think local act personal

COMMISSIONING THE FUTURE: **WORKSHOP 4**

People who use services taking the lead in shaping commissioning – Planning end of life care

Facilitator's Notes, July 2012

ipc institute of public care

'Commissioning The Future – Workshop materials to start a new conversation between people, providers and commissioners of services' represents the work of the Think Local Act Personal (TLAP) National Market Development Forum. These materials have been designed to help those involved in strategic commissioning rehearse and explore new ways in which the public care market might develop. The exercises are offered in the context of – and can help you deliver on – the TLAP Making it Real markers of progress for personalised, community based support.

This 'Commissioning The Future' pack offers all involved in strategic commissioning an opportunity:

- To rehearse the issues they face.
- To do this outside the context of a particular negotiation, contract or agreement.
- For all people to play different roles than they do in 'real life' and explore the issues from a range of perspectives.

Each exercise represents real issues that are faced by all involved in commissioning public care. They support commissioners, providers and people who use services and carers to adopt some of the key skills and behaviours advocated in "Stronger partnerships for better outcomes: a protocol for market relations".

Workshop 4 Facilitator's Notes

People who use services taking the lead in shaping commissioning – Planning end of life care

Group size: 18 participants

Resources:

- Room large enough to set out a meeting for 9 people, with space around the meeting for chairs for an additional 9 participants.
- Scenario background information (Resource 1).
- Summary of scenario background information written on flip chart paper (Resource 1).
- Activity cards x 2 for each role (Resource 2).
- Newspaper Article (Resource 3).
- Flip chart and marker pens.

Learning aims to explore:

- Responding to feedback from people using services and carers.
- Working together on an equal footing on decisions about how public money will be allocated and spent.
- Promoting high quality despite financial constraints, i.e. how to use a smaller pot of money better.
- Commissioning quality of response across a range of settings.

Scenario outline:

This scenario is focussed on responding to feedback from people who use services and carers on end of life care, both from a specific initiative to promote the commissioning of excellent end of life care and from their general experience.

This is a workshop session to address the requirement from the Health and Wellbeing Board. It brings together key stakeholders to discuss how to implement excellent commissioning of end of life care, within the resources available, including both the choice and contract issues identified in the residential sector, and the community issues raised by Gillian's case and others.

This discussion should lead to agreement being reached on how to reflect end of life care in contracts, both for residential and community services as the basis for the strategy development. It should cover the common issues for both settings and key priorities for action.

How to run the workshop

Total time: 3 hours

TIME	ACTIVITY	METHOD	RESOURCES
15 minutes	Welcome, introductions, aims and scenario	Ask participants to introduce themselves very briefly stating their name, role and one hope for the session. State the learning aims and scenario outline for the session as shown above.	
10 minutes	Setting the scene	Read the background information aloud to the group. Have the bullet points written on a flipchart and displayed so that the key points can be seen by the group as you read the information and throughout the session.	Background information Bullet points written on flipchart (Resource 1) Copies of newspaper article for each participant
15 mins	Newspaper article	Give participants copies of the newspaper article. Ask them to read it and then to work in fours or fives to discuss this and the background information. The key points from each group can be noted on flipchart during the discussion and placed on the wall for display afterwards.	Copies of newspaper article (Resource 3) Flipchart paper and marker pen for each group
5 minutes	Activity Cards	Distribute two sets of the activity cards so that each participant is given an activity card and a copy of the Meeting Agenda. The activity cards for people using services should be given to three pairs to ensure that they are fully represented at the meeting. Be mindful of the confidence and comfort levels of your participants when allocating activity cards. Some participants may not feel that they have the experience and knowledge required to take part in the activity if allocated a role other than their own.	Activity cards (Resource 2) x 2 (+ 2 extra sets of the activity cards for people using services)
15 minutes	Meeting preparation in pairs	Participants should find the other person in the group who has the same activity card as themselves. The pairs should then work together for ten minutes to discuss what they, as the person described on the card, would like to get out of the meeting. They should note	Flipchart and marker pens

TIME	ACTIVITY	METHOD	RESOURCES
		points that they would like to raise and questions they would like to ask. Each pair should then be asked for suggestions for the agenda and an agenda should be quickly agreed and written on a flipchart for all to see. Participants should decide which person in each pair will take part in the meeting and who will support from the side (become the coach and supporter – see The Meeting below).	
85 minutes	The Meeting	The chairperson (as stated on activity card) chairs the meeting to the given meeting agenda. As noted on the chairperson's activity card, it should be made clear to all participants that the chairperson should aim to ensure that the group achieve a consensus or agreement by the end of the meeting, and that all participants are responsible for contributing to this aim. One participant from each of the pairs takes part in the main meeting. The other person with the same activity card sits or stands behind them and acts as a coach and supporter to expand upon or reveal feelings not expressed by the meeting attendee. (If appropriate and where there is sufficient time the meeting can be stopped briefly at various intervals so that one or more participants can be interviewed.)	
10 minutes	Feedback in pairs	The participants with the same activity cards work together for a second time to discuss how the meeting went from their perspective. Did they raise all points and ask all questions as planned? What were they happy with and were there any frustrations? Would they do anything differently next time?	
40 minutes	Whole group feedback and next steps	Ask for feedback from the whole group and note useful points on flip chart. Ask participants what their next steps might be in terms of taking their learning forward.	Flip chart and markers

RESOURCE 1

Background information

(To be read aloud to all participants. Bullet points can be written onto a flipchart for display during the reading and throughout the activity).

Care home providers, people who use services and their relatives had been working on finding out and respecting people's wishes regarding the end of their lives.

This included:

- Ensuring there was a discussion with residents and/ or their families about their wishes about end of life care.
- Enabling people to remain in their homes ie the residential home at the end of their lives rather than being admitted to hospital.
- The use of advanced directives about end of life care.
- The need for a shared understanding between the various agencies who might become involved in a health crisis about how the service user's wishes are known and respected.

As a result of this work, people who use services and their families have asked the local authority and NHS to build expectations about end of life care into contracts with care providers.

Alongside this, the local media have recently covered the case of Gillian as part of a "Facing up to Cancer" series, and have highlighted some of the difficulties for local people in getting access to sufficient advice and support in terminal illness. She thinks that she would prefer to die at home or nearby in a community setting but does not know who to have that conversation with as she currently sees an oncologist, Macmillan nurse and her GP, and no-one has discussed it with her. A newspaper article about this is attached.

As a result of these two issues and the national expectations about End of Life Care, the Health and Wellbeing Board, including the emerging Clinical Commissioning Group, has asked for a strategy proposal on End of Life Care that picks up both on the request from the residential care project and the issues about community support.

South Wessex is a largely rural county with a population of 350,000 where health and social care monies are centred largely on caring for an aging population. Resources for younger people with illness or physical disability are limited. It is a relatively healthy county with average life expectancy higher than England as a whole. However, there are some areas of deprivation where there are significant health and social care issues.

The county is attractive to live in; is overall highly achieving in education and there is a demand for holistic high quality services for end of life care, more than has been specifically allocated in commissioning budgets. The population has a 23.4% rate of growth and is much higher than the national growth rate of 11.8% and the regional growth rate of 13.3%. The majority of this growth is within the older age groups of the population and it is recognised that this will have a significant impact on the provision of services, particularly for older people.

There are two large hospital trusts in the county and a joint Local Authority /NHS community end of life care team, but the latter is concentrated only in the more densely populated area of the one main city in the neighbouring county.

The End of Life Intelligence Network states that in the county, compared with the average for England, deaths in hospital are above average, deaths in care homes above average, deaths at home below average, and deaths in hospices below average and a significant outlier. There is one hospice only in neighbouring inner city area.

The local authority has already made cuts to grant funded initiatives and the local NHS has planned to make savings of £20m over the next year by ensuring efficiencies in end of life care, dementia, urgent care and management of long term conditions. A new 30-bed community hospital is due to open (in a few months time) in the centre of the county and the 12 beds within each of the 2 other community hospitals decommissioned. This is largely to cater for the anticipated older population. The current total spend on end of life care is unknown. From surveys and anecdotal evidence the Local Authority and NHS recognises that end of life is an area where people who use services seem to have variable experiences.

Bullet Points for Display

- End of life care:
  - Discussion with residents and families
  - Enabling people to remain in their homes
  - Use of advanced directives
  - Shared understanding between agencies.
- People who use services want expectations to be built into contracts with providers.
- The press have highlighted the difficulty of access to advice and support.
- The Health and Wellbeing Board have asked for a strategy proposal.
- Largely rural population of 350,000.
- Monies centred on caring for an ageing population, which is growing.
- Deaths in hospitals and care homes are above average.
- Deaths in hospices and at home are below average.

- There is one hospice in neighbouring inner city area.
- The LA has made cuts and the NHS plan savings of £20m over next year.
- A new community hospital is due to open in a few months time.
- The current total spend on end of life care is unknown.

RESOURCE 2

Activity Cards

JOINT COMMISSIONING MANAGER FOR LEARNING DISABILITIES

(YOU WILL BE CHAIRING THE MEETING – It is your role to ensure that the group come to some kind of consensus or agreement by the end of the meeting).

You are aware that end of life care has a raft of policy initiatives to support its implementation centred on the Department of Health End of Life Care Strategy and the National Institute for Clinical Excellence end of life quality standard which was published in November 2011. You and the Local Authority Commissioner are jointly responsible for the report back to the Health and Wellbeing Board, so need to identify the highest priorities that will affordably support best practice both in community and residential settings.

You are already involved in planning to deliver this year's NHS Operating Framework directives for Primary Care Trusts to deliver improved services for End of Life which stress:

- Promoting high quality care for all adults at the end of life
- Working to offer patients the choice of where to be cared for as they approach the end of life, and where to die, regardless of their condition
- Ensuring that staff are trained for this
- Commissioning the care people want
- Coordinating care across sectors
- Ensuring that adequate 24/7 community services are available in their locality.

Current performance is below average and you will be looking for realistic and affordable priority actions to start the change process. You need the Clinical Commissioning Group representative to be on your side, and he has no experience of commissioning large scale change.

RESIDENTIAL CARE PROVIDER

You took part in the research work and saw the positive results for residents and their families, and also the positive impact on staff of being able to plan with residents and feel confident about their wishes.

You are keen to see the approach further developed, but it does take time and you and your fellow providers are under significant cost pressures now and in the future. You support the general aims of the proposed strategy but will want to be sure the resources are there to support it.

You will also want to know that all agencies will be involved in delivering it as you have had difficulties getting adequate GP support at times.

PEOPLE USING RESIDENTIAL SERVICES AND FAMILY MEMBERS

You took part in the research work and are keen to ensure that the opportunities you had through that work to consider all the options open to you and confirm your preferred arrangements for the end of your or your family member's life are available to all residents of care and nursing homes. You had experience of the deaths of a spouse or friend not being well handled and your anxieties have been relieved by the implementation of best practice in your / your relative's care home.

You will be stressing the need for GPs and the Ambulance Service to be involved in future implementation so that they understand the importance of the new arrangements to their patients. You are also aware that some older people die in care homes who might prefer to die at home.

SPECIALIST PALLIATIVE CARE PROVIDER

In the county there is a specialist community palliative care service provided by MacMillan Nurses and Marie Curie, although referring patients like Gillian into community beds is often subject to a bed being available. There is one hospice in the neighbouring city so accessing beds and day services are subject to availability. Macmillan work in partnership with local consultants from each of the two hospitals. You want to see the provision of end of life care services much more evenly spread across the county and challenge the lack of information about investment on these services and therefore their vulnerability to "invisible" cuts. You welcome the residential care project and want to see much more consistent standards of training and awareness of end of life care in the sector.

As well as your own professional knowledge and promotion of effective community support to people with terminal illness, your organisation has had contact with Gillian, so know she wants to influence the provision of the right range of services in the community. As well as the points in the newspaper article, she had experience of joining a local cancer support group thinking it would be a good forum to think about her choices regarding her place of death. She discovered that many others in the group did not have the same supportive network of friends as she had and were quite isolated. They used the group for more social purposes and current concerns and talking about death itself seemed to be too scary.

COMMISSIONER 2 – LOCAL AUTHORITY

You are aware that end of life care has a raft of policy initiatives to support its implementation centred on the Department of Health End of Life Care Strategy and the National Institute for Clinical Excellence end of life quality standard which was published in November 2011. You and the NHS Commissioner are jointly responsible for the report back to the Health and Wellbeing Board, so need to identify the highest priorities that will affordably support best practice both in community and residential settings.

You are pleased that the issue of end of life care has been raised by providers and people who use services, as you are aware of variable standards across the sector. However, you are concerned that at the moment it tends to be the more expensive providers that are offering the excellence aspired to and you need to find a way for that practice to become more generally applied without additional costs.

HEALTH AND WELLBEING BOARD MEMBER – A GP REPRESENTING THE EMERGING CLINICAL COMMISSIONING GROUP (CCG)

You are present to have some oversight of the strategy work. You are an enthusiastic participant in the development of the CCG and are enjoying your new role in it and on the Health and Wellbeing Board. You are not an expert in palliative care, but have plenty of practical experience of managing end of life care in a range of circumstances. You have no experience of commissioning large scale change and some aspects of this discussion will feel very unfamiliar to you.

Think Local, Act Personal is a sector-wide commitment to moving forward with personalisation and community-based support, endorsed by organisations comprising representatives from across the social care sector including local government, health, private, independent and community organisations. For a full list of partners visit www.thinklocalactpersonal.org.uk