Developing an Outcomes Framework for Hospices and other SPC services

The Case for Change

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Overview of presentation:

1. Why bother?
2. Why now?
3. What should we be considering?
4. Who needs to be involved?
My perspective

- Commission into the future of hospice care
- My role at Help the Hospices
- My role in a local hospice
• Stand up everyone who is delivering or managing a hospice/spc service
• Stay standing if you know how many people you care for a year
• Stay standing if you know what difference your efforts make to the people in your care (not as a hunch but in some objective way)
• Stay standing if you know how this difference compares to the difference that other similar services make to their users
• Stay standing if you are confident about what explains this difference
Why bother?
• We need to know what difference we make at:
  – Local level
    • To inform plans for service improvement/development within and beyond our services
    • To confirm our value to commissioners
  – National level
    • To develop a more sophisticated understanding of the sector
    • To advocate for hospice/SPC services
    • To guide future models of care
  – International Level
    • To discern how hospice/spc is best delivered in the future
Why bother now?
Current demands

• Clinician driven curiosity
• Leader driven scrutiny
• Commissioner demands
• Regulator requirements
• Public interest – quality accounts
• New business opportunities
Preparing for current and future challenges

“It might not be raining hard yet, but we can be sure it will be soon”
Future challenges for hospices (and other providers of SPC)

- Demographic and epidemiological changes
- A shift towards outcome oriented healthcare
- Increasing competition in the health and social care systems
- *Reducing levels of statutory funding*
Key operating principles

3. Planning, analysing & acting on good data

There is an acute need for greater ‘thinking inside the box’ – better information, sharper analysis, more entrepreneurial strategic planning. This means rectifying the frequently appalling lack of systematic measurement of performance, analysis of data and use of evidence in decision making. ‘Thinking inside the box’ also means

6. Telling a clear story and marketing it

Hospices must be more active in clearly articulating the value of hospice care – beyond the bricks and mortar. It is too easy to get stuck in the heat of

Data needs to be of sufficient quality, collected over time and at patient level to maximise opportunities to drill down and identify changes over sustained periods
Final recommendations

Step Two
Strengthen understanding of the contribution of hospice care

This is a call for hospices, their leadership organisations, and other players, including academic centres, to work together to establish a clear and evidence-based description of the role that hospice care plays in supporting people with life-shortening conditions, their families, carers, communities and broader society. (5)

Achieving this step will require hospices to provide clear information for potential users that clarifies referral criteria and processes, confirms what care is available, and tells an evidence-based story in relation to anticipated outcomes and the degree to which they are achieved.
What should we be considering?
More than pictures and stories..
To knowing more about:

- Who benefits and how?
- How much?
- When?
- With what kind of combination of care?
- How similar/different is the picture between services?
The kinds of data needed

- Structural, process, and organisational data
  - Largely at organisational level

- Demographic and clinical data, including patient and family outcomes
  - At individual patient and family level

- Bereavement outcomes
  - At family level

- Social capital and volunteering
Who needs to be involved?
Essential ingredients

- Change agents
  - Strong intelligence about what data to collect, how to interpret and act in response
  - Mechanisms for collecting, analysing and presenting the data at local and national levels
  - Local data – which can be scrutinised, compared with other services and over time
Strong partnerships

- Hospices/other specialist palliative care providers
- Help the Hospices
- The Cicely Saunders Institute and funders
- The National Council for Palliative Care
- NHSIQ
- Public Health England
Final thoughts

• We need to work collectively on this
• It is key to our success in the future
• We must move away from localism to being sector strong on this
• We must bring together separate activities in our various organisations to get it right
• We could do something incredible together!
This workshop was hosted in partnership with Help the Hospices and we would like to extend our gratitude for their help and contributions.

Thank you for your participation in this workshop, for more information please contact francesca.cooper@kcl.ac.uk or visit our webpage www.csi.kcl.ac.uk/oacc.html