NHS

Diabetes

Commissioning Diabetes End of Life Care Services

Supporting, Improving, Caring

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Commissioning Diabetes and End of Life Care Services

NHS Diabetes would like to thank the following for their advice and contribution to the development of this commissioning guide:

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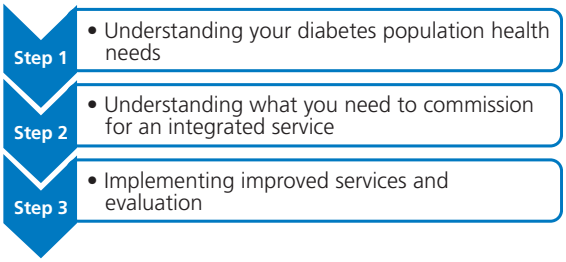
And to Thoreya Swage who wrote this publication.

Contents

Commissioning for Diabetes End of Life Care services

The NHS Diabetes commissioning approach helps to deliver high quality integrated care through a three-step process that ensures key elements needed to build an excellent diabetes service are in place. The approach is supported by a wide range of proven tools, resources and examples of shared learning.



Step 1 – involves understanding the local diabetes population health needs by developing a local Health Needs Assessment and setting up a steering group with key stakeholder involvement including a lead clinician, lead commissioner, lead diabetes nurse and lead service user

Step 2 – involves the development of a service specification to describe the model of care to be commissioned. This becomes the document on which tenders may be issued.

Step 3 – involves monitoring the delivery of the service specification by the provider and evaluating the performance of the service. Input from the steering group with service user representation will be an important mechanism for monitoring the service as well as patient surveys.

This commissioning guide has been developed by NHS Diabetes with key stakeholders including clinical and social services professionals and patient groups represented by Diabetes UK.

It is not designed to replace the Standard NHS Contracts as many of the legal and contractual requirements have already been identified in this set of documents. Rather, it is intended to form the basis of a discussion or development of diabetes End of Life Care services between commissioners and providers from which a contract for services can then be agreed.

This commissioning guide consists of:

- A description of the key features of good diabetes End of Life Care
- A high level intervention map. This intervention map describes the key high level actions or interventions (both clinical and administrative) diabetes End of Life Care *services* should undertake in order to provide the most efficient and effective care, from admission to discharge (or death) from the service.

It is not intended to be a care pathway or clinical protocol, rather it describes how a true 'diabetes without walls'[1] service should operate going across the current sectors of health care.

The intervention map may describe current service models or it may describe what should ideally be provided by diabetes End of Life Care services.

- A diabetes End of Life Care contracting framework that brings together all the key standards of quality and policy relating to diabetes and End of Life Care
- A template service specification for diabetes End of Life Care services that forms part of schedule 2 part 1 / Module B, Section 1, of the Standard NHS Contract covering the key headings required of a specification. It is recommended that the commissioner checks which mandatory headings are required for each type of care as specified by the Standard NHS Contracts.

For further detail on how to approach the commissioning of diabetes services please see http://www.diabetes.nhs.uk/commissioning_resource

[1] Commissioning Diabetes Without Walls , 2011, http://www.diabetes.nhs.uk/commissioning_resource/

Features of high quality Diabetes End of Life Care Services

A high quality diabetes End of Life Care (EoLC) service should:

- ensure that all individuals approaching the end of life and their carers should:
  - o have their physical, emotional, social and spiritual needs and preferences assessed by professionals who have appropriate expertise
  - o have a care plan for their diabetes and end of life care
  - o have their needs, preferences and care plan reviewed as their condition changes
  - o carers have access to bereavement support
  - o know that there are systems in place to ensure that information about their needs and preferences can be accessed by all relevant health and social care staff 24 hours 7 days per week
  - o maintain dignity and respect for the individual
- ensure that there is optimal delivery of care across all relevant services in all settings
- ensure that there is good quality care in the last days of life
- ensure there is effective and timely verification and certification of death and care after death
- ensure that there are equalities in access to and provision of end of life care services
- demonstrate a clear and effective pathway of care which ensures how diabetic, renal, cardiac, stroke or care of the elderly services will identify patients approaching the end of their life and utilise all relevant support and coordinate care provided by generic and specialist staff to deliver high quality EOLC.
  - o Such best practice consists of
    - Anticipatory Care planning
    - Use of the GP supportive or palliative Care Register
    - Use of tools for delivery of high class EOLC eg Liverpool care of the dying pathway, Gold Standards Framework, preferred priorities of care tools
    - Effective Standards for Out of Hours primary care services (eg Harmoni standards)

In addition the service should:

- be developed in a co-ordinated way, taking full account of the responsibilities of other agencies in providing comprehensive care ensuring people are at the centre of decisions about their care and support - 'no decision about me without me'[i]
- be commissioned jointly by health and social care based on a joint health needs assessment which meets the specific needs of the local population, using a holistic approach as described by the generic long term conditions model[ii]
- provide effective and safe care to people with diabetes in a range of settings including the patient's home, in accordance with the NICE Quality Standards for Diabetes[iii]

[i] Available on the DH website at http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_117353

[ii] Available on the DH website at http://www.dh.gov.uk/en/Healthcare/Longtermconditions/DH_120915

[iii] Quality Standards: Diabetes in adults, http://www.nice.org.uk/guidance/qualitystandards/qualitystandards.jsp

- deliver the outcomes for diabetes as determined by the NHS Outcomes Framework[iv]
- assess and manage the emotional, psychological and mental wellbeing of the patient[v]
- take into account all diverse and personal needs with respect to access to care
- ensure that services are responsive and accessible to people with Learning Disabilities[vi]
- ensure that the family/carers of people with diabetes have access to psychological support
- have effective clinical networks with clear clinical leadership across the boundaries of care which clearly identify the role and responsibilities of each member of the diabetes healthcare team
- ensure that there are a wide range of options available to people with diabetes to support self management and individual preferences
- ensure coordination of services provided by health, social care and the voluntary sectors
- provide patient/carer/family education on diabetes not only at diagnosis but also during continuing management at every stage of care
- provide education on diabetes management to other staff and organisations that support people with diabetes
- have a capable and effective workforce that has the appropriate training and updating and where the staff have the skills and competencies in the management of people with diabetes
- provide multidisciplinary care that manages the transition between adult and older peoples' services
- have integrated information systems that record individual needs including emotional, social, educational, economic and biomedical information which permit multidisciplinary care across service boundaries and support care planning[vii]
- produce information on the outcomes of diabetes care including contributing to national data collections and audits[viii]
- have adequate governance arrangements, e.g. local mortality and morbidity meetings on diabetes care to learn from errors and improve patient safety
- take account of patient experience, in the development and monitoring of service delivery
- actively monitor the uptake of services, responding to non-attenders and monitoring complaints and untoward incidents

[iv] Available on the DH website at http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_122944

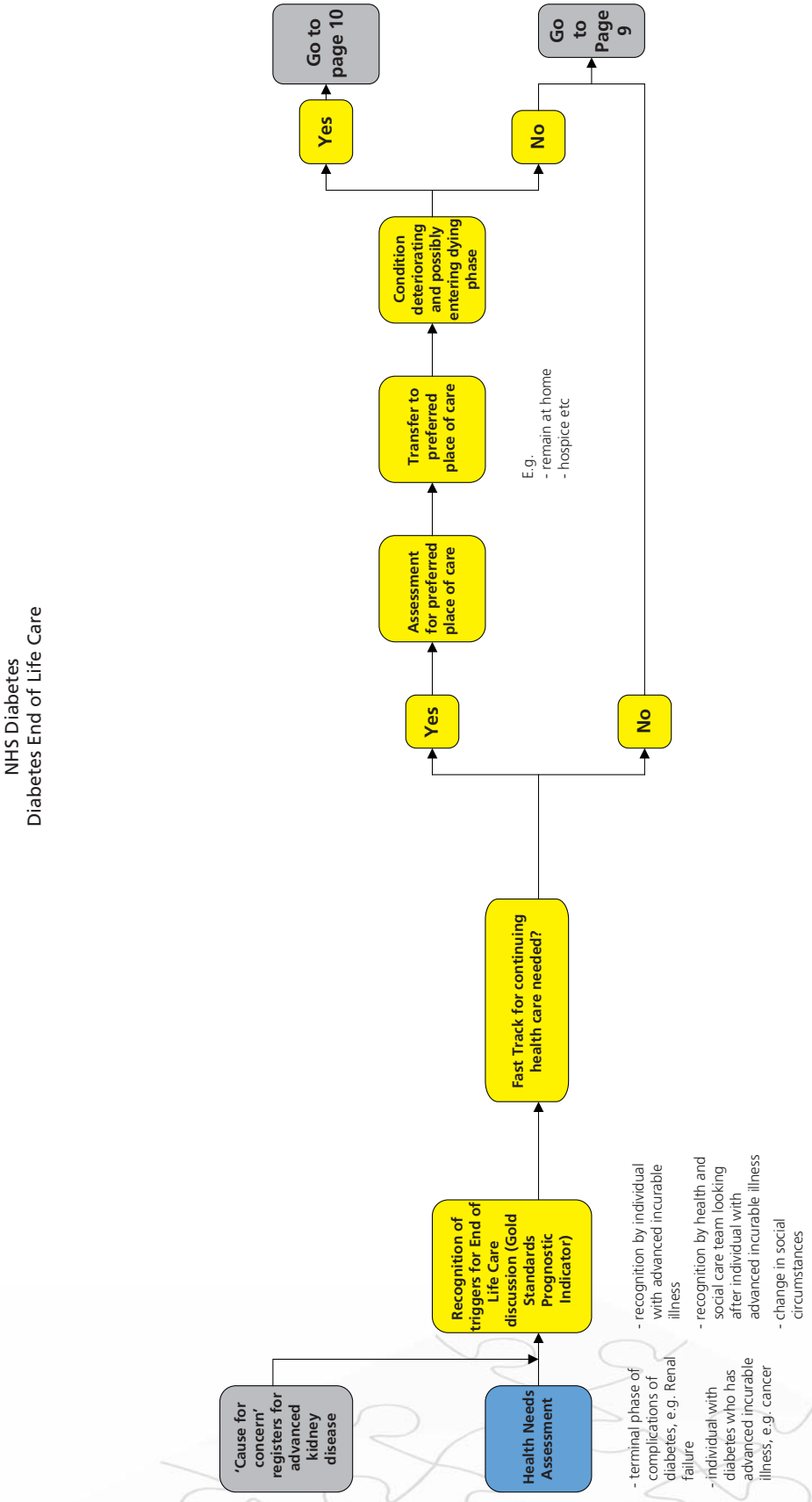
[v] Emotional and Psychological Support and Care in Diabetes, Joint Diabetes UK and NHS Diabetes Emotional and Psychological Support Working Group, 2010 http://www.diabetes.nhs.uk/our_work_areas/emotional_and_psychological/

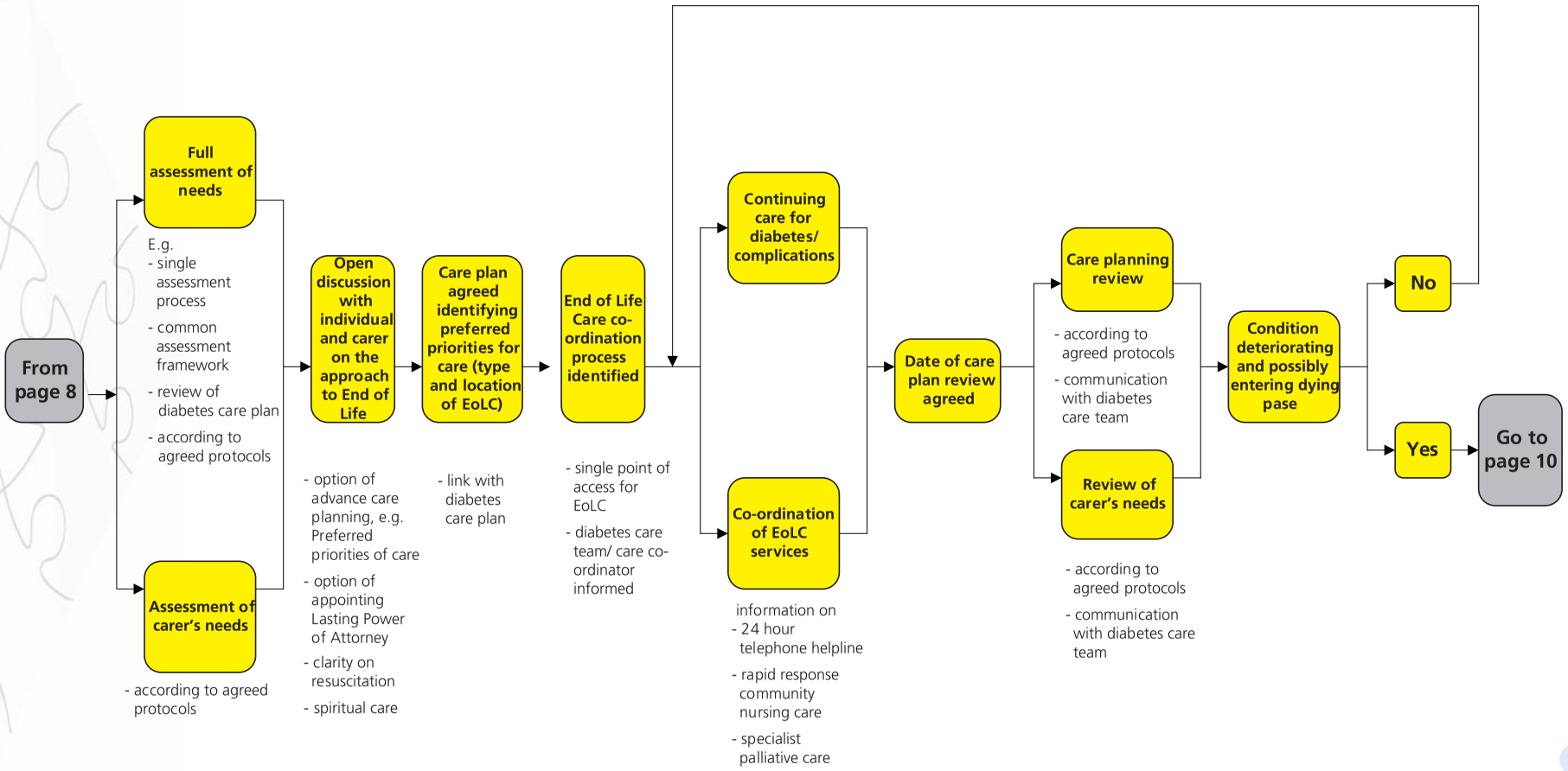
[vi] http://www.diabetes.nhs.uk/commissioning_resource/

[vii] See York and Humber integrated IT system at http://www.diabetes.nhs.uk/ year_of_care/it/

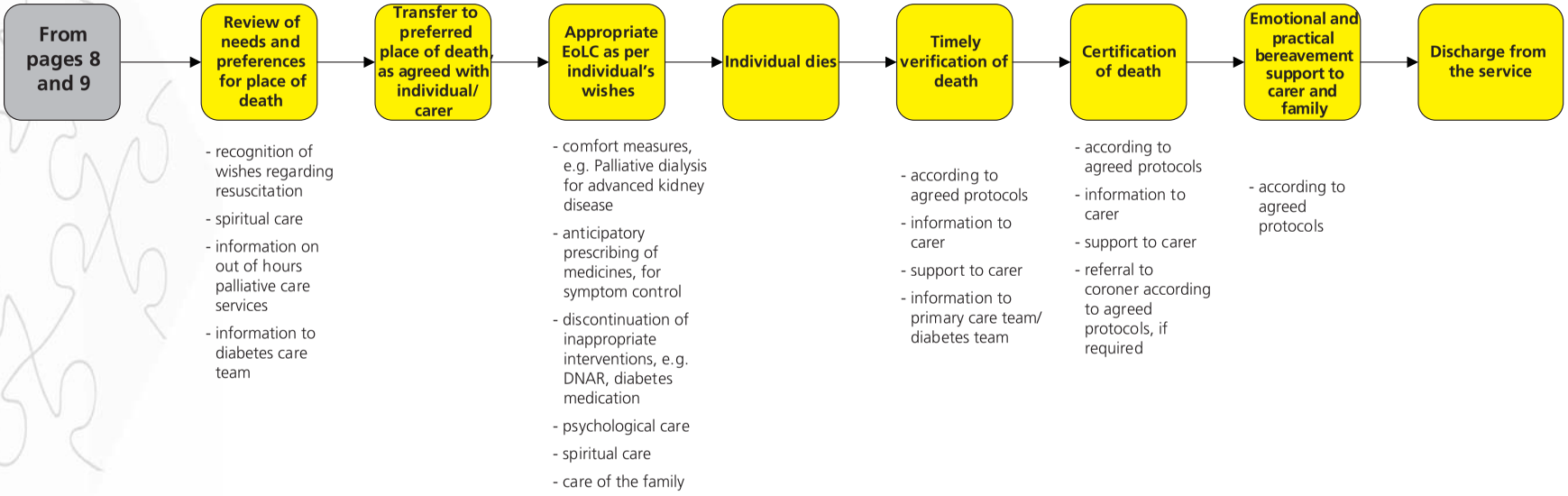
[viii] European Diabetes Working Party for Older People. Clinical Guidelines for Type 2 Diabetes Mellitus. Available on: www.instituteofdiabetes.org

Diabetes End of Life Care Services intervention Map




From page 8
Full assessment of needs
E.g.
- single assessment process
- common assessment framework
- review of diabetes care plan
- according to agreed protocols
Assessment of carer's needs
- according to agreed protocols
Open discussion with individual and carer on the approach to End of Life
- option of advance care planning, e.g. Preferred priorities of care
- option of appointing Lasting Power of Attorney
- clarity on resuscitation
- spiritual care
Care plan agreed identifying preferred priorities for care (type and location of EoLC)
- link with diabetes care plan
End of Life Care co-ordination process identified
- single point of access for EoLC
- diabetes care team/ care co-ordinator informed
Continuing care for diabetes/ complications
Co-ordination of EoLC services
information on
- 24 hour telephone helpline
- rapid response community nursing care
- specialist palliative care
Date of care plan review agreed
Care planning review
- according to agreed protocols
- communication with diabetes care team
Review of carer's needs
- according to agreed protocols
- communication with diabetes care team
Condition deteriorating and possibly entering dying pase
No
Yes
Go to page 10

NHS Diabetes
Diabetes End of Life Care
Care in the last days of life



Contracting Framework for Diabetes End of Life Care Services

Introduction

This contracting framework sets out what is required of clinically safe and effective services that are providing End of Life Care for people with diabetes. The framework is designed to be read in conjunction with the Diabetes End of Life Care services intervention map, which describes the interventions and actions required along the patient pathway as well as entry and exit points and the standard service specification template for Diabetes End of Life Care services.

The framework brings together the key quality areas and standards that have been identified by NHS Diabetes, Diabetes UK, the Royal Colleges and other related organisations. This framework supports the National End of Life Care Strategy[1] and Information to commissioners[2] on commissioning these services.

The principles that establish a safe pathway for patient care

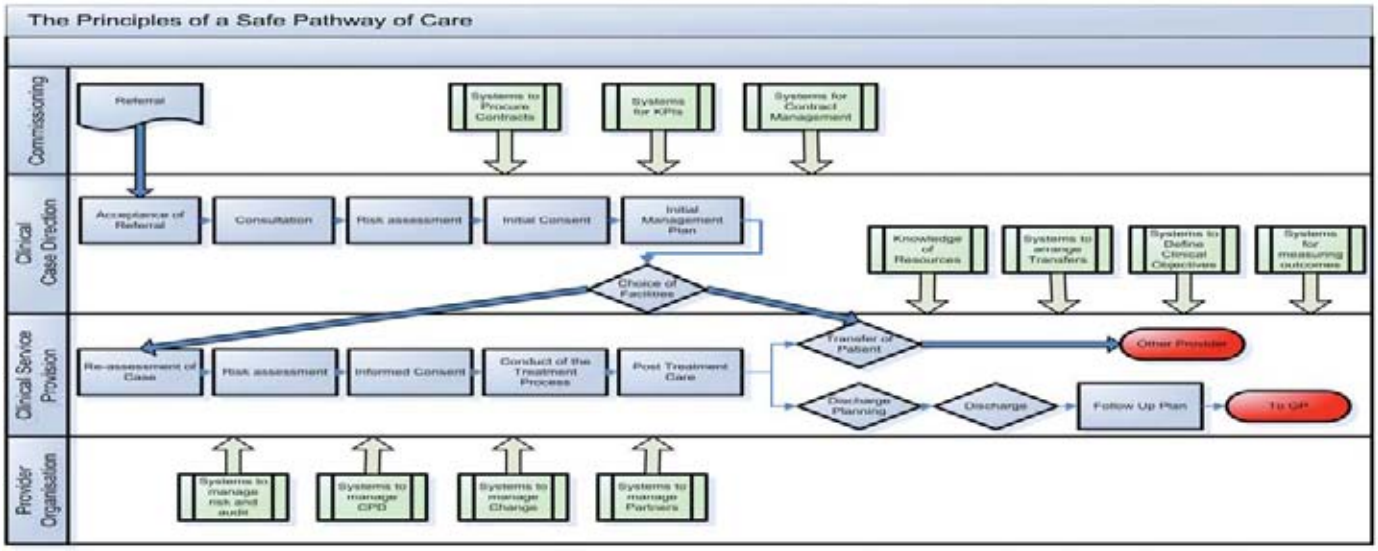
Establishing the principles that underpin the systems and processes of pathways for patient care leads to more efficient patient throughput and can reduce risk of fragmentation of care and serious untoward incidents. The principles operate at four layers within a patient pathway:

- Commissioning
- Clinical Case Direction or the overall Care Plan (i.e. the management of an individual patient)
- Provision of the clinical service or process
- Organisational platform on which the clinical service or process sits (the provider organisation)

A straightforward or simple pathway is one in which the overall management including both Clinical Case Direction and the delivery of the clinical processes conventionally sits within one organisation. However, with a more complex pathway, there is a danger that fracturing the overall management pathway into components carried out by different clinical teams and organisations will require duplication of effort leading to inefficiency and increased risk at handover points.This can be managed by establishing clear governance arrangements for all the layers in the pathway.

In addition, Commissioning Bodies must balance the benefits of fracturing the pathway against increased complexity and ensure that the increased risks are mitigated.

The governance arrangements required for all three layers and the commissioner responsibilities are shown below:



In essence, at each level, there are governance arrangements to ensure sound and safe systems of delivery of patient care with clear lines of accountability between each level.

Diabetes end of life care

The key principles of good diabetes end of life care services is to provide a high quality service that is reliable in terms of delivery and timely access for patients requiring that care.

Diabetes end of life care services are provided by a number of different teams in the primary, community and acute setting. It is essential that there is co-ordination of care of the patients through the care planning process and that the individual's GP/consultant diabetologist and specialist palliative care professionals retain joint clinical accountability and responsibility for overall patient care and overall responsibility for the management of side effects. Each professional is, however, responsible for their own actions.

As with other diabetes services, the management of individuals with diabetes who require end of life care should include an assessment of their physical, emotional and psychological well-being, together with timely access to appropriate psychological and biological/psychiatric interventions[3]. In addition, support for carers and families, the provision of timely information and access to spiritual care services are essential components of care for people nearing the end of life[1].

The services themselves will also have clinical oversight and accountability for governance purposes.

This contracting framework describes the care to be provided for:

i) individuals with diabetes who have advanced, incurable illness,

ii) individuals who are in the terminal phases of the complications of diabetes, e.g. advanced renal disease, heart failure or stroke

This Contracting Framework should also be read in conjunction with the diabetes commissioning guides for diagnosis and continuing care, older people and the complications of diabetes (diabetes and kidney care, and cardiovascular complications of diabetes) follow the principles for the effective commissioning of services for people with Learning Disabilities[4].

Ensuring quality

Commissioning Bodies should ensure that the diabetes and End of Life Care services commissioned are of the highest quality. There may, in addition, be some organisations that wish to offer their services, but do not have a history of providing such care.

i) for provider organisations already involved in the delivery of diabetes and End of Life Care services, there should be retrospective evidence of systems being in place, implemented and working.

ii) for organisations new to the arena the commissioner should reassure itself that the provider has the organisational attributes, governance arrangements, systems and processes set up to provide the platform for safe and effective delivery of diabetes and End of Life Care services to be provided.

This framework describes what the Commissioning Body needs to ensure is present or addressed in its discussions with the provider organisation.

Under the 'elements' column there are cross references to the Standard NHS Contract for Community Services – bilateral (main clauses and schedules)[5]. (The cross references also apply to the clauses and schedules in the Standard NHS Contract for Acute Services).This is to assist commissioners and providers in having an overview of how the elements link to the Standard NHS Contract. Some of the areas are open to interpretation and consequently the references are not exhaustive.

TOPIC	ELEMENTS	CHARACTERISTICS, SKILLS AND BEHAVIOURS	OUTPUTS	DIABETES SERVICES SPECIFIC OUTPUTS/COMMENTS
Governance	Leadership *Cross references to the Standard NHS Contract for Community Services* *Module C: 11,16,19,33, 48,49,51,53, 60* *Module D: Schedules: 6 ,15*	Clarity of the organisation's purpose with explicit commitment to providing high quality services A culture that demonstrates an open learning ethos An organisation that is legal and ethical in all its activities	Provider must have organisational structure that provides leadership for all professions and disciplines In particular, there must be a corporate clinical director with the responsibility and accountability for the clinical service There must be a learning framework in the organisation	There should be a designated clinical director with responsibility and accountability for the diabetes end of life care services
Governance	Integrated Governance *Cross references to the Standard NHS Contract for Community Services* *Module C: 11,19,27,48,49, 51,53,54,56,60* *Module D: Schedules: 6,12,15*	An organisation that is guided by the principles of good governance: - clarity of purpose - participation and engagement - rule of law - transparency - responsiveness - equity and inclusiveness - effectiveness and efficiency - accountability An organisation that accepts responsibility and accountability for all its actions	Clear organisational and integrated governance systems and structures in place with clear lines of accountability and responsibilities for all functions. This includes interfaces and transitions between services	Quality Governance in the NHS. A guide for provider boards[6]
Governance	Clinical Governance *Cross references to the Standard NHS Contract for Community Services* *Module B: Sections: 1 (part 2), 3, 4* *Module C: 4,4A,6,9,10,12,14, 15,16,17,19,21,26 27,29,31,32,33, 48,49,51,53, 54*	Explicit commitment to quality and patient safety Patient focused with respect for the personal wishes of patients in all aspects of their care A commitment to innovation and continuous improvement	Clinical Governance systems and policies should be in place and integrated into organisational governance with clear lines of accountability and responsibility for all clinical governance functions e.g. • Clinical Audit • Clinical Risk Management • Untoward Incident Reporting • Infection Control • Medicines Management • Informed Consent • Raising Concerns	All sub-contractors must meet governance and leadership arrangements of the main provider organisation Commissioner, provider and/or NHS Litigation Authority must review the Clinical Negligence Scheme for Trusts arrangements /or other organisational / professional indemnity arrangements The service should have in place written protocols and procedures defining clear lines of accountability and responsibility. The service is required to comply with guidelines, public health guidance and appraisals published by the National Institute for Health and Clinical Excellence that are relevant to the care provided by the service [7]

TOPIC	ELEMENTS	CHARACTERISTICS, SKILLS AND BEHAVIOURS	OUTPUTS	DIABETES SERVICES SPECIFIC OUTPUTS/COMMENTS
Governance	*Module D:* *Schedules:* *3,6,10,11,15,17*		• Staff Development • Complaints Management • Patient and Public Involvement • Patient dignity and respect • Equality and diversity • Introducing new technologies and treatments • An externally accredited Quality Assurance system and internal error reporting involving all staff groups. CG systems should have clear and demonstrable links to other NHS systems with collaborative CG activities and sharing of experience and learning Provider should produce annual Clinical Governance reports as part of NHS CG reporting system Providers are required to agree Commissioning for Quality and Innovation schemes (CQUIN) for diabetes care, e.g. model CQUIN scheme proposed by the NHS Institute for Innovation and Improvement [11]	In addition, the service is required to comply with the following: i. Guidance published by NICE • Improving supportive and palliative care for adults with cancer [8] • Medicines adherence: involving patients in decisions about prescribed medicines and supporting adherence [9] ii. Guidance published by the Department of Health and Marie Curie Palliative Care Institute • Guidelines for Liverpool Care Pathway Drug Prescribing in Advanced Chronic Kidney Disease [10]
Clinical quality	Quality assurance *Cross references to the Standard NHS Contract for Community Services* *Module C:* *4,12,16,17,18, 19, 20,21,31, 32,33, 54* *Module D:* *Schedules:* *2,3 ,6,10,11* *Module E:* *3,4*	Understanding the concept of clinical quality Has concern for quality while working efficiently An understanding of the use of audit, patient and staff feedback to improve quality An organisation that provides clarity of objectives and promotes reflective practice to improve quality of patient care	Quality assurance systems must be in place and approved by commissioning body with regular reporting of outcomes Providers are required to publish quality accounts for the public reporting of quality including safety, experience and outcomes Providers should participate in national audit programmes	Diabetes services must comply with the performance measures required of NHS services, i.e meeting: [12] • Referral to Treatment waits (95th percentile measures) • A&E Quality Indicators The Provider is required to meet the quality markers and measures for End of Life Care [13] The Provider is required to participate in agreed audits e.g.: • National Care of the Dying audit [14] • Views of Informal Carers – Evaluation of Services [15] • Diabetes E [16]

TOPIC	ELEMENTS	CHARACTERISTICS, SKILLS AND BEHAVIOURS	OUTPUTS	DIABETES SERVICES SPECIFIC OUTPUTS/COMMENTS
Clinical quality	Workforce/ staff Clinical staff attributes critical to safety and quality of interventions *Cross references to the Standard NHS Contract for Community Services* *Module C: 11,16,19,26,33,48,56* *Module D: Schedules: 10*	The provider organisation has systems and procedures in place to assure the commissioner that their clinical team has the necessary qualifications, skills, knowledge and experience to deliver the service	Staff are competent and fit for purpose Provider to satisfy commissioner that all staff have current appraisal, clearances and registration checks and have demonstrated competence in all procedures relevant to pathway.	The Provider to satisfy commissioner that they can recruit (or procure) and retain a competent clinical team to deliver the service The staff providing diabetes end of life care services in all organisations, e.g. medical practitioners, nurses, allied health professionals, pharmacists, social care staff, chaplains, mortuary and ambulance staff etc must hold the relevant registration with their professional bodies, where appropriate. They must also have appropriate level of postgraduate training The workforce groups are [1]: Group A – staff working in specialist palliative care who spend most of their working lives dealing with end of life care. This group should have specialist training in end of life care including communication skills, assessment, advance care planning and symptom management Group B: e.g. staff working in diabetes care who frequently deal with end of life care as part of their role. This group should have specialist training in end of life care including communication skills, assessment, advance care planning and symptom management. Specifically this group should have the skills to deal with the 'trigger' discussions at the start of the pathway and continuing care Group C: e.g. staff working in diabetes care who deal infrequently with end of life care. This group should have a basic grounding in the principles and practice of end of life care and know when to refer or seek expert advice All healthcare professionals involved in delivering diabetes end of life care are required to have the relevant competencies [17] There should be training on death certification for junior doctors in training[1]. All health and social care professionals should have core competencies in spiritual, cultural and religious care [1]

TOPIC	ELEMENTS	CHARACTERISTICS, SKILLS AND BEHAVIOURS	OUTPUTS	DIABETES SERVICES SPECIFIC OUTPUTS/COMMENTS
Clinical quality	Workforce/ staff *Clinical staff competencies in use of equipment* *Cross references to the Standard NHS Contract for Community Services* *Module C: 5, 11, 16, 17, 19, 26, 33,48*	The provider organisation has systems in place to assure the commissioner that their clinical team are competent to use all equipment needed to deliver the service	Provider to satisfy the commissioner that all staff have had documented competence assessment relative to all equipment used in contract.	All healthcare professionals involved in delivering diabetes and end of life care are required to have the relevant competencies in using appropriate equipment e.g. blood glucose and ketone monitors, insulin delivery devices including insulin pumps
Clinical quality	Workforce / staff Development *Cross references to the Standard NHS Contract for Community Services* *Module C: 11,16,19,48*	The provider organisation has systems in place to assure the commissioner that their clinical team is formally inducted and receives ongoing assistance to develop their skills, knowledge and experience to ensure that they are always fully updated	Provider to satisfy commissioner of their commitment to induction and CPD relevant to roles Provider to satisfy the commissioner of their commitment to train staff to meet future service needs	All Health Care professionals should have sufficient study leave allocation (time and finance) to enable them to develop skills appropriately Information to support health and social care professionals on end of life care can be found at www.endoflifecareforadults.nhs.uk
Clinical quality	Registration and licensing *Cross references to the Standard NHS Contract for Community Services* *Module B: Sections: 3,5* *Module C: 4,4A,5,9,10, 11,12,14,15,16 17,18,19,21,26,27, 29,33,34,35,36,38, 40, 43,48,49,52, 53,54,56,60* *Module D: Schedules: 6,10,11,12,15*	Comprehensive understanding and commitment to implementing national standards	Compliance with Care Quality Commission requirements for registration for primary and secondary care	Compliance with the following National Service Frameworks and Strategies, where applicable: • Long Term Conditions NSF [18] • Renal NSF [19] • National End of Life Care Strategy [1] • End of Life Care in Advanced Kidney Disease [20] Compliance with Care Quality Commission Reviews

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Clinical quality	Outcomes *Cross references to the Standard NHS Contract for Community Services* *Module B: Section: 1 (part 3),3* *Module C: 4A,14,* *Module D: Schedule 11*	Comprehensive understanding and commitment to delivering and improving outcomes of care	Compliance with the NHS Outcomes Framework[21]	Compliance with the Quality Standards for Diabetes [22] Compliance with the Quality Standards for End of Life Care [23]
Clinical quality	Patient pathway *Cross references to the Standard NHS Contract for Community Services* *Module B: Sections: 1* *Module C: 4,4A,9,10,12,14,15, 16,17,18,19, 20,21,27,29,31, 33,34,35,36,38,40, 52,54* *Module D: Schedules: 2,3, 4, 9,11,17* *Module E: 5*	Responsiveness and participative approach to including patients' views about their care in the design of care pathways Collaboration with other organisations involved in the patient pathway to provide a seamless pathway of care	All possible entry and exit points must be defined with comprehensive patient pathways that facilitate smooth passage and effective, efficient care for patients All interfaces in the pathway must be defined so that continuity of clinical care is ensured with no fracturing of the pathway There must be specification of clear timelines and alert mechanisms for potential breaches There should be audit of pathway to ensure that standards are met There must be explicit specification of provider and commissioner responsibilities for the whole patient episode from registration to care after death Accountabilities should be agreed and documented by all stakeholders There are a number of services supporting patients with diabetes who require End of Life care and there must be clear sub contracts stating the referral criteria and access to these supporting services.	The pathway should follow the principles identified by the National End of Life Care Strategy [1] i. discussions as the end of life approaches ii. assessment, care planning and review iii. co-ordination of individual patient care iv. delivery of high quality services in different settings v. care in the last days of life vi. care after death End of Life Care discussions: This includes: • early identification of a patient who may be approaching the end of life • recognition of triggers for end of life care discussion (Gold Standards Prognostic Indicator)[24] Assessment, care planning and review: This includes: • fast track assessment for preferred place of care if the patient's condition is deteriorating rapidly • Full assessment of needs of the patient and their carer, e.g. single assessment process or common assessment framework • Agreement of a care plan that identifies the preferred priorities for care (type and location of end of life care) • Co-ordinating the End of Life Care plan to the diabetes care plan, as appropriate • There should be 'do not attempt resuscitation' policies that are

TOPIC	ELEMENTS	CHARACTERISTICS, SKILLS AND BEHAVIOURS	OUTPUTS	DIABETES SERVICES SPECIFIC OUTPUTS/COMMENTS
Clinical quality	Patient pathway		At entry to pathway: The Commissioner should assure themselves that the provider has systems and processes in place to i) register patients ii) collect relevant clinical and administrative data iii) manage the appointment process, (reappointment and DNA process, if appropriate) iv) provide information to patients v) undertake initial assessment in the appropriate location At point of intervention: The Commissioner should assure themselves that the provider has systems and processes in place to ensure that: i) the intervention is conducted safely and in accordance with accepted quality standards and good clinical practice. ii) the patient receives appropriate care during the intervention(s), including on treatment review and support, in accordance with best clinical practice iii) where clinical emergencies or complications do occur they are managed in accordance with best clinical practice iv) the intervention is carried out in a facility which provides a safe environment of care and minimises risk to patients, staff and visitors v) the intervention is undertaken by staff with the necessary qualifications, skills, experience and competence vi) There are arrangements for the management of out of hours care according to best clinical practice	consistent with other local providers in the locality Co-ordination and delivery of patient care: This includes: • Identification of a co-ordinator for the end of life care • Communication with the diabetes care team • Information on o 24 hour telephone helplines o rapid response community nursing care o Specialist palliative care • Continuing care of the patient by the diabetes team, as appropriate Care in the last days of life: This includes: • Recognition that the patient's condition is deteriorating • There should be protocols in place to recognise patients who are approaching the end of life, or who are at substantial risk of dying on admission to hospital • Review of needs and preferences for place of death • There should be handover and communication protocols in place to ensure that out of hours providers who receive calls from patients approaching the end of life immediately identify and transfer these calls to an appropriate clinician who is aware of the background to the call, the patient's wishes and if possible Advance Care Planning. There may be a dedicated telephone line • There should also be timely access to equipment, e.g. syringe driver, medication etc during working and out of hours • Transfer to the place of death, if required, as agreed with the patient/carer • Appropriate end of life care as per the patient's wishes Care after death: This includes: • There should be policies in place to ensure the timely verification of death. This may include verification by nurses • Certification of death (reference should be made to diabetes as a cause of death) • Emotional and practical bereavement support to carer and family

TOPIC	ELEMENTS	CHARACTERISTICS, SKILLS AND BEHAVIOURS	OUTPUTS	DIABETES SERVICES SPECIFIC OUTPUTS/COMMENTS
Clinical quality	Patient pathway		At exit from pathway: The Commissioner should assure themselves that provider has systems and processes, which are agreed with all parties and networks, in place to: i) provide timely feedback to the referrer re: End of Life care and care after death	• There should be policies in place to ensure the sensitive handling of the deceased and relatives according to their cultural and spiritual wishes • There should be protocols in place to ensure the correct identification of the deceased and that personal possessions are handled in a safe and sensitive way Patients and their families/carers may need to access a complex combination of different services as part of their palliative care as follows [1]: • Primary care • District nursing care • Personal social care • Psychological support • Acute medical care • Specialist palliative care • Out of hours care • Ambulance/transport • Information services • Respite care • Speech and language therapy • Equipment • Occupational therapy • Physiotherapy • Day care • Pharmacy • Financial advice • Dietetic advice • Carer support • Spiritual care • Community and voluntary sector support • Interpreter services • Welfare support • Employment support • Bereavement counselling Patients and their families/carers should have information on the range of services available for End of Life care, e.g. a directory of local services Providers are required to take note of the results of the National Survey of People with Diabetes [25]

TOPIC	ELEMENTS	CHARACTERISTICS, SKILLS AND BEHAVIOURS	OUTPUTS	DIABETES SERVICES SPECIFIC OUTPUTS/COMMENTS
Clinical quality	Clinical emergency situations *Cross references to the Standard NHS Contract for Community Services* *Module C: 6,11,12,14,15,18, 20,32, 32, 42, 54* *Module D: Schedules: 2, 3, 4, 6, 9,11*	Ability to negotiate and agree arrangements with appropriate personnel and organisations to provide effectively for emergency situations	The Commissioners should satisfy themselves that provider has systems, processes and competent personnel are in place and implemented to ensure that all clinical emergencies and complications are handled in accordance with best practice	There should be protocols in place to recognise patients who are approaching the end of life, or who are at substantial risk of dying on admission to hospital [1] There should be protocols in place to ensure that out of hours providers who receive calls from patients approaching the end of life transfer immediately identify and transfer these calls to an appropriate clinician/or there may be a dedicated telephone line (see above) [1]
Clinical quality	Estates and equipment *Cross references to the Standard NHS Contract for Community Services* *Module C: 5, 33,56* *Module D: Schedules: 2, 3,4,6,11,17*	Understanding of building regulations Access to advice on "fit-for-purpose" equipment and facilities	Commissioners must assure themselves that patient care is delivered in appropriately built and equipped facilities which meet relevant HTMs and Building Notes, and, where appropriate, are registered and are safe and clean. Equipment must be fit for purpose Commitment to efficient use and satisfactory maintenance of equipment	Any buildings in which care is provided and mortuary facilities should be of a high standard and should meet the needs of relatives and carers, including those who wish to view the body after death [1]
Clinical quality	Knowledge and understanding of health and safety *Cross references to the Standard NHS Contract for Community Services* *Module C: 4A,5,11,17,19, 54, 56, 60*	Understanding of clinical accountabilities of health and safety policies	H&S strategy and policies in place and implemented with awareness throughout the organisation Accessibility to executive responsible for H&S for quicker, first contact services	Health and safety policies as per provider agreement with commissioners

TOPIC	ELEMENTS	CHARACTERISTICS, SKILLS AND BEHAVIOURS	OUTPUTS	DIABETES SERVICES SPECIFIC OUTPUTS/COMMENTS
Data and information management	Strategy and policies *Cross references to the Standard NHS Contract for Community Services* *Module B: Sections: 5* *Module C: 9,17,18, 19, 21,23,24,27,29, 32, 33,54, 56, 60*	Strategy and policy development skills The ability to analyse data and have access to information that can predict trends and that could identify problems The ability to capture evidence based practice from R&D National Service Frameworks, NICE guidance The ability to use data and information appropriately to improve patient care Transparency and objectivity	The Provider should have an explicit data and information strategy in place that covers • Types of data • Quality of data • Data protection and confidentiality • Accessibility • Transparency • Analysis of data and information • Use of data and information • Dissemination of data and information • Risks • Sharing of data and compatibility of IT across different providers with respect to care of patients across a pathway This information should be included in the Data Quality Improvement Plan There should be policies in place that include: • Confidentiality Code of Practice • Data Protection • Freedom of Information • Health Records • Information Governance Management • Information Quality Assurance • Information Security There must be a named individual who is the Caldicott Guardian	The Provider is required to have information systems that record individual needs including emotional, social, educational, economic and biomedical information which permit multidisciplinary care across service boundaries and support care planning for both diabetes and End of Life care[1, 26] The provider must ensure that robust systems are in place for chaplains who request access to patient information to have obtained prior patient consent[1] The Provider is required to contribute to/support locality wide registers on people with diabetes who are in receipt of End of Life care The Provider must obtain the patient's consent prior to placing an individual on an End of Life Care register The Provider is required to use the following for the collection and production of data, where appropriate: • NHS Outcomes Framework [21] • National Diabetes Information Service [27] • Diabetes E [16] • Quality and Outcomes Framework[28] • Myocardial Ischaemia Audit Project[29] • Hospital Episode Statistics[30] • Patient Experience [31] • Patient Satisfaction [24]

Source documents

Commissioners and providers should take responsibility for making references to the latest version of the various documents and guidance.

1. National End of Life Care Strategy - promoting high quality care for all adults at the end of life, July 2008, http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_086277
2. Information for commissioning end of life care, National End of Life Care Programme, 2008, http://www.endoflifecare.nhs.uk/eolc/files/NHS-EoLC_Info_for_Commissioning_EoLC_Dec2008.pdf
3. Emotional and Psychological Support and Care in Diabetes, Joint Diabetes UK and NHS Diabetes Emotional and Psychological Support Working Group, to be published early 2010
4. The NHS Diabetes Commissioning Guides are available on the NHS Diabetes website at http://www.diabetes.nhs.uk/commissioning_resource/
5. Standard NHS Contracts http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_124324
6. National Quality Board, Quality Governance in the NHS, 2011 http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_125239.pdf
7. NICE Diabetes guidance, http://guidance.nice.org.uk/Topic/EndocrineNutritionalMetabolic/Diabetes
8. NICE, Improving supportive and palliative care for adults with cancer, http://guidance.nice.org.uk/CSGSP, 2004
9. NICE, Medicines adherence: involving patients in decisions about prescribed medicines and supporting adherence, Jan 2009, http://guidance.nice.org.uk/CG76
10. Department of Health and Marie Curie Palliative Care Institute, Guidelines for LCP Drug Prescribing in Advanced Chronic Kidney Disease, 2008, http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_085997.pdf
11. NHS Institute for Innovation and Improvement, model CQUIN scheme: inpatient care for people with diabetes, 2009
12. Department of Health, The Operating Framework for the NHS in England 2011/12, 2010, http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_122738
13. End of Life Care Strategy, quality markers and measures for end of life care, 2009, http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_101684.pdf
14. The Marie Curie Palliative Care Institute Liverpool, Royal College of Physicians and Clinical Effectiveness and Evaluations Unit, National Care of the Dying Audit, 2006/07, http://www.rcplondon.ac.uk/clinical-standards/ceeu/Documents/NCDAH-Generic-Report.pdf
15. Views of Informal Carers – Evaluation of Services (VOICES)
16. DiabetesE - https://www.diabetese.net/
17. National End of Life Care Programme, Skills for Health, Skills for Care, Department of Health, Core competences for end of life care. Training for health and social care staff, 2009, http://www.endoflifecare.nhs.uk/eolc/files/NHS-EoLC_Core_competences-Guide-Jul2009.pdf
18. Department of Health, The National Service Framework for Long Term Conditions, March 2005 http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4105361
19. Department of Health, The National Service Framework for Renal Services, January 2004 http://www.dh.gov.uk/en/Healthcare/Renal/DH_4102636
20. End of Life Care for Advanced Kidney Disease, A framework for implementation, 2009, http://www.endoflifecare.nhs.uk/eolc/files/NHS-EoLC_Advanced_Kidney_Disease_Framework-Jun2009.pdf

21. Department of Health, The NHS Outcomes Framework 2011/12, December 2010 http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_122944

22. NICE, Quality Standards: Diabetes in adults, March 2011, http://www.nice.org.uk/guidance/qualitystandards/qualitystandards.jsp

23. NICE, End of life care Quality Standard (in development) due Nov 2011 http://www.nice.org.uk/guidance/qualitystandards/indevelopment/endoflifecare.jsp

24. Gold Standards Framework, http://www.goldstandardsframework.nhs.uk/

25. Healthcare Commission, National Survey of People with Diabetes, 2006, www.cqc.org.uk/usingcareservices/healthcare/patientsurveys/servicesforpeoplewithdiabetes.cfm

26. York and Humber integrated IT system http://www.diabetes.nhs.uk/

27. National Diabetes Information Service, www.diabetes-ndis.org

28. Quality and Outcomes Framework, http://www.nice.org.uk/aboutnice/qof/qof.jsp

29. Myocardial Ischaemia Audit Project (MINAP) www.rcplondon.ac.uk/CLINICAL-STANDARDS/ORGANISATION/PARTNERSHIP/Pages/MINAP-.aspx

30. Hospital Episode Statistics, www.ic.nhs.uk/statistics-and-data-collections/hospital-care/hospital-activity-hospital-episode-statistics--hes

31. The King's Fund, The point of care. Measures of patients' experience in hospital: purpose, methods and uses. July 2009

Standard Service Specification Template for Diabetes End of Life Care Services

This specification forms Schedule 2, Part 1, or section 1 (module B) 'The Services - Service Specifications' of the Standard NHS Contracts[a]

Service specifications are developed in partnership between commissioners and provider agencies and are based on agreed evidence-based care and treatment models. Specifications should be open to scrutiny and available to all service users/carers as a statement of standards that the user/carer can expect to receive.

The following documentation, developed by the Diabetes Commissioning Advisory Group, provides further detail/guidance to support the development of this specification:

- The diabetes End of Life Care intervention map
- The contracting framework for diabetes End of Life Care services

This specification template assumes that the services are compliant with the contracting framework for diabetes End of Life Care services.

This template also provides examples of what commissioners may wish to consider when developing their own service specifications.

Description of diabetes End of Life Care services:

End of Life care is the support provided for an individual when they have advanced, incurable illness, e.g. cancer, until they die. This care is marked at the beginning of this phase in life by a comprehensive assessment of supportive and palliative care needs of the individual concerned and their family. The support includes the management of pain and other symptoms, provision of psychological, social, spiritual and practical help as well as support to the carers during the illness and into their bereavement.

Individuals with diabetes may require end of life care for the complications of the condition, e.g. renal failure, heart disease, strokes etc.

The final specification should take into account:

- **national, network and local guidance and standards for diabetes End of Life Care services.**
- **local needs.**

This specification is supported by other related work in diabetes commissioning such as:

- the web-based Diabetes Community Health Profiles (Yorkshire and Humber Public Health Observatory)
- the web-based Health Needs Assessment Tool (National Diabetes Information Service).

These provide comprehensive information for needs assessment, planning and monitoring of diabetes services.

Introduction

- A general overview of the services identifying why the services are needed, including background to the services and why they are being developed or in place.
- A statement on how the services relate to each other within the whole system should be included describing the key stakeholders/relationships which influence the services, e.g. multi-disciplinary team etc. This should describe the diabetic services and their interactions, as well as the specialist palliative care services and then the relationship between the services
- Any relevant diabetes and supportive and palliative care clinical networks and screening programmes applicable to the services

[a] Standard NHS Contracts http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_124324

- Details of all interdependencies or sub-contractors for any part of the service and an outline of the purpose of the contract should be stated, including arrangements for clinical accountability and responsibility, as appropriate

Purpose, Role and Clientele

1. A clear statement on the primary purpose of the services and details of what will be provided and for whom:
   - Who the services are for (e.g. individuals with diabetes who require end of life care, i.e. a recognition by the patient and/or professional team that palliative care is required).
   - What the services aim to achieve
   - The objectives of the services
   - The desired outcomes and how these are monitored and measured

Scope of the Services

2. What do the services do? This section will focus on the types of high level therapeutic interventions that are required for the types of need the services will respond to.
   - How the services responds to age, culture, disability, and gender sensitive issues
   - Assessment – details of what it is and co-morbidity assessment and referrals to all relevant services/care
   - Service planning – High level view of what the services are and how they are used; how patients enter the pathway/journey; what are the stages undertaken and follow up care. The aims of service planning are to:
     - o Develop, manage and review interventions along the patient journey
     - o Ensure access to other services/care, as appropriate
     - o Ensure that care planning is undertaken by the diabetes multi-disciplinary team (as defined locally) with a clear care co-ordination function between hospital and community diabetes, primary care and specialist palliative care services
   - Holistic review of individuals who have diabetes using the principles of an integrated care model for people with long term conditions that is patient-centred, including self care and self management, clinical treatment, facilitating independence, psychological support and other social care issues
   - Risk assessment procedures
   - Detail of evidence base of the services – i.e. the contracting framework for diabetes end of life care, guidance produced by the Royal College of Physicians, Diabetes UK, etc
   - The scope of the services should reflect the key actions and co-ordination of care mapped out on the intervention map

Service Delivery

3. Patient Journey/pathway
   Flow diagram of the patient pathway showing access and exit/transfer points – see the diabetes end of life care intervention map as a starting point

4. Treatment protocols/interventions
   Include all individual treatment protocols in place within the services or planned to be used

5. This will include a breakdown of how the patient will receive the services and from whom. It should be a clear statement of staff qualifications/experience and/or training (if appropriate) and clinical or managerial supervision arrangements. It should specify, as appropriate:
   - Geographic coverage/boundaries – i.e. the services should be available for all individuals of all ages groups who live in the clinical commissioning group area
   - Hours of operation including, week-end, bank holiday and on-call arrangements
   - Minimum level of experience and qualifications of staff (i.e. doctors – diabetologists and GPs, Nursing staff – diabetes nurse specialists, district, practice nurses etc, other allied health professionals, e.g. podiatrists, dietitians, optometrists, pharmacists etc and other support and administrative staff). Each palliative care service should comply with the Standards contained in the NICE Guidance on Supportive And Palliative Care (2004).

- Confirmation of the arrangements to identify the Care Co-ordinator for each patient with diabetes at the end of life (i.e. who holds the responsibility and role). Alternatively, a key worker should be identified in each team to ensure close liaison and working relationships between them.
- Staff induction and developmental training. There should be a minimum level of training for diabetic staff according to those specified core competencies in the National End of Life Strategy and agreed core competencies for the Specialist Palliative Care Team in Diabetes management

6. Equipment.
   - Upgrade and maintenance of relevant equipment and facilities
   - Technical specifications, e.g. specification for insulin or subcutaneous end of life care pumps according to agreed or national criteria

Identification, Referral and Acceptance criteria

7. This should make clear how patients will be identified, assessed (if appropriate) and accepted to the services.
   - Acceptance should be based on types of need and/or patient.
   - This should include a fast tracking facility for patients who require continuing healthcare whose condition is deteriorating rapidly and who may be entering a terminal phase.

8. How should patients be referred?
   - Who is acceptable for referral and from where
   - Details of evaluation process - Are there clear exclusion criteria or set alternatives to the service? How might a patient be transferred?
   - Response time detail and how are patients prioritised

Discharge/Service Complete

9. The intention of this section is to make clear when a patient and their carer/family no longer require the diabetes and end of life care services.
   - State how the service determines that a patient and their carer/family may improve so as to no longer require end of life care
   - What procedures are followed up after the death of an individual who has used the diabetes and end of life service?
   - State the services offered in bereavement care

Quality Standards

10. The service is required to deliver care according to the standards for clinical practice set by the National Institute for Health and Clinical Excellence[b]

11. As a minimum, the Provider is required to agree a local Commissioning for Quality and Innovation scheme for services for people with diabetes. *(Insert details of the CQUIN Scheme agreed)*

12. The service is required to deliver the outcomes for diabetes as determined by the NHS Outcomes Framework[c]

Activity and Performance Management

13. This must include performance indicators, thresholds, methods of measurement and consequences of breach of contract. These will be set and agreed prior to the signing of the overall agreement.

14. Activity plans – Where appropriate, identify the anticipated level of activity the service may deliver; provide details of any activity measures and their description /method of collection, targets, thresholds and consequences of variances above or below target.

[b] http://www.nice.org.uk/guidance/qualitystandards/qualitystandards.jsp

[c] http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_122944

Continual Service Improvement

15. As part of the monitoring and evaluation procedures, the service will identify a method of agreeing measurements for continuous improvement of the service being offered and work to ensure unmet need is both identified and brought to the attention of the commissioner.

16. Review
    This section should set out a review date and a mechanism for review.

    The review should include both the specifications for continuing fitness for purpose and the providers' delivery against the specification.

    This should set out the process by which this review will be conducted.

    This should also identify how compliance against the specification will be monitored in year.

17. Agreed by
    This should set out who agrees/accepts the specification on behalf of all parties.

    This should include the diabetes providers, commissioner and network

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