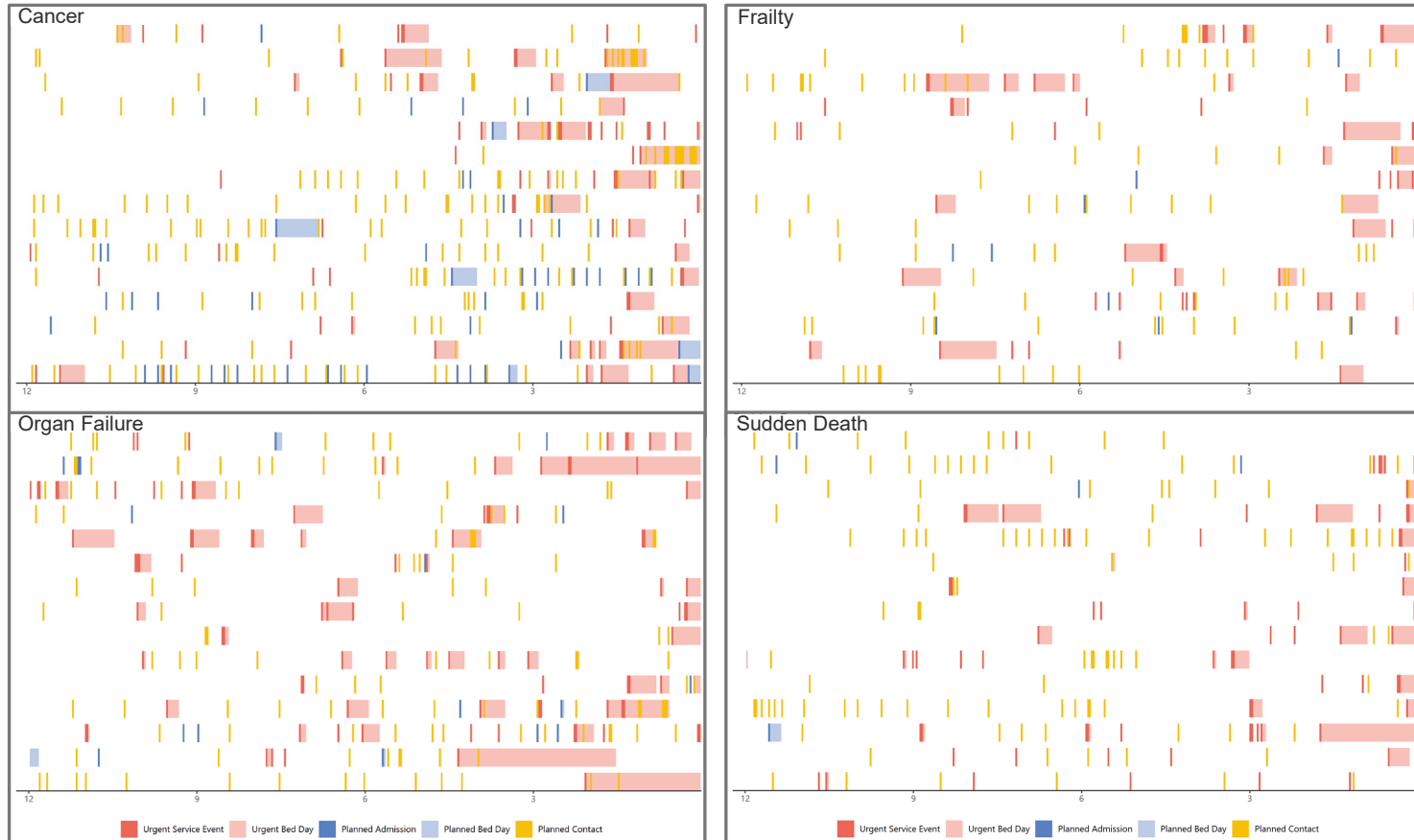
# What does pathway look like for someone who has a sudden death?



# What does pathway look like for someone who has an other terminal illness?

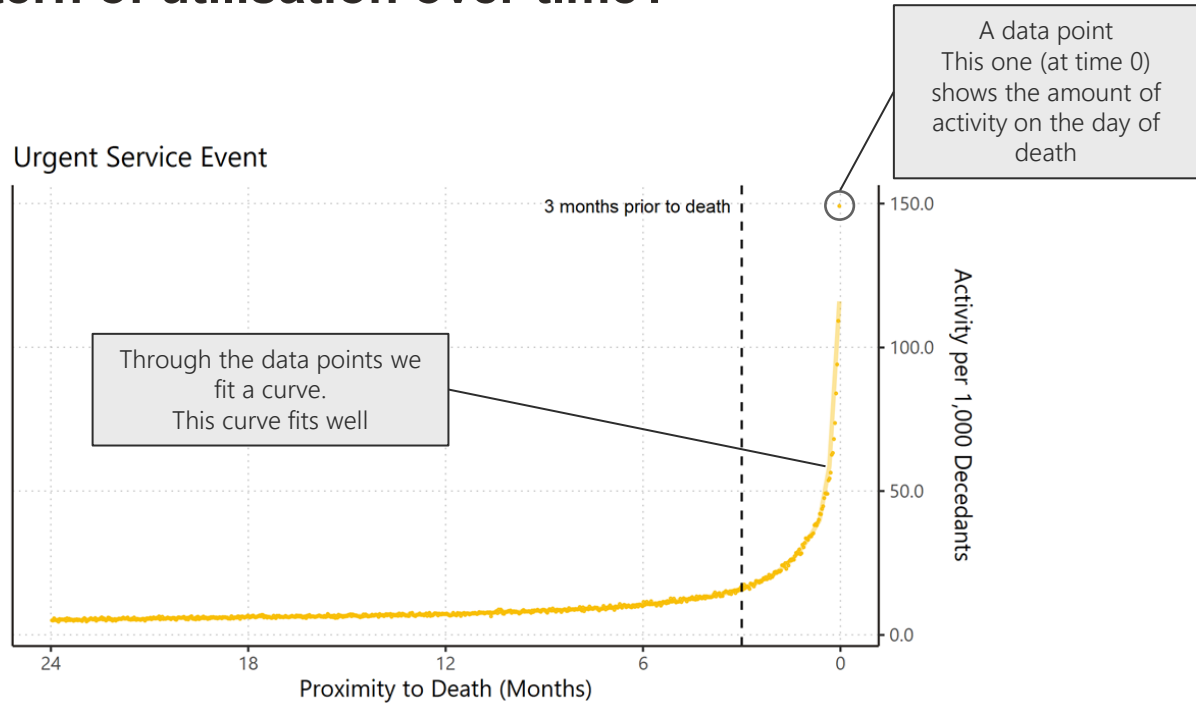


# How do pathways compare to each other?





# What is the pattern of utilisation over time?



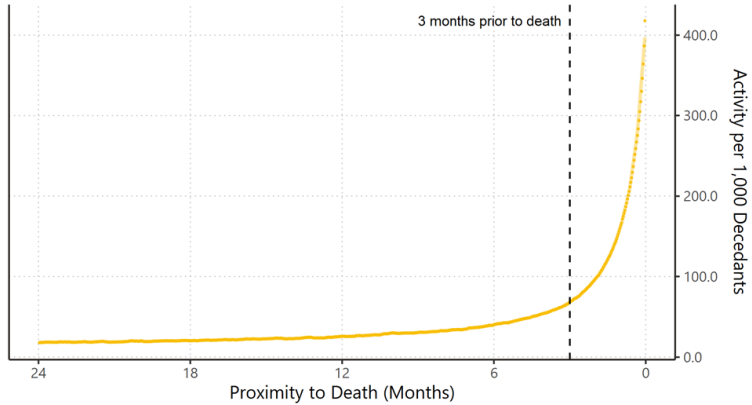
### Planned admissions



### Planned contacts



### Bed days



### Critical care bed day

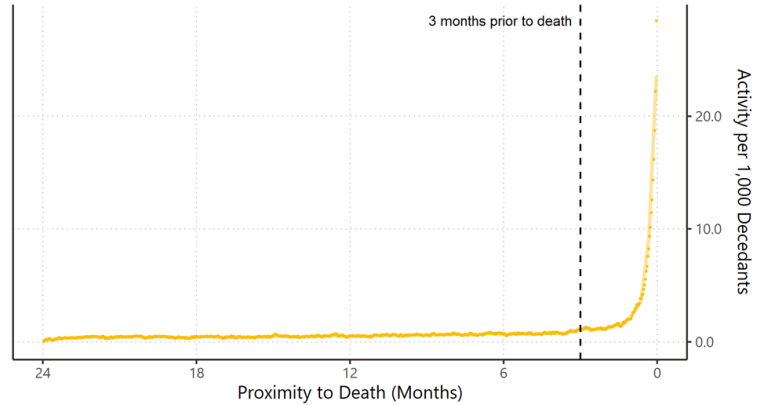




Figure 19 : Patterns of service use for people dying from other terminal illness

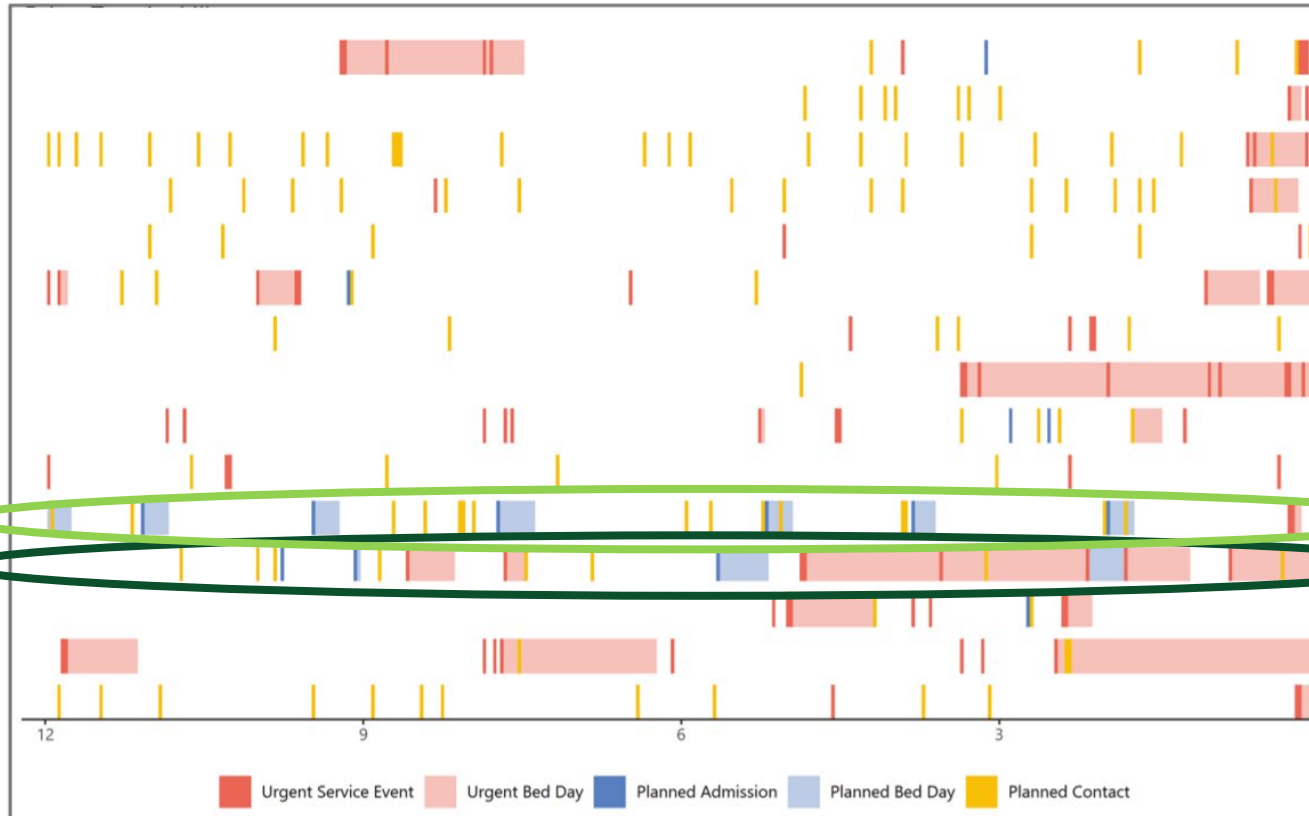


Figure 19 : Pattern

What if....?

ACP:  
Being at home  
matters most

Realistic medicine:  
DNACPR  
discussion

LPA: discussion about  
options for symptom  
management at  
home



What if....?

Early introduction  
to adult services?

Presence of a  
transition  
service?

ACP for age 18:  
BI instead of  
parental consent







# Data with stories

- We cannot make a business case without access to reliable data
- The decision-makers need to understand what the data mean
- Data explain a big picture, and help us to make sense of what is happening to populations, organisations and services
- Stories help us to relate the data to what is happening to individual people, families and groups
- We need both:

Data for the head, stories for the heart

A decorative graphic in the top left corner featuring a large blue circle with a thick red border. Inside this circle are several smaller blue circles of varying sizes, some overlapping each other, set against a dark grey background.

# Healthcare use in the last 2 years of life

Dr Ollie Minton

CD for cancer and consultant palliative  
medicine



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# Background

- Over 80% attend A&E at least once in the two years prior to their death
- 90% access acute services
- 30% of all acute admissions are in the last year of life – 10% of which die on that admission (LOS median 2 days)
- Link to treatment escalation plans / respect / primary care communication

# National Picture

- **29%** NHS spending is on patients in the **last year of their life**
- **1:3** of the adult inpatient population is in the last year of their life
- **1:10** is in their last admission
- Supportive and palliative care intervention is evidenced to **reduce cost of hospital admission by 14-24%**

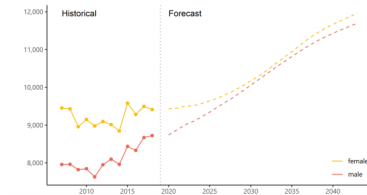
# 66% of people say they would like to die at home. In Sussex Health and Care Partnership just 22% do so

## 3.2 Deaths will increase for both males and females

Trends and forecasts in Sussex Health and Care Partnership reflect those in England. Figure 2 shows the annual increase in deaths over the last decade. In 2018/19 16,894 adults died in Sussex Health and Care Partnership. Between 2020 and 2030 the number of deaths is expected to grow 19% to 20,170 per annum. As the size of the decedent population grows so too will demand on services.

There has also been a shift towards increasing numbers of deaths in males, narrowing the gap between genders. In future years deaths for males increase closer to deaths for females.

Figure 2 : Historical and forecast deaths by gender - Sussex Health and Care Partnership ICS



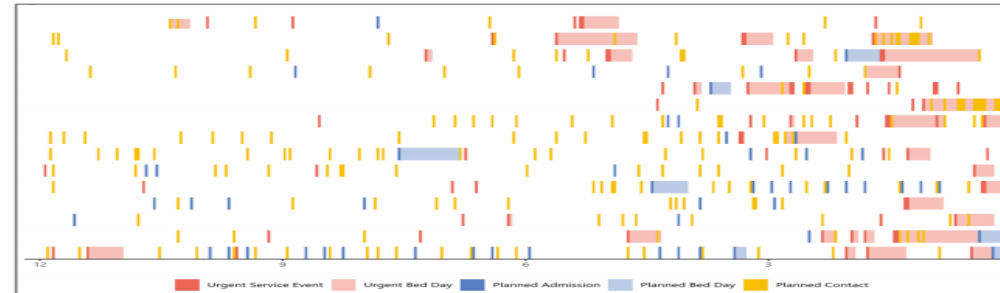
- Ageing population
- More co-morbidities
- Fits true north of reduction in crude mortality
- Earlier recognition of deterioration

# Cancer as an example

## 5.4.2 Planned care features highly for those dying of cancer

Analysis of the sample of those dying from cancer (Figure 16) suggests frequent planned contacts and planned admissions. This group is also more likely to have a planned stay in hospital and experience urgent bed days than other cause of death groups. Urgent events and associated urgent bed stays are more likely to occur in the last six months of life.

Figure 16 : Patterns of service use for people dying from cancer

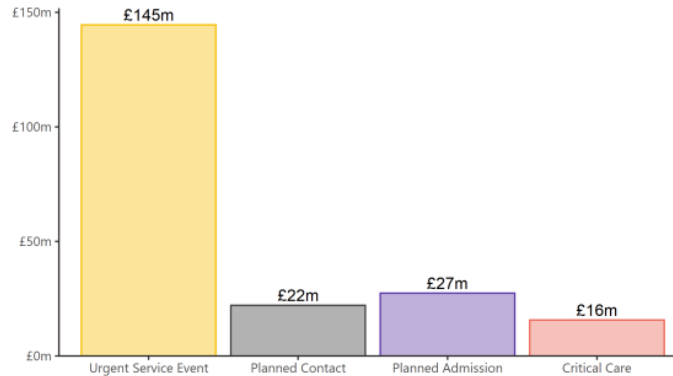


# Opportunities

## 8.1 Urgent care accounts for two-thirds of expenditure

The calculated total hospital spend in the last two years of life in Sussex Health and Care Partnership is £210 million. Figure 51 shows spend by activity type. Urgent services dominate spend, consuming two-thirds of end of life resource.

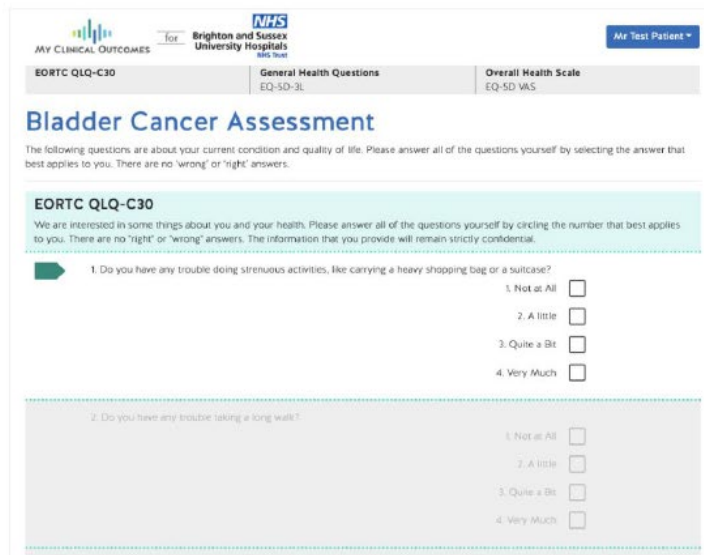
Figure 51 : Total spend by activity type in two years prior to death – Sussex Health and Care Partnership ICS



# PROMS

## MCO for BSUH

### Assessment



EORTC QLQ-C30	General Health Questions EQ-5D-3L	Overall Health Scale EQ-5D VAS
---------------	--------------------------------------	-----------------------------------

### Bladder Cancer Assessment

The following questions are about your current condition and quality of life. Please answer all of the questions yourself by selecting the answer that best applies to you. There are no 'wrong' or 'right' answers.

#### EORTC QLQ-C30

We are interested in some things about you and your health. Please answer all of the questions yourself by circling the number that best applies to you. There are no 'right' or 'wrong' answers. The information that you provide will remain strictly confidential.

1. Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?

1. Not at All

2. A little

3. Quite a bit

4. Very Much

2. Do you have any trouble taking a long walk?

1. Not at All

2. A little

3. Quite a bit

4. Very Much



#### Assessments:

- EORTC QLQ-C30 (Questionnaire developed to assess the quality of life of cancer patients)
- EQ-5D-3L (General Health Questions)
- EQ-5D VAS (Overall Health Scale)

Patients receive an email reminder to complete scheduled assessments at 2-week intervals, regardless of their cancer type

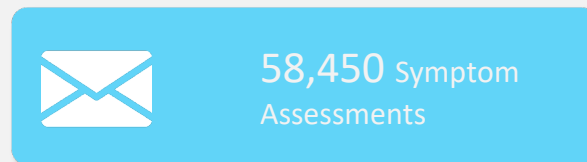
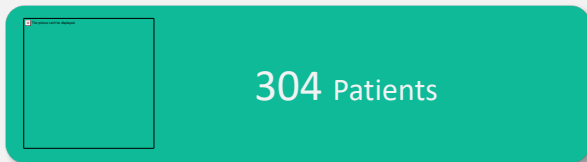
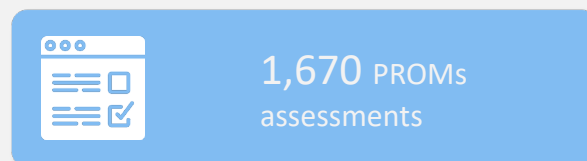
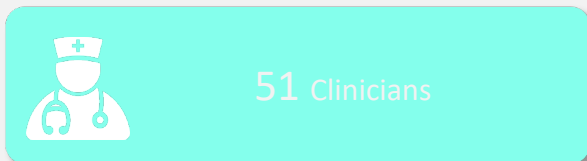
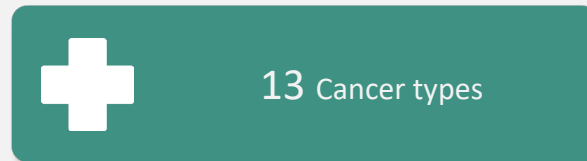
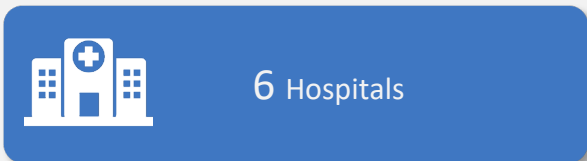




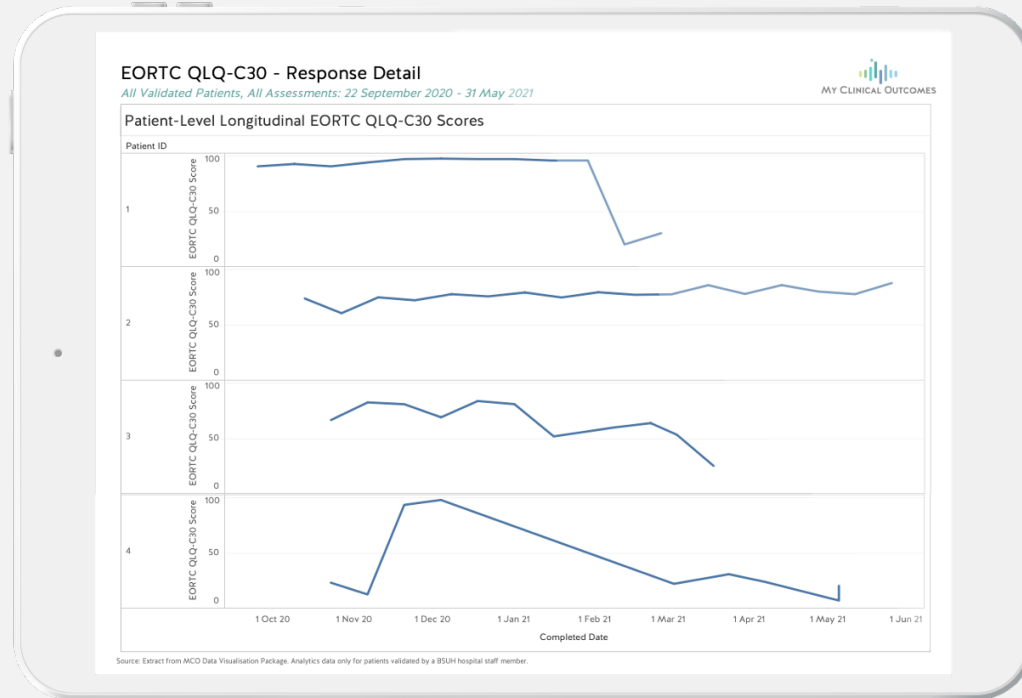
**MCO is a digital health platform for remote, long-term collection and real-time analysis of Patient-Reported Outcome Measures in routine clinical practice**

## BSUH ESC Summary

22nd Sept 2020 – 11<sup>th</sup> August 2021



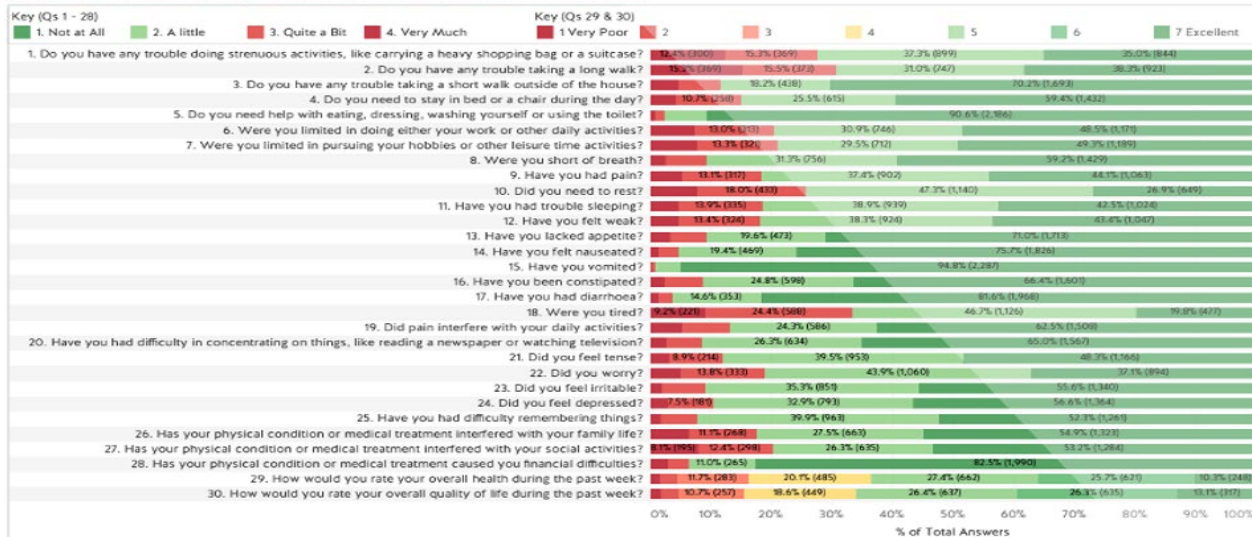
# Overall quality of life changes



# Symptom burden

## EORTC QLQ-C30 - Response Detail

All Validated Patients, All Assessments: 22 September 2020 - 31 May 2021



### Total Assessments By Cancer Type

Breast (Primary)	Bladder	Bowel	Breast (Secondary)	Kidney	Liver	Lung	Oesophageal	Other	Ovarian	Pancreatic	Prostate	Stomach	Total
19	26	27	763	44	40	37	41	728	62	46	539	40	2,412

Source: Extract from MCO Data Visualisation Package. Means calculated across all completed assessments. Analytics data only for patients validated by a BSUH hospital staff member.

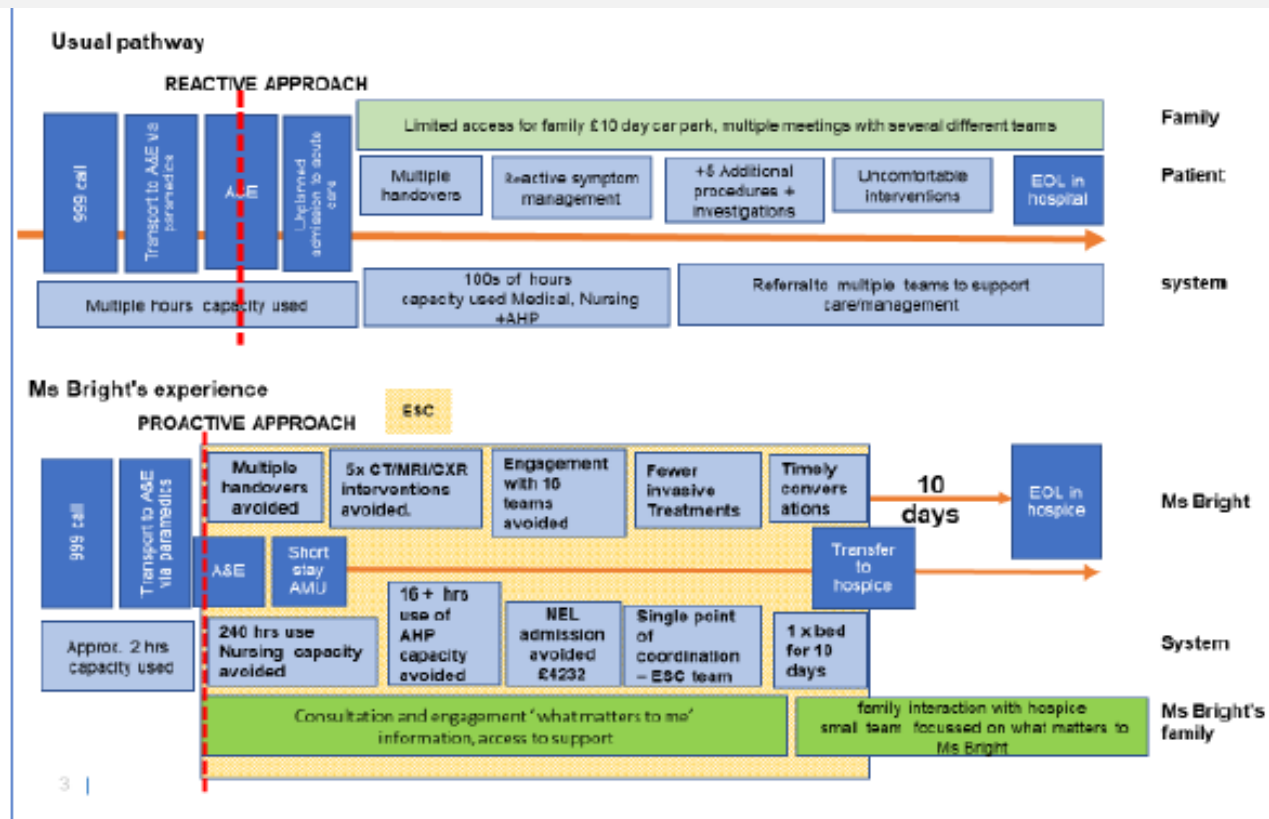
# The Project

- 2 year fixed term project
  - Funded by NHS England
- Initially staffed by:
  - 3x Clinical Nurse Specialists
  - 1x Clinical Fellow
  - Data support from the Academic Health Sciences Network
- Project Aims
  - To reduce number of unnecessary admissions, clinical investigations and length of stay
  - To provide quicker symptom management and holistic care needs
  - To provide earlier access to specialist services and AHP reviews
  - Initially provided to those with a cancer diagnosis on a treatable but curative pathway

# What We Learned

- Soon realised that zoning in on such a specific patient population was too limiting
- Now we see patients across the Acute Floor who:
  - Have a cancer diagnosis, irrespective of their treatment options
  - Have unmet palliative or supportive care needs
  - Are at risk of clinical deterioration

# Mrs Bright



# Mrs Bright

Modelling of potential system benefits from ESC using Ms Bright's experience

	Service	Ms Bright	1 x Ms Bright per month	1 x Ms Bright per week
Costs Avoided £	Acute care tests and procedures	5,500	66,000	286,000
	Non elective admission	4,232	50,784	220,064
Total (minimum)		<b>£9,732</b>	<b>£116,784</b>	<b>£506,064</b>
Capacity regained	Acute care - hrs	270	3240	14,040
	Bed days freed	10	120	520
	A&E - hrs	8	96	416
	Paramedic services - hrs	2	24	104
Total (minimum hrs)		<b>290</b>	<b>3480</b>	<b>15,080</b>

Benefits of involving the ESC team in A&E meant that Ms Bright's wishes were respected; she was moved to a hospice and supported by her family for the remaining days of her life. This was achieved with less than five hours of ESC team clinical time (£125) and support from the hospice (£1100 for 2 weeks). The savings generated from ESC engagement exceed £10k. – the costs here reflect the minimum of 'bed and board' cost. Together with at least 270 hours of capacity, that could be used for caring for other patients – including 240 hours of nursing time, over 16 hours of AHP capacity and ten days of bed use.



# What patients and staff say

*"I hate coming into hospital, so if teams can see I'm not doing so well through this site and stop that, then I'm all for it"*

*"I'm willing to try anything that may help or improve the care that I receive from the hospital"*

*"With a MCO assessment available a phone call can take 5 mins; if not, it takes longer and you risk missing something"*

*"Strong consideration should be given to the use of validated PROMS for patients to record symptoms of disease and side-effects of treatment experienced as a regular part of clinical care.*

*Systematic monitoring would facilitate communication between patients and their treatment teams by better characterising the toxicities of all anticancer therapies.*

*This would permit early intervention of supportive care services, thus enhancing quality of life.*

*"Its like a NEWS score for cancer"*

*"By using MCO I can call the right people who need help, and just monitor others remotely. It'll save me so much time!!"*

# An Oncologists Perspective



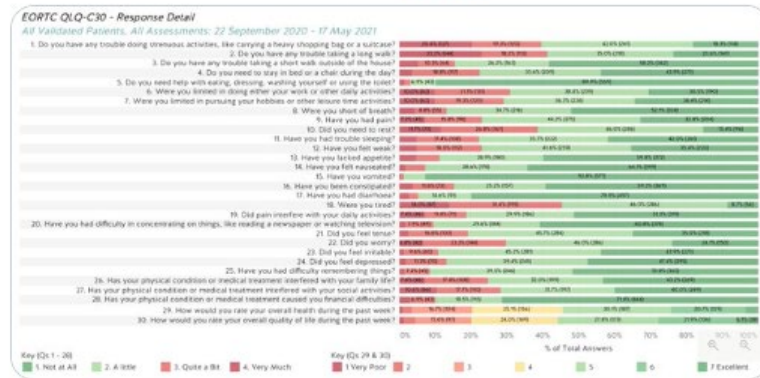
**Richard Simcock** @BreastDocUK · May 20



Routine PROM collection @UHSussex helps me understand an individual's concerns in the clinic.

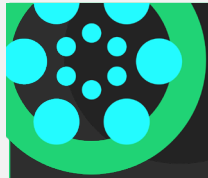
The summary reports from @MyClinOutcomes help me see the unmet needs for the population.

Fatigue leaps out from this report (and @drol007 has a trial ready for that).



# Conclusions

- Changes in Quality life scores sensitive indicator – toxicity / progression etc
- Attending as an emergency – regardless of reason - clear indicator of deterioration vs elective care – should mandate supportive / palliative care discussions
- Collaboration key for an in reach service – acute medicine want guidance for all oncological problems and don't discriminate



# Up and coming events

Date	Time	Event name
Monday 4th October	10:00-11:15	Festival welcome and opening event. A brave new world: Should health and care systems trust algorithms? ( <a href="#">Register</a> )
Tuesday 5th October	10:00-11:00	What can we learn from the pandemic to reduce health inequalities? ( <a href="#">Register</a> )
Wednesday 6th October	12:30-13:30	How do we move insight into action for adult social care? The IMPACT Centre and panel discussion ( <a href="#">Register</a> )
Wednesday 6th October	14:00-15:30	Insight to Action – what works? ( <a href="#">Register</a> )
Thursday 7th October	11:00-12:00	Midlands Analyst Network Huddle - Special Edition – a new perspective on outpatient attendances ( <a href="#">Register</a> )
Monday 11th October	10:00-11:30	The most valuable value - a health & care resourcing dilemma ( <a href="#">Register</a> )
Monday 11th October	14:00-15:00	Sharing your awesomeness! ( <a href="#">Register</a> )
Tuesday 12th October	09:00-10:00	Reducing health inequalities: the practical & ethical challenges ( <a href="#">Register</a> )
Tuesday 12th October	13:00-14:00	Data for the head, stories for the heart ( <a href="#">Register</a> )
Wednesday 13th October	10:00–11:00	Insight to action: How can we change behaviour? ( <a href="#">Register</a> )
Thursday 14th October	10:00-11:15	Misinformation and how do we tackle it? ( <a href="#">Register</a> )
Friday 15th October	10:00-11:00	INSIGHT 2021 closing session: Insight to Action – lessons from the think tanks ( <a href="#">Register</a> )

Thank you to everyone for coming and thank you to our guest speakers.



# Contact us

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