Knowledge & Information Repository

Care Planning and Diabetes

Supporting, Improving, Caring

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Care Planning and Diabetes |
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Knowledge and Information Repository

The purpose of the knowledge and information repository (KIR) is to provide easily accessible summaries of the latest guidance and important research relating to specific key topics of relevance to NHS Diabetes. The topic areas have been identified by NHS Diabetes staff and the KIR documents will provide readily available information to support and inform programme managers and others when attending meetings and other functions. Each KIR topic will include a brief summary introduction to each topic, followed by a short collection of latest key policy papers, national body statements, clinical or care guidelines and the latest key research and evaluation papers.

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Care planning and diabetes

Care planning has been described as ‘a process which offers people active involvement in deciding, agreeing and owning how their diabetes will be managed. It aims to help people with diabetes achieve optimum health through a partnership approach with health professionals in order to learn about diabetes, manage it and related conditions better and to cope with it in their daily lives’ (1).

UK national policy

The National Institute for Health and Clinical Excellence (NICE) published the Quality standard for diabetes in adults in March 2011 (2). The standard consists of 13 quality statements, and standard 3 states, ‘people with diabetes participate in annual care planning which leads to documented agreed goals and an action plan’. It is expected that achieving the quality of care described in each of the quality statements set out in this document will reduce the complications associated with diabetes.

In the 2010 White Paper, Equity and Excellence: Liberating the NHS, the current government has expressed their commitment to uphold and expand ‘shared decision-making’ and to introduce choice to personalised care planning during 2011 (3). Furthermore, the government is committed to expanding the use of personal budgets for patients to allow greater integration between health and social care at the level of the individual, and to give people more choice and control over their care (4). These commitments are an extension of the previous government's commitment to improve care for people with long term conditions which were set out in the 2006 White Paper, Our Health, our care, our say (5).

The National Service Framework (NSF) for diabetes was published in 2001 to improve standards of diabetes care. Twelve national standards were set, and key interventions and actions were identified to improve the quality of diabetes services and to address the disparity in diabetes care provision (6). Standard 3 of the NSF aims to empower people with diabetes by encouraging participation in the decision-making processes, thus allowing them to experience the best possible quality of life. Care planning, together with structured diabetes education is a key intervention in implementing Standard 3 of the NSF.

UK national guidelines, reports and tools

Lord Darzi’s report High Quality Care for All highlights the challenges facing the NHS over the coming years (7). The report advocates the use of personalised healthcare, giving patients more rights and control over their care; this includes offering all those with long term conditions a personalised care plan that has been agreed by both the healthcare professional and the patient.

The Department of Health and Diabetes UK published a report on care planning and diabetes in 2006 which contains information and guidance on the care planning process for diabetes services (1). The Department of Health has also published numerous guides and tools for healthcare workers and commissioners to support the implementation of care planning and self care (8-15).

Other UK reports and guidelines

The National Institute for Health Research commissioned a scoping exercise to provide an overview of the current issues and developments in the organisation and delivery of diabetes services in the UK, and published its findings in 2010 (16). In terms of care planning, the report concluded that it was unclear as to the extent to which care planning is being used, and which methods and models were being utilised. The report acknowledges that the Year of Care programme (see overleaf for more details) is a potentially important national initiative in which care planning is used to prompt service development and inform commissioning. Recommendations included the evaluation of various aspects of care planning.
Diabetes UK has recently published a number of documents relating to various aspects of diabetes care, many of which include guidelines or recommendations on aspects of care planning. These include recommendations for the provision of diabetes services in primary care (17), guidelines for care home residents with diabetes (18), Children's Charter for Diabetes (19), a report into integrated diabetes care (20), and improving supported self-management for people with diabetes (21).

**Care planning models and initiatives**
The Year of Care programme sets out how routine care can be redesigned and commissioned to provide a personalised approach for people with long term conditions, and describes the care people with long term conditions should expect to receive in a year. The Year of Care programme published *Getting to Grips with Year of Care: A practical guide* in 2008, and aimed this at commissioners, clinicians and networks interested in setting up Year of Care programmes locally (22).

Co-creating Health is a national initiative coordinated by the Health Foundation, and involves training healthcare professionals and patients to be better collaborators in the care planning process (23).

**Patient-held records and information prescriptions**
Effective care planning requires the patient to have the personal information about their condition, such as biomedical test results and treatment plans, and general information about their condition. This information empowers people with diabetes, putting them at the centre of their care, giving them more choice and control as part of the care planning process. Patient-held records (24, 25) and information prescriptions (26, 27) are important ways of communicating this information.

**Evidence supporting the use of care planning**
Evidence for each of the components of the care planning model is provided by the 2006 report from the Department of Health and Diabetes UK care planning working group, and underpins the theoretical basis of the care planning model (1). A recent systematic review found there is insufficient evidence to draw any firm conclusions about the most effective types of intervention for increasing the adoption of shared decision-making by healthcare professionals (28). A small study explored how care planning and the use of care plans are being used in the management of patients with diabetes; although this study was carried out in Australia, the key findings may be relevant to UK settings (29).
1.0 UK national policy

1.1 NICE quality statements for diabetes in adults.

Available at: http://www.nice.org.uk/guidance/qualitystandards/diabetesinadults/diabetesinadultsqualitystandard.jsp

- Quality statement 3: Care planning
  - People with diabetes participate in annual care planning which leads to documented agreed goals and an action plan.

- Quality measures are defined:
  - Structure:
    - Evidence of local arrangements and provision of resources to ensure people with diabetes participate in annual care planning which leads to documented agreed goals and an action plan.
  - Process:
    - Proportion of people with diabetes who are offered annual care planning including documenting and agreeing goals and an action plan.
    - Proportion of people with diabetes who participate in annual care planning including documenting and agreeing goals and an action plan in the past 12 months.
  - Outcome:
    - Patient satisfaction with diabetes care using validated patient survey criteria.

- The document provides a description of what the quality statement means for each audience.
- Data sources are identified as 'local data collection' for all four measures.
- The document defines care planning and details what the care planning review should incorporate.
- Equality and diversity considerations are also discussed.


Available at: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_117353

- This White Paper outlines the government's proposal for 'shared decision-making: nothing about me, without me' which they believe will consolidate some principles of the NHS Constitution.
- The government has pledged to introduce choice in care for long term conditions as part of the care planning process.
- The government has set out its commitment to extend the use of personal health budgets and plans to encourage further pilot sites to offer the right to a personal health budget as part of the personalised care planning process.


Available at: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_122736.pdf

- 'During 2011, choice should be introduced in care for long term conditions as part of personalised care planning.'
• The government will continue with, and further develop, the personal health budget pilot programme, by extending existing sites and encouraging proposals for additional sites in 2011/12.
• The results of an evaluation of the pilot scheme will inform a wider, more general roll-out of the scheme in 2012.

1.4 Department of Health (2006) Our Health, our care, our say: a new direction for community services.


• Management of long term conditions by encouragement of self care is the foundation of the Our Health, Our Care, Our Say white paper published in January 2006. In terms of care planning, the Department of Health set out its commitment to:
  o Do more to support people with long term conditions to self care.
  o Design services around the individual rather than forcing their needs to fit around the service.
• The white paper stated that by:
  o ‘2008 we would expect everyone with long term health and social care needs to have an integrated care plan if they want one’.
  o ‘2010 we would expect everyone with a long term condition to be offered a care plan’.


Available at: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PolicyAndGuidance/DH_4002951

• Standard 3 of the National Service Framework for Diabetes states: All children, young people and adults with diabetes will receive a service which encourages partnership in decision-making, supports them in managing their diabetes and helps them to adopt and maintain a healthy lifestyle. This will be reflected in an agreed and shared care plan in an appropriate format and language. Where appropriate, parents and carers should be fully engaged in this process.’
• Care planning together with structured diabetes education is a key intervention in implementing this standard.
2.0 UK national guidelines, reports and tools


Available at: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_085825

- A review of the NHS was carried out by clinical leads from 10 strategic health authorities and sets out their visions for the future of health and healthcare.
- The review highlights the changing expectations of the public, 'this will mean allowing people to exercise choice and be partners in decisions about their own care, shaping and directing it with high quality information and support'.
- The report endorses the use of care planning; stating that, 'Care planning creates packages of care that are personal to the patient. It involves working with professionals who really understand their needs, to agree goals, the services chosen, and how and where to access them. Personal care plans are agreed by the individual and a lead professional'.

2.2 Department of Health and Diabetes UK. Care Planning in Diabetes: Report from the joint Department of Health and Diabetes UK Care Planning Working Group, 2006.

Available at: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_063081

- This document contains guidance on the care planning process for diabetes services, and is divided into seven sections:
  Section 1: Introduction
  Section 2: Policy context
  - The national policy documents relating to care planning are summarised, including:
    - The Diabetes National Service Framework.
    - 'Our Health, our care, our say: a new direction for community services' white paper.
    - 'Building on the best: Choice, responsiveness and equity in the NHS' strategy paper.
    - An overview of the 'Year of Care' project is given.
  Section 3: What is care planning?
  - An overview of the principle and processes of care planning are described, and defines care planning as:
    'a process which offers people active involvement in deciding, agreeing and owning how their diabetes will be managed. It aims to help people with diabetes achieve optimum health through a partnership approach with health professionals in order to learn about diabetes, manage it and related conditions better and to cope with it in their daily lives.'
  - The principles of care planning are described, briefly:
    - A holistic approach which is patient-centred rather than condition-centred.
    - Partnership working, with two-way communication, negotiation and joint decision-making.
    - The person with diabetes and the healthcare professional make an equal contribution to the consultation.
    - The care planning approach takes into account that people with diabetes will engage in the process in different ways; therefore, the process should be flexible and responsive.
    - Care planning can be used for all long term-conditions, and for people with more than one long term condition, care planning can provide a single patient-centred review, rather than multiple reviews for each condition.
• The Disease-Illness Model has been proposed as a way of achieving the principles of care planning, and is described, briefly:
  o The model suggests the healthcare professional's perspective of disease and pathology should be considered alongside the patient's experience of the condition (e.g. ideas, concerns, expectations, thoughts, feelings etc.); both perspectives should be given equal importance.
  o During the care planning consultation, the person with diabetes and the healthcare professional should raise and discuss their respective concerns; these should be prioritised, and followed by a discussion of the options available to make mutually agreed informed decisions about continuing care.
  o The benefits of care planning:
    ✷ For the individual, the process should ensure all personal, social and healthcare matters are considered.
    ✷ For the organisation, care planning should 'enhance and promote coordination of health and social care services and support local commission'.

• Details of the 'care planning model' are described; the model was developed by the National Diabetes Care Planning Working Group and is based on the Diabetes NSF and the Matrix report Good care planning for people with long term conditions commissioned by the NHS Modernisation Agency.
• The model is based on evidence from clinical practice, psychology and education, and provides a process of negotiation and shared decision making between the healthcare professional and the person with diabetes (and carers/family members where appropriate).
  o The healthcare professional and the person with diabetes bring their agenda/story to the consultation.
  o The process provides an opportunity for the person with diabetes to ask questions and raise concerns about the topics they have brought to the consultation.
  o The model lists four potential broad topics for discussion: learning about diabetes, managing diabetes, living with diabetes, and other health and social issues. These topics are designed to encompass the overall impact diabetes can have on the individual; therefore, psychological and social issues are addressed alongside the biomedical management of the condition and prevention of disease complications.
  o Information is shared and discussed and an agenda is negotiated. The healthcare professional should ensure the discussions and decisions are made in full collaboration with the individual; healthcare professionals may need to develop specific listening, communication and consultation skills, particularly when dealing with difficult or challenging situations.
  o An agreed action plan should be developed, with responsibilities attributed to each of the actions, together with a timeline for the actions to be reviewed.
  o The outcomes of the care planning consultation should be recorded in some form of document (e.g. a care plan); the document should include choices, preferences and action plans. The care plan should be available when the person with diabetes accesses any part of the service including during an inpatient or acute episode.
  o The importance of distinguishing between the process of care planning (i.e. a verb) and a care plan (i.e. a noun) is highlighted.

Section 4: Evidence base for care planning
• Evidence providing the theoretical basis of the care planning model is presented. Evidence for each component of the model is reviewed, including:
  o The individual's story and the professional's story.
  o Learning about and managing diabetes.
Living with diabetes and other health and social issues.
Sharing information and negotiating an action plan.
Taking action.

Lessons for the implementation of care planning and the need for further research are also discussed.

Section 5: Workforce
The challenges of changing from a condition- or practitioner-led approach to a patient-led approach are discussed; one important aspect of this change is equipping healthcare professionals with the skills and competencies necessary to support patients in the management of their own condition.
The National Workforce Competences for Diabetes produced by Skills for Health relating to care planning are presented.
Examples of specialist competences for staff with particular roles are also given.
Identification of competencies of individuals or groups of staff can provide the basis of skills development; further discussion of the workforce skills profile, identification of gaps and the development of strategies to fill gaps are presented.

Section 6: Putting it into practice
Key elements of the care planning process, together with suggestions and examples of how to put them into practice are set out in this section.
Commissioning care planning: essential elements that need to be in place in order to put care planning into practice are detailed. A discussion of what these elements mean for people with diabetes, healthcare professionals, and managers/team-leaders is presented.
Systems and processes: a series of processes (to be used before, during and after the care planning consultation) that can aid the care planning process are listed.

Section 7: Quality assurance
The purpose and processes of quality assurance in care planning are outlined.
The document defines quality assurance as, 'a systematic process of developing and using a set of indicators to assess whether a service or intervention is being delivered to specified requirements. It is concerned with the process of care planning rather than the outcomes.'
Example questions (regarding the care planning service and process), and a case study are presented to help develop quality assurance for care planning.

2.3 Department of Health (2006) Supporting people with long term conditions to self care: A guide to developing local strategies and good practice.
Available at: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4130868.pdf
This best practice guidance discusses the various approaches to self care, including the use of care planning.
Details of how the NHS can support self care in people with long term conditions are set out, including:
Developing a self care support strategy
Skills and training
Information
Tools and devices
Support networks.
2.4 Department of Health (2009) Your health, your way: a guide to long term conditions and self care – Information for healthcare professionals.
Available at: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_097586.pdf

- A booklet designed to raise awareness of the different aspects of ‘Your Health, your way – a guide to long term conditions and self care’, which was launched by NHS Choices in November 2008.
- ‘Your health, your way’ is not a new policy, but brings together work and information that already exists.
- The primary aims of ‘Your health, your way’ are to ‘empower and support people with long term conditions to understand their own needs and be able to make informed choices about the self care support they wish to access from the resources available.’ Promoting the discussion between health and social care professionals and individuals with long term conditions about the options available to support self care is an essential part of this process.
- Definitions for ‘self care support’, ‘personalised care planning’, ‘self care’, ‘a care plan’ and ‘an information prescription’ are given.
- The booklet outlines the importance and value of self care for individuals living with long term conditions and explains how supporting self care can improve quality of life.
- The different approaches of self care support and strategies for effective self care are described.
- Five areas of self care have been identified as being key to achieving the aims of ‘Your health, your way’ and are all discussed in detail:
  1. Information
  2. Skills and knowledge training
  3. Tools and self-monitoring devices
  4. Healthy lifestyle choices
  5. Support networks
- Supporting self care by the process of personalised care planning is discussed.
- The care plan is discussed; a cautionary reference is made to the use of templates in the care planning process.


- Provides commissioners of health and social care services with information and support to embed personalised care planning at a local level.
- The document describes personalised and integrated care planning, highlighting the benefits, and explains what it means for commissioners and how it can be implemented locally.
2.6 **NHS Primary Care Commissioning (2009) Outline specification for personalised care planning.**


- An Outline Service Specification developed to ‘assist commissioners put into place appropriate arrangements to ensure people with long term conditions have informed choice of, and access to, services that best enable them to manage their own condition’.
- This specification was designed to sit alongside the Commissioning Personalised Care Planning document (see section 1.4).

2.7 **Department of Health (2010) Improving the health and well-being of people with long term conditions: World class services for people with long term conditions – information tool for commissioners.**

Available at: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_111122

- An information tool highlighting the vision of what a good service for people with long term conditions is, and provides commissioners with practical suggestions to help them achieve this vision.

2.8 **Improving care for people with long term conditions: 'at a glance’ information sheets for healthcare professionals.**

Available at: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_121603

- A series of information sheets for healthcare professionals, those delivering health budgets, and anyone supporting people with long term conditions.
- Topics include care planning, care coordination, managing need and assessment of risk, motivating people to self care, goal setting and action planning and end of life care.

2.9 **NHS information prescriptions online resource.**

Available at: http://www.informationprescription.info/resource/

- Information prescriptions can be provided as part of a care plan; signposting people with long term conditions to reliable sources of information that enable them to take more control in managing their condition.
- This website contains information and ideas for health and social care organisations on how to start developing processes for delivering information prescriptions; examples of information templates, prescribing procedures, patient leaflets etc. from pilot sites are provided.

2.10 **Personal health budgets.**

- Around half of the primary care trusts in England are currently participating in the personal health budgets pilot programme.
- Nine of the pilot sites include personal health budgets for people with diabetes in their scope.
- Details of the personal health budgets pilot programme can be found on the Department of Health website, available at: http://www.dh.gov.uk/en/Healthcare/Personalhealthbudgets/DH_109426
3.0 Other UK reports and guidelines


Available at: http://www.sdo.nihr.ac.uk/projdetails.php?ref=08-1809-249

- The aim of this scoping exercise was to provide an overview of the current issues and developments in the organisation and delivery of diabetes services in the UK, and consists of: a review of the literature, the description and findings of a patient participation event and an e-survey of diabetes professionals and patients, and a confirmatory event.

Literature Review
- A summary of the literature relating to the organisation and delivery of diabetes services is presented. In terms of care planning:
  - The principles of the Year of Care project are discussed.
    - The Year of Care is a whole system approach that integrates care planning with population level analysis, service development, commissioning and evaluation.
  - Co-creating Health, coordinated by the Health Foundation, is also discussed.
    - Co-creating Health is a national initiative focusing on training healthcare professionals and patients to be better collaborators in care planning.
  - The Chronic Care Model (CCM) is a whole systems model developed in the USA to address the complexities of chronic disease management and is discussed in the review (Year of Care draws upon this model).

E-survey
- 423 diabetes professionals, predominantly dietitians (37.6%) and diabetes nurses (32.0%), and 495 patients took part in the e-survey. In terms of care planning, the following findings were found:
  - 30% of professional respondents reported that care was rarely patient led.
  - 27% of professional respondents reported that care planning occurred most of the time.
  - 35% of patients felt care decisions were made jointly with healthcare professionals most of the time.
  - 27% of patients felt care decisions were made jointly with healthcare professionals some of the time.
  - 38% of patients felt care decisions were rarely or never made jointly with healthcare professionals.
  - Overall, 65% of patients indicated that they were involved in their care most of the time.

3.2 Diabetes UK (2005) Recommendations for the provision of services in primary care for people with diabetes.

Available at: http://www.diabetes.org.uk/Documents/Professionals/primary_recs.pdf

- Guidance for healthcare professionals working in primary care on the organisation and delivery of services for people with diabetes, including the process of planning.
- The recommendations relating to care planning include:
  - Diabetes care should be patient-centred and should aim to empower people with diabetes to manage their own condition.
  - Professionals involved in the care of people with diabetes should encourage shared decision making to allow people with diabetes to have choice, input and control of their care.
  - A negotiated and agreed care plan should be set out in an appropriate format and language for each individual, and reviewed as part of the care planning process.
  - Where appropriate, parents and carers should also be fully engaged in the care planning process.
  - Members of the healthcare team involved in diabetes care need to be trained in care planning skills.
  - The importance of dietary care planning is also highlighted.

Available at: http://www.diabetes.org.uk/Documents/About%20Us/Our%20views/Care%20recs/Care-homes-0110.pdf

- A number of deficiencies in the provision of diabetes care for people residing in care homes have been identified; one of the key gaps in care is the lack of care planning.
- Effective diabetes care requires a documented individualised care plan that has been agreed between the resident (or family/carer), GP and care home staff. Specific care plan details are provided and should include:
  - Details of the key roles and responsibilities of healthcare professionals and care home staff.
  - Information on the individual's specific signs/symptoms of hypoglycaemia.
  - Dietary plan.
  - Details of related complications, co-morbidities, current and ongoing medical and social care.
  - Rehabilitation programme.
  - Annual review procedure.
  - Regular screening for diabetes-related complications.
  - A set of agreed metabolic targets.
  - A series of outcome measures to ensure quality of care.


- The Children's Charter was developed by Diabetes UK in collaboration with children and young people with diabetes, their carers and healthcare professionals. The charter consists of a series of ‘bold statements about what must happen to ensure high quality care, and to help achieve good physical and emotional wellbeing’.
- The Children's Charter statements relevant to care planning are:
  - ‘All children and young people with diabetes should have a say in decisions about their care and in designing the services they receive.’
    ✤ Using the care planning process actively involves people ‘deciding, agreeing and owning how their diabetes will be managed’.
    ✤ More research is required to establish how ‘best to implement the care planning process involving children and young people, their families, healthcare professionals and schools’.
  - ‘All children and young people with diabetes should experience services that address all their needs in a joined up manner.’
    ✤ Among other things, to ensure this happens, ‘care planning needs to be effectively embedded as a process by all health and social care teams, to ensure that care delivery is needs-led and effectively coordinated’.


Available at: http://www.library.nhs.uk/diabetes/viewResource.aspx?resID=381285

- A Task and Finish Group was set up in 2008 to address concerns expressed by people with diabetes and healthcare professionals about the lack of integration between primary and secondary care.
- The importance of care planning in facilitating integration is highlighted in this document.
- The report proposes that individualised care planning, together with training in consultation skills required for effective care planning, are key characteristics of an integrated diabetes service.


- This document considers the components of good support for self-management of diabetes and highlights the findings from key surveys. The report also outlines the minimum that should be provided to each person living with diabetes to enable them to self-manage their condition.

- In relation to care planning, key survey findings include:
  - **2008 Local progress**
    - About half of PCTs in England require personalised care plans to be agreed with people with newly diagnosed diabetes (this has decreased from two-thirds requiring this to be in place in 2007).
    - In Wales, over three-quarters of local health boards (LHBs) require that personalised care plans are agreed with people with diabetes, and over half have trained all their healthcare professionals in care planning.
    - In Northern Ireland, two out of three Trusts that responded provide 24-hour telephone support, personalised care planning and training of healthcare professionals.
  - **2009 Member survey**
    - About two-thirds of members said they had discussed their goals in caring for their diabetes in the last 12 months.
    - However, only about a third of people were given their test results before their annual review.
  - **2009 Children and young people member survey**
    - When children and young people were asked about the extent to which they had been able to talk about goals around caring for their diabetes, 39 per cent said almost always, 41 per cent said some of the time and less than 20 per cent said rarely or not at all.
  - **Non-member short survey**
    - Over two-thirds of respondents felt confident or very confident in how they manage their diabetes.
    - While not asked specifically about care planning, anecdotal evidence suggested that they felt more discussion and agreement was needed between themselves and their healthcare professionals, highlighting monitoring, maintaining a healthy diet and exercise, blood pressure and blood glucose monitoring targets in particular.

- The report concludes:
  - Although some progress is being made in involving people in the management of their diabetes through care planning, there is still some way to go before care planning is available to all as an integral part of their care process.
  - Training for healthcare professionals needs to be in place to ensure that they are able to support care planning.

- Key priority areas for action relating to care planning include:
  - Provision of, and signposting to, tailored information and awareness programmes in varying formats.
  - Structured and regular diabetes-specific and general self-management education for people with newly diagnosed and established diabetes.
  - Enhanced partnership working and goal setting through care planning, including contextualising tests, measurements and self-monitoring.
  - Making results available to people before their appointments.
  - Appropriate access to self-monitoring equipment and education to help people with diabetes interpret and use results.
  - All healthcare professionals should have access to skills-based training to support self-management and care planning, including group facilitation, active listening, goal setting and problem-solving skills.
4.0 Care planning models and initiatives

4.1 Year of Care.

- The Year of Care programme aims to learn how routine care can be redesigned and commissioned to provide a personalised approach for people with long term conditions.
- The initiative is a partnership between the Department of Health, Diabetes UK, The Health Foundation and NHS Diabetes.
- There were three initial pilot sites: North of Tyne, Calderdale, and Kirklees and Tower Hamlets.
- NHS Diabetes funded Diabetes UK to develop and deliver a national care planning training package within England.

4.1.1 Year of Care website.

Available at: http://www.diabetes.nhs.uk/new_year_of_care/

- A comprehensive guide to Year of Care.
- Resources include:
  - Thank you for the Petunias, a guide and supporting documentation for developing and commissioning non-traditional providers to support the self management of people with long term conditions
  - A report detailing the findings from the pilot project.
  - Videos capturing the experiences of service users and healthcare professionals.

4.1.2 Getting to Grips with Year of Care: A Practical Guide, October 2008.

Published by the Year of Care Programme (Diabetes UK, NHS National Diabetes Support Team1, Department of Health, Health Foundation).


- This guide is aimed at commissioners, clinicians and networks interested in setting up Year of Care programmes locally.
- Focus is on the first year (‘preparatory phase’) of Year of Care, and provides information and guidance on what needs to be put into place, particularly in terms of commissioning.
- The guide summarises the benefits of Year of Care to: Chief Executives and Boards, people with long term conditions, clinicians and commissioners.
- A summary of the principles of Year of Care are described:
  - Year of Care describes ‘the care people with long term conditions should expect to receive in a year, including support for self management’, which can be costed and commissioned.
  - This approach puts people with long term conditions ‘in the driving seat of their care and supports them to self manage’.
  - A key process at the heart of Year of Care is care planning; the collaborative regular consultations between clinicians and the individual with a long term condition.
  - Care planning can be seen as ‘micro-level commissioning’; that is, the choices individuals make about the services or support options available to them.
  - The challenge is to link the choices made by individuals into commissioning decisions made at a population level (macro-level commissioning).

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1 Now NHS Diabetes
To achieve the best outcomes, both effective care planning and commissioning have to be in place and working together.

- Year of Care is further clarified by a discussion of 'what the Year of Care is not'.
  - For example, it is highlighted that Year of Care is not about describing new models or pathways of care; however, the Year of Care pilot sites have found that to take full advantage of everything that Year of Care has to offer, the underlying model of care needs to be addressed.

- A justification of why Year of Care should be adopted is presented.
  - Although most people with diabetes have regular diabetes checks, less than half discuss their goals in managing their condition; having clearly articulated goals is the most important link with changing health behaviours.

- The policy context of Year of Care is set out, including; Lord Darzi's 2008 report, 'High Quality Care for All: NHS Next Stage Review Final Report' and NSF for Diabetes.

4.2 Co-creating Health.

Co-creating Health webpage, available at:
http://www.health.org.uk/areas-of-work/improvement-programmes/co-creating-health

Co-creating Health briefing paper, available at:

- Co-creating Health is a current national initiative coordinated by the Health Foundation, and involves training healthcare professionals and patients to be better collaborators in care planning.

- The programme aims to embed self management support within mainstream health services across the UK and equip individuals and clinicians to work in partnership to achieve better outcomes.

- The programme focuses on 'developing the skills and attitudes of both people with long term conditions and their clinicians, while also ensuring systems and services are designed to support and facilitate self management'.

- Four pilot sites are focusing on self management support for people with diabetes, and are delivering the Co-creating Health programme across primary and secondary care.

- There is an ongoing evaluation of the project, which focuses on the experience of care rather than the clinical effects of this shift in care provision.

- The Co-creating Health Briefing paper describes The Health Foundation's Co-creating Health initiative and outlines the need for an effective integrated approach to self-management support, and also includes early experiences from the Co-creating Health teams.
5.0 **Patient-held records and information prescriptions.**

5.1 **Diabetes UK position statement on patient-held records.**

Available at: http://www.diabetes.org.uk/About_us/Our_Views/Position_statements/
Patient_Held_Records

- Briefly, Diabetes UK endorses any initiative that supports people with diabetes to manage their condition.
- Patient-held records can:
  - Empower people with diabetes, putting them at the centre of their care, giving them greater choice and control as part of the care planning process.
  - Support integrated diabetes care by facilitating communication between primary and secondary care services.
- The purpose of patient-held records needs to be communicated to patients to maximise benefit.
- People who do not wish to hold their records should not be forced to do so.
- Consideration should be given to the needs of those in particular groups; the development of patient-held records should be sensitive to cultural, ethnic and linguistic differences.
- The needs of people with disabilities, low literacy and communication or learning difficulties must also be addressed.

5.2 **Diabetes UK general guidelines and a standard template for a patient-held record.**

Available at: http://www.diabetes.org.uk/About_us/Our_Views/Care_recommendations/Patient_held_records/

- The content of patient-held records will vary from group to group, for example, an adult's record will be very different from that of a child.
- Records will also vary between individuals depending on what the user wants them to contain.
- As a minimum, the following should be included in all patient-held records:
  - Patient contact details
  - Patient's medical details
  - Explanatory details
  - Instruction for emergencies
  - Education checklist
  - Personal treatment plan
  - Regular (3-6 month) checks
  - Annual review checks
  - Space for patients own notes
  - Glossary of medical terms.

5.3 **NHS Employers (2010) Information prescriptions.**

Available at:
http://www.nhsemployers.org/PlanningYourWorkforce/LongTermConditions/InformationPrescriptions/Pages/AboutInformationPrescriptions_Final.aspx

- NHS Employers have produced an e-learning package and self-assessment management tool to support staff in the delivery of information prescriptions.
• An *introduction to delivering information prescriptions* e-learning module is a free interactive training course designed to help health and social care staff understand and deliver information prescriptions, develop the skills and competencies required for assessing information needs, and prescribing appropriate information.

• The *self-assessment management* tool covers the steps an organisation needs to take to provide information prescriptions, as well as identifying what organisational and workforce support is needed.

### 5.4 Evaluation of Information Prescriptions: Final Summary Report.

Available at: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_086888.pdf

• The Department of Health recruited 20 pilot sites to test and provide evidence on the effectiveness and impact of information prescriptions on patients, carers, professionals and organisations, including the voluntary sector.

• The pilots were located in a range of health and social care settings, and addressed a variety of conditions including diabetes.

• Many of the pilots were delivered on the basis of partnership arrangements between national voluntary sector organisations and local statutory health and social care services.

• The report provides a brief summary of each pilot site, and provides numerous recommendations to support national and local delivery of information prescriptions.
6.0 Online training and education tools


Available at: http://www.e-lfh.org.uk/projects/pcp/

- A personalised care planning e-learning course developed by NHS Employers on behalf of the Department of Health and delivered by the Department of Health e-learning for Healthcare (e-LfH).
- Aimed at health and social care professionals involved in caring for people with long term conditions.
- The course comprises three modules which can be completed at the users own pace.
  - Module 1: An Introduction to personalised care planning.
    - Understand what personalised care planning is, who it is for and why it is important.
  - Module 2: Understanding how personalised care planning works.
    - Understand the steps needed to introduce personalised care planning and the four phases of the consultation cycle.
  - Module 3: Skills and behaviours for effective personalised care planning.
    - Understand the skills required to implement personalised care plans effectively.
- The course also includes two case studies and a knowledge assessment; in addition, there is information on common core principles and the NHS Knowledge Skills Framework.
7.0 The evidence base for care planning.

7.1 Department of Health and Diabetes UK. Care Planning in Diabetes: Report from the joint Department of Health and Diabetes UK Care Planning Working Group, 2006.

Available at: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_063081

- This report contains a review of the evidence base for the development of the care planning model for diabetes, but highlights much of the evidence comes from related conditions rather than diabetes, therefore more research is required.
- The review presents evidence for each of the components of the care planning model described in the report (see appendix for details of individual references), briefly:

  • The individual’s story and the professional’s story.
    - Provides evidence from observation studies of an association between communications skills and health outcomes.
    - Training healthcare professionals in patient-centred approaches to clinical consultations may increase measures of patient-centred care; however, there is limited evidence to suggest this translates into improved clinical outcomes.
    - One study suggests healthcare professionals may find it difficult to sustain a patient-centred approach, particularly if there is a perceived conflict with clinical outcomes.
    - Another study reports that although patients receiving care from professionals trained in patient-centred diabetes care reported better communication, treatment satisfaction and wellbeing, they had gained weight and had lower knowledge scores compared with patients receiving usual care. The authors conclude that professionals should not lose focus on disease management.

  • Learning about and managing diabetes.
    - Evidence suggests written information tailored to the needs of the individual or a group of people is more likely to be perceived as relevant and lead to behaviour change.
    - Computerised knowledge management is becoming a vital component of quality diabetes care, and may be beneficial in improving diabetes-related outcomes.

  • Living with diabetes and other health and social issues.
    - The review highlights some of the other reviews and theoretical literature indicating that self-management can improve psychological health, empower the individual and enhance self-efficiency, leading to behaviour change and improved clinical outcomes.

  • Sharing information and negotiating an action plan.
    - Evidence suggests patient behaviour can be changed by directly enhancing patient participation via pre-consultation coaching, learner-centred group education, group consultations, or automated telephone management. These interventions have shown to be beneficial in improving patient self care and diabetes outcomes.
    - The review also highlights that good decision aids can make a useful contribution to the care planning process, by improving knowledge and participation in the decision making process.

  • Taking action.
    - Evidence assessing the adherence of medicine regimes in people with diabetes appears to be inconclusive.
    - A review of studies from across a range of conditions found most simple measures lead to adherence of short-term treatment regimes; however, these were less effective for long term conditions.
In addition to the evidence presented in this report, the following papers have been identified:


- A systematic review assessing the effectiveness of interventions to improve healthcare professionals’ adoption of shared decision making.
- Randomised controlled trials (RCTs), well-designed quasi-experimental studies (controlled clinical trials, controlled before and after studies, and interrupted time series analyses) that investigated any intervention aimed at improving the adoption of shared decision making by healthcare professionals were included in the review.
- Five RCTs were identified, all of which were conducted in outpatient settings (four studies targeted physicians only and one targeted nurses only).
- Only two of the studies demonstrated that the intervention had a statistically significant effect on professionals adopting shared decision making.
- The first of these studies compared two single patient-mediated interventions: the Statin Choice decision aid versus a standard Mayo patient education pamphlet.
  - The Statin Choice decision aid group performed better than the educational pamphlet group.
- The second study compared multifaceted intervention (distribution of educational material, educational meeting and audit, and feedback) to usual care.
- The authors conclude they could not draw any firm conclusions about the most effective types of intervention for increasing healthcare professional adoption of shared decision making.


- A small study carried out in Australia designed to understand how multidisciplinary care plans are being used in the management of patients with diabetes, and assess the role of collaboration in care planning.
- Participants: 38 people from three New South Wales Divisions of General Practice and included 19 GPs, eight diabetes-related allied health providers (AHPs), two endocrinologists, and nine adults with type 2 diabetes.
- Regarding the perspectives and use of care plans, the study found:
  - GPs used care plans to organise clinical care and help patients access allied health providers, but GPs rarely used care plans to communicate information about patients to other providers (other forms of communication are preferred e.g. referral letters/telephone calls).
  - Written care plans were used by GPs to educate patients about their care and to motivate behaviour change.
  - Other healthcare providers thought care plans were more beneficial for GPs than for themselves.
  - AHPs felt care planning had increased GPs’ use of their services and had improved patient access to services.
  - Many AHPs felt sceptical about the benefits of written care plans as they rarely included personal information other than a list of medical problems.
  - AHPs and endocrinologists did not change their approach to management on the basis of a written care plan.
Patients recalled very little about their care plans and none of the patients reported using their written plans in the day-to-day management of their diabetes.

• Regarding care planning, the study found:
  o In general, GPs did not discuss care plans with other healthcare providers.
  o Several GPs reported care planning has increased their knowledge of AHPs skills, and most GPs thought it was disrespectful to give other healthcare providers specific instructions; therefore, care plans described their roles in general terms.
  o GPs felt a strong sense of responsibility for the patient's health outcomes and felt negotiation about treatment goals was an abdication of their professional responsibility.
  o Other healthcare providers reported care planning had not changed their beliefs about their roles, and that GPs were the coordinators of care and most other healthcare providers did not expect to be consulted during the development of a care plan.
  o Several AHPs thought their role was to translate the care plan into a set of achievable self-management goals and tasks, believing that GPs rarely had the time to personalise care and focused on the 'medical-model' whilst they had more expertise in the 'patient-centred' model.
  o Patients did not expect to participate in care planning; mainly because the care plans were seen to document clinical goals and activities of which they had no expertise. Furthermore, patients did not believe there was any uncertainty about the best treatment so thought there were no real options to discuss.
8.0 References


14. NHS information prescriptions online resource. Available at: http://www.informationprescription.info/resource/


24. Diabetes UK position statement on patient-held records. Available at: http://www.diabetes.org.uk/About_us/Our_Views/Position_statements/Patient_Held_Records

25. Diabetes UK general guidelines and a standard template for a patient-held record. Available at: http://www.diabetes.org.uk/About_us/Our_Views/Care_recommendations/Patient_held_records/


9.0 Appendix

The following references detail the evidence presented in section 7.1
