

# **Data-driven Palliative & EoLC:** the view from a managed clinical network

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Trust

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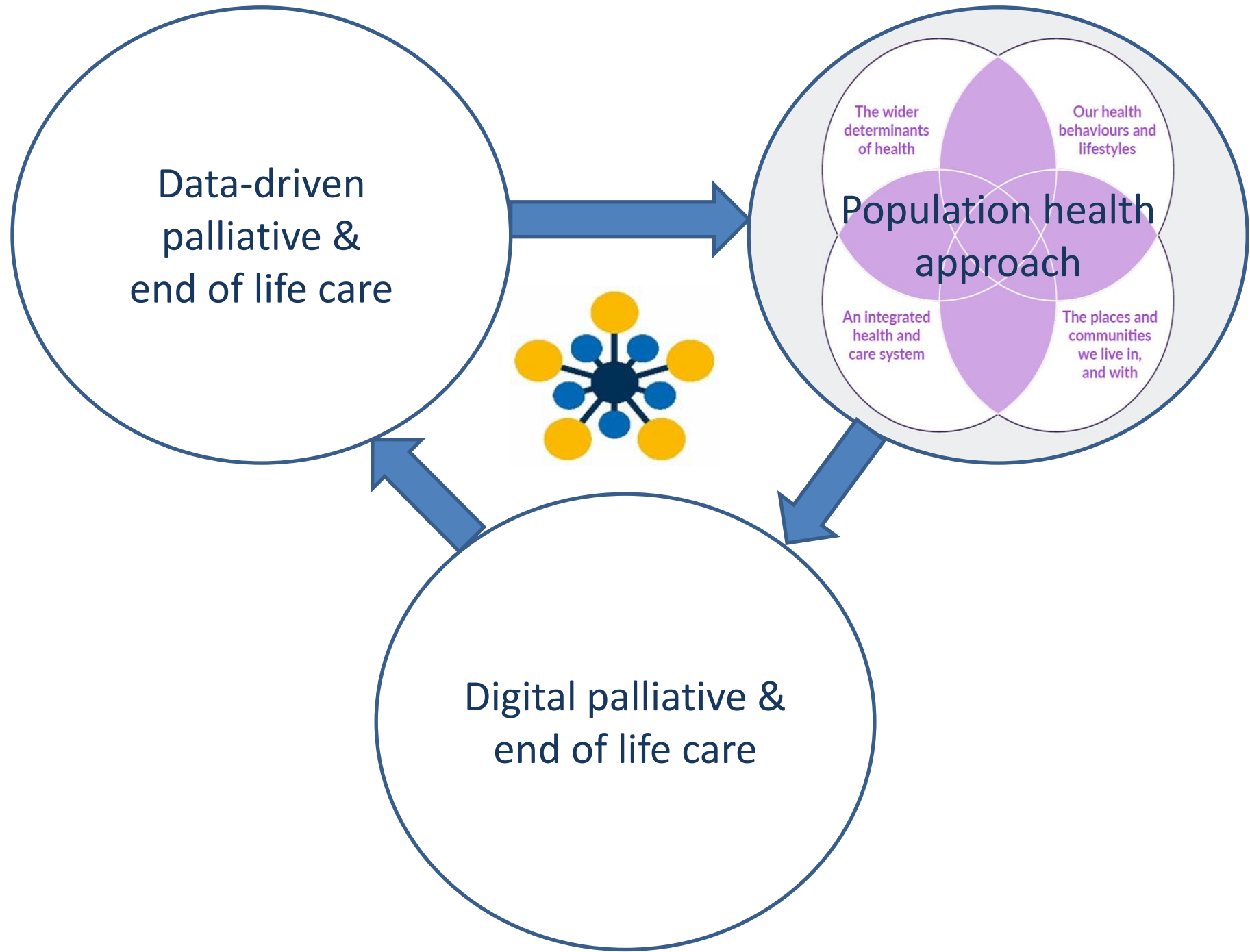




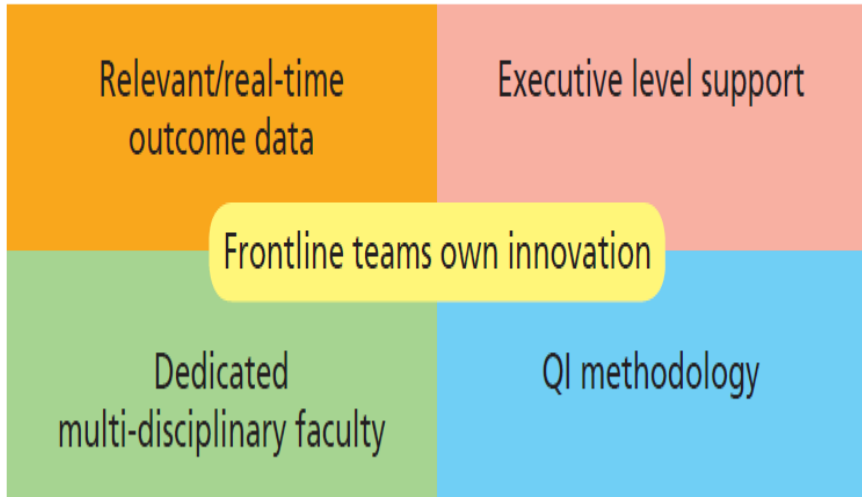
# Leeds Palliative Care Network



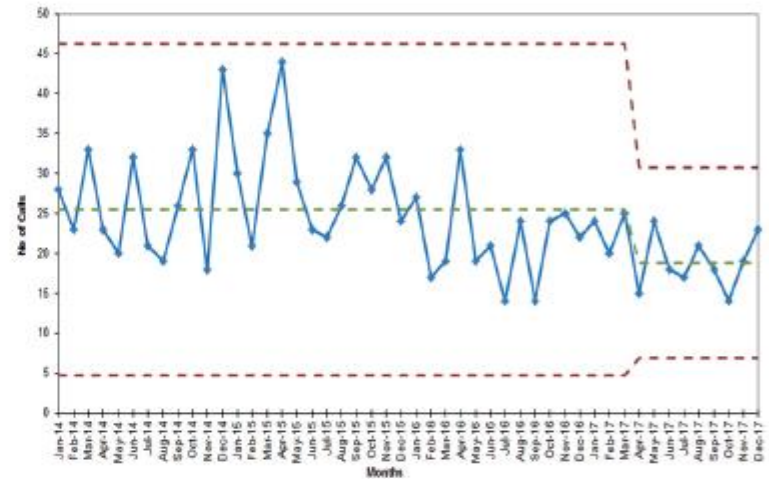
- Education & Research
- Quality assurance & patient experience
- Workforce and service improvement
- Medicines management



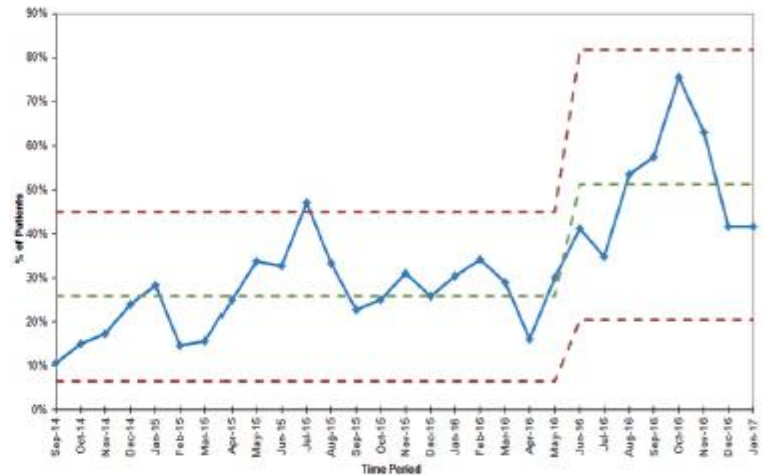
# Building Blocks of Success



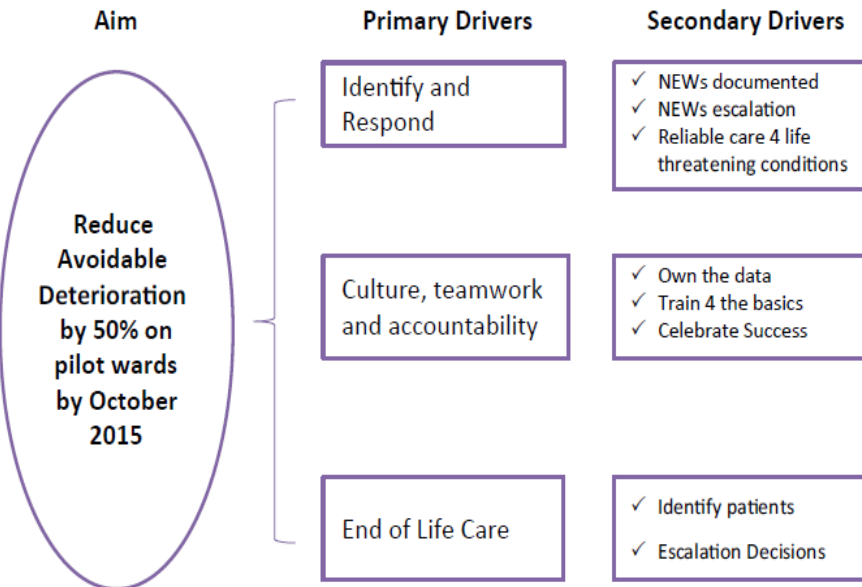
## SPC 1 - 2222 Cardiac Arrest Calls at LTHT



## SPC 3 - Percentage of Patients with a CPR Decision (Pilot Wards)



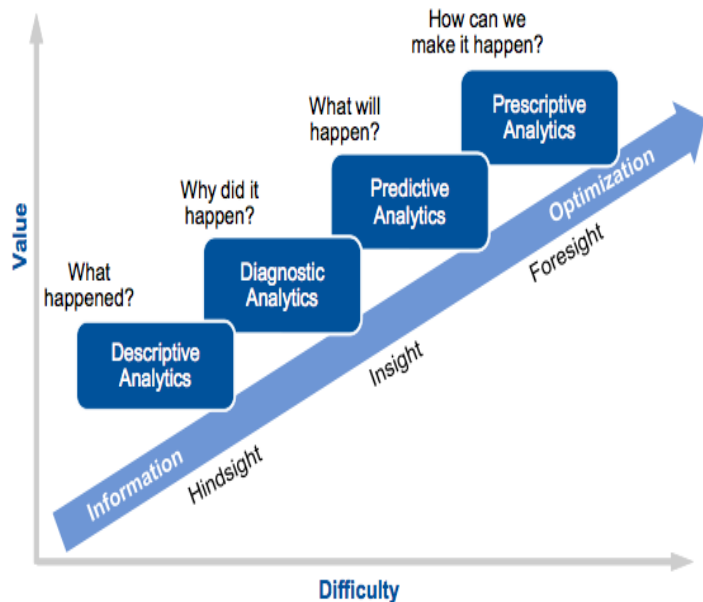
### Driver Diagram



# Data Strategy for Health and Social Care

“...we need to find safe, secure, collaborative and efficient ways to turn that raw data into insights and action, to improve patient care for all.”

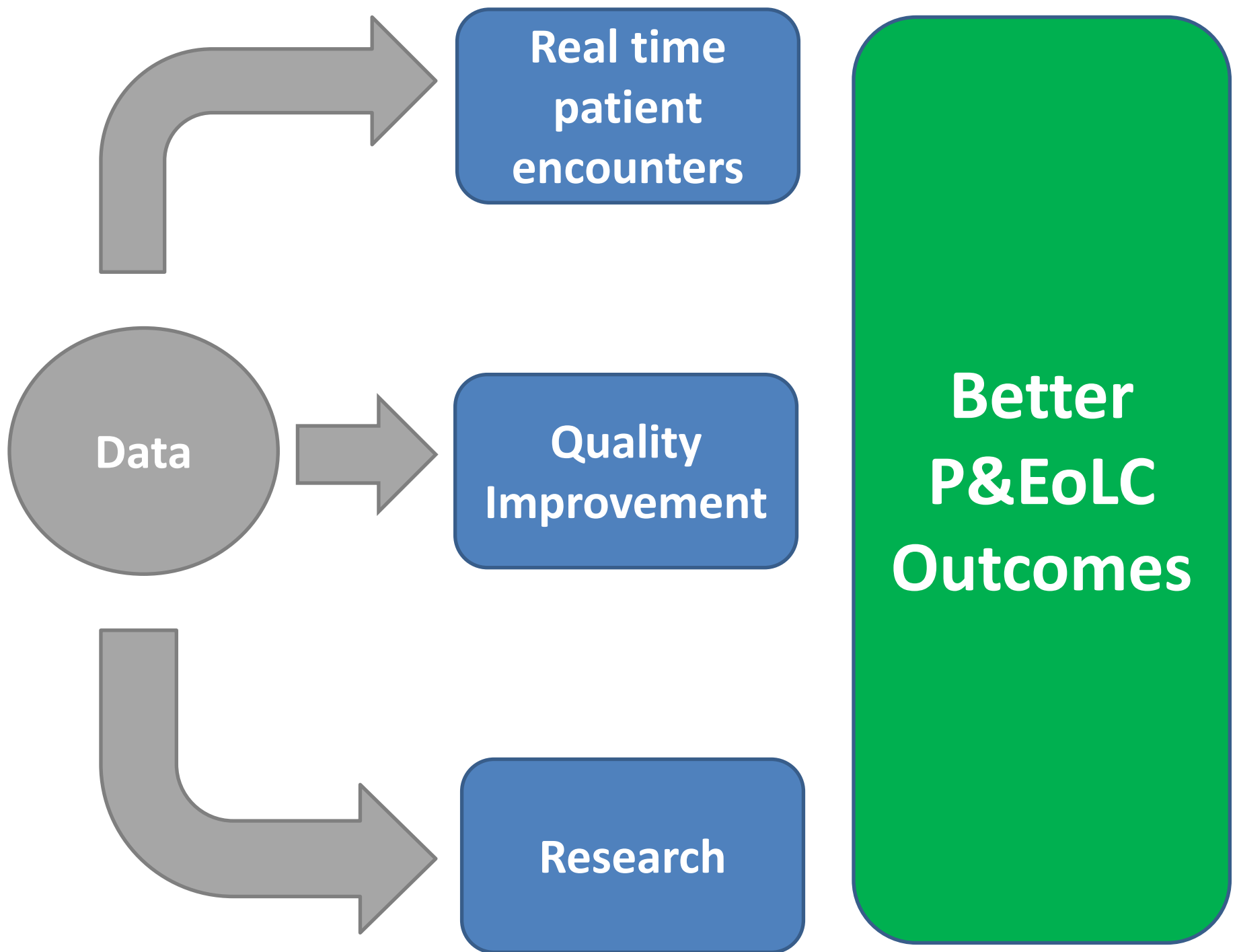
Figure 2. Gartner Analytic Ascendancy Model



Source: Gartner (March 2012)

Data  
↓  
Information  
↓  
Intelligence





Outcomes tracked to guide care

Equitable Access To care

High Quality Care

£

Data available @ PoC 24/7

Recognition

Research



Data-driven palliative and end of life care



Level 1 Basic	Level 2 Opportunistic	Level 3 Systematic	Level 4 Differentiating	Level 5 Transformational
<ul style="list-style-type: none"> <li>Data is not exploited, it is used</li> <li>D&amp;A is managed in silos</li> <li>People argue about whose data is correct</li> </ul>	<ul style="list-style-type: none"> <li>IT attempts to formalize information availability requirements</li> <li>Progress is hampered by culture; inconsistent incentives</li> </ul>	<ul style="list-style-type: none"> <li>Different content types are still treated differently</li> <li>Strategy and vision formed (five pages)</li> </ul>	<ul style="list-style-type: none"> <li>Executives champion and communicate best practices</li> </ul>	<ul style="list-style-type: none"> <li>D&amp;A is central to business strategy</li> </ul>
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**Infrastructure**

**Culture**

**Expertise**

**Aligned with:**

- **Vision**
- **Strategy**
- **Work-plan**



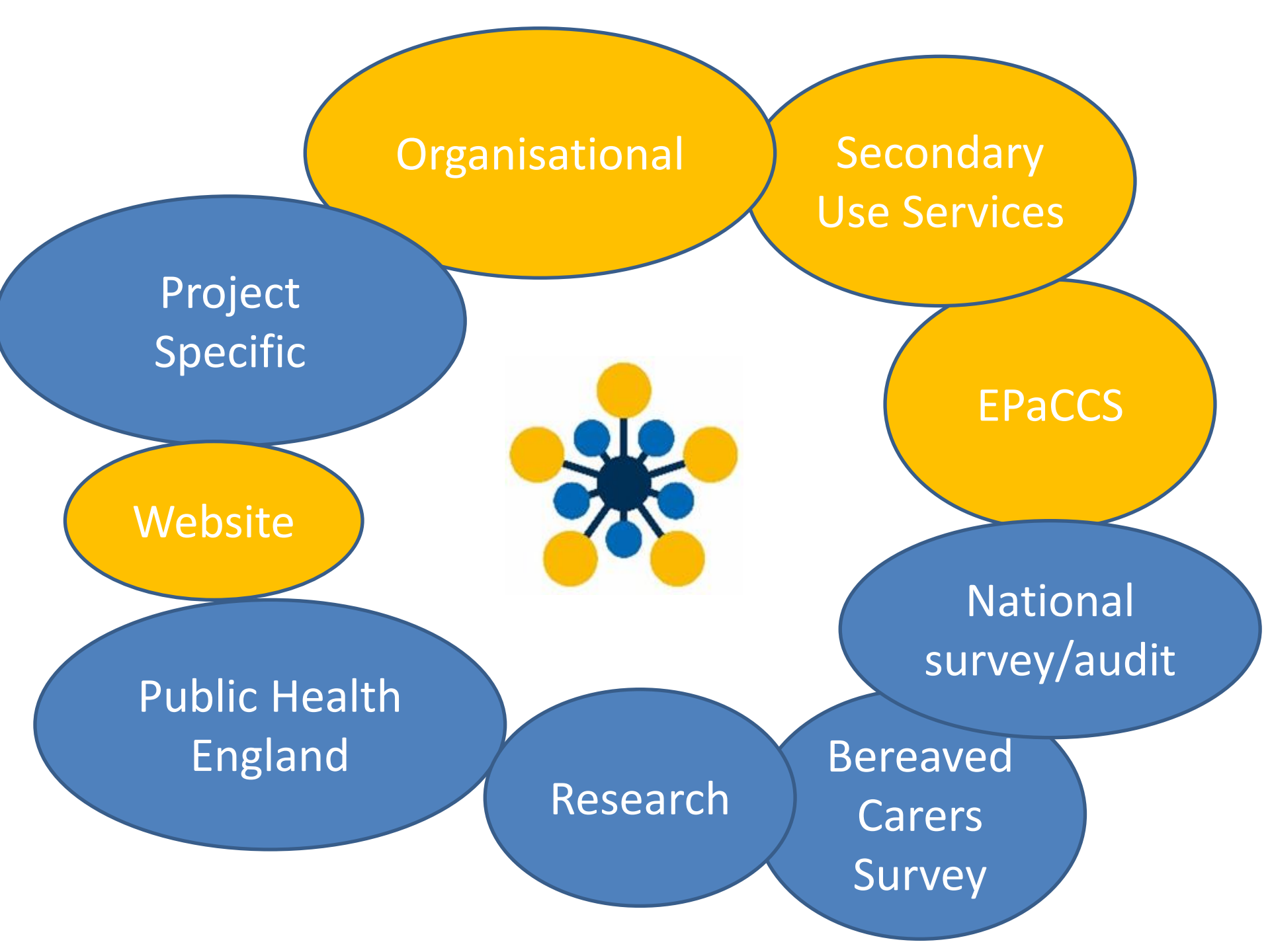
Define all data sources

Assess & improve data quality

Integrate data sources

Identify analytics need

Secure and manage the data life cycle



Organisational

Secondary  
Use Services

Project  
Specific

EPaCCS

Website

National  
survey/audit

Public Health  
England

Research

Bereaved  
Carers  
Survey

Strategic

Clinical

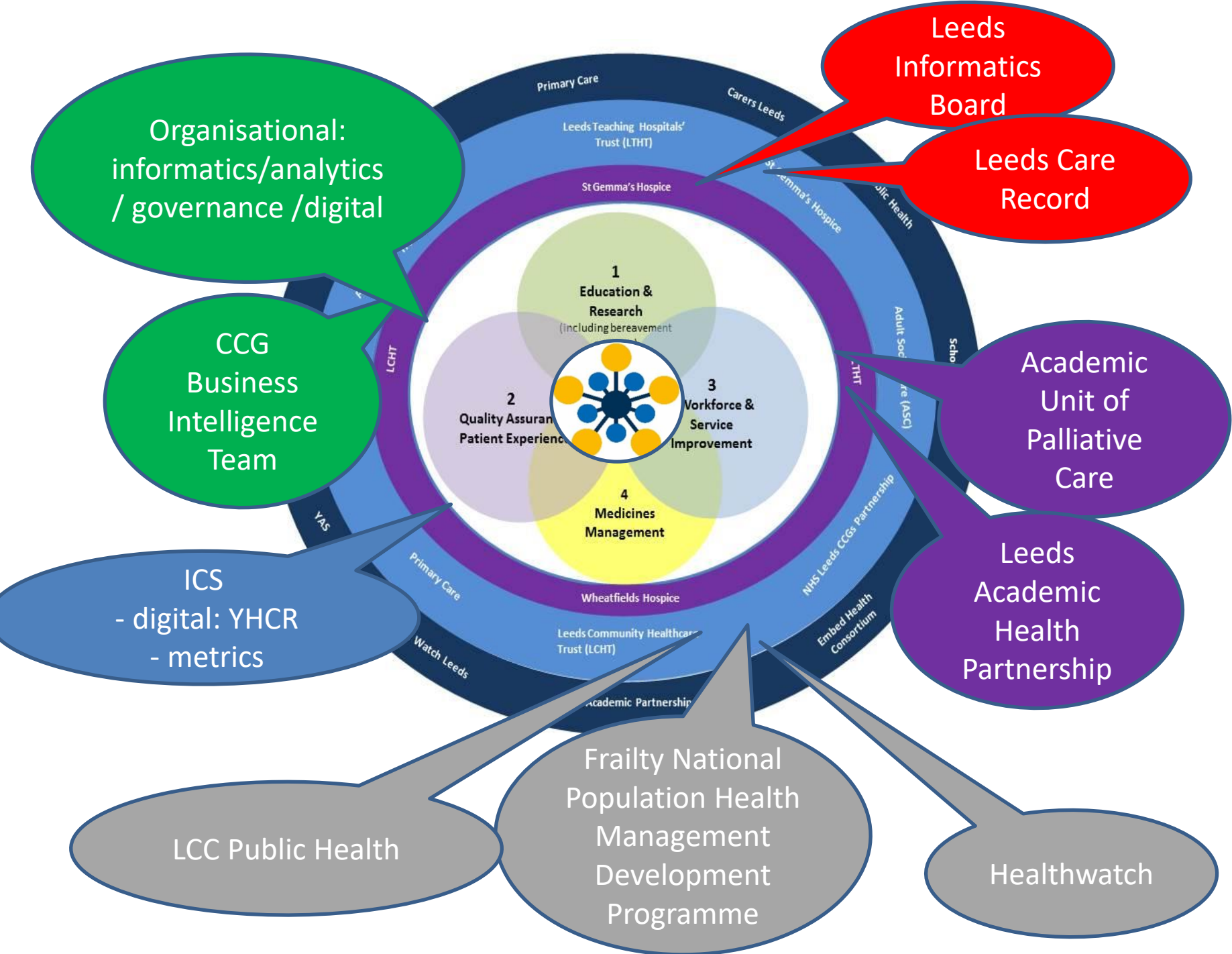
Team

Analytic

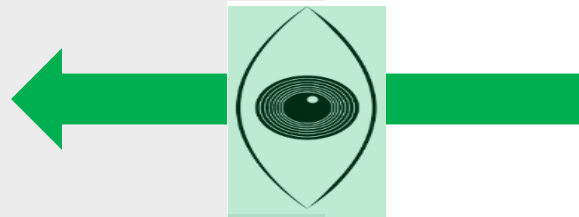
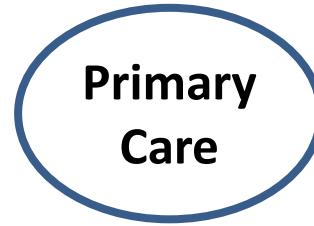
Technical



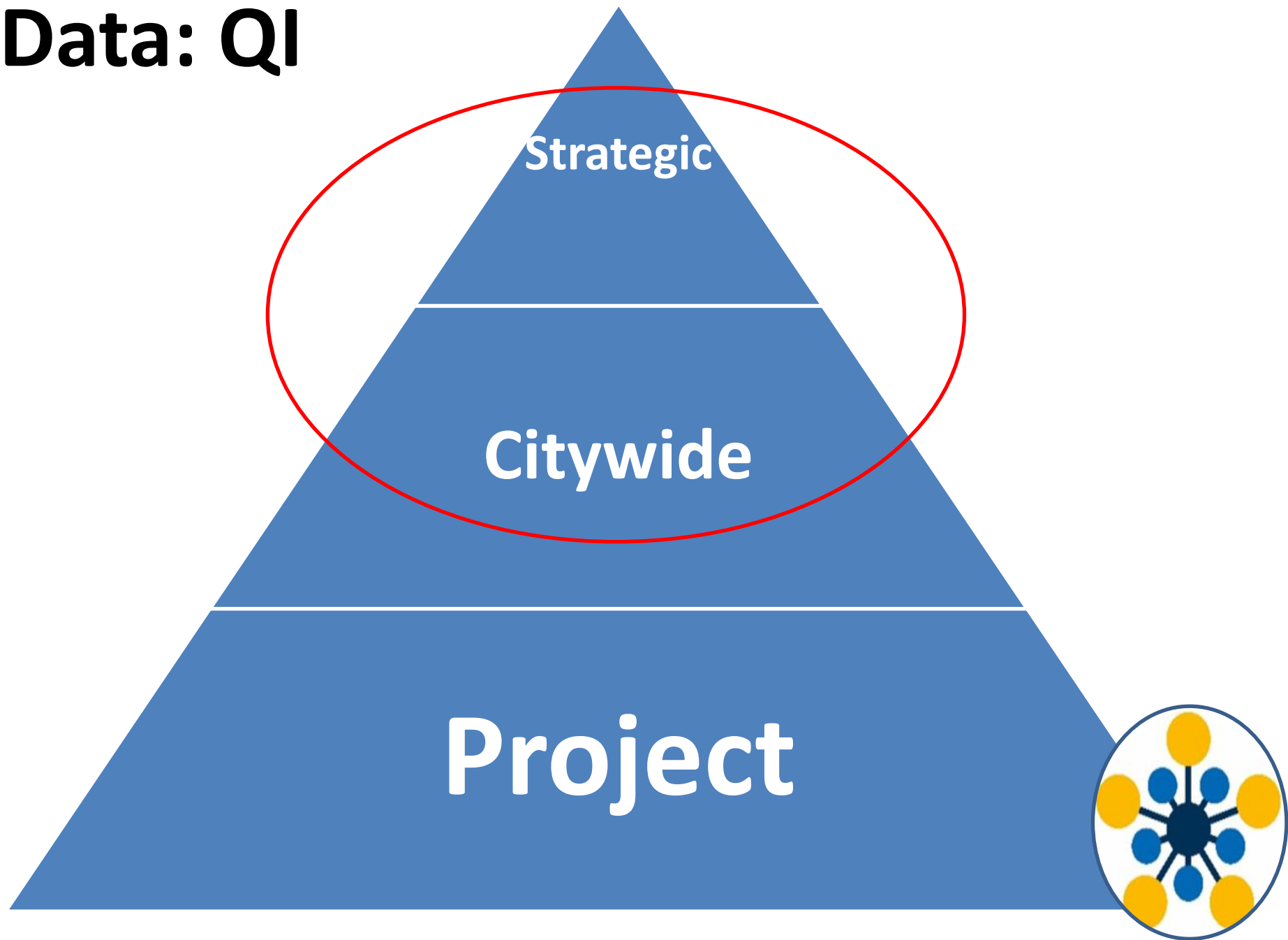
Service users



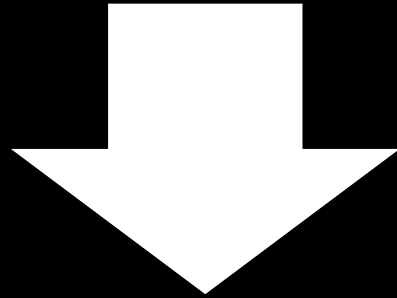
# Data: PoC



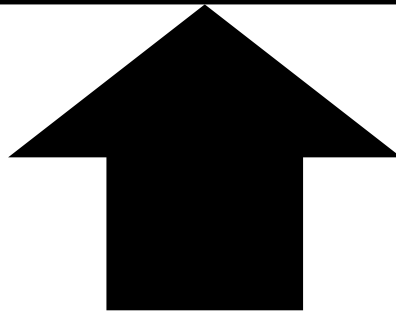
# Data: QI



**Measure what matters**



**Metrics**



**What you can measure**



Improving Quality

### LESSONS LEARNED

Implementing an Electronic Palliative Care Co-ordination System (EPaCCS)



## Bereaved Carers Survey about End of Life Care in Leeds

People's experiences of end of life care and support for their loved ones in hospices, hospitals, in their own homes and care homes

January to March 2020



Digital

Search

NHS Digital > Services > Secondary Uses Service (SUS)

## Secondary Uses Service (SUS)

The Secondary Uses Service (SUS) is the single, comprehensive repository for healthcare data in England which enables a range of reporting and analyses to support the NHS in the delivery of healthcare services.



# ROeSPECT

## Digital PPM+





Digital  
Innovation

Data  
Reporting

➤ **EPaCCS**

➤ **ReSPECT**



**EPaCCS**  
  
 connecting healthcare

Primary Care

Community Nursing

**EPaCCS**  
 SystemOne

Data Services for Commissioners Regional Offices (DSCRO) 

Hospices

**NHS**  
 The Leeds Teaching Hospitals  
 NHS Trust



**NHS Digital** Search

NHS Digital > Services > Secondary Uses Service (SUS)

**Secondary Uses Service (SUS)**

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EPaCCS Outcome Report

NHS Leeds CCG

2020/21 Report (Q1) - CCG Level

Data Source: SystemOne and EMIS  
 Data Provided by: Health Care Plus (Leeds), Leeds Community Healthcare, St. Stephen's Hospital, Sue Ryder (Leeds) Hospice and Data Quality Team (NHS Leeds CCG)  
 Report Compiled by: Business Intelligence Team, NHS Leeds CCG



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



DSA

EPaCCS Outcome Report

NHS Leeds CCG

2020/21 Report (Q2) - CCG Level

Data Source :            SystemOne and EMIS  
Data Provided by :      Health Care Hub (Leeds), Leeds Community Healthcare, St Gemma's Hospice, Sue Ryder  
                                  Wheatfields Hospice and Data Quality Team (NHS Leeds CCG)  
Report Compiled by :    Business Intelligence Team, NHS Leeds CCG

- % adults who die with EPaCCS
- % adults who die in/out of hospital
- % cancer/non-cancer diagnosis
- Preferred place of death
- Actual place of death
- % Preferred place of death achieved
- **No. patients: elective/unplanned admissions./ED attendance last 90 days + costs**
- **Total bed days elective/unplanned last 90 days**
- **Median/mean number bed days/person last 90 days**
- **Length of stay: unplanned admissions**
- **% 3 or more unplanned admissions last 90 days**
- **Reasons for admission**
- **ReSPECT code**
- **Ethnicity data**

## Bereaved Carers Survey about End of Life Care in Leeds

People's experiences of end of life care and support for their loved ones in hospices, hospitals, in their own homes and care homes

January to March 2020

Your independent watchdog ensuring people's voices are at the heart of shaping health and care services in Leeds.

3. Do you feel that your relative or friend died in the right place? (Please tick one only)

Yes  No  Don't Know

If no please tell us more below.

4. During this time how satisfied were you with the care given to your friend or relative in each of the following areas. (Please tick one per row)

	Very satisfied	Satisfied	Neither satisfied nor dissatisfied	Dissatisfied	Very dissatisfied	N/A
Relief of pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Relief of symptoms other than pain (e.g. nausea, restlessness)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Religious, cultural & spiritual support	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Respecting wishes before and after death	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Being cared for with privacy and dignity	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Personal care e.g. help with washing/ going to the toilet/ change of position	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**% who died with an EPaCCS (digital ACP) record**

**% satisfied/very satisfied with symptom management**

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

**% who achieved their preferred place of death**

# Health Needs Data Update

## End of Life Care Services for Adults in Leeds

# Inequalities



On behalf of the Director of Public Health, Leeds City Council

Date  
December 2019

Leeds Adult Palliative and End of Life Care Strategy 2023-2028

5 yr strategy

deeper dive

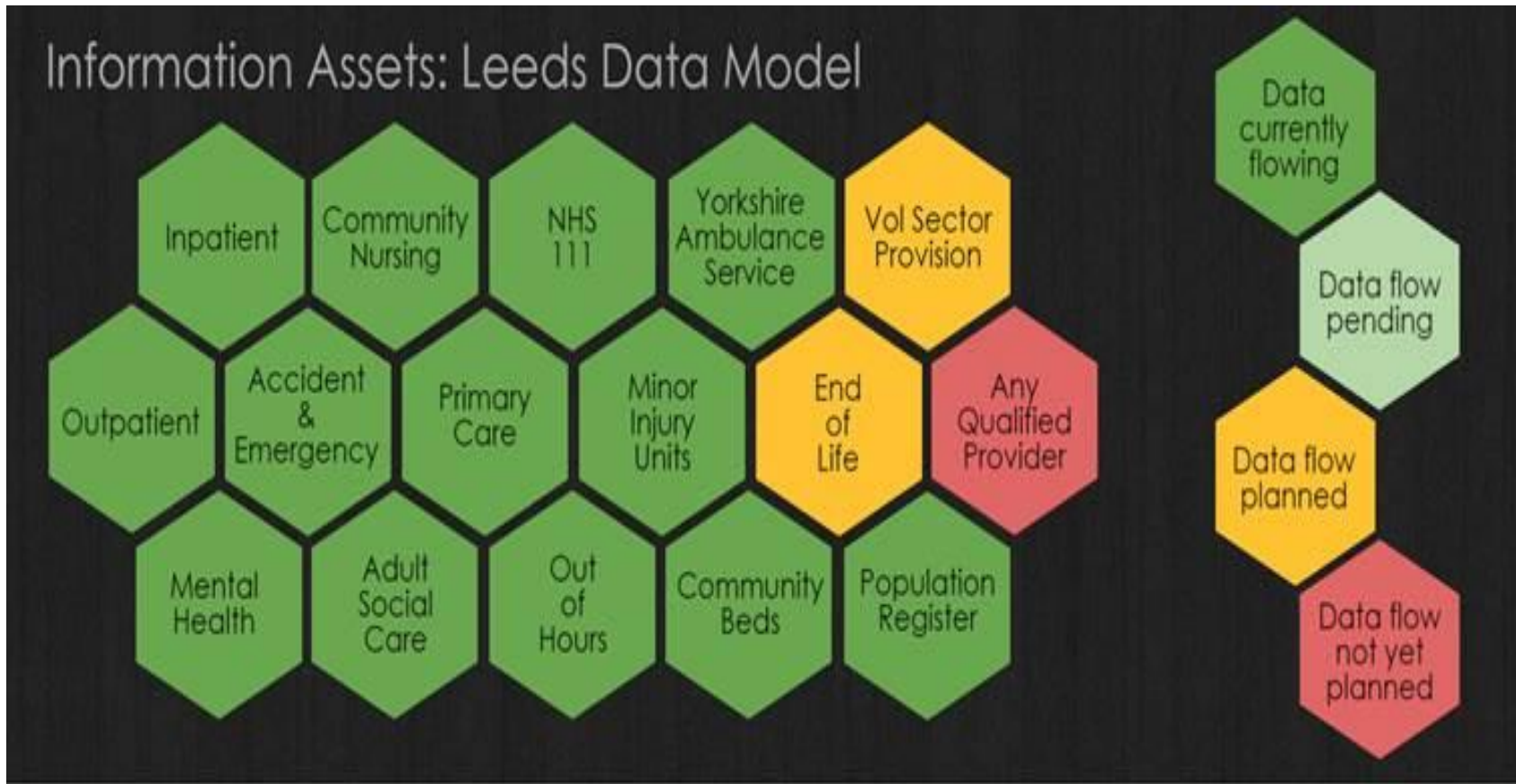
DSA

Ward	Population	Number of patients	Proportion of EPaCCS records	2011 census proportion
White	5131	87.55%	85.0%	
Mixed/Multiple ethnic groups	15	0.25%	2.7%	
Asian/Asian British	131	2.23%	7.7%	
Black/African/Caribbean/Black British	70	1.20%	3.5%	
Other ethnic group/not defined	255	4.34%	1.1%	
Missing data	259	4.42%	-	

Ethnicity	Number of patients	Proportion of EPaCCS records	2011 census proportion
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- Fewer people of black & mixed ethnicity had PPD recorded or achieved PPD
- Fewer men had EPaCCS & lower % had PPD recorded or achieved PPD
- Two of three postcode districts with achievement of less than 60% two were in more deprived wards

# Example of the Leeds Data Model







**Whole Population Data**

**PROMs/PCOMs**

**Interoperability/Linkage  
across all data-sets**

**Advanced analytics**

**Data strategy**

# Strengths

- Strong foundational relationships
- Strong clinical, digital, IG, analyst engagement
- Strategically aligned
- Seen as a CCG priority
- Engagement with wider structures: city, ICS
- Digital developments: data-need considered from outset
- Data multi-use: LPCN, public health, AUPC, primary care

# Challenges

- Governance
- Data quality: place of death, diagnosis
- Timing: challenges with reliable reporting schedule
- Optimal means of display - how much information
- BCS: response rate, language + cultural barriers
- Culture- feels peripheral
- Routine Project level data
- Challenges: other data e.g. education & training

# Enthusiasm/persistence

Opportunism

Strategy

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D&A = data and analytics; ROI = return on investment

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Relationships



“Data! Data!  
Data!” he cried  
impatiently. ‘I  
can’t make bricks  
without clay.’”