Scottish
Cancer Network

NHS
SCOTLAND

Workshop 4: How should we measure quality of cancer care in Scotland? How do we ensure meaningful patient input to that assessment?

James Mander, Co-Chair of National Cancer Quality Steering Group (NCQSG).

Professor Peter Hall, Professor of Medical Oncology (Cancer Informatics), The University of Edinburgh.

Transition to A National Cancer Quality and Improvement Board

How do we evolve things and build on work already being done in order to have greatest impact?

Where Have We Come From

- National Cancer Quality Steering Group
  - Established approx. 2008
  - Focusses Predominantly on QPIs
  - Also looks at survival data

QPIs

- Positives
- Effect big changes (in first cycle)
- Excellent engagement
- Started National dialogue

- Challenges
- Resource intensive
- Less effective after multiple cycles
- Service and Board Involvement
- HIS scrutiny
- Relevance to outcomes
- Development of overlapping groups

What is quality cancer care?

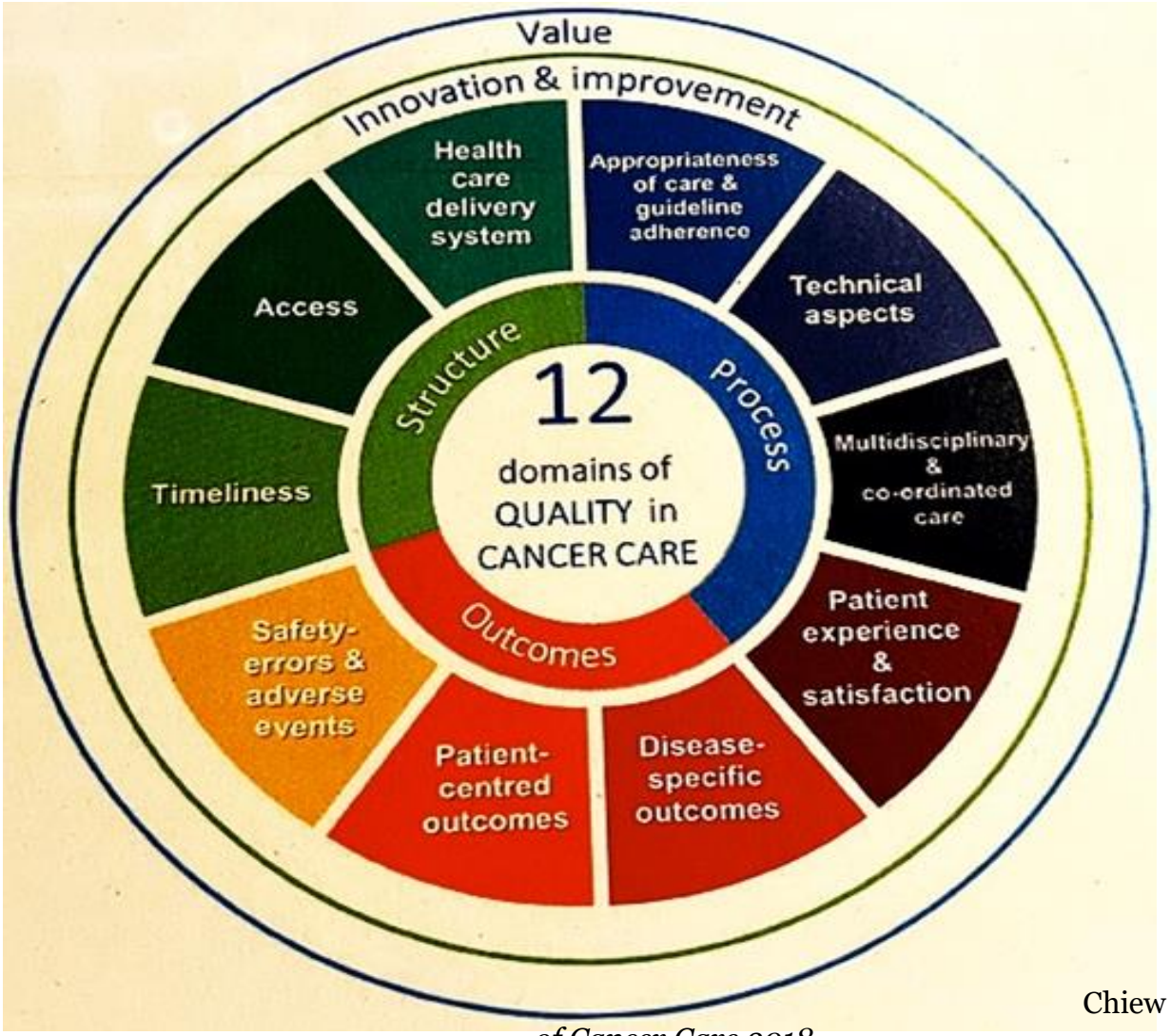
Is the right treatment being given?

Is treatment being done well?

Is the patient being treated in addition to the disease?

Vardy. *Ann Onc 2004*

What is in scope?



Chiew KL et al, *Eur J of Cancer Care 2018*

What are we already doing?

Access	Optimal* Pathways	**Patient Exp & Satisfaction**	Nat Patient Exp Survey# Care Opinion #>	**Healthcare Delivery System**	
Timeliness	Cancer Performance Reporting #	**MD & Co-ord Care**	MDT Improvement : regional/local & through cancer mgt framework~#	**Disease Specific Outcomes**	QPIs~ Survival Analysis^ UK/International Benchmarking^
Safety – errors & adverse events	SACT 30 day mortality^	**Technical Aspects**		**Value**	
Patient Centred Outcomes	PROMs~	**Appropriateness of Care/Guideline Adherence**	CMPs" Optimal Pathways* Clinical Trial Reporting	**Innovation & Improvement**	QPI Action & Improvement Plans>
Organisation Leads: SCN";Networks~; CfSD*; SGHD#; PHS^ Boards>					

Transitioning from NCQSG to NCQIB

- Identify and agree key elements of quality programme
- Define and agree key deliverables
- Agree how current workstreams can be aligned to support delivery, including defining roles/responsibilities and lead organisations
- Define type of quality measures that will be used to drive improvement
- Define and agree governance framework

Proposed Approach - NCQIB

- Oversee delivery of QPI Programme
- Deep dive into 3 or 4 cancer pathways p.a in line with agreed national priorities
- Consider health care delivery system, performance, outcomes and improvement
- External scrutiny via HIS

Next steps

- Agreement to stand down NCQSG by the National Cancer Strategic Board on23rd Feb 2024 and form NCQIB
- Develop new Terms of Reference and Membership
- Establish a workplan

Quality measurement

SAFETY → QUALITY → OUTCOME

VARIATION

PROMs

Types of quality measures

- Clinical Process Measures
- Patient Outcomes Measures
- Patient Experience Measures
- Safety Measures
- Efficiency Measures
- Access Measures
- Population Health Measures
- Financial Measures

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- **Patient Outcomes Measures**
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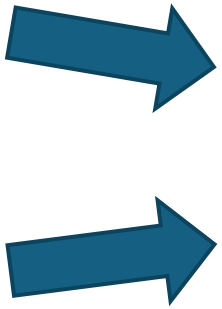
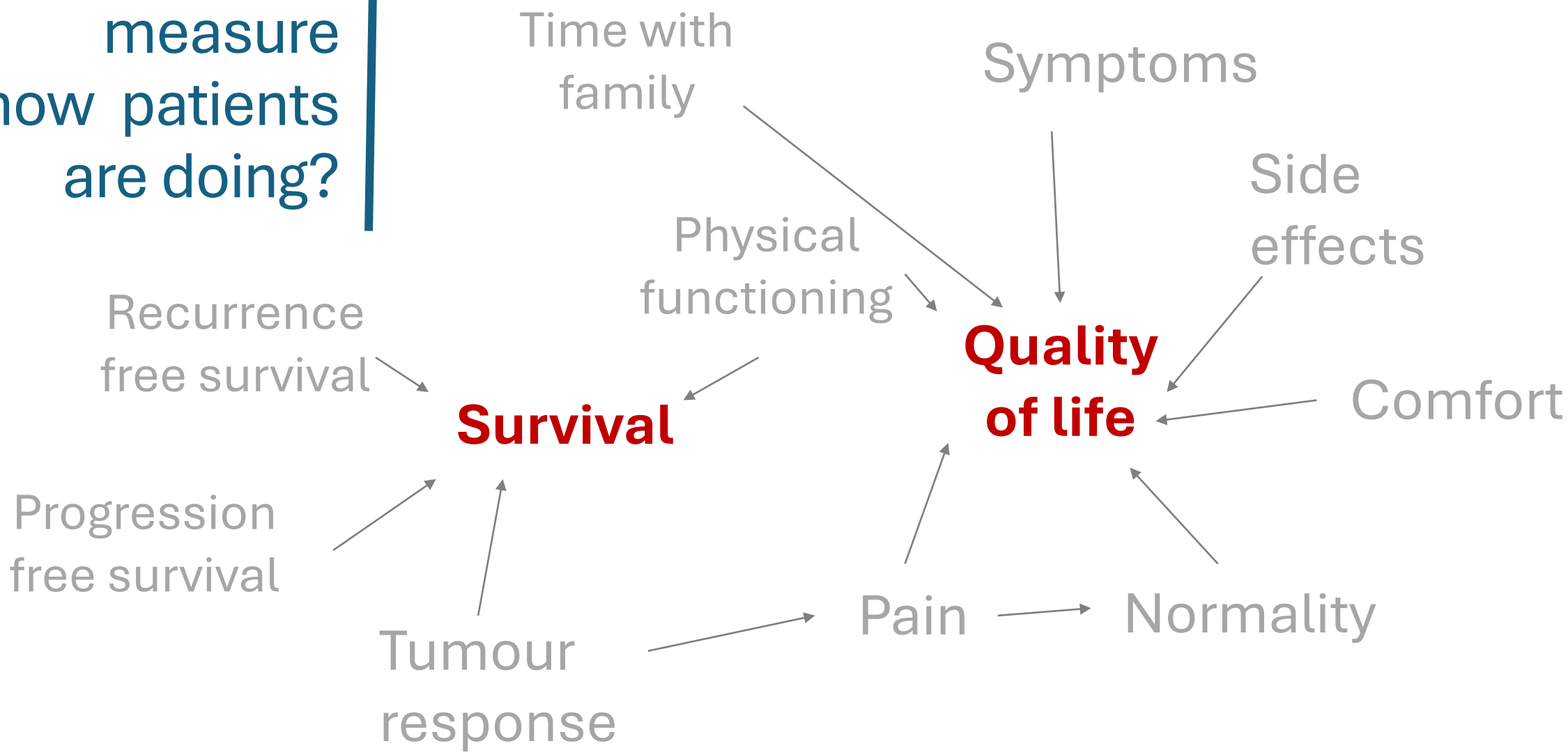


Patient Outcomes Measures

Patient Experience Measures

Outcomes

How do we measure how patients are doing?



Value Based Healthcare

Value-Based Health Care: Key metrics in VBHC include patient outcomes, patient satisfaction, and the cost of care. The emphasis is on measuring and maximizing the value of healthcare services.

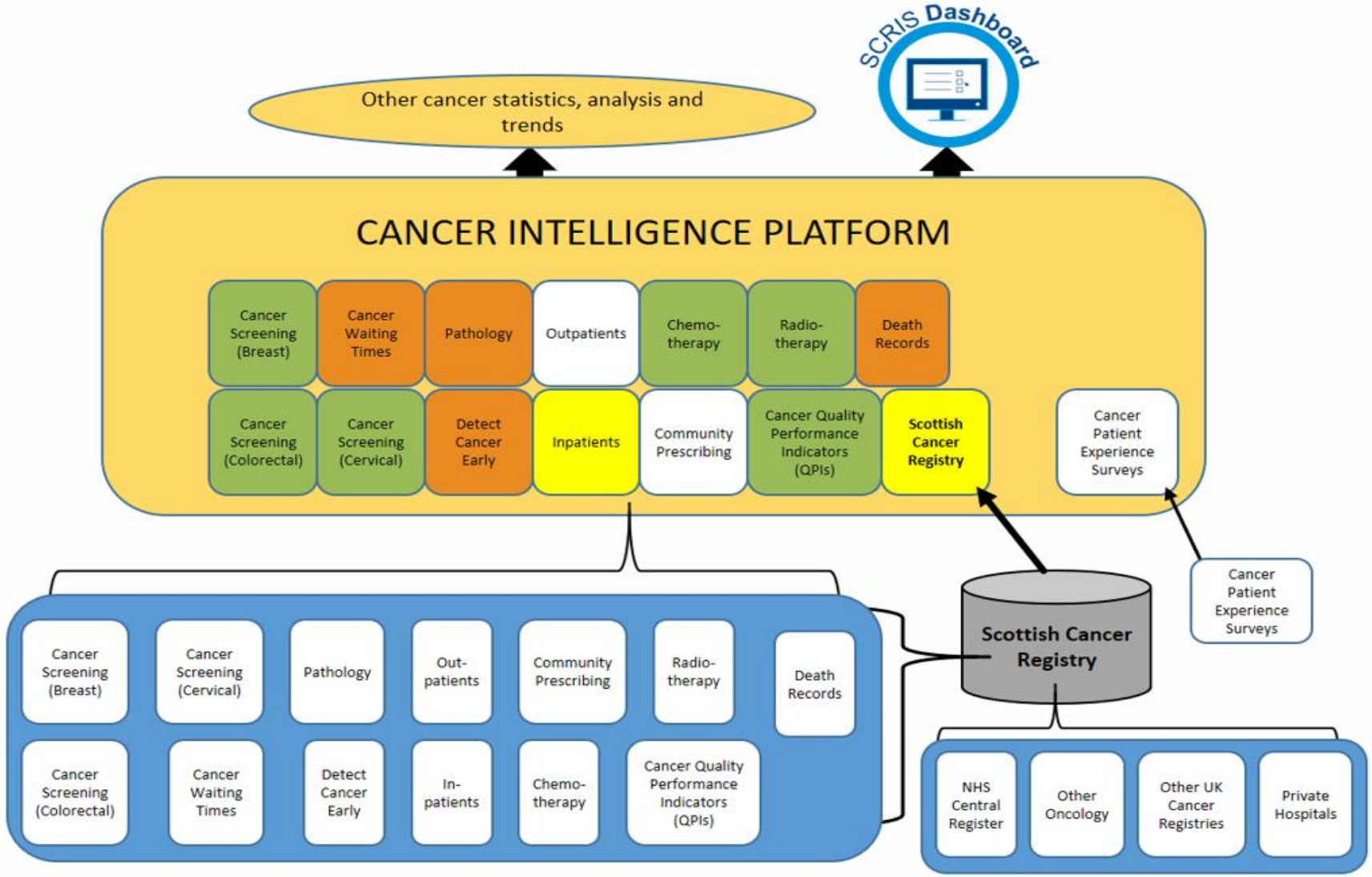
Continuous Quality Improvement: CQI uses various quality improvement tools and methodologies, often involving performance metrics, process measures, and outcome indicators. It seeks to continually monitor and enhance the quality of care provided

Mechanisms of measurement

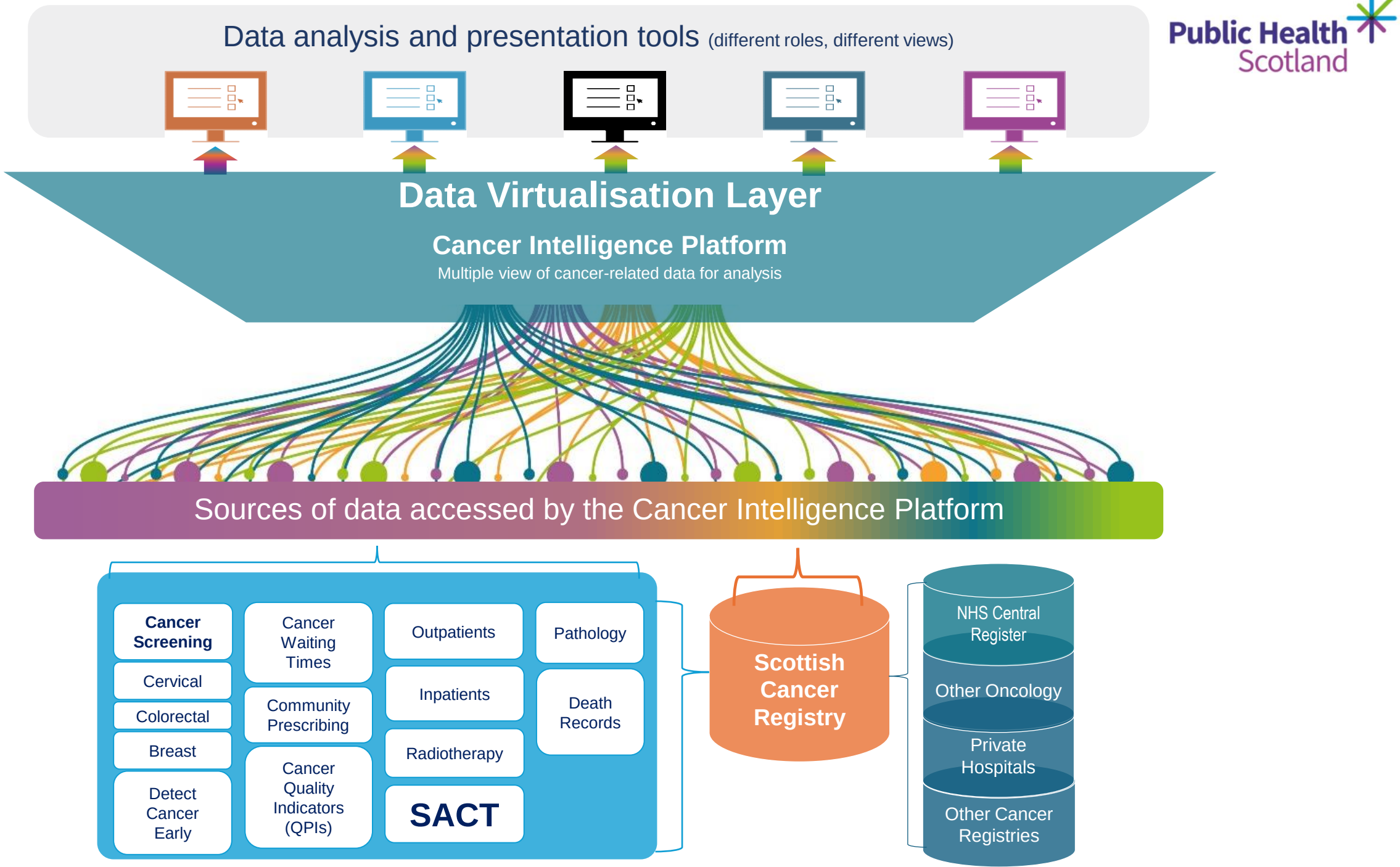
- Manual audit
  - Whole population
  - Sample-based (% of time or % of population)
- Routine data
  - e.g. 30 day mortality after SACT
- PROMs
  - e.g. EPIC 27 after prostate cancer surgery
- Qualitative?

Routine data opportunities?

The Future - Cancer Intelligence Platform – what will go in over the next two years



Sources of data accessed by the Cancer Intelligence Platform


Data analysis and presentation tools (different roles, different views)
Public Health Scotland
Data Virtualisation Layer
Cancer Intelligence Platform
Multiple view of cancer-related data for analysis
Sources of data accessed by the Cancer Intelligence Platform
Cancer Screening
Cervical
Colorectal
Breast
Detect Cancer Early
Cancer Waiting Times
Community Prescribing
Cancer Quality Indicators (QPIs)
Outpatients
Inpatients
Radiotherapy
SACT
Pathology
Death Records
Scottish Cancer Registry
NHS Central Register
Other Oncology
Private Hospitals
Other Cancer Registries

Key data opportunities

Cancer waiting times

Admitted patient care (SMR01)

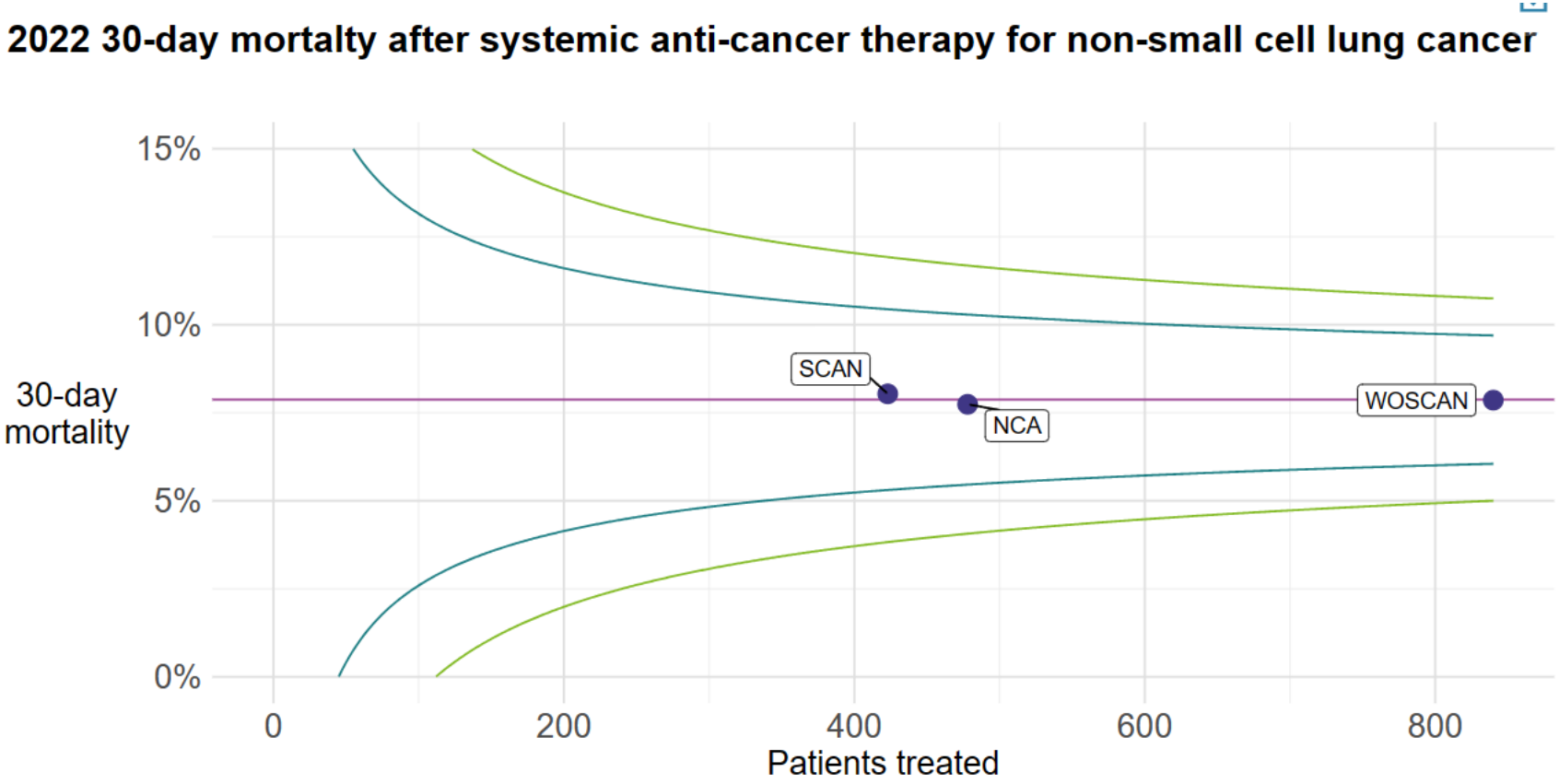
Community prescribing (PIS)

Screening

SACT

(Radiotherapy)

30 day mortality



Quality control

Comprehensive audit

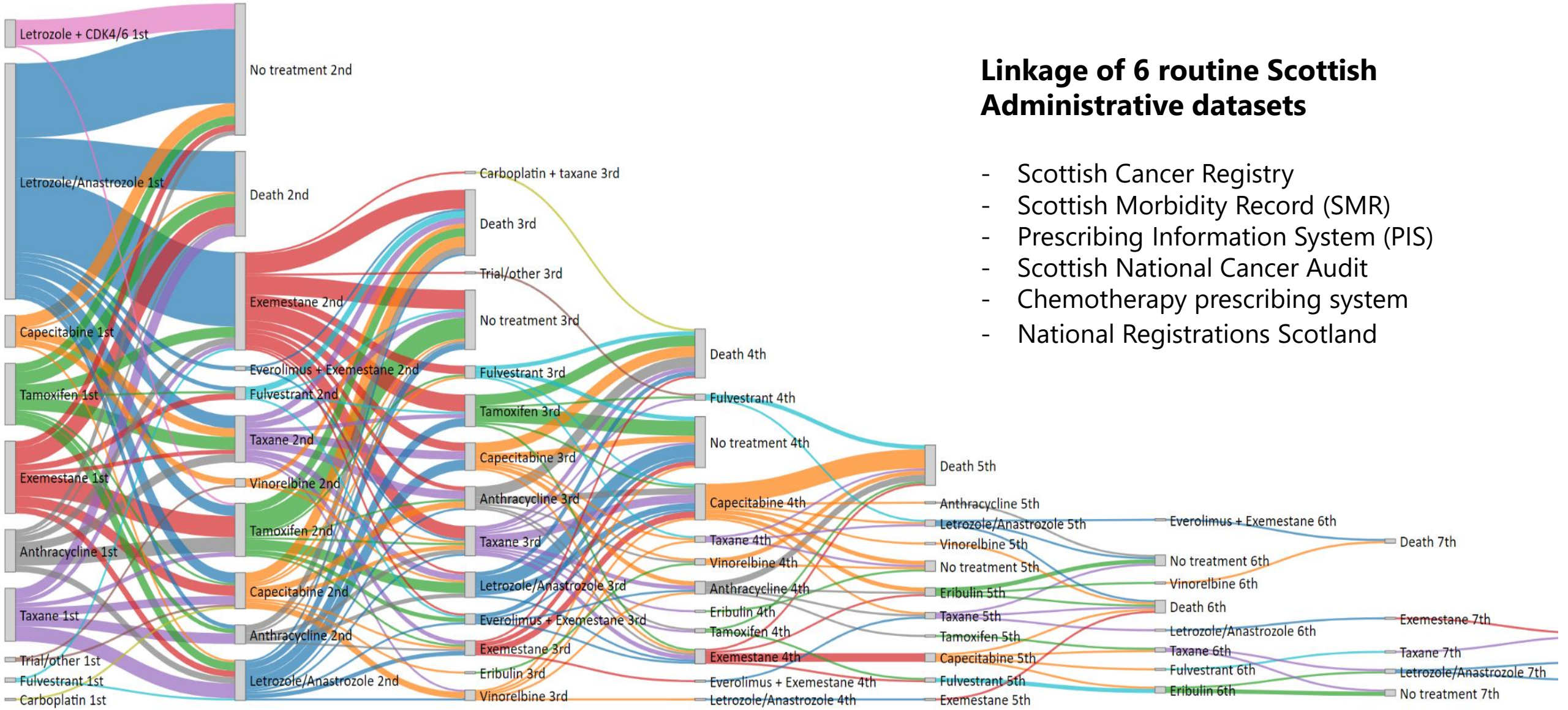
vs

Routine data extraction with QA sampling

Real World Treatment Sequencing Patterns in Secondary Breast Cancer (ER+ HER2–)

Pathway Visualisation Using National Datasets

Edinburgh Cancer Informatics Programme



Linkage of 6 routine Scottish Administrative datasets

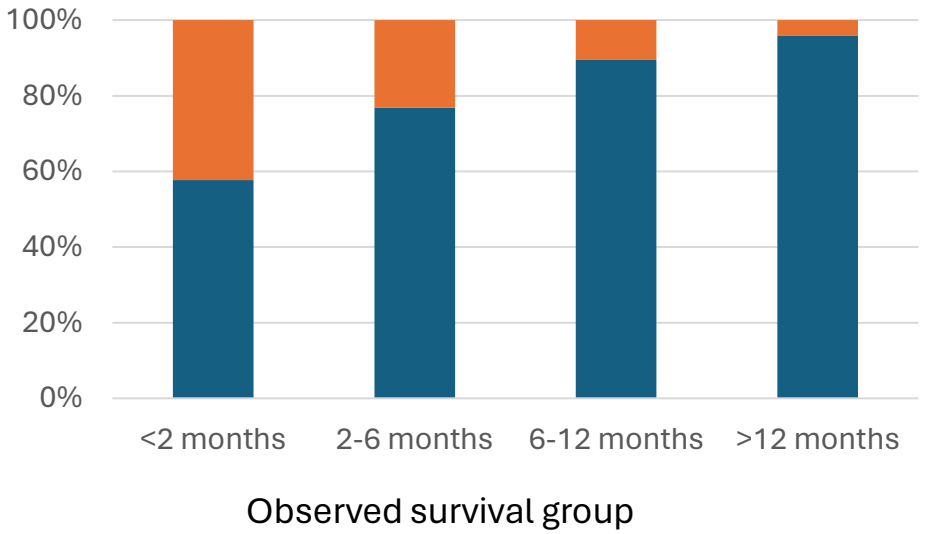
- Scottish Cancer Registry
- Scottish Morbidity Record (SMR)
- Prescribing Information System (PIS)
- Scottish National Cancer Audit
- Chemotherapy prescribing system
- National Registrations Scotland

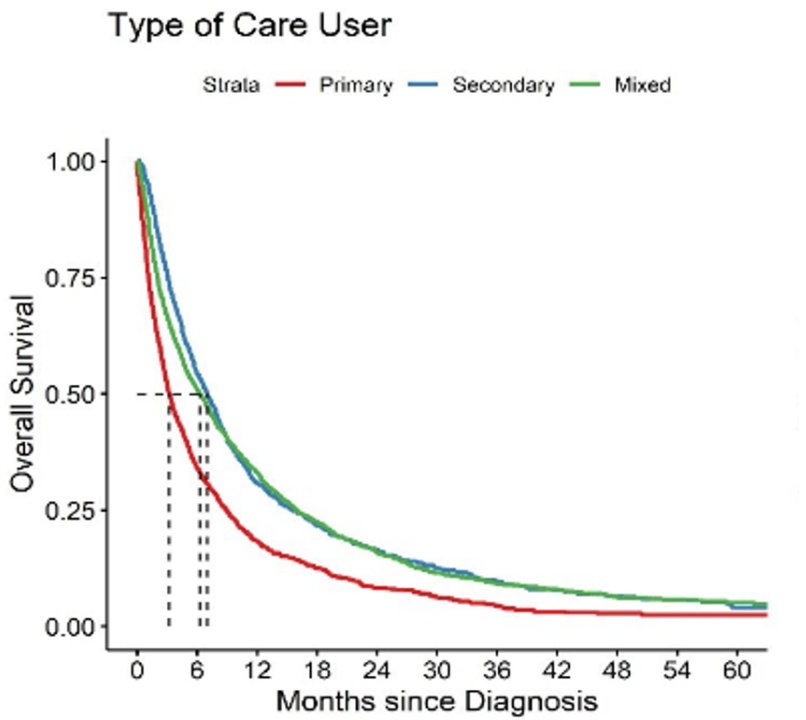
Palliative context?

Place of Death	N	%
Home	1245	30
Hospice	503	12
Hospital	1774	43
Residential/Nursing Home	265	6
Alive	325	8

No. of Biopsies within 2 months of diagnosis	N	%
0	2681	65
1	977	23
2	275	7
3+	179	4

% Remaining life as inpatient





PROMs

Patient Reported Outcome Measures

Use case 1: Cohort analysis

- Population-level analysis
- Service / system / policy design
  - Improve quality of care
  - Measure outcomes
  - Assess variation

  - Ratify the value assessment of newly adopted technologies

- AUDIT

Use case 2: Individual patient care

- Detailed assessment at diagnosis + repeat intervals
  (e.g. holistic needs assessment)

1. Monitoring side-effects of treatment
   (e.g. during chemotherapy, post-surgery)
   - Opportunity for self management
   - Alerts to clinical team
2. Monitoring after treatment
   (e.g. monitoring pain scores, late effects)
   - Survivorship

Feedback to clinical care team

Change patient care (real-time)

PROMs

- Generic (e.g. EQ-5D)
- Disease specific (e.g. EPIC 27)

EQ-5D

Under each heading, please tick the ONE box that best describes your health **TODAY**

MOBILITY

- I have no problems in walking about ☐
- I have slight problems in walking about ☐
- I have moderate problems in walking about ☐
- I have severe problems in walking about ☐
- I am unable to walk about ☐

SELF-CARE

- I have no problems washing or dressing myself ☐
- I have slight problems washing or dressing myself ☐
- I have moderate problems washing or dressing myself ☐
- I have severe problems washing or dressing myself ☐
- I am unable to wash or dress myself ☐

USUAL ACTIVITIES (e.g. work, study, housework, family or leisure activities)

- I have no problems doing my usual activities ☐
- I have slight problems doing my usual activities ☐
- I have moderate problems doing my usual activities ☐
- I have severe problems doing my usual activities ☐
- I am unable to do my usual activities ☐

PAIN/DISCOMFORT

- I have no pain or discomfort ☐
- I have slight pain or discomfort ☐
- I have moderate pain or discomfort ☐
- I have severe pain or discomfort ☐
- I have extreme pain or discomfort ☐

ANXIETY/DEPRESSION

- I am not anxious or depressed ☐
- I am slightly anxious or depressed ☐
- I am moderately anxious or depressed ☐
- I am severely anxious or depressed ☐
- I am extremely anxious or depressed ☐

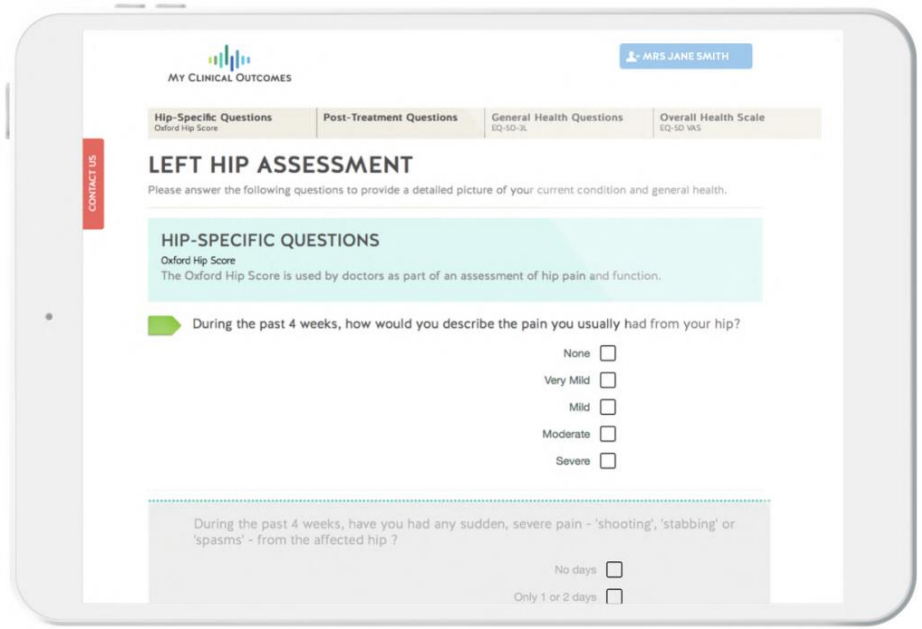
EPIC 27

HRQOL Domain	Number of itens	Mean Score (sd)	Internal consister reliability
HRQOL Domain Summary Scores			
Urinary	12	82.2 (12.1)	0.87
Bowel	14	96.7 (2.1)	0.81
Sexual	13	35.2 (16.3)	0.94
Hormonal	11	94.0 (9.2)	0.74
Domain-Specific HRQOL Subscales			
Urinary Subscales			
Function	5	82.9 (14.9)	0.69
Bother	7	81.7 (11.0)	0.84
Incontinence	4	73.0 (8.7)	0.94
Irritative/Obstructive	7	89.3 (9.5)	0.78
Bowel Subscales			
Function	7	96.2 (2.5)	0.53
Bother	7	97.1 (1.6)	0.87
Sexual Subscales			
Function	9	29.1 (14.0)	0.94
Bother	4	48.9 (13.1)	0.93
Hormonal Subscales			
Function	5	89.7 (12.8)	0.57
Bother	6	97.6 (2.0)	0.66

Product Overview: Patients and Clinicians

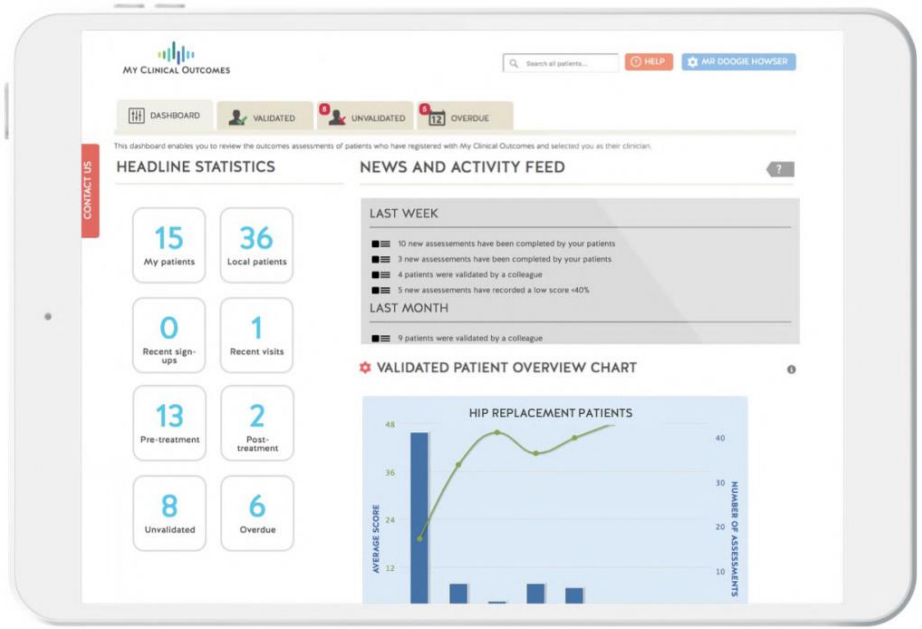
MY CLINICAL OUTCOMES

Patient Account



- Quick and easy registration
- Regular automated assessments
- Monitor QoL impact on personal dashboard

Clinician Dashboard



- Use of the data to assess individual patients and inform treatment decisions
- Compare impact between cohorts

Clinical cohorts

- Bladder Cancer [Surgery]
- Pelvic cancers [Radiotherapy]
- Lung Cancer [Radiotherapy]
- Cancer of Unknown Priamry [Whole pathway]
- Liver cancers [Surgery]
- Breast cancer [Medicines]

3 month pilot implementation

- Flyers given out by clinical teams
- Dedicated project manager
- On-boarding support via helpline
- Facilitators in clinics and treatment areas

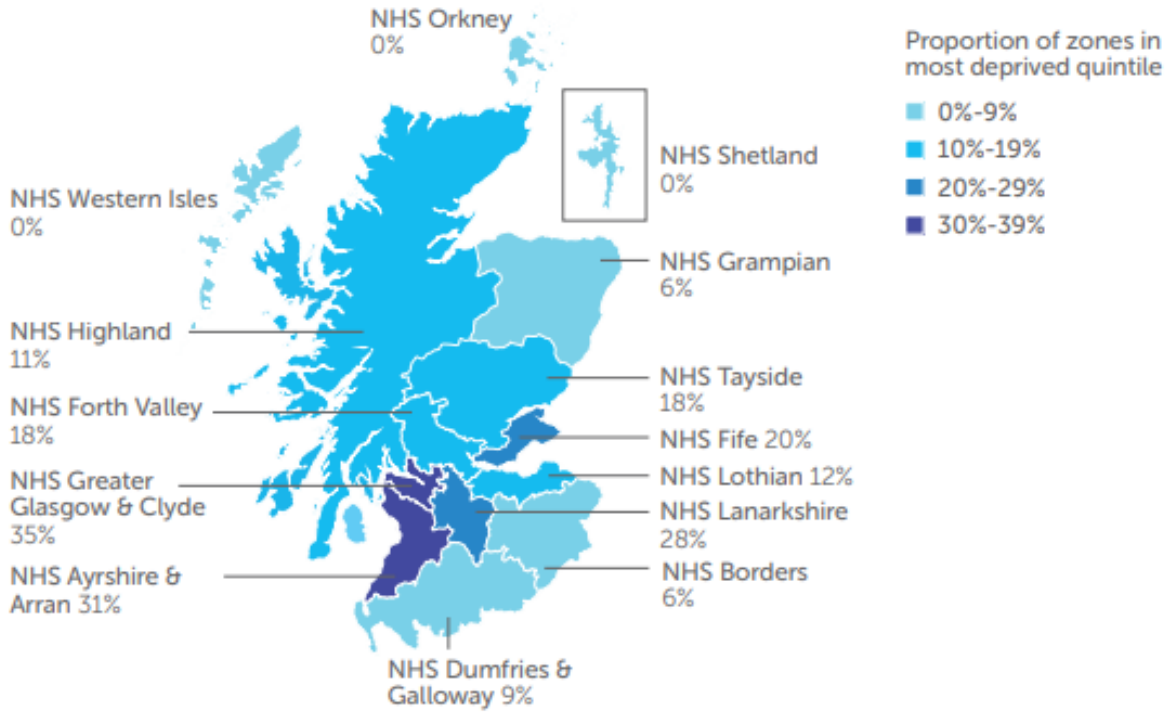
Experience

- Approx 50% registration by approached patients
- Rapid attrition beyond 3 month pilot
- Most engagement with bespoke breast cancer RT assessment
- But increase in time taken for 6 week clinical assessment!

Variation as a core concept

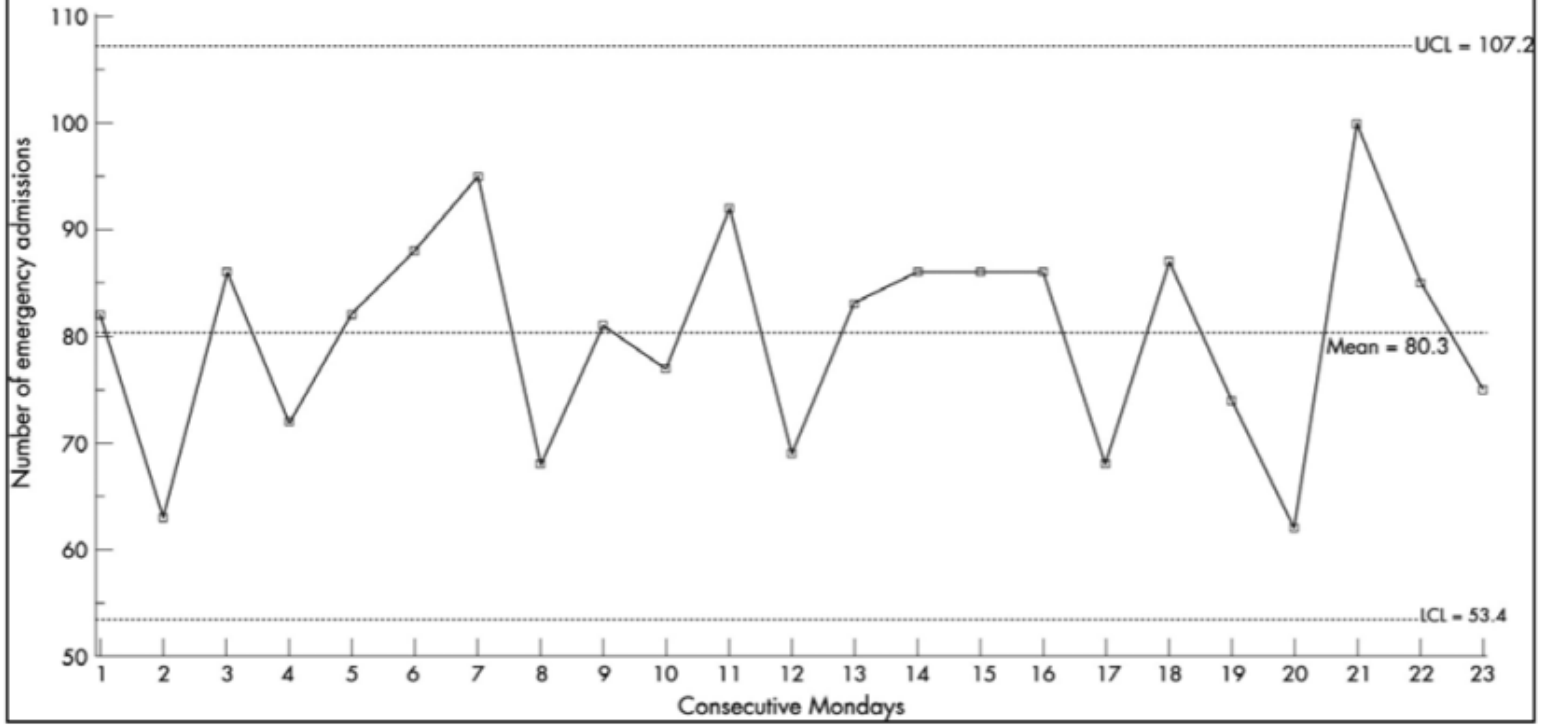
- Warranted variation

- Unwarranted variation
  - Poor quality, waste, harm, inequity

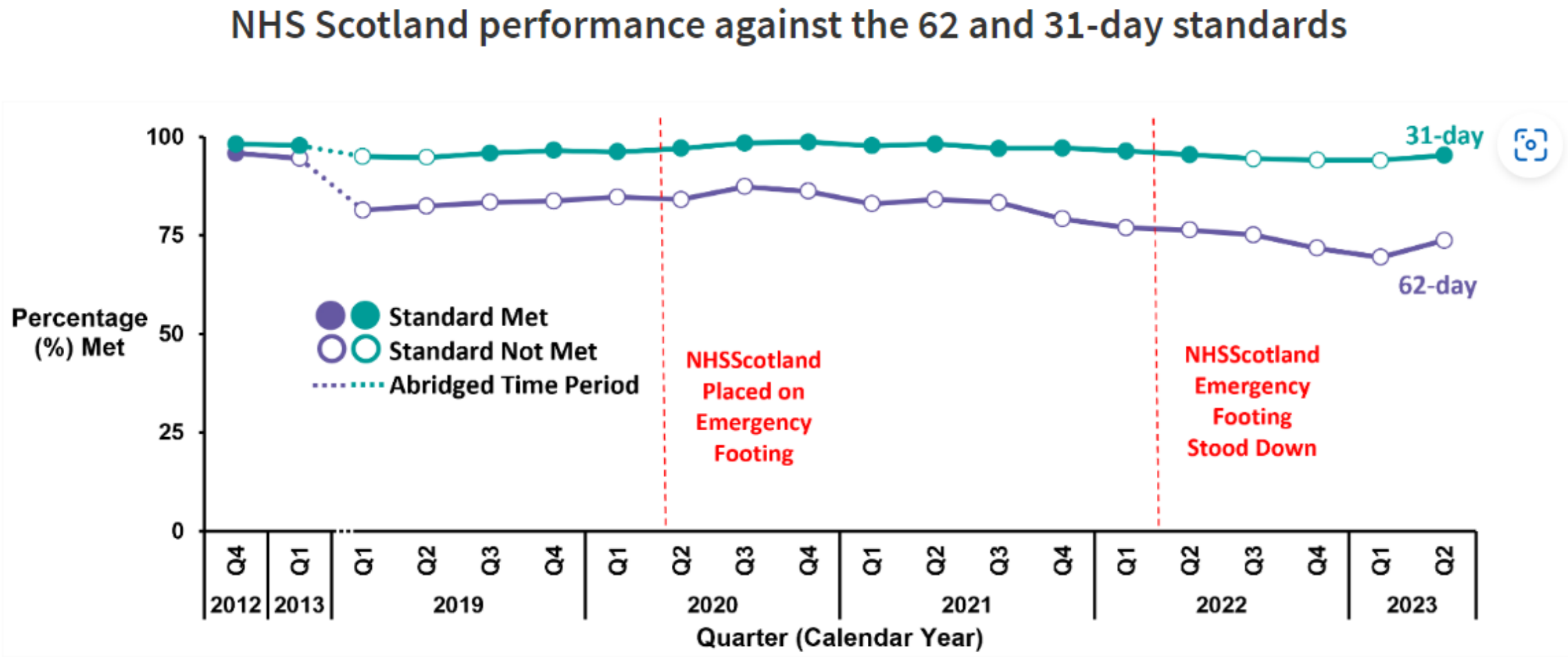


Statistical Process Control

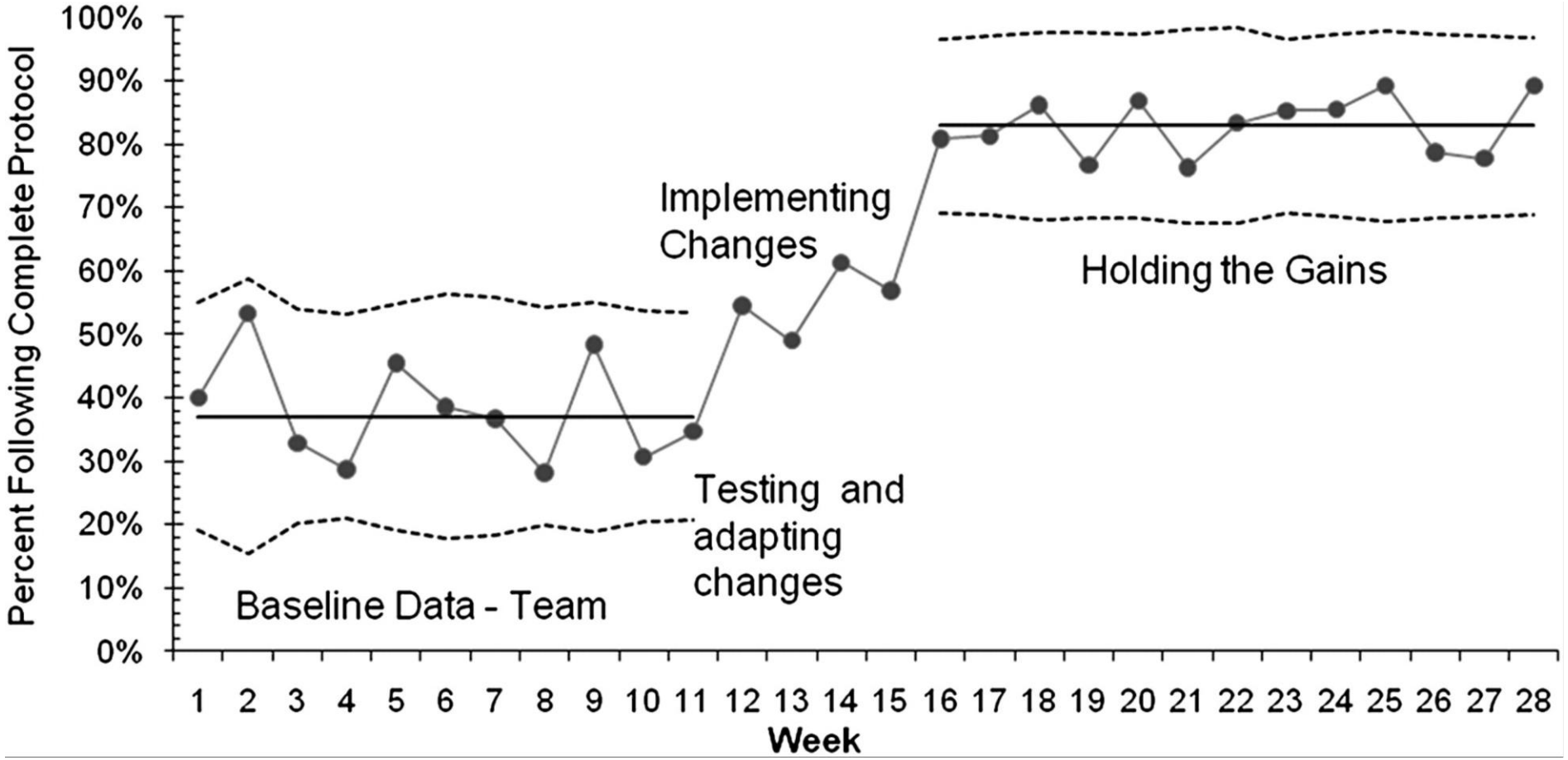
Monday number	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22
Number of emergency admissions (c)	82	63	86	72	82	88	95	68	81	77	92	69	83	86	86	86	68	87	74	62	100	85



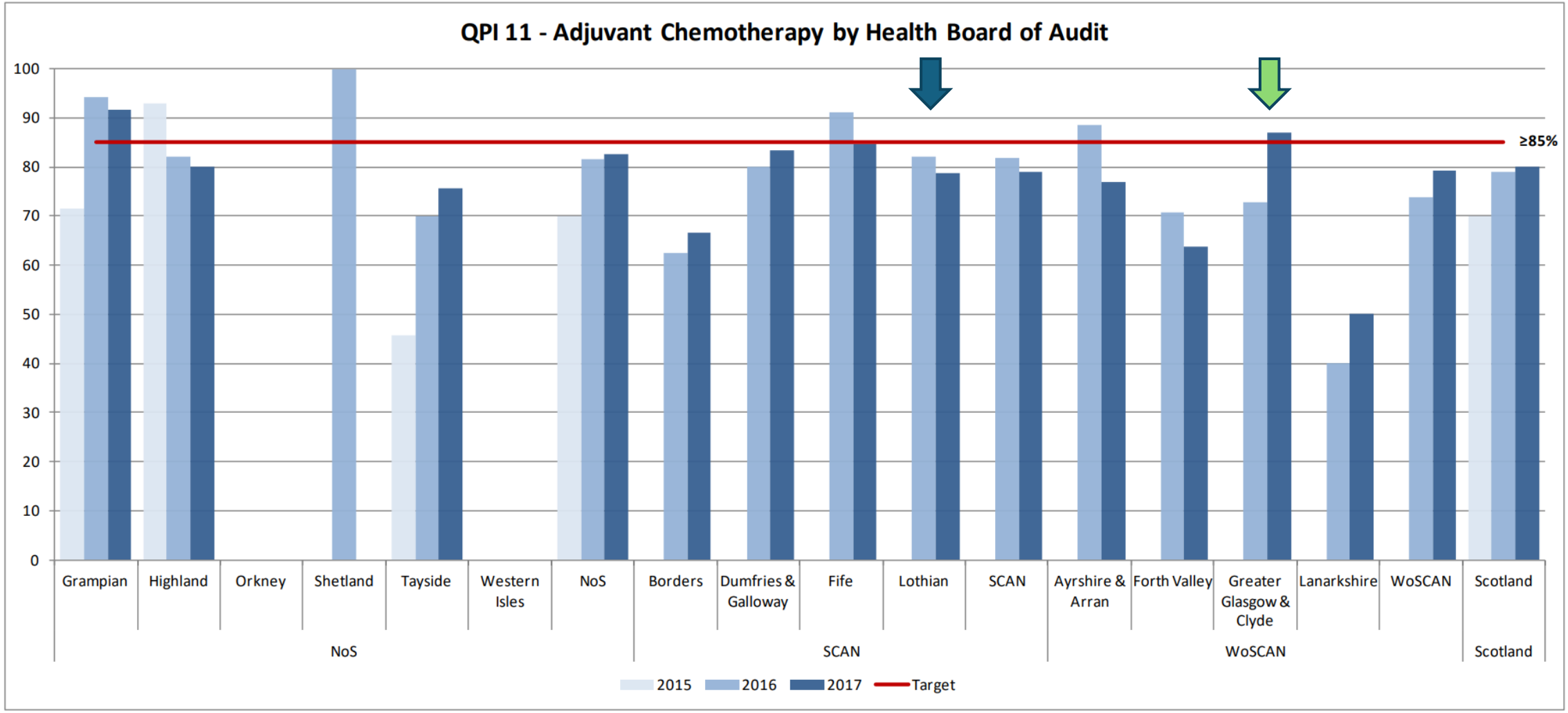
Cancer Waiting Times



Statistical Process Control

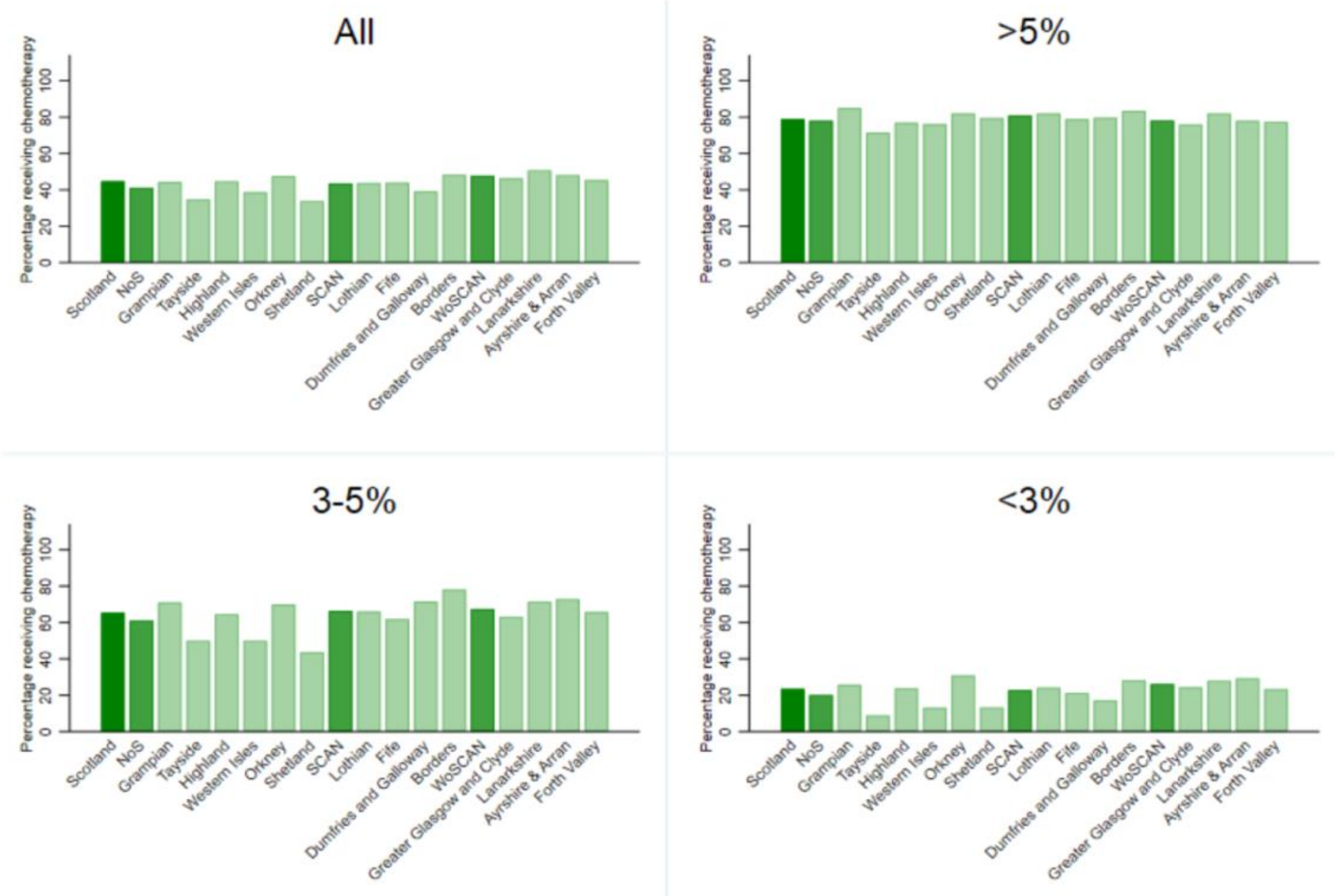


National Cancer Quality Performance Indicators

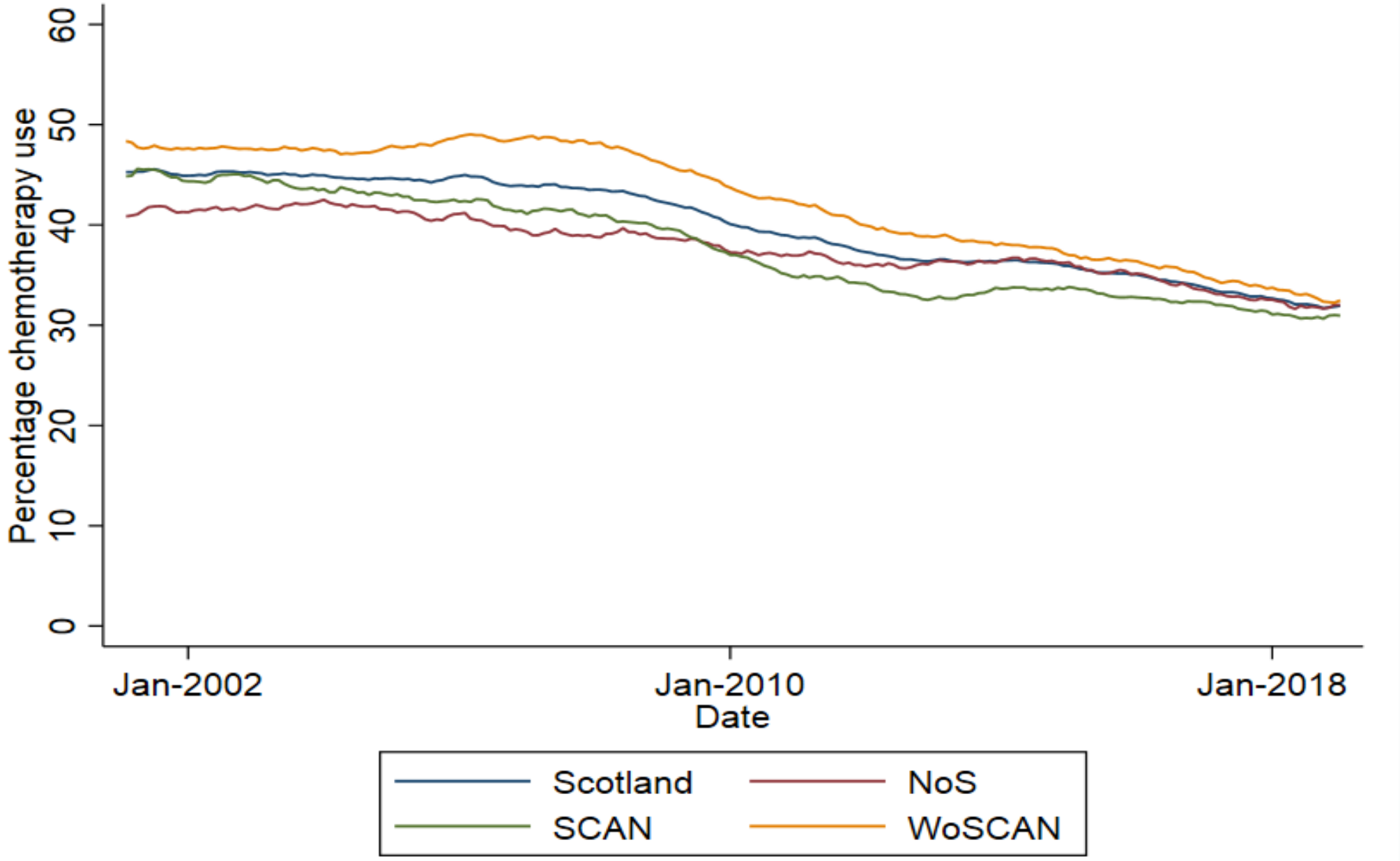


Predicted >5% mortality benefit | exclusion pre-operative chemo | exclusion clinical trials participation

% chemo use for EBC 2001 - 2015



Convergence towards National Clinical Management Pathways, Driven by Quality Performance Indicators

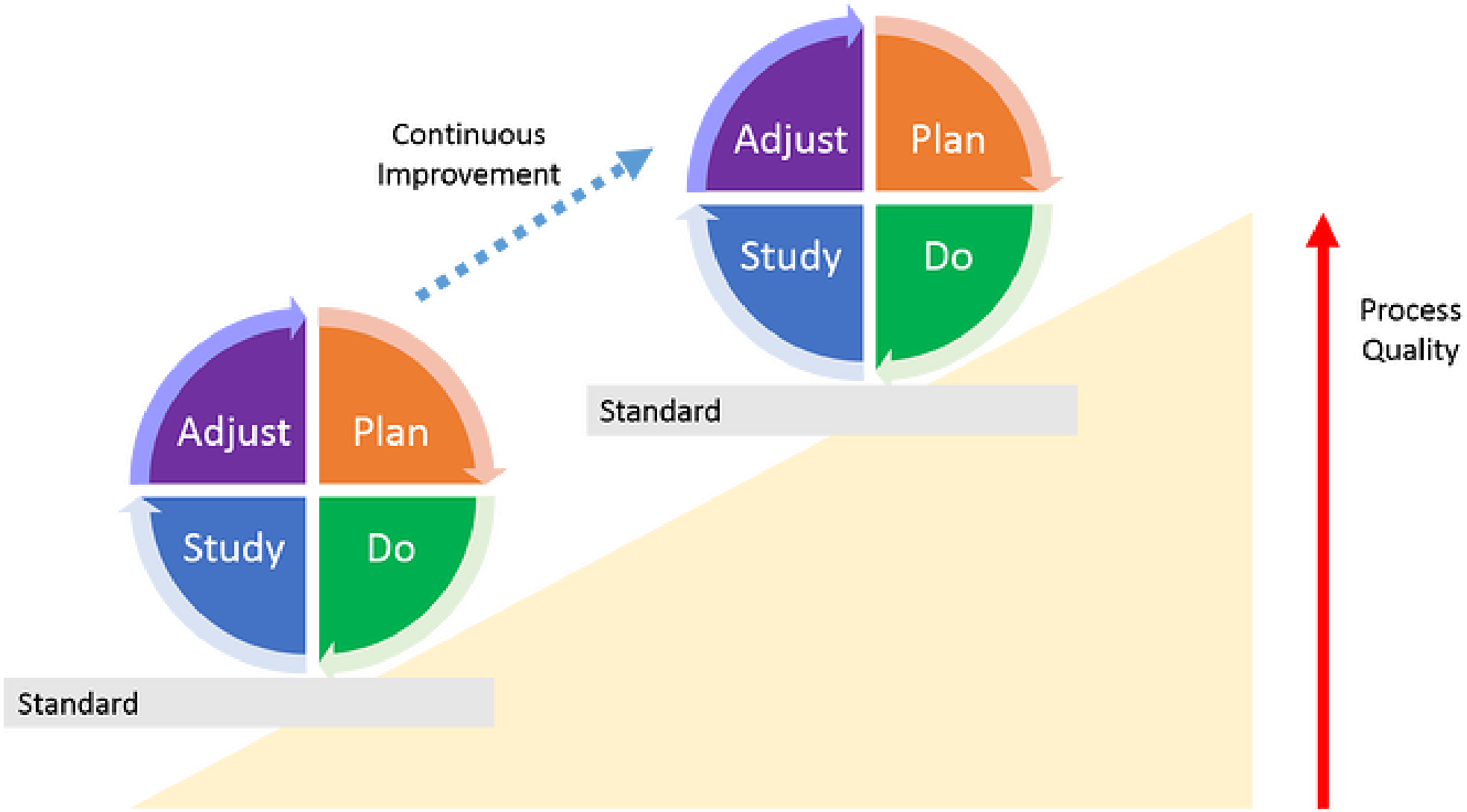


Proportion using chemotherapy, adjusted

	Unadjusted		Adjusted	
Health Board	Proportion chemotherapy	95% CI	Proportion chemotherapy	95% CI
Glasgow (GG&C)	**0.35**	**[0.33,0.37]**	**0.36**	**[0.346,0.37]**
Edinburgh (Lothian)	**0.31**	**[0.29,0.34]**	**0.36**	**[0.339,0.37]**

Probit model, adjusting for NHS Predict covariates and co-morbidity

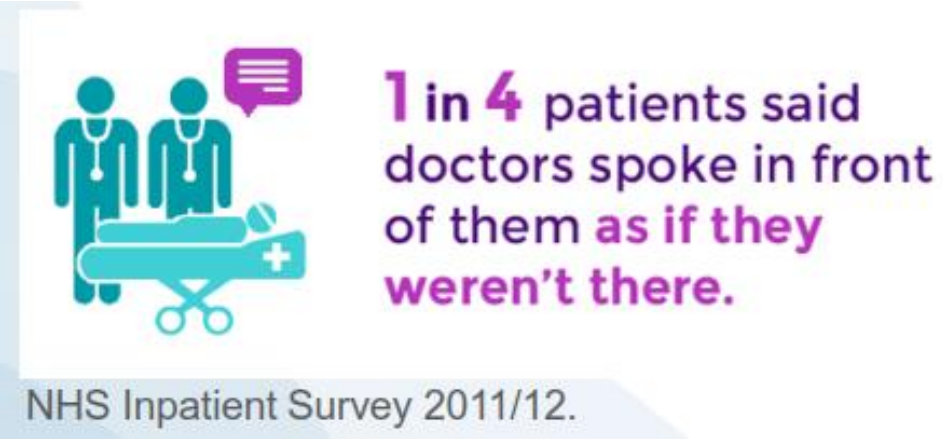
Statistical Process Control



PREMS

Patient experience

- Purpose: allows patients to provide direct feedback on their care to drive improvement in services.
- Historical methods:
  - Surveys (paper and electronic)
  - Focus groups
  - Patient story/journey
  - Observation



MACMILLAN CANCER SUPPORT

NHS SCOTLAND

Healthier Scotland
Scottish Government

2024 Scottish Cancer Patient Experience

Interpretation

Discuss

History of quality measurement

Nightingale (1850s) Clinical audit

Codman (1910) Surgical audit → public release of outcomes data

Donabedian (1970s) Systems approach → structure-process-outcome

Berwick (1980s) Industrial models for quality improvement

Patient centred, achieving change from audit

1990s Evidence-based medicine

Clinical guidelines

Care pathways

Clinical governance

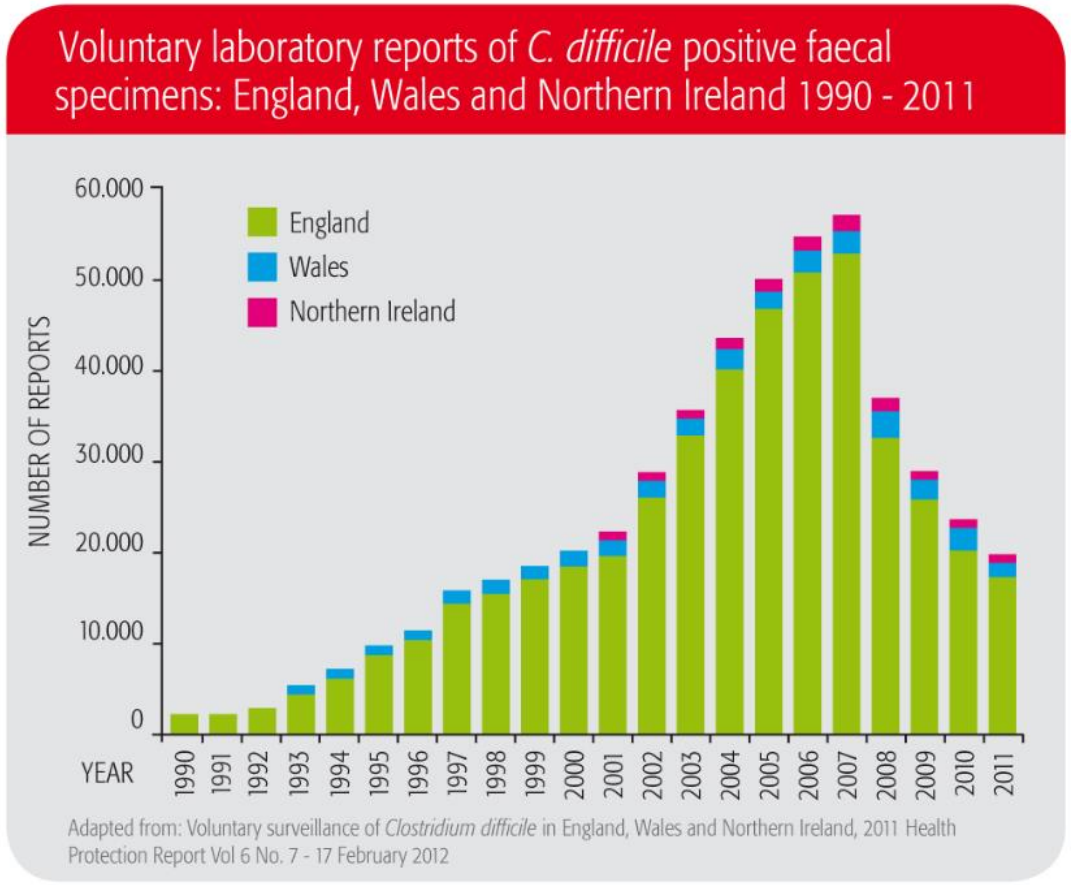
2000's Total Quality Management / Continuous Quality Improvement /PDSA

Characteristics of measures

- **Relevance:**
  - Quality measures should be directly related to the goals and outcomes that are important in healthcare. They need to address meaningful aspects of patient care and health outcomes.
- **Validity:**
  - Measures should accurately reflect the quality of care provided. They should be based on sound scientific evidence and have a clear conceptual basis. Validity ensures that the measure is measuring what it is intended to measure.
- **Reliability:**
  - Reliable measures produce consistent results when applied under similar conditions. This reliability is crucial for ensuring that variations in measured performance are due to actual differences in quality rather than measurement error.
- **Feasibility:**
  - Measures should be practical to collect and report. They should be feasible to implement within the constraints of healthcare settings, taking into account factors like data availability, resources, and ease of measurement.
- **Sensitivity to Variation:**
  - Quality measures should be sensitive enough to detect meaningful differences in performance among healthcare providers or systems. They should be able to distinguish between levels of quality and identify areas for improvement.
- **Risk Adjustment:**
  - To account for patient case-mix and variations in population health, quality measures often benefit from risk adjustment. This ensures that providers are not unfairly penalized or rewarded for factors beyond their control.
- **Timeliness:**
  - Timely reporting and feedback are crucial for continuous quality improvement. Measures that provide real-time or near-real-time information enable healthcare organizations to make prompt adjustments to their practices.
- **Transparency:**
  - Transparency in the development and reporting of quality measures is essential for building trust among stakeholders. Clear documentation of measure specifications, data sources, and methodologies promotes accountability and understanding.
- **Actionability:**
  - Quality measures should provide actionable information. This means that the results should guide healthcare providers and organizations in making improvements, whether at the individual or system level.
- **Alignment with Patient-Centered Care:**
  - Measures should align with the principles of patient-centered care, focusing on outcomes that matter to patients and incorporating their perspectives and preferences into the evaluation of quality.
- **Interoperability:**
  - In an increasingly connected healthcare landscape, interoperability is crucial. Measures should be designed with interoperability standards to facilitate seamless data exchange and integration across different healthcare systems and settings.

Performance vs Quality

- Performance indicators (waiting times, financial targets, staff and patient survey indicators)
- 2006 Healthcare Commission Report: Clostridium difficile outbreaks → need for investment in isolation facilities.
- Delayed allocation of budget



Industrial Quality Improvement Concepts

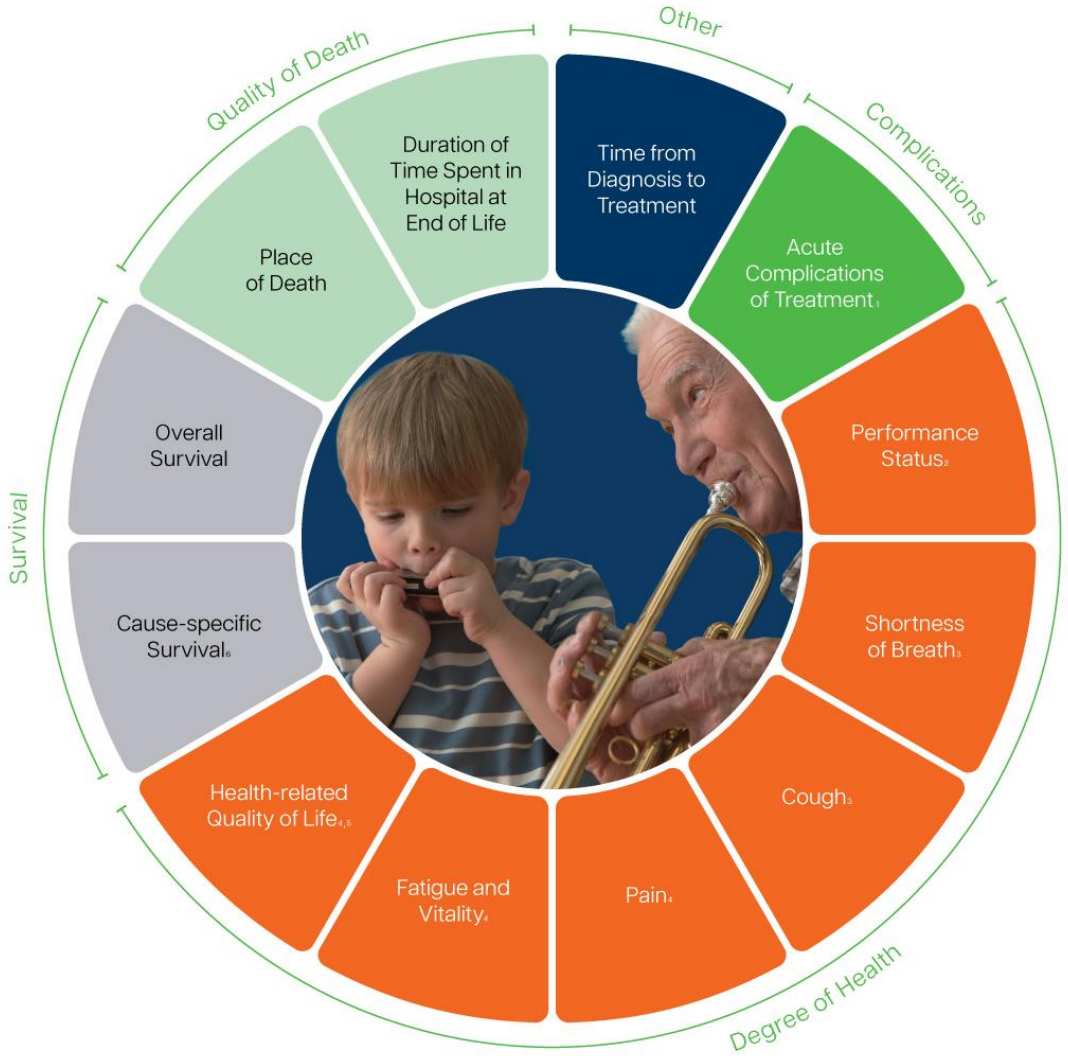
- Role of leadership
- Enabling transformation
- Clear identification of the patient as customer
- Build quality into processes from initiation

- Total Quality Management / Continuous Quality Improvement
- Lean management, Six Sigma etc.

- Demming et al. PDSA method

Value Based Healthcare 2

ICHOM



Quality improvement perspectives

Clinically-led

Craft-based approach, dependent on workforce training

Assessed by clinical audit

Internal peer review → external regulatory mechanism (Shaw 1980)

Management-led

Targets

Waiting times

Financials

Patient-led

Patient outcomes

Patient experience