DEVELOPMENT

Using care profiles to commission end-of-life services

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Aim: In early 2010, Liverpool Primary Care Trust (PCT) undertook a project to establish whether a care profiles methodology could be used to commission end-of-life (EoL) services. The Department of Health (DH) originally used them for a variety of services in the 1990s. The project sought to adapt the original care profiles structure for commissioning purposes, and produce a series of care profiles that would cover the full EoL care pathway. **Background:** The DH required PCTs in England to undertake local reviews of EoL services ahead of its publication of the National EoL Strategy in 2008. Related cross-sector work in Liverpool highlighted the need for a means of specifically commissioning EoL services. It was contended that care profiles offered the opportunity to set service requirements in respect of skill mix, delivery, quality and outcomes for each stage of the EoL pathway, which could be costed subsequently. **Methods:** An iterative approach was adopted involving workshops and consensus, based on action learning events, which incorporated and adapted past approaches for developing care profiles. Four half-day workshops were held, each targeting one EoL stage, with the outputs evaluated by an external reference group. A full cross-section of commissioning, provider and service user interests were involved. **Findings:** The project was successful, with its recommendations subsequently used to commission EoL services across Liverpool. It was concluded that the basic service requirements for EoL care are the same, irrespective of the related disease. The strength of care profiles is their simplicity and flexibility. They complement and augment integrated care pathways, and by requiring the recording of outcomes throughout the care process, they aid quality and audit processes. They should be transferable to other conditions, with benchmarking enabling improved efficiency. They represent the type of clinically relevant and detailed vehicle essential for clinical commissioning groups.

Key words: care profiles; commissioning; end of life; integrated care pathways; methods; outcomes

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Introduction

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The Department of Health (DH, 2006) required Primary Care Trusts (PCTs) in England to undertake local reviews of end-of-life (EoL) services

during 2007–2008, ahead of the publication of its National EoL Strategy (DH, 2008). Local work within Liverpool PCT (2008) recommended that it should 'specifically and comprehensively commission EoL services'. This reflected the fact that EoL services were usually one small component of a wide range of services commissioned and they were rarely the focus of attention. The question was how could this recommendation be met? Tebbitt (2009) demonstrated the need for the different stages of the Palliative Care/EoL process to be quantified, together with the associated outcomes. It was contended that a suitable vehicle for describing and quantifying the different stages of the EoL care pathway (see the section 'EoL care pathway stages'), and making explicit the related outcomes, was already in existence, but had not been used within the National Health Services (NHS) for some time. This involved 'Care Profiles', which had been used and developed by the NHS Executive Information Group in the 1990s (Gandy *et al.*, 1998). They had been used to specify cancer services within the community, amongst others, and were considered an appropriate means of constructing related contracts (NHS Executive Information Group, 1997; Gandy *et al.*, 1998). This paper describes how Liverpool PCT developed care profiles for commissioning EoL services over the period January–March 2010, and how the approach can be used more widely.

Care profiles

Definition and history

Care profiles make explicit the expected service offered to a patient group to meet their needs. They are defined as 'a strategic outline of the health and social care to be provided to meet the health needs of a patient, or group of patients, to achieve an expected outcome to an explicit standard of quality' (Gandy *et al.*, 1998).

A care profile will set out the expected resource input, quality standards and outcomes in a format that supports monitoring and evaluation processes. It describes patterns of care or treatment, and therefore helps clarify the relationship between clinical practice and resource use. They are dynamic and within the monitoring process will be maintained and updated when new evidence is available. They are designed to reflect

or guide patterns of care but not dictate them (Gandy *et al.*, 1998).

The concept was first mentioned in 'Describing Community Care' (King, 1993) and was considered, along with care aims and health needs groups, as a means of describing care provided in a community setting, which would support its planning, delivery and monitoring. Three community Trusts (Bradford, Chester & Halton, and South Warwickshire) then produced initial care profiles, identifying them as important clinical tools that assisted clinicians and clinical managers in their day-to-day business (Gandy *et al.*, 1998).

The common framework has consistent constituent elements, which facilitate comparisons, although providing sufficient flexibility to accommodate local variations in content. Making such comparisons is useful, both internally and externally, as it enables current practices to be reviewed and improved upon where appropriate. Individual care plans are developed for patients from within the framework (Gandy *et al.*, 1998).

It is important to emphasise that care profiles are different from integrated care pathways (ICPs). The latter contain the actual clinical care provided to an individual patient within a clinical care category or treatment plan. The fact that an ICP forms the individual's patient record containing all professional input to the care given, distinguishes it from a care profile. The two are complementary to one another (Gandy *et al.*, 1998).

Care profiles became unfashionable in the late 1990s, when the DH focused on the development of ICPs. Despite very positive responses to a national enabling project for cancer care profiles (NHS Executive National Casemix Office, 1997), funding was not forthcoming.

Structure

The generic care profile template enables set information to be recorded as to what service 'an average patient' would be expected to receive at a particular stage of a given disease process. The template involves numbered sections covering the range of information required (Gandy *et al.*, 1998):

1. Health needs group (eg, Neoplasm)
2. Care aim
3. Expected/measurable outcome

4. Plan/protocol
   - Skill mix
   - Frequency
   - Duration
   - Location
   - Outcome
5. Consumables
6. Costs
7. Limiting factors
8. Quality standards.

The care aim describes the overall aim and purpose of a period of care. It does not refer to specific planning goals or individual patient/client contacts, but to the main reason why care is being delivered. Eight care aims descriptions were developed in the past work: anticipatory, curative, enabling, health assessment, maintenance care, palliative and bereavement care, rehabilitation and supportive care (Gandy *et al.*, 1998).

Tailoring care profiles for commissioning purposes

The proposition of developing care profiles to commission EoL services was agreed in principle by Liverpool PCT and relevant partner organisations. One issue to be addressed was that historically care profiles had been developed within community organisations on a uni-disciplinary basis. For example, what services community nurses deliver at each cancer stage (Gandy *et al.*, 1998). Commissioning, by definition, is multi-disciplinary, covering all service requirements across all professions and service provider organisations.

A workshop was held by the PCT at the end of 2008 to validate how to apply the approach for commissioning purposes (Liverpool PCT, 2009). Twenty-eight professionals from across the PCT and local professional EoL networks, including patient representatives, concluded that care profiles should be structured on the basis of EoL Stage, followed (in order) by professional group, diagnostic group and provider.

Consequently, care profiles enable commissioners to specify: what service(s) a patient can expect to receive, at what stage in the disease process, with what resources and with what expected outcomes.

The details should reflect what services *should* be delivered, rather than the actual current practice.

The view was taken that EoL care profiles should focus on services delivered primarily in a community setting, given that this was where care profiles had been successfully applied in the past. Because of limited resources, support given by Specialist Palliative Care Teams in hospitals could not be accommodated within the work, and were therefore excluded. This would need to be the subject of future work.

The 'building block' approach of care profiles needed to be taken into account (Gandy *et al.*, 1998). This acknowledges that an individual patient can be in receipt of care for different symptoms/conditions concurrently. For example, many EoL patients will have one of cancer, chronic obstructive pulmonary disease or dementia. It is impractical to try and design single care profiles to embrace all potential permutations and combinations. Therefore, a comprehensive care profile approach to commissioning would mean an individual patient would receive multiple, complementary care profiles, each designed to deal with specific conditions or clinical problems. In practice, clinicians would tailor combinations of profiles according to patients' needs and circumstances (Gandy *et al.*, 1998).

Although the care profile structure includes 'costing', this was excluded from the developmental work, which was to determine agreed types and levels of EoL care. Any costing would be included in the resultant commissioning process.

EoL care pathway stages

There are several published pathways relating to EoL services. Some cover the whole of the period from diagnosis to support for the bereaved, whereas others focus on the last days of life. The latter include the Liverpool Care Pathway for the Dying Patient (Marie Curie Palliative Care Institute Liverpool, 2010), which is recommended by the DH (2008).

One comprehensive EoL care pathway is the Gold Standards Framework (GSF, 2010), which uses needs-based coding – using the question '*Would you be surprised if the patient died within the next 12 months?*' to predict main areas of need and support required:

A. Blue: stable – year plus prognosis
B. Green: unstable/advanced disease – months prognosis
C. Yellow: deteriorating – weeks prognosis

D. Red: final days/terminal care – days prognosis
Navy: 'after care'.

Another comprehensive EoL care pathway is
the North West EoL Care Model (Merseyside
and Cheshire Cancer Network, 2010), which
divides the process slightly differently:

1. Advancing disease – timeframe one year or more
2. Increasing decline – timeframe six months
(approximate)
3. Last days of life – timeframe last few days
4. First days after death – timeframe first few days
5. Bereavement – timeframe one year.

Work had already progressed within Liverpool
to design and construct a local EoL supportive
care register (SCR), which would record the EoL
stage relevant to each patient (Gandy *et al.*, 2010a).
This had included seeking the establishment of Read
codes that could specify stages of the EoL care
pathway, taking into account the GSF and North
West approaches. This resulted in four specific stages
as follows (Gandy *et al.*, 2010a):

- Stage A – Supportive care (6–12 months ahead
of projected death)
- Stage B – Palliative care (one to six months
ahead of projected death)
- Stage C – Anticipatory palliative care (final
days – one month)
- Stage D – Final days pathway.

Structure/design of project

An iterative approach was adopted involving
workshops and consensus, based on action learning
events (Brockbank and McGill, 2006), which incor-
porated and adapted past qualitative approaches for
developing care profiles (Gandy *et al.*, 1998) for
each specified stage, which formed a case study.

Aims

The primary aim was to produce a series of care
profiles that would cover the full EoL care path-
way. These needed to be consistent with defini-
tions within the local EoL SCR, used to record
the current EoL stage relevant to each patient, as
set out above (Gandy *et al.*, 2010a). (The only
slight adjustment was that any care profile for
Stage D should include post-death/bereavement

support to relatives and carers, given that this was
inter-twined with the direct care given to the
patient.)

The project aimed to identify any other relevant
EoL care support required for patients with specific
diseases, or conditions, such as dementia. (As
described above, the disease-specific treatment such
patients required would be covered by separate
care profiles, outside the scope of the project.)

The project design aimed to maximise owner-
ship amongst local EoL providers.

Participants

Participants included representatives of: clin-
icians and managers at acute, mental health and
community trusts; ambulance services; care homes;
commissioning; community nursing; General Prac-
titioners (GPs); hospices; information technology;
out-of-hours services; patients and carers; personal
social services; specialist palliative care teams; and
therapy professionals.

These were recruited from across the PCT and
local professional EoL networks. Anyone who
was unable to attend the project workshops, was
able to receive and comment on the draft outputs
as part of an external reference group.

Methods

Four half-day workshops were held, each tar-
geted at one stage and forming a case study. They
addressed the four stages in reverse order, that is,
the first workshop looked at Stage D. This
enabled participants to get used to the concept of
care profiles in the context of services that were
most clearly defined.

To make best use of time, a draft care profile
was prepared in advance of each workshop, using
the above-set structure, with numbered sections.
Only section 4 (Plan/protocol) was subdivided to
reflect the separate identified components of care
for that particular stage. The types of information
required can be seen in Figures 1 and 2.

Each draft care profile was prepared by a
senior community nurse involved in EoL services,
supported by the project facilitator. It was
deemed easier for workshop participants to con-
sider a well-prepared draft, and then suggest
amendments or make criticisms, rather than pro-
duce one from scratch within the workshop itself.

1	% in group	Core Service Group(s)	End of Life – Stage D: Final Days Pathway (plus post-death bereavement support up to time of funeral)				
2		Care Aim	Provide a consistently high standard of End of Life care in the last days of life				
3		Measurable outcomes	**Patient specific:** • Death in place of choice (60% achieved) • Symptoms managed and controlled (95% symptoms managed)				
4		Plan/Protocol	Skill Mix	Frequency	Duration	Location	Outcomes/ Outputs
….	….	….	….	….	….	….	….
4.2H	100%	Assessment: Home setting	1 x Band 6 DN 1 x Band 5 DN	Once	Range 1 – 2hrs Mean 1 hr 20min	Home	Goals assessed & Care plan identified Related medicines received Initial care delivered & Symptoms managed Variances recorded with outcomes Information provided Equipment/sundries identified & received
			GP**	Once	30min		
			** GP face-to-face visit required at some point as GP normally certifies death certificate, which requires GP seeing patient within the 2 weeks prior to death				
….	….	….	….	….	….	….	….
4.3H		Ongoing Assessment and Treatment: Home setting					
	100%	Morning	1 x Band 6 DN Plus 1 x Band 3	Once daily	Range 1hr 30min–2hr Mean 1hr 45min	Home	
		Afternoon	1 x Band 5 DN plus 1 x Band 3	Once daily	Range 30-45 min Mean 35 min	Home	LCP completed at each visit Goals reassessed Care plan delivered Symptoms managed Variances recorded with outcomes Carer/ families reassured / information supplied Patient supported Care provided in place of choice
		Evening	1 x Band 5 DN plus 1 x Band 3	Once daily	Range 30-45 min Mean 35 min	Home	
	35% Day 55% Night & 10% 24/7	Support worker depending upon need	Support worker 1x Band 3	As required	Range 1-24hr	Home	
	40%	CSPN (Specialist or Matron) - accompanying DN when DN on (above) scheduled visit	1x Band 7 DN	Once over pathway	Range 30–45min Mean 35 min	Home	
….	….	….	….		….		….
5		Consumables	• Syringe drivers • Giving sets • Needles/Sharps boxes • Intravenous/Subcutaneous fluids • Key safes (for Homes)			Nebuliser and oxygen products Continence products Information leaflets Other equipment provided by Community Equipment Stores	
6		Costs	Not Applicable for purposes of Project				
7		Limiting factors	• Non-acceptance of service. • Inability to maintain patient at home. • Inappropriate admission to hospital • Carer breakdown			Access to broader support team/MDT – whole team approach Capacity/Resources (staff and skills) IT access	
8		Quality Standards	• NHS Liverpool Community Health agreed standards • National end of life care quality markers • NICE guidance on Supportive & Palliative Care			The timing of the delivery of different components of service will be in line with set standards, e.g. wait for delivery of: 1 Equipment max.4hours 9-5pm Mon-Fri. 2 Emergency drugs max. receipt within 1hour of need being identified, 24/7. 3 NICE Guidance on Supportive/Palliative Care 4 NMC & all relevant professional bodies	
Key:	CSPN = Community Specialist Palliative Care Nurse; DN = District Nurse; GP = General Practitioner; LCP = Liverpool Care Pathway; MDT = Multi-disciplinary Team; NICE = National Institute for Health & Clinical Excellence; NMC = Nursing & Midwifery Council						

Figure 1   Care profile for end of life Stage D: final days pathway – edited to show only two components of treatment (4.2H and 4.3H)

The draft care profile was presented in outline to the full workshop, with comments and queries invited. The opportunity was given for amendments to the main plan/protocol components. Any special groups of patients requiring ancillary services to be specified, could also be identified.

The workshop then broke into small, multi-interest groups to evaluate the profile details and suggest amendments. The responses from each group were collated by their respective facilitators, with the main points and issues fed back to the whole workshop for general debate and decision wherever possible.

Following the workshop, a second draft version of the care profile was produced, taking into account the agreed amendments and improvements. This was circulated to the external reference group for further comment and validation. Responses

Stage B		Stage C		Stage D	
4.1	Decision that patient has entered stage B or the last 6 months of life (as part of GSF meeting)	4.1	Decision that patient has entered stage C or last month of life	4.1	Decision to commence LCP
4.2H	Initial Assessment: Home setting	4.2	Fast – Track Continuing Health Care: Consideration/ Application	4.2H	Assessment: Home setting
4.2C	Initial Assessment: Care Home setting	4.3H	Initial Assessment Home Setting (New patients only)	4.2C	Assessment: Care Home setting
4.3H	Ongoing assessment and treatment: Home Setting	4.3C	Initial Assessment Care Home setting (New patients only)	4.3H	Ongoing Assessment and Treatment: Home setting
4.3C	Ongoing assessment and treatment: Care Home setting	4.4	Range of care provided according to level of dependency (inc. assistance with normal activities of daily living)	4.3C	Ongoing Assessment and Treatment: Care Home setting
4.4	Patient receiving Day Therapy from Hospice	4.4H	Ongoing assessment and treatment: Home setting	4.4	External & Internal Communication (After commencement and death)
4.5	Palliative care consultant advice/outreach*	4.4C	Ongoing assessment and treatment: Care Home setting	4.5H	Death: Home setting
4.6	Patient undergoing treatment from other General Palliative Care Services	4.5	Re-priming Syringe Driver in Care Home setting	4.5C	Death: Care Home setting
4.7	Patient undergoing treatment from other Specialist Palliative Care Services	4.6	External and Internal Communication	4.6	Days after death: Bereavement visit
4.8	Apply for CHC funding (Nurse-led MDT discussion)			4.7	Death certified
4.9	Social care needs identified			4.8	Collection of equipment
4.10	External and Internal Communication			4.9	LCP audit
Key:	GSF = Gold Standards Framework; CHC = Continuing Health Care; LCP = Liverpool Care Pathway; MDT = Multidisciplinary Team;				

* Palliative care consultant advice/ outreach is only required for a projected 5% of home patients during Stage B. Figure 3 provides details of the agreed case vignette that would be applied.

Figure 2 Agreed components for Section 4 (Plan/protocol) for each of the End of Life Care Profiles for Stages B, C and D

were fed into the subsequent workshop, where one facilitated group considered them before confirming the definitive version of the care profile, reporting its findings to the whole workshop.

The revised structure and scope of the care profiles (see section 'Care profiles') meant that the project was dealing with some new ground: some anticipated issues did not materialise and some unforeseen issues arose. Wherever this occurred, there was an open discussion and debate, with a collective decision on the most appropriate solution.

Ethical considerations

As the project was deemed a service development and did not include patients or patient data, local research ethics approval was not required as per national guidance (NRES, 2009).

Results

Participation

Forty-three people participated in the workshops from across sectors and interests, although not all of them attended each and every workshop.

Development of care profiles structure and content

As described above, some issues arose, which had a material impact on the structure and content of the care profiles. First, a distinction was required to be made between the support to EoL patients in their own home or a residential home compared with patients in a nursing care home for particular components of treatment, because the latter has qualified nurses on site. Two types of entry were made in such cases: the letter 'H' depicts requirements for the former, with reference made to 'Home setting'; and the letter 'C' depicts requirements for the latter, with reference made to 'Care home setting'.

Some types of care needed to be available for some EoL patients rather than all EoL patients, for example, specialist nurse input to control complex symptoms. It was agreed that the whole of such an intervention should be included in the care profile; however, a percentage figure should also be recorded to indicate the proportion of EoL patients expected to receive it. The percentages were 'best estimates' from the workshops, although in some cases specific figures could not be agreed. These percentages were considered indicative, rather than definitive – the PCT and its partners needed to establish actual percentages from relevant data following the project.

It followed that there was sometimes a requirement to delineate when such interventions were or were not appropriate. There were two options. The first was to try and create specific rules; however, this was clearly impractical, and arguably inappropriate, given each patient's circumstances were very individual. The alternative was to prepare case vignettes illustrating circumstances where an intervention was appropriate. Given the fact that clinical judgement was always relevant, case vignettes were agreed appropriate and sufficient.

Bereavement support can be required for long periods. Therefore, the post-death/bereavement

support included in the Stage D profile was limited to that provided up to and including the funeral.

The role of the GP in relation to EoL care profiles was discussed. This required wider debate and agreement with representatives not present at the workshops, as it linked in with GP contract matters and negotiations. It was agreed to progress this outside the project.

Special groups

It was originally anticipated that there would be some specific EoL care support required for patients with specific diseases, or conditions, such as dementia. The clear advice from the project was that this was not the case – all types of EoL patients had similar requirements in terms of EoL care. The treatment for their condition was obviously linked, but was separate from this and outside the project remit.

EoL care profiles

The decision was taken not to prepare a care profile for Stage A, because a patient will only be entered on the EoL SCR if a clinician answers '*No*' to the surprise question (GSF, 2010). Generally, this means primary care professionals maintain a watching brief on a patient (Gandy *et al.*, 2010a). When and if their condition deteriorates and their care needs increase, it will be necessary to ensure their requirements are in place for when they enter Stage B. Any information and documentation discussed with the patient during Stage A should be recorded and reviewed at the monthly GSF meeting where patients on the SCR are reviewed.

Specific care profiles were determined for each of Stages B, C and D. These reflected the increasing support required as patients' condition deteriorates. A separate 'Uncertainty' care profile was produced to cover what happens when a patient/carer is uncertain of what to do, when they are on their own and a problem or crisis arises.

Figure 1 sets out the structure and content of the agreed care profile for EoL Stage D (Final days pathway). It uses the established numbered sections described above (Gandy *et al.*, 1998), but for reasons of space, the full details are shown for only two of section 4's components (4.2H and 4.3H). Figure 2 lists all of the components for each of Stages B, C and D. Within section 4 of an

- 65 year old gentleman with advanced motor neurone disease and recently diagnosed prostate cancer.

- Recent admission to hospital for respiratory assessment. Did not tolerate cough assist.

- Now multiple symptoms: chest secretions, difficulties to expectorate, frequent panic attacks, dyspnoea, minimal oral intake, struggling to take oral medication, intense night sweats with hormone manipulation for prostate cancer, musculoskeletal pain, not wanting information, wife concerned that patient nearing end of life and scared to ask questions in front of patient, PPC home.

- Community matron, community physiotherapy, speech and language therapy, GP involved.

- Patient too frail to attend neurology clinic.

- Domiciliary visit by pall care consultant jointly with community pall care nurse specialist.

- Intervention: discussion regarding feeding. Established that patient to continue with oral diet, too frail to consider PEG/RIG, oral medication rationalised to essential medication, hormone injection stopped, medication for control of chest secretions and dyspnoea instigated, EOL care drugs discussed with partner and appropriate prescribing instigated, DNAR discussed, documented and communicated to all relevant agencies including ambulance control.

- Follow up by CNS community palliative care

Points to highlight through this case:

- Motor neurone disease patients are often complex and commonly need face to face input by palliative medicine specialists to avoid unnecessary admissions

- Assessment by consultant jointly with health care professionals already involved to avoid need of further home visit if possible

Figure 3   Case vignette for domiciliary visit from Palliative Medicine Consultant

individual care profile, components are assigned sequential identifier numbers, always starting with 4.1. However, there is no link between components that might have the same identifier number in the different care profiles.

Where a component of treatment can be delivered either in a patient's own home/residential home or in a nursing care home, then the same component number is retained, but with letters 'H' and 'C' assigned, respectively. The 'percentage in group' figure clarifies the degree to which each component applies to all patients.

It can be seen that profiles enable both over-arching measurable outcomes for the whole of the stage, and specific outcomes and outputs for each component of the treatment delivered.

Where 'percentage in group' is less than 100%, case vignettes illustrate when that component of treatment is applicable, as described above. Figure 3 provides an example of a case vignette, which

relates to component 4.5 of the care profile for Stage B. Multiple vignettes were prepared for a given component of care, if this helped demonstrate the range of circumstances that could apply.

Care profiles itemise all the different aspects of treatment: the grade, type and number of staff involved; the frequency; the time involved (range and mean); and the location. Certainly, the care delivered to an individual patient will reflect his or her specific needs, which may be much greater or much less than that stated, according to circumstances; the care profile presents the agreed level of care pertaining to the most typical patients.

The duration of care recorded is the time taken to deliver the care itself and the associated *in situ* actions. It does not include travel time, and similar. This is deliberate because, for example, the average travel time between visits to patients' homes is likely to be greater in rural compared with urban environments.

The inclusion of GP visits in Stage D (see Figure 1) was to highlight the benefit of regular GP visits to patients in their final days, thereby addressing the requirements of death certification. It does not conflict with what is stated above in relation to GPs.

Standards to be applied across care profiles

Certain standards were applicable to all three stages, with access to relevant services being a priority. These included: 24/7 telephone specialist palliative care advice for clinicians working in all locations; single point of contact for patients/carers for support/advice; rapid response assessment/treatment service; and specialist multi-professional, multi-agency community palliative care service (compliant with NICE (2010) Improving Outcomes Guidance Supportive & Palliative Care).

In addition, a number of common outcome measures were relevant throughout the pathway: the EoL SCR should be used; anticipatory prescribing should increase by 10% (against baseline); avoidable hospital admissions should reduce by 10% (by 2012); and there should be a good carer experience (measured by carer experience audits).

All assessments should include physical, psychological, emotional and spiritual needs.

Some mental health issues

Although care profile requirements were agreed to be no different for people with dementia (see section 'Care profiles'), it was decided it was appropriate for Advanced Care Planning questions and issues to be discussed when the person was still capable, which could be years ahead of death. It was important to establish the practicalities, but this was outside the project's remit.

One concern involved a small but important group relating to mental health/learning disabilities and palliative care. Patients' communication could sometimes present problems, and often professionals from one side might diagnose a problem as being more relevant to the other professional group. Further work is needed to address this issue.

Discussion

Outcome of project

The project was considered successful, with its recommendations endorsed by the PCT as a basis for commissioning EoL services across Liverpool. It brought together personnel from across all sectors and interests to transparently develop a view of what services patients can expect to receive at the different stages of the EoL care pathway (Gandy *et al.*, 2010a). This cross-sector approach ensured an appropriate balance in the resultant recommendations. One frequent comment was how good it was for the personnel to actually meet with one another to discuss common issues.

The care profiles represent a clear statement, which underpin the commissioning of EoL services and the associated negotiations. They can also be used to inform patients and carers about what services to expect and facilitate audit and training. At the end of the project the PCT integrated the profiles within its formal EoL commissioning process. This included prioritising areas where material improvements could be achieved, having regard for available resources, and the range of existing service providers and agreements.

The flexibility within the project was important. This linked to a preparedness to accept that creating care profiles for commissioning purposes represented a significant development from the original uni-disciplinary approach. Hence, there was a reasonable probability that unanticipated issues would arise, as was the case, and through collective evaluation and debate, solutions were identified (see section 'Results'). It is recognised that further enhancements of the care profile structure will be required in the future to respond to evolving requirements and evaluation of their usefulness in practice once implemented.

The template is generic and EoL care was the first clinical area to which it was applied in the context of commissioning services locally. The 'building block' approach meant that the process served to maximise the local ownership of, and confidence in, the EoL results. The conclusion that there were no special groups and all types of EoL patients had similar requirements in terms of EoL care is particularly important. It reflects the findings of Gandy *et al.* (1998) that care for cancer services was essentially generic in nature, and requirements did not really vary with the site of the cancer.

Gandy *et al.* (2010b; 2010c) highlighted the economic case for improving the quality of EoL support in nursing care homes through training. The transparency of care profiles can enable

commissioners to consider whether there are differences in the local support required for EoL patients who are in nursing care homes that have had training in EoL care and those that have not. This would then inform the cost-benefits of funding the rolling out of EoL training across all local nursing care homes.

Importantly, the care profiles approach for EoL care builds on and serves to emphasise the need for a clear decision that a patient has moved from one stage to the next, thereby ensuring proper co-ordination of care and appropriate communication to all relevant parties (Gandy and Murphy, 1997; Gandy *et al*., 2010a).

Benefits of care profile approach

The benefit of a care profiles approach is that it enables commissioners to break down an ICP into its constituent parts and then identify what services and resources are required for each. Through a process of scrutiny and debate about whether the services are being delivered in the right way and whether the right people are doing the right tasks, it readily facilitates service review and redesign and supports the transformation of community services (DH, 2009).

It can be seen that the approach makes explicit the nature of the care to be provided (Gandy *et al*., 1998), and it supports initiatives such as personal health budgets (DH, 2010a) by inform-ing and educating patients and carers of the full range of care available, relevant to their circum-stances, and the support likely to be required.

It links resources, quality, outcomes and costs throughout the process, supports the develop-ment of ICPs and enables a key worker/care co-ordinator role. It also facilitates benchmarking, although not being dependent upon the avail-ability of Information Management and Tech-nology support to begin (Gandy *et al*., 1998).

Some general attributes of a care profile make the case for their development and use as a quality monitoring tool. For example, the standards descri-bed in each profile are recognised and accepted as a consensus amongst the clinicians delivering the service. This ensures clinical validity. In this context, the provision of care is equitable to each patient, and thus the quality is explicit.

Up-to-date practices are incorporated, thereby ensuring the standard and availability of the care provided. Consideration is given to possible var-iations to the usual care provision in order to ensure the appropriateness of the care.

The profiles should be measurable and repre-sent care of a set standard within an acceptable and affordable standard (Gandy *et al*., 1998).

The fact that the Liverpool project only took a little over 2 months demonstrates how the approach simplified the planning and commissioning processes and made them both manageable and affordable.

However, it will be a new concept to many, and consequently there are potential limitations. For example, there could be variations in local inter-pretation, in part because of how nomenclature regularly used by professionals can vary between places and individuals. Given the learning curve involved, training is important (Gandy *et al*., 1998; 2002).

Care profiles approach and commissioning by clinical commissioning groups

The development of care profiles must be undertaken and subsequently owned by clinicians. A fundamental issue relating to their development is that a review of clinical practice takes place. A care profile embraces the care that will be given on an anticipatory or expected basis. Thus, the pro-spective planning and allocation of resources is facilitated. Further, a care profile provides a tool for the incorporation of evidence-based care into local practice through consensus and local agreement by clinicians. Patient involvement is a major issue in the context of quality care, and profiles also have a role when discussing options with patients and carers (Gandy *et al*., 1998).

Clearly, a care profiles approach readily sits with and supports improved commissioning arrangements and clinical commissioning groups (CCGs), as set out by the DH (2010b; 2011a). This applies not only for EoL services but also for other key services involving primary and com-munity care. The central theme of the reforms is to understand the health needs of a local popu-lation, or group of patients, and of individual patients, and, working with patients and the full range of health and care professionals involved, to decide what services will best meet those needs, and to design these services. This involves the creation of clinical service specifications to form the basis for contracts with providers, which

can then be monitored to ensure that services are delivered to the right standards of quality.

The NHS Commissioning Board will require commissioning for quality improvement and will promote and extend public and patient involvement and choice. It will hold CCGs to account, ensuring that commissioning decisions are underpinned by clinical insight and knowledge of local healthcare needs. CCGs will be required to develop integrated services that make sense to patients and the public (DH, 2010b; 2011a). Care profiles are a straight-forward means, whereby CCGs can make explicit and transparent to the NHS Commissioning Board, their partners and the public, what care they have commissioned to be delivered. The associated process presents the opportunity for service redesign by enabling inclusive, constructive criticism and challenge of the *status quo*.

A key implication of commissioning by CCGs is that the expected role and contribution of GPs in respect of various health services will need to be made explicit. This was specifically excluded from the Liverpool project for the reasons stated. However, there is no reason why their contribution to EoL care could not have been included if this had been required, and the same can be said about care profiles in general.

It is concluded that care profiles represent the type of clinically relevant and detailed vehicle essential for CCGs.

Palliative care funding review

The recommendations of the national Palliative Care Funding Review (2011) were published in July 2011, setting out a new funding system for all palliative care services, which uses national needs-based tariffs. It clarifies which services should be covered by the tariff across health and social care for both adults and children, and proposes a classification system based on phase of illness, first developed in Australia.

The initial classification system involves four levels, as follows (Palliative Care Funding Review, 2011):

- Class 1 – Stable
- Class 2 – Deteriorating
- Class 3 – Unstable
- Class 4 – Dying.

These are different from the stated EoL care pathway stages of both the GSF (2010) and the North West EoL Care Model (Merseyside and Cheshire Cancer Network, 2010). However, this reflects the difference in approach, and it is reasonable to infer a great degree of correspondence between the four classes and the four stages agreed for the Liverpool EoL care profiles.

If the Palliative Care Funding Review (2011) had been published before the Liverpool project took place then there is no doubt that its four classes would have been adopted rather than those shown in the section 'EoL Care Profiles'. This may have meant some differences in the detail of the resulting care profiles; however, it is considered that these would have been small, and the arguments put forward in this paper would not change.

What is critical to recognise is that the Review sets a financial framework for palliative care across the country; however, it does not determine the levels and organisation of services to be delivered in each locale. This would be the responsibility of commissioners to determine within the stated financial framework, and there will be variations between areas. Therefore, EoL care profiles represent an essential commissioning tool to establish the local services required within the available finances.

The Liverpool project focused on services within the community, but the national tariffs cover all relevant hospital, community and social care services. Whether a care profiles approach can also be applied to these other EoL services would be the subject of further work. Nevertheless, it has been demonstrated that care profiles are a practical commissioning tool for what is arguably the largest and most complex component of EoL care.

Practicalities of applying care profiles

The development towards 'best practice' requires comparisons with care practices elsewhere, research evidence and other guidance (Gandy *et al.*, 1998). It follows that care profiles development needs to involve personnel with the relevant knowledge and skills.

One potential means of facilitating best practice in the future would be for any developed care profiles to be benchmarked across commissioners (Gandy *et al.*, 1998). This would enable local solutions to be compared, with a view to further enhancements where like-for-like circumstances

suggest them achievable, thereby enabling a virtuous circle over time.

Although commissioners may be satisfied that their care profiles incorporate best practice, they cannot assume service providers can automatically achieve it. The approach enables difference(s) between current local practice and such a standard to be clarified and quantified. Progress towards the standard is then subject to negotiation.

There is a close relationship with audit, and the inclusion of outcomes in each profile contributes to the clinical audit of patient care. Related audit mechanisms and processes should be in place to ensure that the standards are consistently maintained (Gandy *et al.*, 1998).

The Liverpool project did not seek to establish links between EoL care profiles and data from the related providers' information systems. One reason is that there are multiple providers with different systems. Another is that the mainstream community information systems in the NHS, covering district nurses and community matrons, involve ongoing development with different systems in different parts of the country (Connecting for Health, 2010a). The full clinical system for Liverpool (Lorenzo Regional Care from iSoft, 2010), which includes the use of Snomed codes (Connecting for Health, 2010b), is not planned to be fully operational before Spring 2012. Clearly, it is desirable to determine how mainstream information systems' data can support audit and care profiles, but this represents future work. It should not detract from the merits of using care profiles for commissioning services.

Because care profiles are structured around the average input required, and use 'percentage in group' where support is not universally required, it is possible to project the total activity involved in delivering the related EoL care. This requires empirical data of patients involved in each stage and the periods of time they access services. This total activity can then be costed, including allowances for travel and overheads, which should be sufficient for the purposes of programme budgeting (DH, 2010c) and supporting the implementation of both the Right Care programme (DH, 2011b) and the Palliative Care Funding Review (2011) recommendations.

Gandy *et al.* (1998) recommended the contracting currency to be used for cancer care profiles was 'patient months'. This reflected the time a patient had access to a particular care profile, which is important in respect of so many long-term conditions where the prognosis is uncertain. The applicability of this for EoL care profiles requires confirmation, but it is essential to bear in mind that whereas improved efficiency in acute care is usually associated with reduced interventions and lengths of stay, in EoL care 'success' is generally seen as a patient maintaining a particular stage of the EoL care pathway for as long as possible.

Developmental perspectives

Although the development of EoL care profiles was a local initiative undertaken by Liverpool PCT, it can be seen as readily transferable for commissioning EoL services elsewhere. Arguably the approach is transferable to other care areas with an emphasis on delivery in primary and community care, such as long-term conditions.

The conversion of the uni-disciplinary care profiles model to meet the requirements of commissioning services is a genuine innovation, one that evolved during the project itself.

The continual process of challenge and validation within the project meant that it embraced both reflective and developing practice. By driving the need to be explicit about what care is, and is not required, the project was strongly evaluative and represented a critical, learning experience for its participants.

The benefits of using care profiles to commission EoL services have been shown. Their flexibility enables the presentation of local solutions that reflect local circumstances, avoiding the dangers of attempting 'one size fits all' solutions. Wide dissemination of the approach should yield further improvements in the quality of such care and attendant outcomes, as local solutions are benchmarked against one another.

It follows that the wide application and benchmarking of care profiles for commissioning EoL services, and other areas of care such as long-term conditions, would represent a new area of research. The further development and benchmarking of care profiles is being actively pursued by Edge Hill University (2011).

Conclusions

Care profiles are potentially a useful and practical approach to commissioning. Their strength is

their simplicity and flexibility, and that they complement and augment ICPs. The results from Liverpool in respect of EoL care provide a clear and expeditious means of commissioning services in a way that is very inclusive, with its focus on clinicians, patients and carers.

The approach has the benefit of being explicit and requires the recording of outcomes throughout the care process, which aids quality and audit processes. The results from such processes, together with the publication of new evidence, can be used to continually update and enhance the care profiles dynamically, and thereby improve services.

EoL care profiles support the implementation of the Right Care programme (DH, 2011b). They also complement and support the implementation of the recommendations of the Palliative Care Funding Review (2011) by acting as a tool that commissioners can use to establish what local services should be delivered within the financial resources determined by the national tariff-based system.

A care profiles approach could be widely adopted to enable the commissioning of not only EoL services but also other appropriate services. This should be accompanied by the benchmarking of the resultant profiles to give the opportunity to review and improve them following their implementation. The publication of benchmarked profiles would also aid transferability by informing commissioners, who are using the approach for the first time, about practice elsewhere. The overall consequence could be rapid improvements in the definition and quality of primary and community care based services across the country.

Acknowledgements

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