



**Marie
Curie**

**Care and support
through terminal illness**

What are the questions we should be asking?

1. To be or not to be?
2. What is life all about?
3. Can I travel faster than the speed of light?
4.
5. What is your story?



The 7 Habits of Highly Effective People

1. Be proactive
2. Begin with the end in mind
3. Put first things first
4. Think win-win
5. Seek first to understand, and then to be understood
6. Synergize
7. Sharpen the saw

Stephen Covey

Begin with the end in mind

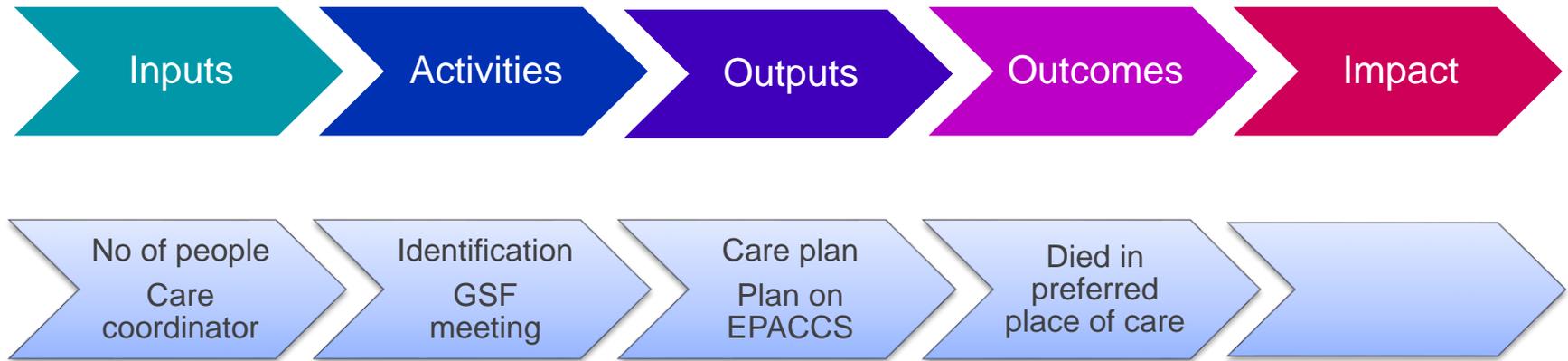
Stephen Covey



What sort of things are we measuring?



What sort of things are we measuring?



What is most important to people?

- Recent publication
- **Good concordance between patients and their professional carers about factors associated with a 'good death and other important end of life decisions**
- A Davies et al, BMJ Supp and Pall Care 2019:9 340-345
- Limitations – all cancer patients
- Known to local palliative care services
- Had a cohabiting non professional carer

Asked about preferred and acceptable places of death

Preferred

- Own home 50%
- Nursing home 1%
- Hospice 45.5%
- Hospital 1%
- Other 1.5%
- No data 1%

Acceptable

- Own home 72.5%
- Nursing home 14%
- Hospice 90%
- Hospital 21%
- Other 6.5%
- No data 1%

What if you ask 'good death' factors to be ranked by patients and their carers

| | Patients | Carers | Carers (themselves) |
|-----------------------------------|----------|--------|---------------------|
| Pain and symptoms well controlled | 1 | 1 | 1 |
| Not to be a burden to family | 2 | 3 | 2 |
| Sort out personal affairs | 3 | 5 | =3 |
| Mentally alert to death | 4 | 4 | 5 |
| Involved in decisions | 5 | 2 | =3 |
| Able to die at home | 6 | 6 | 8 |
| To feel my life is complete | 7 | 7 | 6 |
| Sorted out my funeral | 8 | 8 | 7 |
| Peace with God | 9 | 9 | 9 |
| Not to be a burden to society | 10 | 10 | 10 |



This was selected group of people who had advanced cancer (predictably terminally ill)



How many had a will?

86%

How many had an Advance Care Plan?

27%

Advance care planning is difficult

- Abel study on hospice in-patients
- At start of study only 42% had ACP
- At end of study 69%
- Subsequently 77%
- This means around $\frac{1}{4}$ of all hospice inpatients still didn't do advance care plans

Those with an ACP have better outcomes....

ACP – is there an association with place of death – VOICES BMJ PSC

1. More likely to die in preferred place
2. Better symptom control
3. Get more satisfactory support with care
4. Better overall quality of care
5. However, more likely to have ACP with cancer

Other factors which are linked to better outcomes – being <80, male, solid tumour cancer, in least deprived area and having a spouse or partner

OACC measures

1. Phase of illness
2. Karnofski
3. iPOS – systematic assessment of issues and symptoms
4. Bartell – functional assessment
5. Feedback survey – not well implemented

A useful tool for measuring effectiveness of intervention

Measures outputs and some outcomes

So what questions should we be asking?

Ideally...

What are the persons personal wishes or preferences around the end of their life?

Did they achieve this?

However, this will only work for people who embrace Advance Care Planning

VOICES – views of informal carers, evaluation of services.

1. Demographics
2. Care at home (last 3 months)
3. Urgent OOH care (last 3 months)
4. DN and community support
5. Care from GP
6. Care Homes
7. Last hospital admission
8. Last Hospice admission
9. Last 2 days of life
10. Circumstances surrounding the death

VOICES page 2 – qualitative questions

1. Was there enough help?
2. Was their pain relieved?
3. How often were they visited?
4. Were they treated with respect and dignity?
5. Did the services work well together?
6. Overall what did you think of the care provided?
7. Around death
 - Did they know they were going to die?
 - How was the news broken
 - Were you called in soon enough?
 - Did they die in the right place?
 - Were the family treated sensitively?

Most of the VOICES questions correlate with the issues raised when patients and carers are asked what constitutes a good death (and last 3 months of life)

Limitations

Most of the focus is on 'place' as its easier to measure – however it is only ranked 6 by patients and carers.

Burden was not measured - ?as it is a relative who responds

Sorting out affairs isn't covered

Retrospective and reported by relatives

Not real time

The VOICES is a good tool to measure the impact and effectiveness of services delivered but it is weak on measuring the holistic approach embracing what is important to the person

VOICES – page 3

Good points

It asks about experiences

It covers many if not all aspects of care

It is national and comparable

It is of sufficient size to provide statistical analysis (well powered)

We have data collected over three years – as a base line

What questions should we be asking?

– bilateral approach

1. **Modify VOICES to collect data on the issues patients/people site as their concerns**
2. **Collect VOICES on all our patients**
3. **If people have recorded in issues in their ACP/wishes which isn't covered by VOICES ask a supplementary question such as...**

Your relative recorded that was important to them, were they able to address this in the last three months of their life?

Remember – its their story not ours...

I never said it would be easy – but it is...

- 1. Individualised**
- 2. Personal**
- 3. Proactive**
- 4. Avoids the bias of only recording those who are comfortable with ACP**
- 5. Helps us to identify our weaknesses and bridge the care gap**
- 6. Allows us to collect individualised and standard responses to be compared across settings**

Begin with the end in mind

We want *everyone* to have the
best end of life experience

If we want to know we are having an impact, we need
to systematically measure experience



Question time..

To be, or not to be, that is the question: Whether 'tis Nobler in the mind to suffer The Slings and Arrows of outrageous Fortune, Or to take Arms against a Sea of troubles, And by opposing end them: to die, to sleep No more; and by a sleep, to say we end The Heart-ache, and the thousand Natural shocks That Flesh is heir to? 'Tis a consummation Devoutly to be wished. To die to sleep, To sleep, perchance to Dream; Aye, there's the rub.

William Shakespeare

