



# Cancer Innovation Challenge

PROMs and PREMs clinical context

Peter Hall

How do we  
measure how  
patients are  
doing?

## Outcomes

- Survival
- Cancer recurrence
- Tumour shrinkage
  
- Symptoms
- Side effects
- Comfort
- Normality
- Functioning
- Capability
  
- Quality of life (Sociological, economic, psychological, philosophical, ethical)





# PROMs

## Patient Reported Outcome Measures

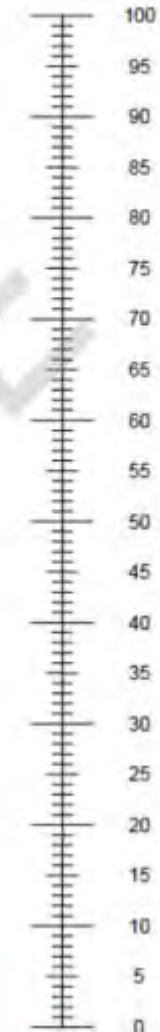
- Capture a person's perception of their health
- Validated tools
- Generic or disease specific
- Measure:
  - Symptoms
  - Distress
  - Unmet need
  - Quality of life

# PROMs Examples

- Quality of life e.g. EQ-5D
- Symptoms e.g. pain score
- Distress e.g. HADS
- Functional ability e.g. NADL
  
- Cancer specific
  - EORTC QLQ-C30
  - FACT

EQ-5D: We would like to know how good or bad your health is today.

The best health you can imagine





- **Physical/nutritional**

- Timed 30 minute walk
- arm circumference
- weight loss
- BMI

- **Mental/cognitive**

- MMSE: 30-point nurse-administered test

- **Co-Morbidity**

- Charlson: 19-point medical co-morbidity score

- **Activities of daily living**

- Nottingham: 21-point ADL scale
- 4 subscales (mobility; kitchen; domestic; leisure)

- **Global QL**

- EQ5D: 5-point QL scale: mobility, self-care, activity, pain, mood

- **Symptoms**

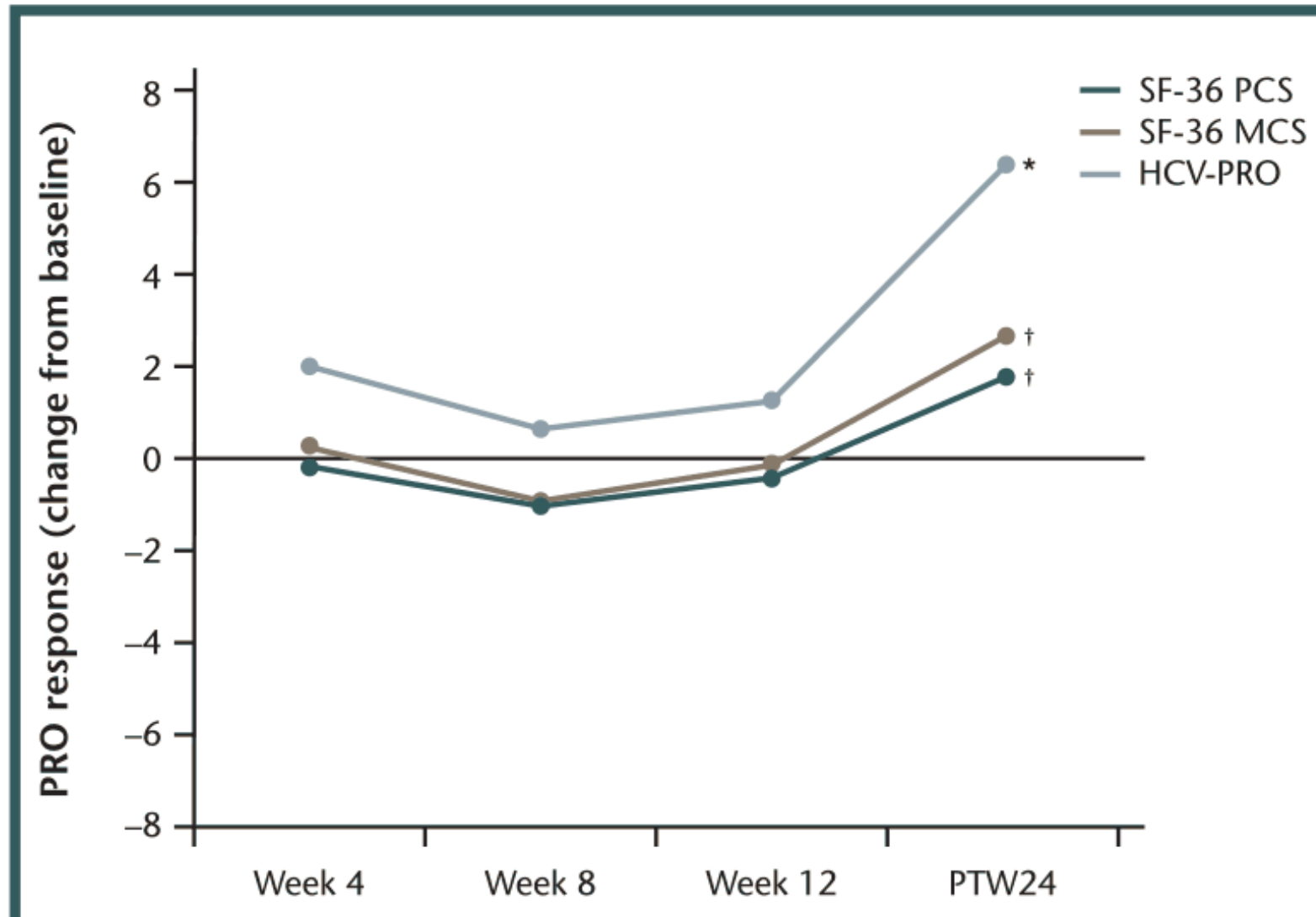
- QLQC30 scales for fatigue, nausea/vomiting, pain, dizziness, sleep disturbance, appetite, constipation and diarrhoea
- mean symptom score

- **Psychological**

- HADS 14-point scale, anxiety and depression subscales



# Reporting PROMs



# 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



**1 in 4** patients said  
doctors spoke in front  
of them **as if they  
weren't there.**

NHS Inpatient Survey 2011/12.





# PREMs Examples

- Time spent waiting
  - Access to services
  - Involvement in decision making
  - Knowledge of care plans
  - Quality of communication
- 
- Scottish Cancer Patient Experience Survey

<http://www.gov.scot/Publications/2016/06/3957>

# PROMS &PREMS use cases



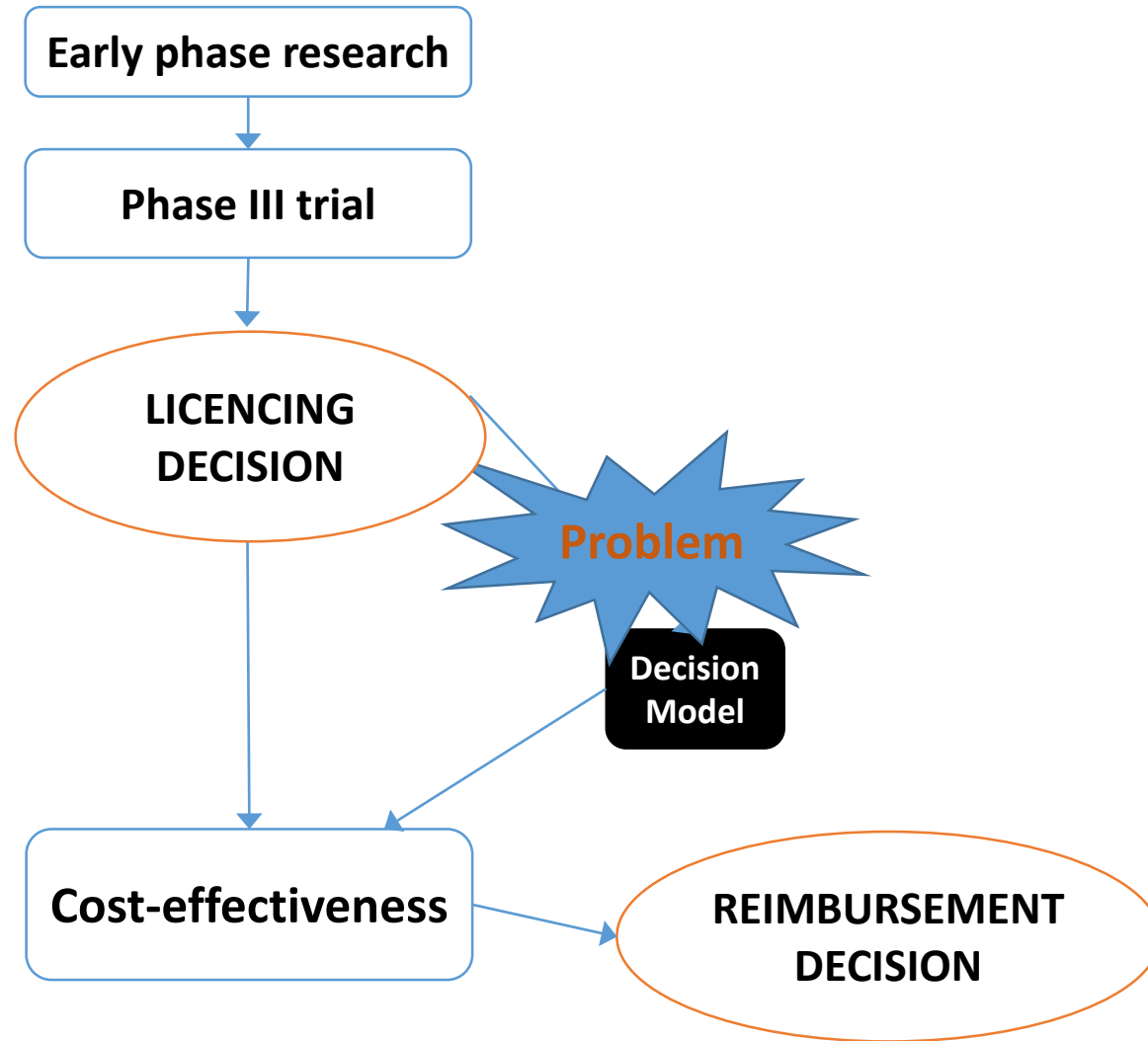
1. Cohort analysis
2. Individual patient care



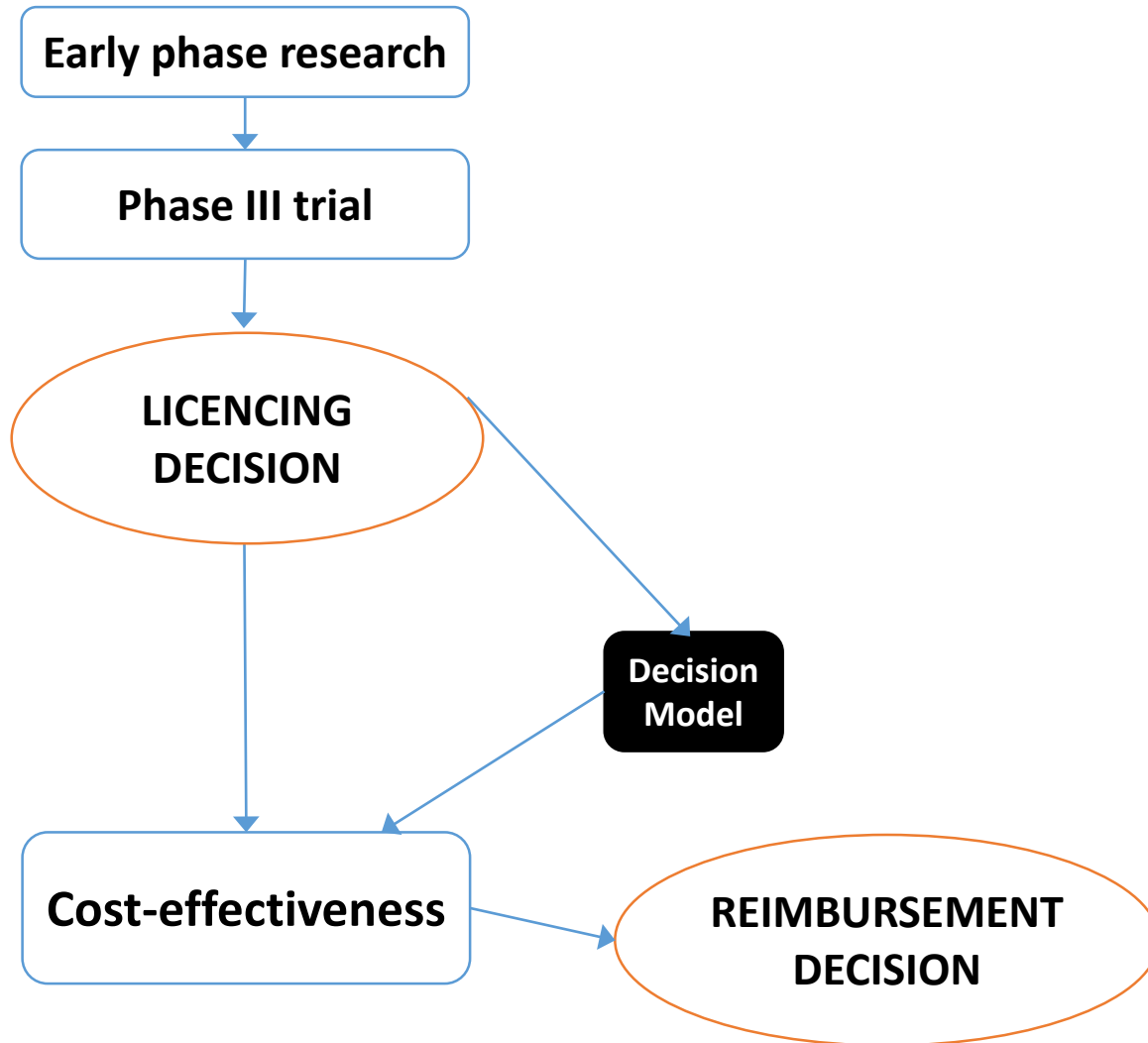
# Use case 1: Cohort analysis

- Population-level analysis
- Service / system / policy design
  - Improve quality of care
  - Inform care planning and management
  - Identify what is working
  - Identify areas for improvement
  - Evaluate system of integration and outcomes
- Ratify the value assessment of newly adopted technologies

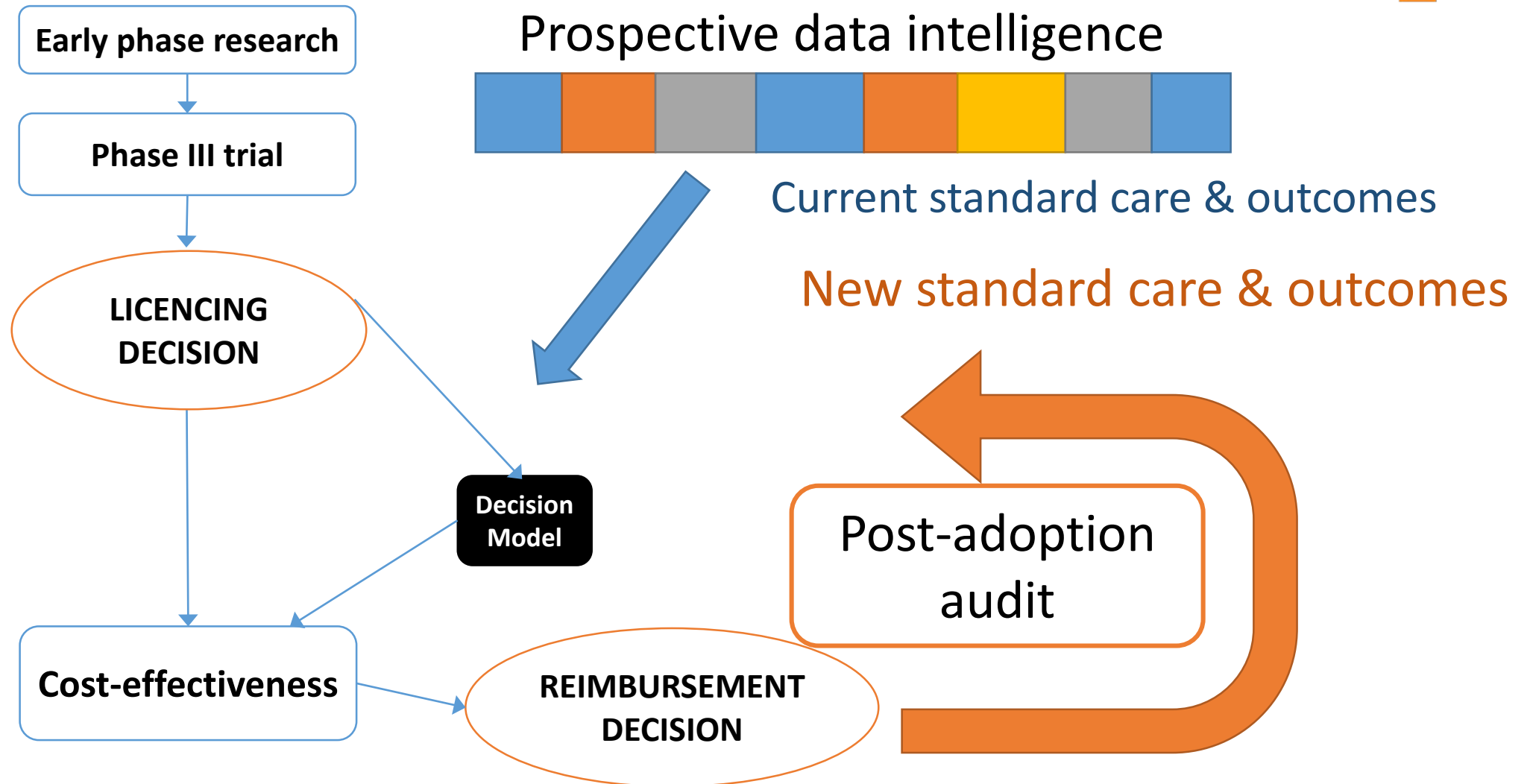
# Pharmaceuticals development process



# How can we do better?

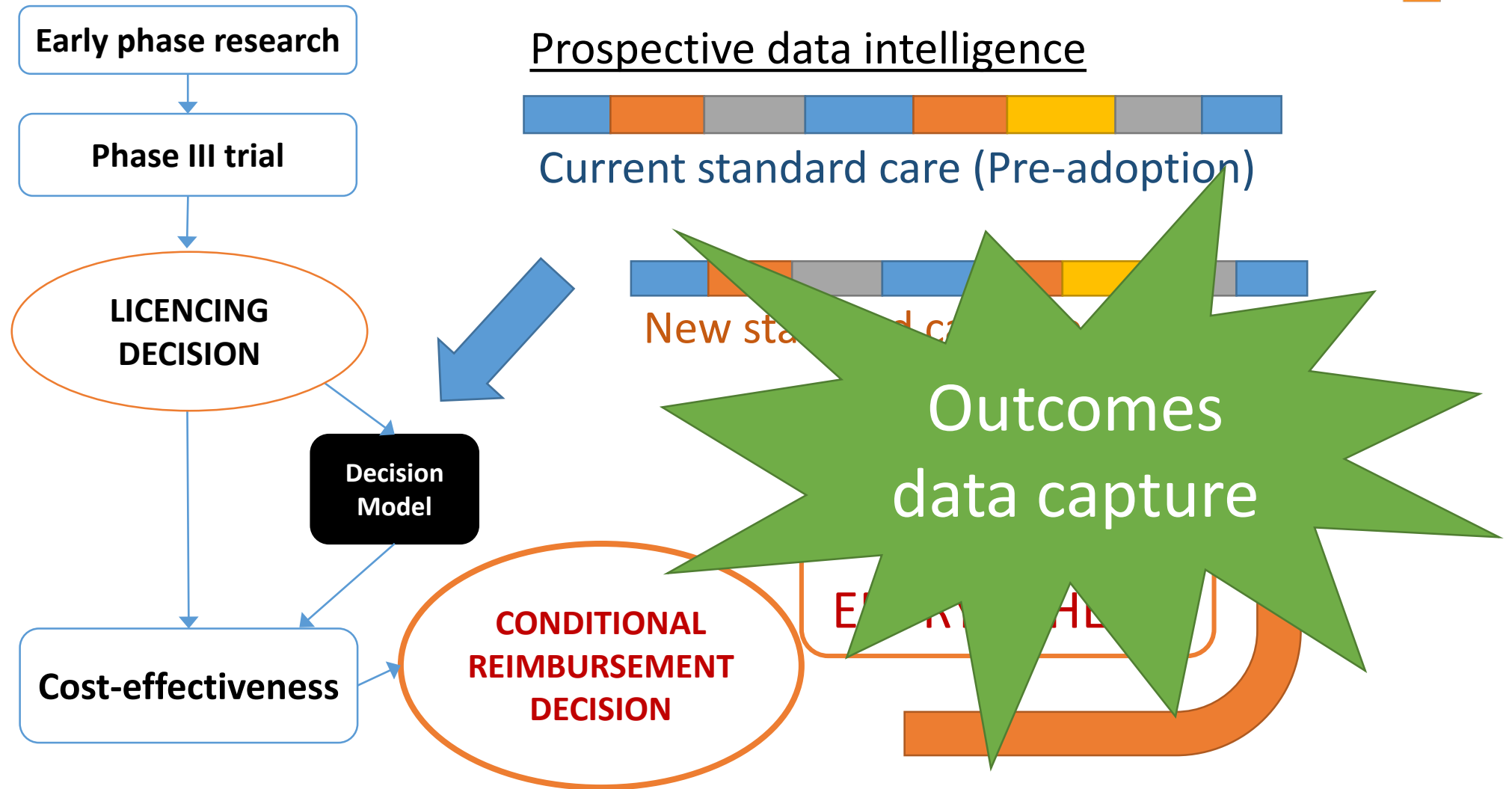


# Real-world data





# Real-world data





# Data availability

- Flow into national cancer datasets held by NSS/ISD
- Interpretable only alongside existing data
  - Cancer registry
  - Scottish Morbidity Record
  - National SACT data
  - Regional Cancer Audit
- National drive to routinely collect outcomes data



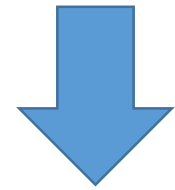
# Use case 2: Individual patient care



- Detailed assessment at diagnosis + repeat intervals  
(e.g. holistic needs assessment)
- Monitoring after/off treatment  
(e.g. monitoring pain scores)
- Monitoring side-effects of treatment  
(e.g. during chemotherapy)
  - Opportunity for self management
  - Alerts to clinical team



**Feedback to clinical  
care team**



**Change patient care  
(real-time)**

# Clinical utility



- Useable and with impact
- Responses need to be readily available to clinical care team
- Visible along side other clinical results, lab tests etc.
- A separate system (with login) will not be used

# EPR

InterSystems  
**TRAKCARE™**



http://localhost/ - T2012 - Windows Internet Explorer

Home | Tools | Messages (7) | Logout User: EEM101 | Location: Trauma/Emergency H1 | Lock

**EPR** TrakCare by InterSystems

[EPR](#) | [Order](#) | [Prescribing](#) | [Patient Chart](#) | [Triage](#) | [Add Detention](#) | [Clinician](#)

**Harold SIMPSON** Sex: Male DOB: 04/09/1967 (45 Yrs) Weight in kg: 105.5 Height in cm: 186

000300670 (23/09/2012 - -) Trauma/Emergency H1 C/P: (Trauma/Emergency H1)

**Print**

**Summary**

Patient History View

Patient History Tabs

Progress Notes

**Clinical Assessment**

Nursing Assessment

Observations

**Pathology**

Medical Imaging

Medications

**▼ Allergy Profile: Allergies**

**Patient Allergy Details**

Allergen	Onset Date and Description	Severity	Priority	Status	Allergen	Tag	Select
Bananas		Severe	Active				<input type="checkbox"/>
Aspirin	Swelling - generalised	Mild	Active		Generic Drug		<input type="checkbox"/>

**▼ Alerts**

**Patient Alert List** [New](#) [Update](#)

Alert Category	Alert	External ID	Message	Status	Closed	Date Entered	Expiry Date	Date Closed	Clinically Significant	CS Report Flag	Time Entered
Clinical	Bleeding Disorder	669ALM3		Active	<input type="checkbox"/>	24/09/2012			<input checked="" type="checkbox"/>		05:29

**▼ Present Illness** [New](#)

Select	Edit	Diagnosis Status	ICD Description	Description	Body System	Problem	Sub-Problem	Onset Date	End Date	Keywords
<input type="checkbox"/>		Active	Presence of cardiac device	Pacemaker inserted 2007						
<input type="checkbox"/>		Active	Headache	Headaches following fall				23/08/2012		

# Trends over time



TABLE. Progression of the patient

	On admission	Day 4	Day 10	4 Months later	Reference range
Total white cell count ( $\times 10^9$ /L)	12.9	15.2	12.7	9.9	4-10
Total platelet count ( $\times 10^9$ /L)	122	92	340	350	150-500
INR	1.36	1.49	1.19	<1.00	-
AST (IU/L)	339	2173	251	18	<37
ALT (IU/L)	210	1898	796	17	<45
ALP (IU/L)	65	87	156	75	49-128
Serum bilirubin ( $\mu\text{mol/L}$ )	31	62	49	14	<21
Serum albumin (g/L)	34	27	31	44	35-50

Abbreviations: ALP = alkaline phosphatase; ALT = alanine aminotransferase; AST = aspartate aminotransferase; INR = international normalised ratio

# Evidence of effectiveness



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JOURNAL OF CLINICAL ONCOLOGY

ORIGINAL REPORT

## Symptom Monitoring With Patient-Reported Outcomes During Routine Cancer Treatment: A Randomized Controlled Trial

Ethan Basch, Allison M. Deal, Mark G. Kris, Howard I. Scher, Clifford A. Hudis, Paul Sabbatini, Lauren Rogak, Antonia V. Bennett, Amylou C. Dueck, Thomas M. Atkinson, Joanne F. Chou, Dorothy Dulko, Laura Sit, Allison Barz, Paul Novotny, Michael Fruscione, Jeff A. Sloan, and Deborah Schrag

See accompanying editorial on page 527

### A B S T R A C T

#### Purpose

There is growing interest to enhance symptom monitoring during routine cancer care using patient-reported outcomes, but evidence of impact on clinical outcomes is limited.

#### Methods

We randomly assigned patients receiving routine outpatient chemotherapy for advanced solid tumors at Memorial Sloan Kettering Cancer Center to report 12 common symptoms via tablet computers or to receive usual care consisting of symptom monitoring at the discretion of clinicians. Those with home computers received weekly e-mail prompts to report between visits. Treating physicians received symptom printouts at visits, and nurses received e-mail alerts when participants reported severe or worsening symptoms. The primary outcome was change in health-related quality of life (HRQL) at 6 months compared with baseline, measured by the EuroQol EQ-5D Index. Secondary endpoints included emergency room (ER) visits, hospitalizations, and survival.

#### Results

Among 766 patients allocated, HRQL improved among more participants in the intervention group than usual care (34% v 18%) and worsened among fewer (38% v 53%;  $P < .001$ ). Overall, mean HRQL declined by less in the intervention group than usual care (1.4- v 7.1-point drop;  $P < .001$ ). Patients receiving intervention were less frequently admitted to the ER (34% v 41%;  $P = .02$ ) or hospitalized (45% v 49%;  $P = .08$ ) and remained on chemotherapy longer (mean, 8.2 v 6.3 months;  $P = .002$ ). Although 75% of the intervention group was alive at 1 year, 69% with usual care survived the year ( $P = .05$ ), with differences also seen in quality-adjusted survival (mean of 8.7 v 8.0 months;  $P = .004$ ). Benefits were greater for participants lacking prior computer experience. Most patients receiving intervention (63%) reported severe symptoms during the study. Nurses frequently initiated clinical actions in response to e-mail alerts.

#### Conclusion

Clinical benefits were associated with symptom self-reporting during cancer care.

Ethan Basch, Mark G. Kris, Howard I. Scher, Clifford A. Hudis, Paul Sabbatini, Lauren Rogak, Thomas M. Atkinson, Joanne F. Chou, Dorothy Dulko, Laura Sit, Michael Fruscione, and Deborah Schrag, Memorial Sloan Kettering Cancer Center, New York, NY; Ethan Basch, Allison M. Deal, and Antonia V. Bennett, University of North Carolina, Chapel Hill, NC; Amylou C. Dueck, Mayo Clinic, Scottsdale, AZ; Allison Barz, Children's Hospital of Philadelphia, Philadelphia, PA; Paul Novotny and Jeff A. Sloan, Mayo Clinic, Rochester, MN; and Deborah Schrag, Dana-Farber/Harvard Cancer Center, Boston, MA.

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Authors' disclosures of potential conflicts of interest are found in the article online at



# What we need

- A solution that enables:
  - Patients to be identified and engaged
  - Responses to PROMs & PREMs to be captured
  - Data to flow into NHS data systems
- 1. For national analysis within national CHI-linked data infrastructure
- 2. For individual patient care within electronic health records



# What we don't need

- To be told which PROMs to use
  - see CMOP, eSMART etc.
  - If in doubt use EQ-5D...



# Considerations

- Information Governance and data protection
- Compatibility with existing NHS eHealth infrastructure
- Human factors
- National policy and analytics integration  
(e.g. SMC, QPIs, Realistic medicine)
- Route to implementation





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