From Worms, Butterflies and Veils to Outcomes

Annual Conference 2015

good life good death good grief

#sppc15

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Scottish Partnership for Palliative Care

Its all about informed discussions… informed decisions… and informed care

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EC4H Effective Communication for Healthcare www.ec4h.org.uk

THE UNIVERSITY OF EDINBURGH

1. How can we identify patients with deteriorating health, limited reversibility and at risk of dying?

2. How can we make sure the ‘right conversations’ happen with patients and those important to them?

3. How can we share and use this information to improve outcomes ?

Context

- **Most people have a hospital admission in the last year of life**[1]
  - Around 9% die during that admission
  - 21% will have died by 6 months
  - Nearly 30% of all hospital inpatients die in the next year
  - 50% of healthcare expenditure is in the last 6 months of life
- NHSL : variation across clinical areas/predominant groups
  23% at 6 months, 51% by 12 months
- **Uncertainty … who** will die and **when**, and **what matters** to them?

We need to identify people *at risk* and have the right conversations with them about what is happening and 'what matters'

[1] Clark et al. *Palliative Medicine* 2014; doi: 10.1177/0269216314526443

How can we identify people whose health is deteriorating such that they are at risk of deteriorating further and dying?

www.spict.org.uk

SPICT™

The SPICT™ is a guide to identifying people at risk of deteriorating health and dying. Assess these people for unmet supportive and palliative care needs.

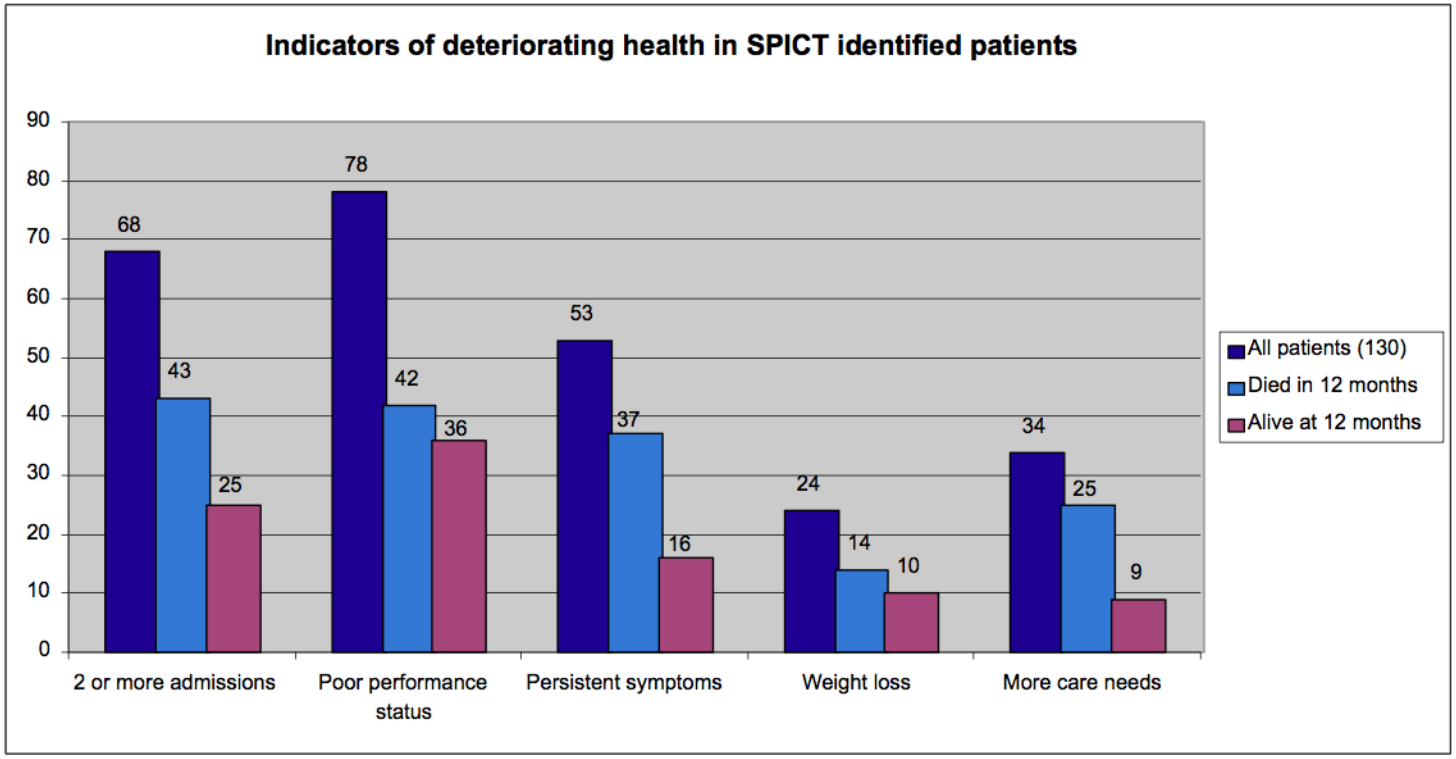
Look for two or more general indicators of deteriorating health.

- Performance status is poor or deteriorating (the person is in bed or a chair for 50% or more of the day); reversibility is limited.
- Dependent on others for most care needs due to physical and/or mental health problems.
- Two or more unplanned hospital admissions in the past 6 months.
- Significant weight loss (5-10%) over the past 3-6 months, and/ or a low body mass index.
- Persistent, troublesome symptoms despite optimal treatment of underlying condition(s).
- Patient asks for supportive and palliative care, or treatment withdrawal.

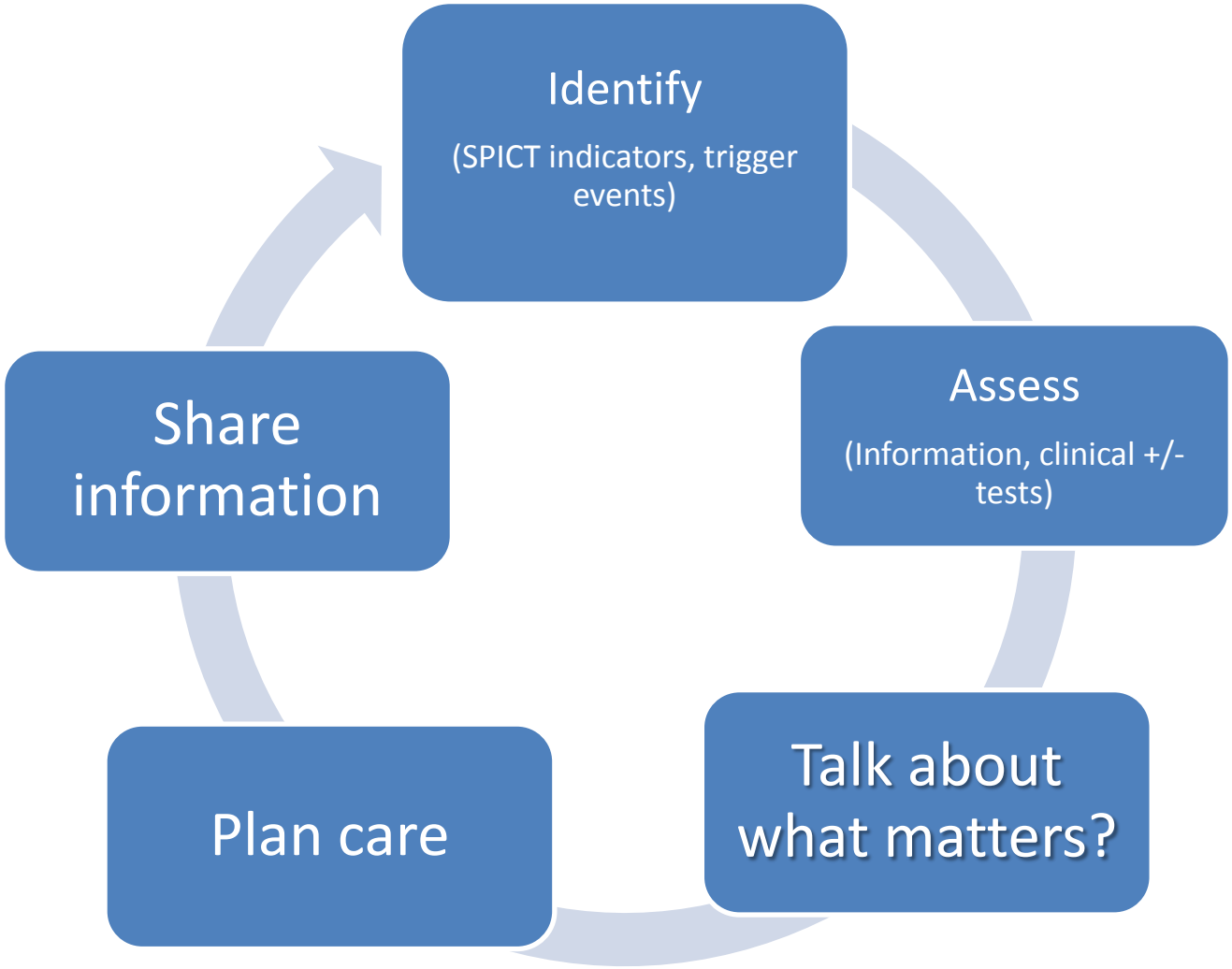
Performance status scores (WHO, ECOG, Karnofsky)
Indicators of Relative Need (iORN) – functional status
Scottish Patients at Risk of Admission and Readmission (SPARRA)
Care home admission

Does SPICT help us identify patients at risk? YES

Acute hospital



- 29% mortality at 6 months
- Median SPARRA risk score – 65%
- Multimorbidity – 80% +


Identify
(SPICT indicators, trigger events)
Assess
(Information, clinical +/- tests)
Talk about what matters?
Plan care
Share information

"I was worried I was going to die…. I'm glad to be feeling better and don't want to think more about the future right now" Patient

"these are not the kind of discussions for when you're really not well" Patient

"It is upsetting, but its much worse when you don't know what's happening…." Patient & wife

"they have to tell you like it is……I don't want to live like I died a while ago"

Patient

"It all sounded so hopeless- I just didn't want to hear any more" Patient

"She [doctor] *hedged around, it took a while til' I saw what she was getting at"* Patient

Every time I'm asked I have to go through it….and relive it…. over and over again…. Husband

‘Living well’ with multi-morbidity after discharge home

Hoping

Patient: “*I’ve never broached the subject cause I think like I’d rather be positive. I think “I’m not going to get worse.”*
(Female, 66: Liver failure, diabetes, IHD)

Coping

Carer: ‘*We deal with everything just as it is happening, just day to day stuff and things. We just manage.*’ (Carer for male, 87: renal failure, diverticular disease, mild dementia, prostate cancer,)

Not planning for dying

Patient: ‘I’m not afraid to die but I want to live’ (Female, 79: stage IV heart failure, renal failure)

“I am quite happy to just float along as we are doing now.“ (Female, 89: epilepsy, atrial fibrillation, hypertension, severe aortic stenosis)

Mason B et al. BMJ Supportive Palliative Care 2014;0:1–6. doi:10.1136/bmjspcare-2013-000639

Talking about '*What Matters*'

Future Care Planning

What do you know?

What are you expecting?

What's happening?

What matters?

What would help?

Advance care planning (ACP)
'*When and if*' plans

Anticipatory care planning (AnCP)
'*What to do if*' plans

Final days of life planning
'*What matters now*' plans

Plan the discussion

- Key people
- Urgency
- Capacity
- Information reconciliation
- Understanding/ readiness (*prognostic awareness*)

Share information

Opening conversations about *'What Matters'*

- **Generalisation**
  - *Sometimes people want to choose a family member or a close friend to make decisions for them if they get less well in the future. Have you thought about that?*

- **Hypothetical questions**
  - *If you were less well again like this in the future what do you think we should do?*

- **Hope linked with concern**
  - *We **hope** the* (treatment) *will help, but **I am worried** that at some stage, maybe even soon, you will not get better…. What do you think?*

- **Accept uncertainty, change and diverse views**
  - *Can we talk about what is most important for you now, and how we might cope with not knowing exactly what will happen and when?*

Effective discussions about *'What Matters'*

- Euphemisms or long, vague explanations
  - **causes confusion**
- Talking about '*trying*' or '*the chances*' if a treatment will not work , have a very poor outcome or not help meet the person's goals
  - **directs people to *'want everything done'***
- Using language that is unhelpful or unclear eg. 'futile', 'terminal', treatment limitation' or 'ceiling of treatment/care'
  - **can make people think *'nothing will be done for them'***
- Moving on to treatment options and planning care before understanding '*what matters*'
  - **People need to understand their situation to know what matters**

Institute for Healthcare Improvement

Conversation Ready
Health Care Community

www.ihi.org

EVERY PERSON EVERY TIME
SCOTTISH PATIENT SAFETY PROGRAMME

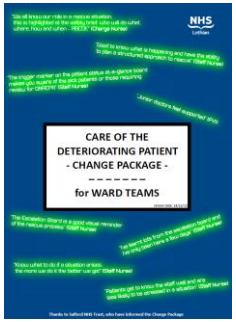
NHS Lothian

Conversation Ready?

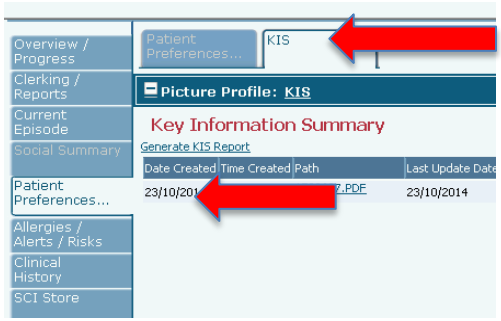
'Palliative Care' and *'Patient Safety'* ?

- SPSP aims
  - 95% of people with physiological deterioration will have a structured response and plan
  - 50 % reduction in CPR attempts
  - Reduction in inappropriate interventions

- Improvement focus and methods
  - Clinically driven
  - Measurement?
  - Familiarity & structure



Information Reconciliation



On Admission to Hospital

ACP Information from **K**ey **I**nformation **S**ummary **(KIS)**, GP letter, previous clinical records

Change/Deterioration

Informed review & care in home setting

Out of Hours : KIS

During Hospital Stay

Key information fields in; clinical records (AnCP/ hKIS), structured ward rounds, MDT meetings, handovers,.

Deteriorating Patient Package

Structured Review Tool

ACCESS

RECONCILE

with patient status, needs & priorities

SHARE

In Primary Care

Key information from hospital episode used to update or create **KIS**

Discharge from Hospital

Key information fields in the immediate discharge letter (IDL)

Informed discussions → **Informed decisions** → **Informed care**

Progress…..

- From 3 clinical teams to projects on all hospital sites;
  acute medicine, general surgery, vascular, renal, respiratory, oncology, MOE, stroke, Hospital at Night … and others

- Breakthrough collaborative: forum 45 members

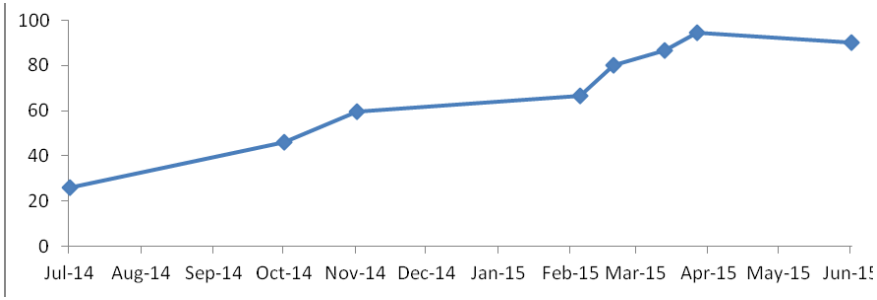
- Local data to inform improvement ….

Baseline: IDL content

PDSA 3

What have we found?

- An Anticipatory care plan / prompts can support reliable planning & response to deterioration
- Anticipatory care planning is possible within busy acute hospitals



Cohort 2: 9 wards

- Acceptability of AnCP discussions for patients & carers
- Challenges for clinicians and support needs

What have we found….so far

- **Language matters-** clear, shared and understood by all
- **Ownership matters** – who are the experts?
- **Context of local care delivery:** team members, roles, patient groups, processes, workload
- **Cross cutting approach** with other programmes e.g. delivering better care, person centred care

Making it all work….

- Identify people at risk
- Review current care and information/ plans
- Have conversations about *what is happening and what matters*
- Plan care with them now and for the future
- Share the information – KIS, emergency plan etc.
- Monitor outcomes/ quality
- *Let people know what to expect – public awareness*
- Have resources available to support staff

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SPICT™ APP

Knowledge Network

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