Palliative outcome measures in a cancer hospital…..

Dr Ros Taylor

The Royal Marsden

@hospicedoctor

Steve

- Age 27 yrs
- Spinal tumour
- Weak hands
- Surgery, radiotherapy and now chemo

- **Goals**
- **Be able to text**
- **Manage in the toilet**
- **Get married**

1992

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For all the saints

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It will take some time but already the squeeze is on. There will be letters, petitions, and well bred squeals of protest. Royalty, if badly advised, will rally. But if good sense prevails a conspicuous aberration in British health care provision will be relegated to an institutional status approximating to that of homoeopathy. And—more importantly—the 700 000 people who die each year in the arms of the National Health Service will be rather better served.

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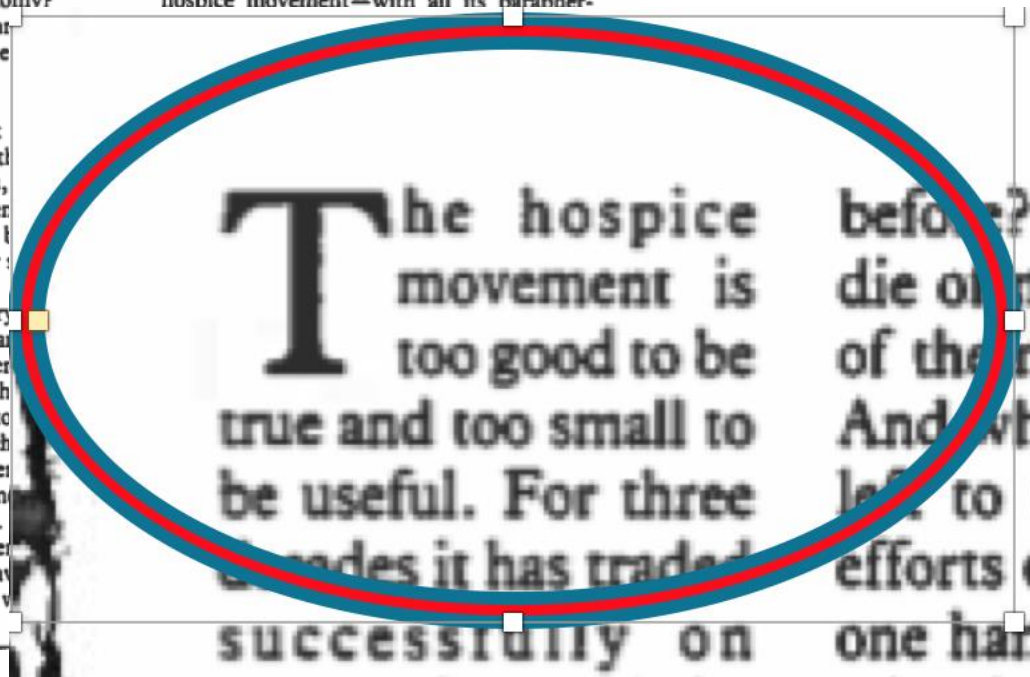
Answers please, on postcards, to the general manager. He will be found. Whatever its larger failings, the reorganisation of the NHS has made managers everywhere to look at how services are provided and at the value for money they offer. Good services, they invariably insist, must also be efficient. But efficient services should also be readily available. Hospices? Did I hear someone say hospices?

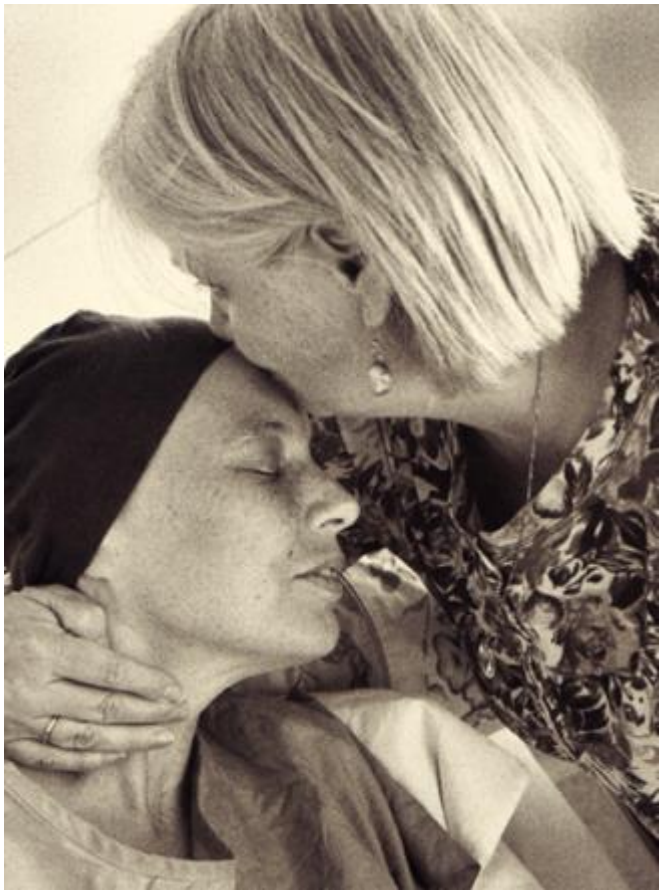
One could almost feel sorry for them as they are pressed as they are by new managers to justify their anomalous existence and their other source of funds, the public, finding it harder and harder to give. Deep into a long recession, charity is not what it was. The hospice movement is just another player in the ever more crowded health sector of the pity market.

In its time the hospice movement has served several useful functions: as a brave new idea when standards of terminal care were lamentable; as a base for the development of nursing skills and service innovations such as home care for the dying; and as a first home for that useful scientific, clinical, and educational endeavour, the specialty of palliative care.

Well done, thanks, and goodbye. The hospice movement—with all its paraphernalia



MANAGING SUFFERING & UNCERTAINTY

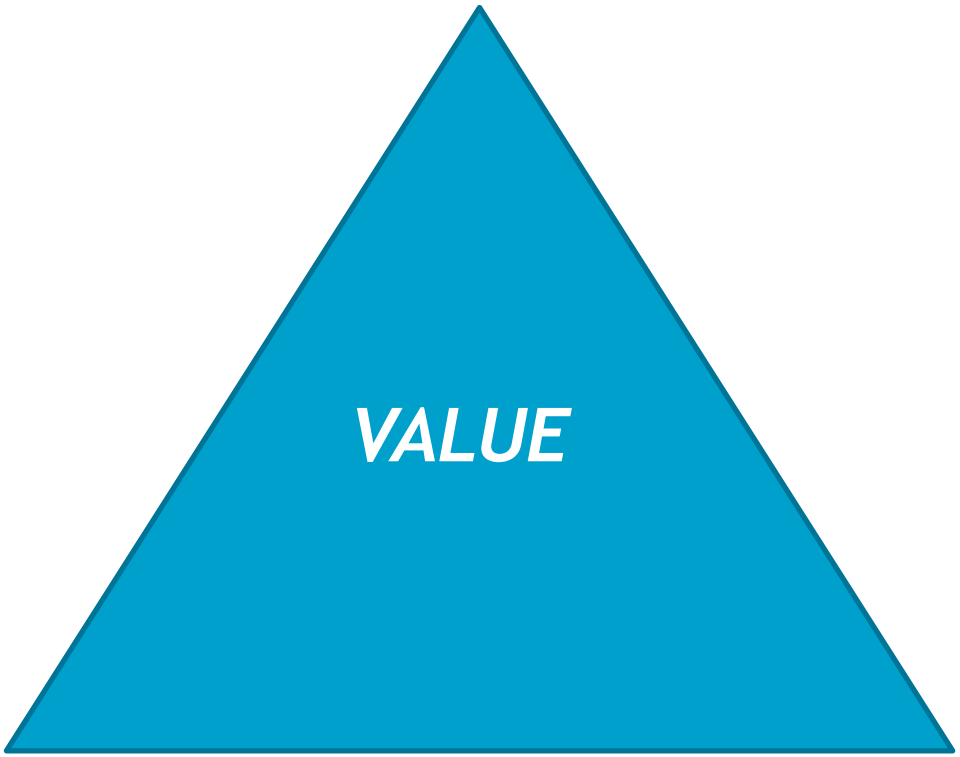


A drawer full of thank-you letters ….

Dame Barbara Monroe

Patient Outcomes

The difference you make **OACC**



Patient Experience

What it feels like

Activity Data

What you do MDS

What matters to people?

-Goals – being listened to

-Symptom control

-Safety, time for preparation and peace

-Information

-Family support

-Coordinated care and 24/7 advice

No triggers for referral

Research….

Patient care/teams/ cancer sites

Demonstrate unmet need

Research

Early intervention of Specialist Palliative Care for patients with cancer

Evidence of benefits:

- Improved Quality of Life
- Better symptom control
- Reduced depression
- Less aggressive care at EOL
- Increased survival
- Improved prognostic understanding

Temel JS et al. NEJM 2010; 363: 733-42
Zimmerman C et al. Lancet 2014; 383: 1721-30
Bakitas M et al. JAMA 2009; 302: 741-9
Ferrell B et al. JCO 2017; 35(1): 96-112

Triggers for referral

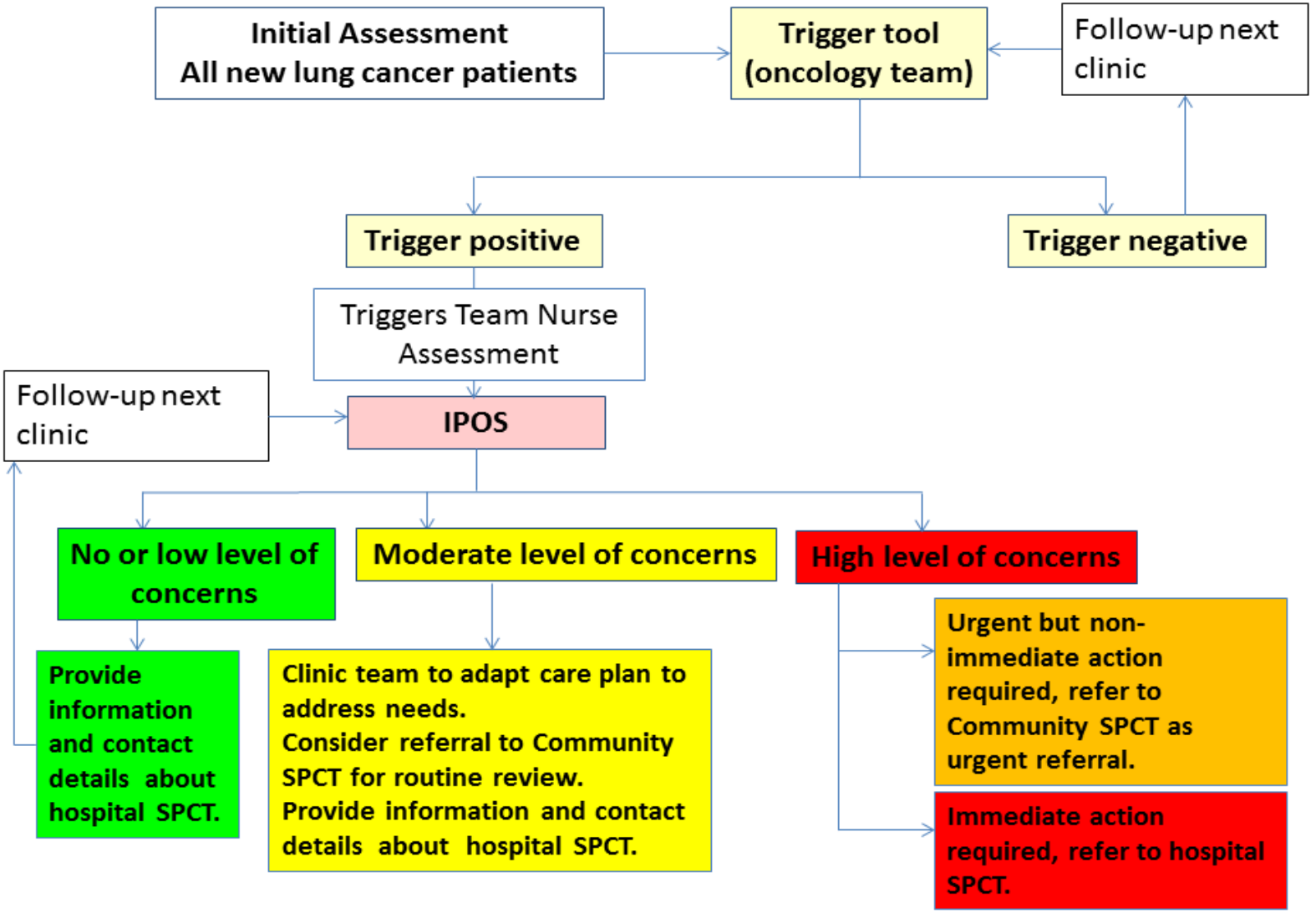
Specialist Palliative Care Referral Triggers Tool

Patient is "Trigger positive" if they have any one of the following:

- Metastatic cancer progressing after 1st line of treatment
- Performance status ECOG 2 and deteriorating
- Acute oncology or unplanned admission
- Severe or overwhelming symptoms
- Anorexia, hypercalcemia, or any effusion
- Moderate or severe psychological or existential distress
- Complex social issues

RM Partners. London Cancer Alliance Palliative Care and End of Life Care Pathway Group. The Transition to Palliative Care.
http://www.londoncanceralliance.nhs.uk

"Triggers": A New Integrated Palliative Care Service



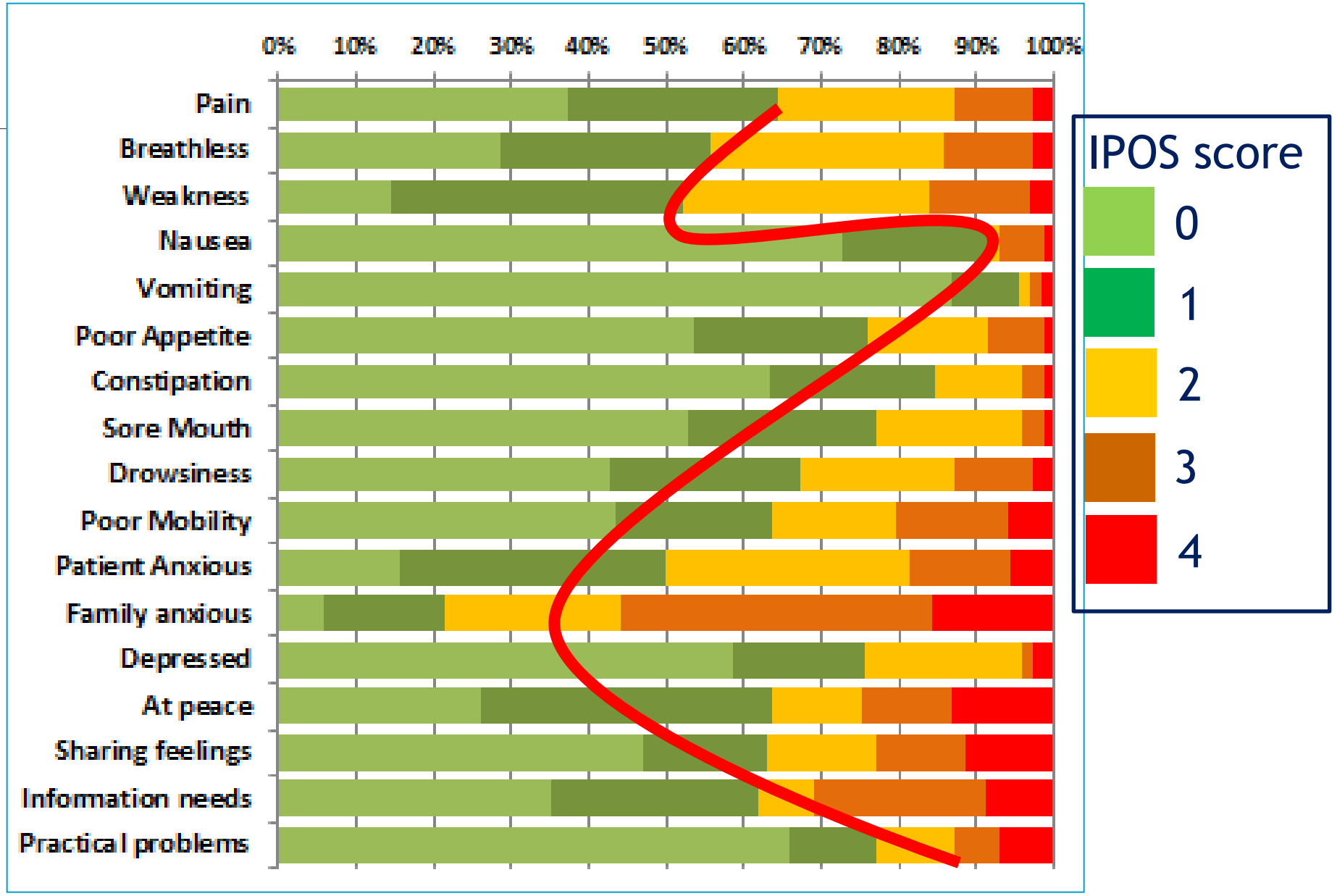
Data from 4 months of new "Triggers" service

100+ patients

73 Trigger positive

81% (57/70) had severe or overwhelming PC need on at least one IPOS item.

Palliative care needs at 1st assessment



Of interest:

Information needs and family anxiety fit with CSNAT assessment globally

Carers Support Needs Assessment Tool

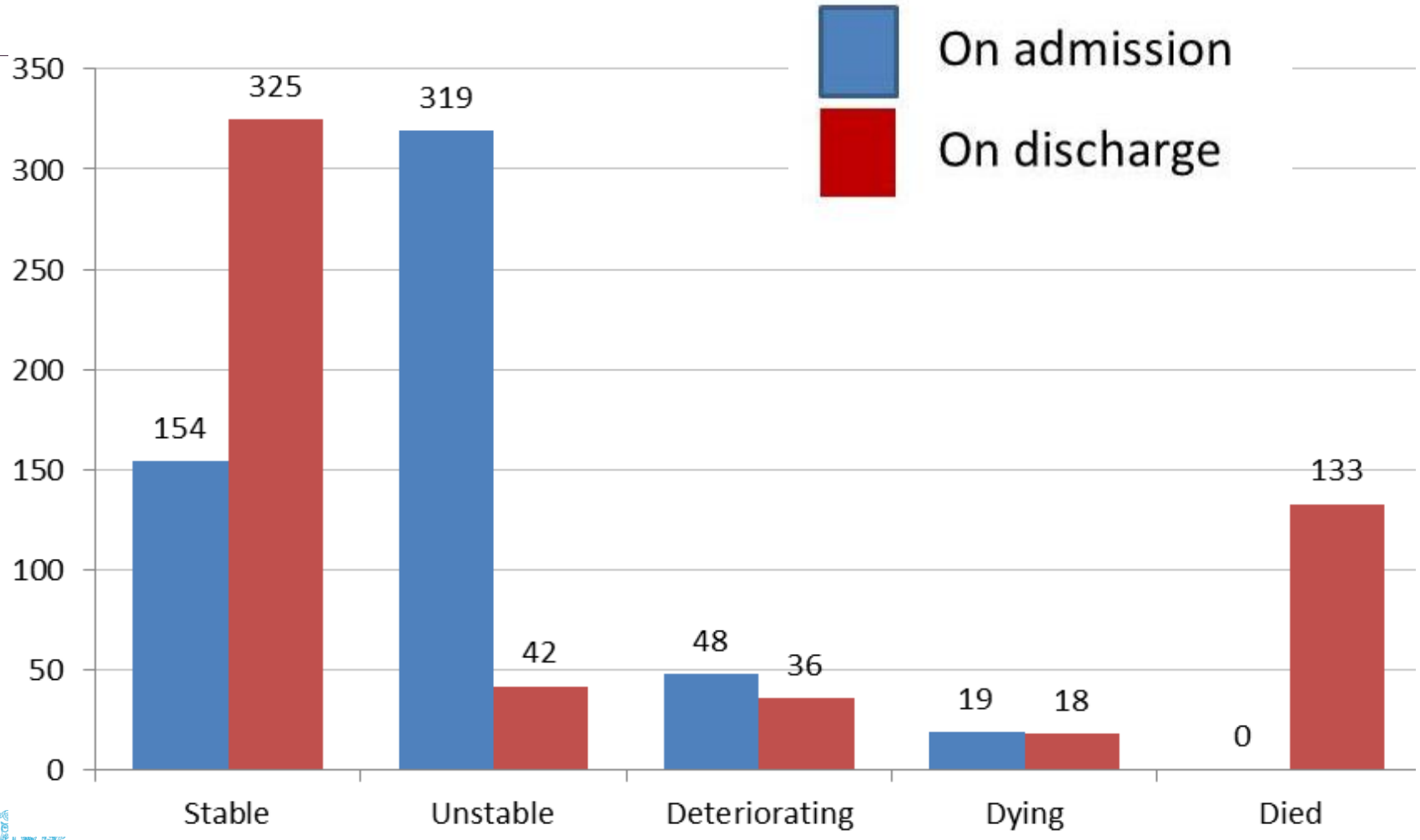
What does that mean for service?

Patients

Phase on every patient, every day

Question – How long unstable for?

Phase as an outcome measure



Complexity of referrals

Phase and AKPS on every new patient discussed at MDT

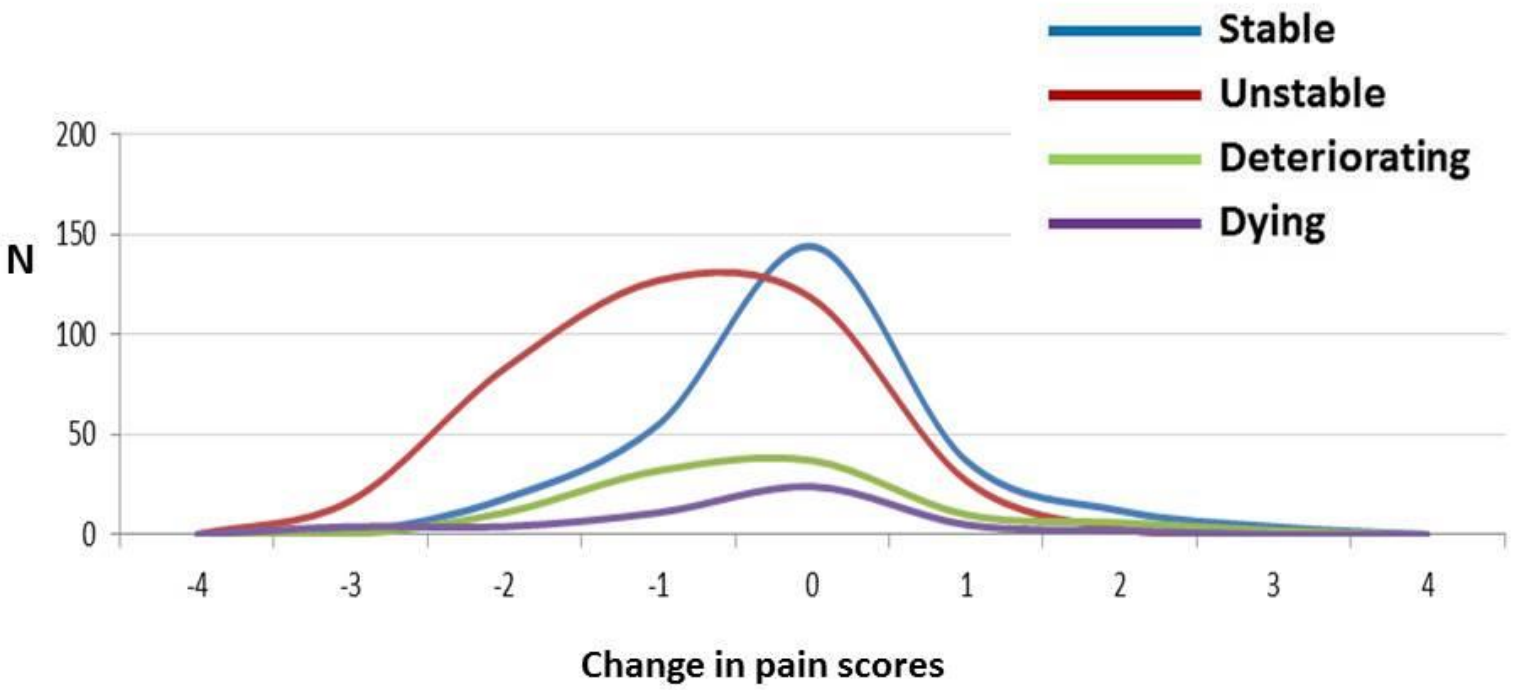
Now

Phase *every patient, every day*

AKPS *for MDT*

IPOS *every 1st assessment and discharge*

Change in pain scores
Start to end of phase



Potential benefits to patients

Improved holistic assessment

Identification of unmet need

Efficient prioritisation

Targets - examples

Unstable phase less than 3 days
Proportion of patients with symptom scores less than 2

Potential benefits to hospital palliative care team

Needs driven service

Effective MDT

Benchmarking with other hospital services

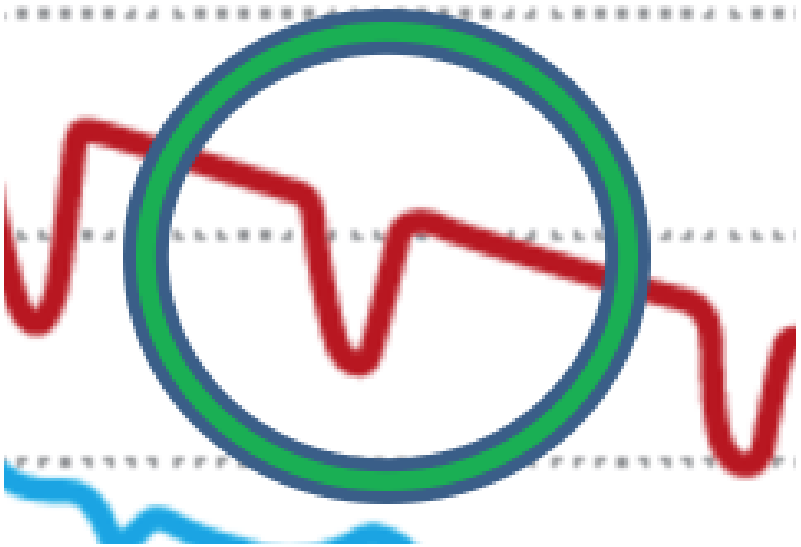
Demonstrable measure of value

Unmet need

Too much focus on the physical….

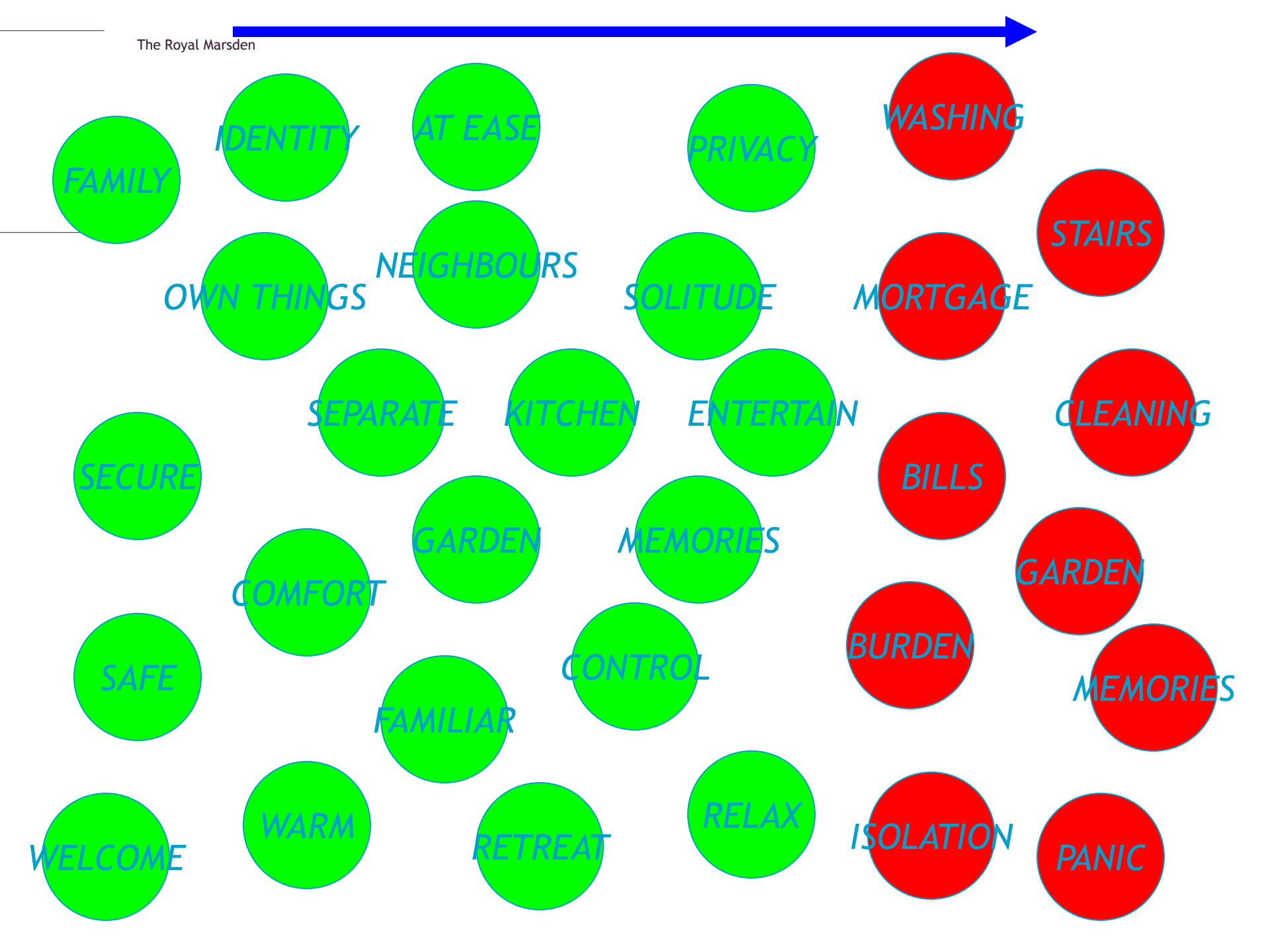
Event-centred care?

Treat each **event** as a discrete reversible episode without taking into account trajectory



RESCUE

© Lightstone & Taylor


FAMILY
IDENTITY
AT EASE
PRIVACY
WASHING
STAIRS
OWN THINGS
NEIGHBOURS
SOLITUDE
MORTGAGE
SEPARATE
KITCHEN
ENTERTAIN
CLEANING
SECURE
BILLS
GARDEN
MEMORIES
GARDEN
COMFORT
BURDEN
SAFE
CONTROL
MEMORIES
FAMILIAR
WARM
RELAX
ISOLATION
WELCOME
RETREAT
PANIC


You told me you'd spend your whole life trying to make me happy.
I didn't expect to live this long.
©Original Artist

Family anxiety

- Who matters to you ?

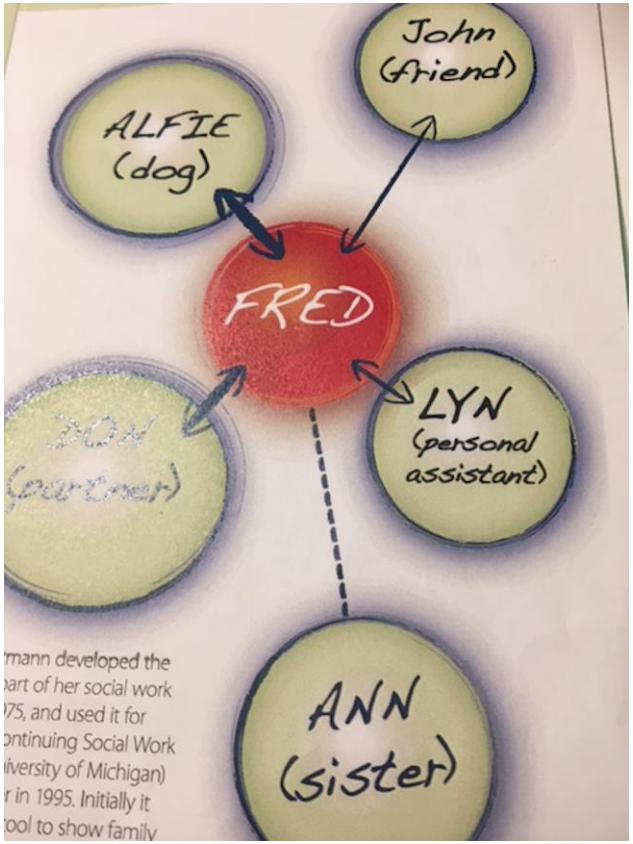
- Family meeting skills

- Unravelling the anxiety

Family-centred care

Genogram
or
EcoMap

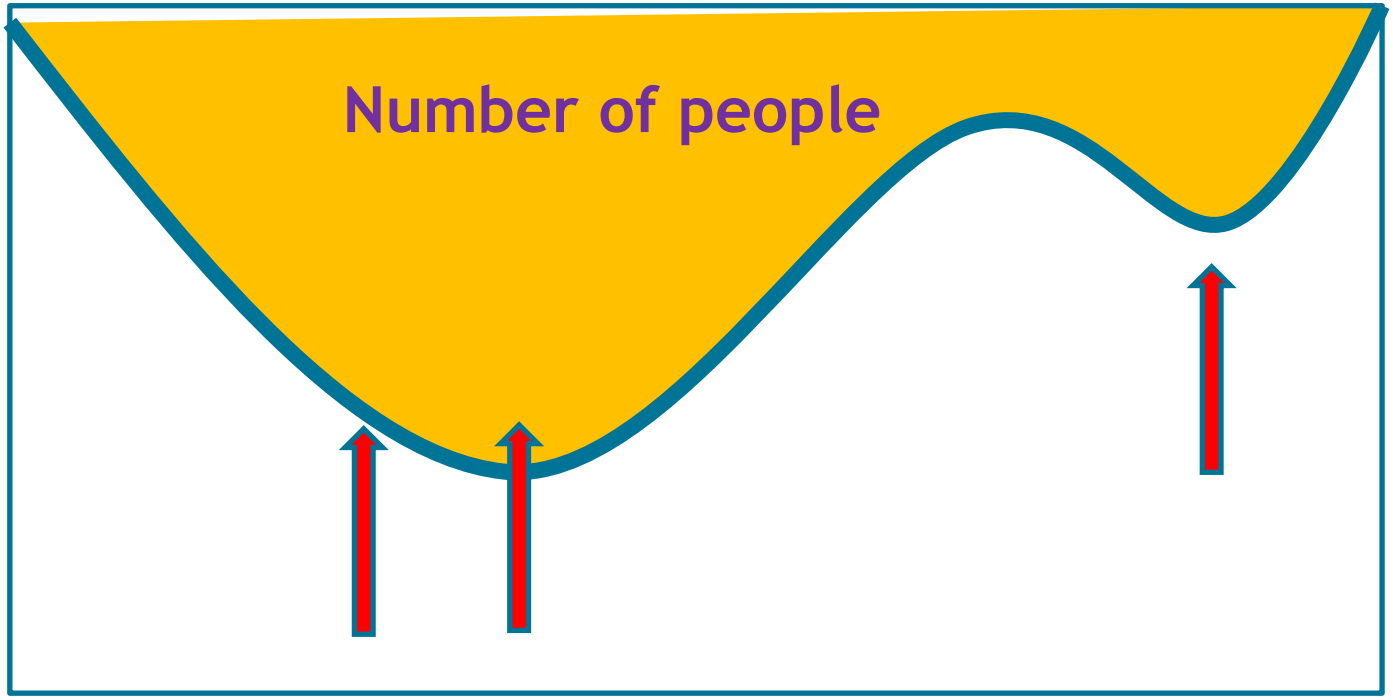
Who matters to you?



Need for more psycho-social support

Gynae Oncology Patients

IPOS at 1st clinic



Moderate , severe or overwhelming (scores 2,3,4)

Patient anxious, family anxious and information needs

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The more us stream s care su home ca most dif places w front lin general hospital doctors s in the re doubt se Why no trail?—c *Edinburg*

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The ROYAL MARSDEN
NHS Foundation Trust

My future questions….

How do we make the team decision from deterioration to dying?
How can we influence family anxiety?
How do we link outcomes with goals?

NHS