Appendix D – Expert testimony

Section A: NCCSC to complete	
Name:	Claire Henry
Job title:	Chief executive
Address:	The National Council for Palliative Care & Dying Matters
Guidance title:	Transition between inpatient hospital settings and community or care home settings for adults with social care needs
Committee:	Guideline Development Group
Subject of expert testimony:	The effectiveness of services or interventions to support transitions at the end of life for adults with social care needs. The focus is on services in use (and preferably which have been evaluated) in the UK.
Evidence gaps or uncertainties:	*What is the impact of specific interventions to support people with end of life care needs during transition from general inpatient hospital settings to community or care home settings? (9a)* and *What is the impact of specific interventions to support people with end of life care needs during transition to general inpatient hospital settings from community or care home settings? (9b)*

For each of our review questions we search for, assess and present evidence relating to views and experiences as well as evidence about the impact of specific interventions within the review area. In the case of our end of life care questions, we presented evidence of views and experiences from 5 studies of mainly good quality, including 1 UK study. User, carer and practitioner views were all represented and we considered this to provide a moderate amount of evidence on which GDG members were able to develop recommendations. In contrast, there was a small amount of effectiveness evidence (1 study), which was judged to be of moderate quality (quality ratings are low [-], moderate [+] and good [++]).

The one effectiveness study was from the US and it found that patients seen by a specialist palliative care service were significantly more likely to be transferred home or to a hospice during the end of life phase. This is clearly an important measure of outcome because we know from our evidence on views and experiences that people prefer to die at home or in a hospice. However, it was unclear how people had been referred to the service and this, combined with the fact that the home health service (which supported people following transfer from hospital) was available under Medicaid, raised questions about the transferability of the findings to the UK context.

In light of these limitations, the GDG agreed to try and supplement the impact data through inviting an expert witness. Members are looking for the witness to present evidence relating to the costs and outcomes of an innovative service or intervention aimed at improving transitions at the end of life for adults with social care needs. Transitions include hospital discharge and admission to hospital from the community, including care homes.
In summary, evidence on the following aspects of end of life care would enable the GDG to formulate additional recommendations or add weight to those already drafted:

- the effectiveness and cost-effectiveness of different approaches or services for supporting or improving end of life transitions (with a specific focus on social care input)
- collaborative working
- information-sharing
- support for carers in the context of end of life transitions
- end of life transitions involving care homes
- reducing hospital readmissions (within 30 days).

Section B: Expert to complete

Summary testimony:	[Please use the space below to summarise your testimony in 250–1000 words – continue over page if necessary]

Transition between inpatient hospital settings and community or care home settings for adults with social care needs is critical at any time, but especially in end of life care as timeliness is crucial. The issues that can cause delays or problems include poor communication, assumptions that family members will look after the person, bed shortages or the person leaving against medical advice. Staff can also feel under pressure, especially if bed occupancy is high, to discharge people quickly as this can often be the case when people who are classed as medically fit may have little notice to make arrangements or adjustments for them to return home. Staff may also not fully understand referral processes and time required to arrange for a person's needs to be addressed, whether within their own home or moving to a care home.

Other specific aspects include access to equipment; a recently shared example was that an individual was admitted to hospital for almost 2 weeks because of an inability to get a bed installed at home over the Christmas period. Access to medication, especially pain relief, is often easier within an inpatient setting rather than a community setting **(VOICE Survey 2013)**, as there can be difficulty finding a pharmacist who is open, or who stocks the medication required, or where administering medication may require a particular skill set from healthcare staff who are not always available (e.g. setting up a syringe driver) **(BMA Hospital Discharge Jan 2014)**. There are many other cases similar to this given in the 'National review of choice for end of life care data' which is not yet published.

If people are discharged without the support needed, this group of people will be readmitted and the whole cycle starts again.

Access to health and social care needs to be simplified from its current complex state, and should range from people with relatively low levels of need being able to access non-means-tested help through to personal budgets and fully funded care for those with the highest needs, including the end of life.

The current lack of coordination increases stress and creates confusion, complexity and perverse incentives **(Report on the Commission on the Future of Health and Social Care in England, Barker Commission)**.

The report on 'How could free social care at end of life work in practice?', written by Office of Public Management in June 2014 and commissioned by Macmillan Cancer Support, the Motor Neurone Disease Association and Sue Ryder, shows the success of integrated health and social care services in some areas, highlighting examples of joined-up working between health and social care services, such as STARS Care Liverpool, and makes the case for extending this nationwide.

The report notes an absence of national guidance on implementation and a lack of understanding on how the current system operates, which leads to restricted choice for people at the end of life, and suggests:

- improving access to high quality free social care services for people at the end of life

- collaborating with local partners to deliver integrated health and social care services
- monitoring needs and existing services more closely to inform the development of innovative new services.

As part of the manifesto briefing jointly published by NCPC, MCC, Hospice UK, Sue Ryder, CSI and Macmillan, MNDA supports the idea of fully funded and quick to access social care at the end of life. Currently, some die waiting to access care even though access to social care can reduce the chance of being admitted to hospital.

Alongside this services need to be better coordinated so that all care providers have access to a person’s medical information, family information and preferences. Lack of access to this information can similarly result in increased hospital admissions **(‘The crisis facing terminally ill people and their families’, Marie Curie 2014)**.

Social care and access to shared care records (EPaCCS)

The specialist palliative care sector was surveyed on a number of IT issues, including the current state of planning and implementation for EPaCCS (Electronic Palliative Care Coordination Systems). The previously available data on this came from Public Health England and was published in April 2014 from a 2013 survey of CCGs, which found that social care providers were least likely to have access to EPaCCS.

Table 12: Care setting access and format as reported by 33 CCGs with an operational system

	Access format							
Care setting	No access	Direct electronic system to system transfer	Batch/overnight electronic transfer	Access via shared web interface/viewer	Access via coordination centre	Information shared by automated email	Sent by letter or fax	Total
GP	0	8	2	11	5	2	4	32
Out of hours	1	9	0	9	4	1	0	24
Ambulance	2	4	0	5	4	4	5	24
Hospital A&E	5	5	0	3	5	0	0	18
Hospital other than A&E	5	4	0	7	2	0	0	18
Community health providers	2	7	0	10	4	0	0	23
Social care	12	1	0	0	2	0	0	15
Specialist palliative care	1	9	0	9	4	0	0	23

Source: ‘Electronic palliative care co-ordination systems in England’, Public Health England (April 2014)

Respondents to the NCPC survey (who were largely based in hospices, hospitals or community teams) indicated varying levels of involvement with the EPaCCS initiative in their area, but what was clear overall was that these systems are still least likely to join up with social care systems, which has continuing implications for information-sharing between health and social care services.

	How complete is your access to the EPaCCS in your locality? Other than my own service, I can access records from ...						
	Hospice	**Hospital**	**Community**	**GPs**	**Ambulance**	**24/7 care**	**Social care**
% of respondents with EPaCCS in place indicating access to records from other services	**53%**	**38%**	**53%**	**53%**	**18%**	**18%**	**8%**

Source: *NCPC IT survey 2014, unpublished*

Costs

In regard to funding the **Care and Support Alliance/Care Act implementation** recommend that rather than setting the new National Eligibility Criteria (for entitlement to funding for care and support) at around the FACS level of substantial as it will be from next year, that the threshold is instead eased to encompass everyone with moderate care and support needs. PSSRU estimate that the cost of doing so would be around £2.8 billion; this is almost half the cost of the current estimate of working hours lost to provision of informal care by family and close friends which sits at £5.3 billion.

Consequently, raising the threshold would bring enormous benefits to the 546,000 people who would receive access to more proactive care, but it would also have the potential to improve the quality of life of the 5.43 million individuals who provide informal care across England, as well as paying for itself to an extent through increased economic productivity amongst this group.
Source: **How Social Care Can Decide the 2015 General Election, The Care and Support Alliance**

Georghiou T, Davies S, Davies A, Bardsley M (2012) Understanding patterns of health and social care at the end of life. Nuffield Trust on costs, concluded the following:

- In England social care is a significant part of care for people in the last 12 months of their life, with some form of local authority-funded social care being given to around 27.8% of people who died. On average, 14.9% of all people who died had some residential or nursing care service in the last year of life.
- Many more people used hospital care than social care in the last year of life (89.6% versus 27.8%), and total hospital costs in this period were approximately double those of social care services. However, for those people who did use a service, the average local authority social care costs exceeded hospital costs (£12,559 per social care user versus £7,415 per hospital user).
- Social care needs were apparent well before the end of life. While hospital costs showed a sharp increase in the final few months, social care costs rose gradually up until death. The greatest increases in social care use were observed in care home use.
- Individuals with the highest social care costs had relatively low average hospital costs – this was broadly the case irrespective of age, and suggests that use of social care may prevent the need for hospital care. This is linked with a phenomenon observed elsewhere concerning people in residential care settings (Bardsley et al., 2012): that they tend to use less hospital care than people in intensive home care settings.

References (if applicable):

Included in the main testimony