Empowering patients through the House of Care: building a patient centred future for people with type 2 diabetes

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It is hard to imagine a healthcare system being sustainable unless a lot more people take control over their own health and their own healthcare”

Sir David Nicholson
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Foreword by Jamie Reed MP

I am pleased to introduce *Empowering patients through the House of Care: building a patient centred future for people with type 2 diabetes*, a report which outlines some of the key challenges preventing the delivery of personalised care planning for people with type 2 diabetes in the NHS.

The growth in the number of people with diabetes is a public health crisis. The latest figures indicate that 3.2 million people in the UK are currently living with either type 1 or type 2 diabetes, with as many as 630,000 people unaware they have the condition at all.¹ The NHS already spends over £10 billion every year on treating diabetes, with a significant amount of this due to patients developing avoidable complications.¹ This problem will only get worse as nearly one in four UK adults are clinically obese and over seven million people are at risk of developing type 2 diabetes.²,³

I believe that the provision of personalised care planning for people with type 2 diabetes should be a priority for the NHS. We know that when patients are actively involved in the planning of their own care, their outcomes are often better than those who do not. Yet I am aware that too few people are given the opportunity to do this. Diabetes UK reports that nearly two-thirds of people with diabetes do not have a care plan despite it being recommended by NICE and one of Diabetes UK’s 15 Healthcare Essentials.³

The Year of Care pilots undertaken by the Department of Health, the Health Foundation and Diabetes UK demonstrated that care planning can be delivered as part of routine care for people with diabetes and the development of the House of Care provides all local areas with the tools they need to put this best practice in place. However, as the King’s Fund has recently noted, local implementation has been slow.⁴

In July 2014 I chaired a Parliamentary Roundtable to consider the barriers preventing the delivery of care planning for people with type 2 diabetes. Those areas that have been implementing the House of Care tell me that patients are more engaged, that professionals experience greater satisfaction in the workplace and that clinical outcomes improve.

This report is a welcome addition to the work being carried out by the Year of Care Partnerships and the Coalition for Collaborative Care. It is time for politicians, policy makers, clinicians and commissioners to ensure that personalised care planning becomes standard for all people with type 2 diabetes. Ensuring that we are able to continue providing a sustainable future for the NHS relies on patients being supported to manage their own health effectively.

Jamie Reed MP
Member of Parliament for Copeland
Shadow Health Minister
Executive Summary

Type 2 diabetes is one of the biggest challenges facing the NHS. It is estimated that 3.2 million people have been diagnosed with either type 1 or type 2 diabetes and a further 630,000 people are unaware that they have the disease.\(^1\) It is well known that developing complications is a significant risk factor for people with type 2 diabetes. Common complications include heart disease, renal failure and amputations.\(^2\) Estimates suggest that type 2 diabetes costs the NHS £8.8bn every year, with 80 per cent of this cost spent on treating avoidable complications.\(^3\) Furthermore, over 250,000 people in the UK were diagnosed with diabetes in 2012, which is around one person every 3 minutes.\(^3\) By 2025 it is projected that over 5 million people will be diagnosed with diabetes. With a £30bn funding gap identified in the NHS budget, this is simply not sustainable.\(^1\),\(^6\)

Whilst there have been significant advances in improving outcomes for people with type 2 diabetes, the increasing numbers of people being diagnosed with the condition, in parallel with the rise in obesity, suggests that there needs to be greater focus on prevention.\(^7\) It has been recognised that empowering people to take more control over their health can lead to better outcomes and lower healthcare costs as patients experience fewer complications and emergency hospital admissions decrease. However, it is often not clear what empowering patients actually means.

The House of Care provides local areas with a delivery model to help make personalised care planning a reality. The fundamental philosophy behind the care planning approach is for HCPs to have better conversations with patients about what is important to them with regards to their health, what they want to achieve through their treatment and what will help them to manage their type 2 diabetes more effectively. By developing a greater mutual understanding of what matters to the patient, clinicians can ensure that interventions and support are right for that individual. Furthermore, patient education and local support services can give people with type 2 diabetes the confidence to take a more active role in their own healthcare.

Over the long term, this approach could result in fewer complications such as heart failure or amputations.\(^8\) With an estimated 2.7 million people diagnosed with diabetes in England, on average 12,500 people per CCG, the personal and financial impact of truly empowering people with type 2 diabetes could be significant.\(^1\) However, Diabetes UK reports that nearly 66 per cent of people with diabetes do not have a care plan and 31 per cent of people report never being offered structured education, even at initial diagnosis.\(^3\) The time to implement care planning and to have better conversations with patients is now.

The scope

A Parliamentary roundtable was convened to discuss the barriers preventing the implementation of personalised care planning for people with type 2 diabetes in the NHS. The aim of the roundtable was to bring together healthcare professionals and policy specialists with knowledge and experience of the House of Care model implementing care planning, to understand the challenges that they faced and the solutions that they put in place to overcome them. In addition, interviews were conducted with clinicians and health policy experts to provide further information for the development of this report.

This report focuses on type 2 diabetes, however the care planning approach can be applied to all long term conditions.

The report

The report is designed to help Parliamentarians, health policy makers, commissioners, clinical experts, clinical commissioning groups (CCGs) and professionals to understand the value of the House of Care. It provides insight into some of the challenges faced by those CCGs that have implemented care planning. Furthermore, the report includes case studies from Islington, Cumbria and Berkshire West which highlight some of the key challenges faced by clinicians and commissioners when trying to establish care planning in these areas.
It is estimated that 3.2 million people have been diagnosed with diabetes and a further 630,000 people are unaware that they have the disease.”
Roundtable participants

Jamie Reed MP, Chair of the Roundtable and Shadow Health Minister  
Dr Gary Adams, Associate Professor, University of Nottingham and IDDT trustee 
Julia Coles, Lead for Domain 2, Thames Valley Strategic Clinical Network  
Dr Angela Coulter, Visiting Fellow, The King’s Fund 
Jason Davies, Business Unit Director, Janssen  
Dr Angela Coulter, Visiting Fellow, The King’s Fund 
Professor Roger Gadsby MBE, Associate Clinical Professor, Warwick Medical School  
Dr Rob Gregory, Chair, Association of British Clinical Diabetologists 
Robin Hewings, Head of Policy, Diabetes UK  
Sir David Nicholson CBE, Former Chief Executive of NHS England  
Siobhan Pender, Senior Diabetes Specialist Nurse, Royal College of Nursing  
Dr Amrit Sachar, Consultant Liaison Psychiatrist, West London Mental Health Trust  
Claire Scott, Care Planning Project Lead, Berkshire West CCGs

Interviewees

Dr Manik Arora, GP, Nottingham City CCG  
Dr Richard Croft, Diabetes & Respiratory Lead, Berkshire West CCGs  
Dr Katie Coleman, Joint Vice Chair (Clinical), Islington CCG  
Dr Nick Lewis Barned, Clinical Fellow, Shared Decision Making and Support for Self Management, Royal College of Physicians  
Mary Newell-Price, Lead Heath Promotion and Supporting Self Management, Whittington Health  
Dr Rustam Rea, Founding Clinical Chair, First Diabetes  
Dr Sue Roberts, Chair, Year of Care Partnerships  
Bridget Turner, Director of Policy, Diabetes UK  
Dr Robert Westgate, GP, Brunswick House Medical Group

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Recommendations

This report shows that the introduction of care planning can have significant benefits for people with type 2 diabetes, clinicians and commissioners. The insight provided by the experts who attended the roundtable and participated in interviews demonstrates that there are measures that need to be taken at a national, local and individual level to ensure that care planning is understood and embedded in routine care.

1. To ensure that the NHS is truly patient centered there needs to be a significant culture change. NHS England and Health Education England should ensure that care planning training is an essential aspect of undergraduate and professional training which seeks to address a combination of clinicians’ mindset and attitudes, skills and infrastructure. Clinicians should be able to use their mandated training time to attend care planning training.

2. NHS England should implement a communications plan to ensure that local commissioners and healthcare professionals fully understand the concept of the House of Care and the implementation of personalised care planning.

3. NHS England should ensure that CCGs have the resources and guidance in place to build the House of Care at a local level.

4. NHS England should work with CCGs that want to have a greater role in the commissioning of primary care services. Where there is agreement from the CCG, GPs and the acute sector, NHS England should consider implementing locally developed funding flows to support the delivery of care planning for people with type 2 diabetes.

5. The Royal Colleges should seek to play a greater role in ensuring that personalised care planning is properly understood throughout the NHS.

6. Politicians and policy makers should ensure that personalised care planning is one of the foundations of future service re-organisations. Commissioners and clinicians should have to show how service changes will enable patients to play a greater role in their care.

7. NHS England needs to ensure that IT systems are able to share patient information appropriately. Both primary and secondary care professionals should be able to access up to date information about their patients. NHS England should ensure that patients are able to access their own information online.
Every CCG should aim to build its own House of Care. Furthermore, people with diabetes, patient group representatives, health and wellbeing boards and local authority representatives should be actively involved in its development.

Healthcare professionals should make the most of their limited time with patients by collecting information and sharing test results in advance of the consultation.

CCGs should seek to develop clinical leadership and advocacy for building the House of Care. In addition, CCGs should consider commissioning local facilitators or navigators to help practices with some of the organisational and cultural challenges of implementing care planning.

CCGs and local healthcare professionals need to understand that the House of Care presents the opportunity to empower disadvantaged and vulnerable people with type 2 diabetes, such as people with mental health problems or those more at risk from type 2 diabetes such as people from Black and Minority Ethnic (BME) backgrounds.

CCGs and practices should seek to empower patients through allowing online access to records.

CCGs should incentivise GP practices to undertake training in care planning, for example, through introducing a locally enhanced service or providing backfill.

CCGs should recognise that patients’ levels of engagement with care planning will vary according to their skills, knowledge and confidence. CCGs should assess a patient’s level of activation and provide the services that will encourage them to engage with care planning.

People with both type 2 diabetes and mental health problems are likely to have significant issues with self-management. The quality and availability of mental health diagnostics and support has improved over recent years, but people with diabetes often fail to get the help that they need. CCGs and clinicians need to work together to ensure that people with type 2 diabetes can access high quality mental health support if required.

Local Healthwatch representatives should ensure that local CCGs, Health and Wellbeing Boards and clinicians are delivering care planning for people with type 2 diabetes.

People with type 2 diabetes should be able to access a range of services, including those from the third sector, to help them to self-manage their condition effectively. CCGs should employ micro-commissioning to ensure that these services are available and are informed by the wishes of people with diabetes.

People with type 2 diabetes should be supported to demand care planning from their GP and to expect a more collaborative approach to their diabetes care.
Patient centred healthcare in the NHS

The growth in the number of people with long term conditions is a significant concern for the NHS. Currently, there are over 15 million people with a long term condition in England and by 2018 there will be an estimated 29 million people with multiple long term conditions (multi-morbidity). This is a particular problem for patients with diabetes as multi-morbidity is common. A study in 2012 found that 86 per cent of diabetes patients in Scotland had another health problem in addition to their diabetes. The study also found that in the most deprived 10th of the population 24 per cent of patients with diabetes have coronary heart disease, 28 per cent report having a painful condition and 21 per cent have depression. Diabetes is also the biggest cause of complications such as amputation, working age blindness, stroke and renal failure. Furthermore, there are an estimated 20,000 avoidable deaths due to the poor management of diabetes every year.

There have been attempts to improve the integration of health and social care services to provide a more joined-up approach for patients. The Coalition Government’s 14 Integration Pioneers have sought to provide examples of how different aspects of health and social care can be integrated to provide better care for patients. Furthermore, the development of Better Care Fund plans by CCGs and local authorities are designed to engender greater partnership working between local health and social care professionals. The Labour Party has also acknowledged the challenges presented by the growing number of people with long term conditions and the rise in multimorbidity. Andy Burnham MP has advocated the integration of health and social care to create a National Health and Care service. Under this system, CCGs would work with local authorities and health and wellbeing boards to achieve ‘Whole Person Care’ where the NHS treats the person rather than their individual diseases.

Care planning offers the NHS the opportunity to coordinate care around the patient; however there is still a preoccupation with trying to integrate structures to achieve coordination. They are not the same thing. Integrated care does not necessarily lead to coordinated care for patients, and coordinated care doesn’t require integrated structures to be successful.

The importance of care planning has been recognised at a national level. The National Service Framework for Diabetes (2003) called for partnership in decision making and support for self-management to be reflected in agreed care plans. In addition, the Department of Health White Paper *Our Health, Our Care, Our Say* committed to introduce personalised care planning for every person with a long term condition. Furthermore, in 2007 the Year of Care pilots programme, a partnership between the Department of Health, the Health Foundation and Diabetes UK, embedded care planning as the routine way of delivering healthcare.
Empowering patients through the House of Care: building a patient centred future for people with type 2 diabetes

The Government has made commitments to introducing care planning. This is recognised in the Mandate to NHS England which states that by 2015, “everyone with long-term conditions, including people with mental health problems, will be offered a personalised care plan that reflects their preferences and agreed decisions.”

Further to this, the Government’s response to the Health Select Committee Inquiry into Long Term Conditions 2014/15 specifically states that NHS England should “adopt and adapt the principles underpinning the House of Care approach as necessary and should seek to eliminate barriers to effective integrated working.”

Personalised Care Planning is also part of the NICE Quality Standard for people with type 2 diabetes, one of Diabetes UK’s 15 Healthcare Essentials and a policy priority for NHS England Domain Two Director Martin McShane. Furthermore, the Action for Diabetes strategy released in 2014 makes a specific commitment to helping CCGs to implement care planning for people with diabetes.

NHS England has made progress in raising awareness of the House of Care and has published an online toolkit providing CCGs and clinicians with a range of information to support the implementation of the House of Care at a local level. However, despite this, a recent report from The King’s Fund found that progress in delivering care planning has been slow. To help tackle this issue, the Coalition for Collaborative Care (CCC) has been established. The CCC is comprised of organisations such as Diabetes UK, the Royal College of Nursing, the Year of Care partnerships, NHS England, NHS Improving Quality, the Royal College of General Practitioners and National Voices.

What is Care Planning?

The fundamental philosophy behind the care planning approach is for HCPs to have better conversations with their patients about what is important to them with regards to their health, what they want to achieve through their treatment and what will help them to manage their type 2 diabetes more effectively.

Personalised care planning aims to ensure that patients are able to express their wishes and concerns over the way their type 2 diabetes is managed. Patients are encouraged to work with their healthcare team to agree their treatment goals, develop action plans and monitor progress of their condition. This is a continuous process rather than a one-off event. To be successful, care planning must transform the relationship between the clinician and the patient so that patients are equal partners in their care.

The Department of Health describes care planning as “a process which offers people active involvement in deciding, agreeing and owning how their condition will be managed. It is underpinned by the principles of patient-centredness and partnership working... It is an on-going process of two-way communication, negotiation and joint decision-making in which both the person... and the health care professionals make an equal contribution to the consultation.”

The patient must be at the centre of any efforts to coordinate care. National Voices developed a narrative to explain what this looks like from a patient perspective:

“Patients have just four or five hours in contact with healthcare professionals and thousands of hours out there on their own. The number one rule is that care planning should be all about them. However, we often connect all the things around them or for them – so that we are doing things to them, rather than with them.”

Dr Simon Eaton
The care planning process for people with type 2 diabetes

In a traditional model of diabetes care in a primary care setting, a patient would first undergo all of their tests (such as weight measurement, feet check or blood pressure) with a healthcare assistant or the practice nurse before having a consultation with the diabetes practice nurse straight afterwards. Alternatively, a healthcare assistant or practice nurse would take a blood sample in a patient’s first appointment and then send this to be analysed. Two weeks later, the patient would see the nurse again in a 20-40 minute appointment where further measurements would be taken, such as blood pressure and cholesterol levels.

Under the care planning model all of these tasks should be undertaken at the initial appointment. In some cases, healthcare assistants handle the first appointment and gather all of the relevant information from the patient. The results are then posted to the patient so they can look at them in their own time in advance of the consultation. The GP or the practice nurse then takes the second consultation, and the patient should be far more prepared to have an informed discussion about their care. The patient’s results sheet includes prompts to encourage the patient to think about what they want in terms of their goals for managing their condition(s).
The House of Care

The House of Care provides a flexible framework designed to help commissioners, healthcare professionals and patients to embrace and implement a system of care planning. Each component of the House needs to be present for personalised care planning to be truly effective. The components are:

**Truly empowered patients and carers** – patients and carers who are well informed about their disease are better placed to engage with healthcare professionals about their care.

**The engaged healthcare professional** – healthcare professionals who work in partnership with patients to manage their type 2 diabetes.

**Responsive commissioning** – the commissioning of national and local services that reflect the needs and preferences of patients, carers and clinicians.

**Organisational processes** – the development of clinical and organisational processes that support healthcare professionals and patients to deliver personalised care planning.

Instead of imposing nationally driven solutions on local healthcare professionals, who understand the needs of their populations better than anyone else, the House of Care should be designed and built by those who will be using it. The House of Care model is most effective when teams start with a blank house and work together to identify what services are already in place and working well, and what are not working so well or are needed in their local area for care planning to be implemented effectively.
Roundtable Discussion

The purpose of the Parliamentary roundtable was to identify the key barriers facing the NHS in trying to implement care planning and the House of Care. It is hoped that the following points will help to make local commissioners aware of some of the challenges so that these can be anticipated in the development of their own efforts to implement local care planning.

National barriers

Lack of understanding

The roundtable attendees acknowledged that numerous barriers exist at a national level which are preventing the House of Care model of personalised care planning from being implemented. Whilst NHS England and the Department of Health have supported the initiative, the attendees were concerned that there is a misunderstanding about exactly what is required for care planning to be successful.

Attendees agreed that politicians and policy makers need to ensure that care planning lies at the heart of future health policy initiatives and that where care planning is mandated, for example with the Direct Enhanced Service for Avoiding Unplanned Admissions, it is necessary to establish realistic timescales and to ensure that resources are available to allow healthcare professionals to get the appropriate training and support. It is essential that politicians and policy makers understand that the most important part of care planning is the quality of the conversation between healthcare professionals and patients so that it results in the patient taking a more active role in their disease management.

Culture and attitude

The participants noted that one of the biggest barriers to implementing the House of Care lies in the culture of the NHS. Many clinicians and healthcare professionals believe they are already delivering patient centred care. However, evidence from the roundtable suggests that this is not always the case. Furthermore, a review of the evidence on shared decision making literature found that this is one of the commonly held beliefs amongst healthcare professionals. Healthcare professionals have differing training needs in the area of personalised care planning and different understandings of what the term means.

"One of the reasons that we have had so many problems with patients not participating in their own care is because we do not involve them when we make decisions about their care. So now a change of attitude is required.”

Dr Gary Adams

Better training

To help deliver the cultural change required, the fundamental principles of care planning must be embedded in undergraduate training. Health Education England should ensure that accredited training and education courses in personalised care planning are available for all professionals. One healthcare professional noted that ”there needs to be fundamental training in conversation skills, which we did not have”. Furthermore, for the training to be effective, it must be accompanied by a shift in the clinician’s approach towards consultations so that both the person with diabetes and the healthcare professional are equal partners.

Whilst the introduction of the Direct Enhanced Service for Avoidable Admissions requires GPs to provide personalised care plans, it does not provide clinicians with the training to deliver them and serves to reinforce the perception that all GPs already have these skills.

"We need to be addressing all the different aspects of education at the same time. We need to do undergraduate training, postgraduate training, educating the public and educating patients; they all need to happen at the same time. I do not think you can do them one at one time or sequentially.”

Dr Amrit Sachar
Over seven million people could be at risk of developing type 2 diabetes and each year there are 20,000 deaths that could have been avoided. Between 2006 and 2011 rates of retinopathy in people with diabetes increased by 64 per cent, cases of stroke by 87 per cent and cardiac failure by 104 per cent. There is a need for all healthcare professionals who may come into contact with people with type 2 diabetes to have accurate and up to date training so that they can deliver the right care and refer patients to the most appropriate services.

Sharing information

A key aspect of the House of Care is the ability to share information between the patient and the health professionals involved in their care. Given the extent of comorbidities associated with type 2 diabetes, such as heart failure or foot ulcers; this might include a podiatrist or a cardiologist. However, achieving this is difficult for healthcare professionals as the IT systems used by different GP practices or across different sectors are often unable to share data. A significant issue is that secondary care clinicians do not always have access to information about other health problems or medical interventions that may have taken place since a patient’s last visit. A recent survey for YouGov found that 85 per cent of people are in favour of allowing any healthcare professional treating them to have electronic access to secure information from their GP health record. In addition, one third of those surveyed were ‘shocked’ that this was not already in place.

Financial barriers

Roundtable attendees expressed concern that the financial incentives regime in the NHS’ complex financial system does not support care planning. The Quality Outcomes Framework can encourage a ‘tick-box’ attitude rather than prioritising better conversations with patients, which is the central aspect of care planning. Furthermore, interviewees argued that Payment-by-Results (PbR) disincentivises referrals to secondary care due to the financial costs of the tariff and can prevent healthcare practitioners from forming strong relationships with each other, especially in a difficult financial environment.

Local barriers

One of the most important aspects of the House of Care is the process of identifying local needs and designing a House of Care which caters for the local population. It is essential that local clinicians, healthcare professionals, commissioners and patient group representatives contribute to a process which identifies where the local healthcare system needs to change and work together to design a plan to achieve this.

Clinical leadership and advocacy

One of the biggest barriers to achieving a system of local care planning is a lack of engagement with clinical and commissioning leaders to implement these changes. Areas that have been successful in implementing the House of Care such as the Islington, Cumbria, Tower Hamlets and Berkshire West CCGs have strong clinical leadership and a commitment to implementing the organisational and structural changes necessary to allow care planning to work effectively. In part, this is underpinned by an understanding that it is not enough to implement one or two aspects of the House of Care, or that introducing initiatives, such as patient education or training for healthcare professionals, in isolation will have the same effect. The roundtable attendees were clear that it is essential that the ‘walls’ of the House must connect together and work as part of a concerted plan, as otherwise the House will fall down.

In addition, both roundtable participants and interviewees found that one of the most significant barriers to the introduction of the House of Care model
in general practice is the impression that it will simply add to their already significant workload. However, the CCGs that are already implementing effective care planning report that it is a better way of working. It can free up time for GPs and nurses as a result of fewer review appointments and healthcare assistants taking on a greater share of the clinical work. It is important to note that there may be an initial time investment required as both clinicians and patients adapt to change.

A further challenge concerns the role of secondary care in the care planning process. There needs to be greater clarity and communication between primary care and secondary care to ensure that people with diabetes are able to have personalised care planning sessions with all of their healthcare professionals.

“Clinicians think that they don’t have the time to do care planning. Actually, if you take the time, things are more efficient and effective. Once clinicians understand the philosophy and what is required, they really see the benefits of patients being more engaged and involved in their own treatment. It makes for a much easier consultation.”
Claire Scott, Care Planning Project Lead, Berkshire West CCGs

“The messages I try and push whenever I teach healthcare professionals about personalised care planning is that it is just a different way of working. It is not necessarily a longer way of working and it is potentially a more efficient way of working.”
Dr Roger Gadsby

Working in partnership

During the discussion it was acknowledged that attempting any kind of change across multiple organisations and sectors requires a collaborative approach and trust between professionals.

Local authorities have an increasing level of responsibility for delivering public health and social care services to their community. Over 70,000 people with diabetes are currently using local authority funded social care, and this number is expected to rise to 130,000 by 2030, costing an estimated £2.5bn. As many as 37,625 people with diabetes are living in care homes. A recent audit from the Institute of Diabetes for Older People indicates that many of these care homes are failing to provide the necessary basic care and support for people with diabetes.

Furthermore, obesity is a significant problem for local authorities. Over 61 per cent of adults in the UK are considered to be overweight or obese and 23 per cent are clinically obese. With over seven million people at risk of developing type 2 diabetes in the UK, there is a considerable need to ensure that existing interventions are working and that strategies are developed which will improve outcomes further. Partnership working between healthcare commissioners, clinicians and local authorities is essential to tackle the rise of type 2 diabetes. The House of Care presents an opportunity for local leaders to work together to deal with this shared problem effectively.

“Unaligned funding streams

The roundtable attendees acknowledged that the financial and service barriers separating primary, secondary, mental and social care prevent people with type 2 diabetes receiving coordinated care from across different sectors. One particular challenge is that certain areas are funded differently to others. For example, primary care services are commissioned and funded directly by NHS England while acute and community care is commissioned by CCGs. The challenge for local leaders is that care is financed through multiple funding streams, such as the Quality and Outcomes Framework, the Payments by Results Tariff, CQUINs, and Best Practice Tariffs. Furthermore, roundtable attendees expressed frustration that the GP contract is designed and commissioned at a national level with
little consideration of the impact on the initiatives being implemented in local areas. Some of the professionals involved in the roundtable and interviews expressed a desire to have a greater role in the commissioning of GP services so that they align with local priorities.

There are national initiatives being established, such as the Better Care Fund and the co-commissioning of primary care, which can potentially give local commissioners and clinicians greater control over funding streams. Furthermore, alternative arrangements are being developed in parts of the NHS. For example, Somerset CCG only reports against a fraction of the measures in the QOF, with the funds being released to allow local clinicians to develop plans to improve the sustainability and integration of services.28

Training for Healthcare Professionals

The project participants stressed that healthcare professionals need training to deliver care planning properly, however this can be challenging as training takes time. The NHS Year of Care Partnerships provides the only quality assured national training programmes for delivering care planning in the UK.29

To encourage practices to undertake training, some areas, such as Cumbria have introduced a financial incentive through a locally enhanced service. GP practices were paid a small amount of money for every person with diabetes on the practice register. Whilst the incentive was relatively small in financial terms, it was regarded by some of the participants as crucial.

With the introduction of any significant operational change, it is important to help those affected adjust to the changes. In recognition of this, Berkshire West CCG introduced the role of Facilitator to help practices after they have undertaken the training.

The roundtable attendees were keen to highlight that professional care planning training should address three key areas: the healthcare professional’s attitude; the skills required to deliver care planning; and the knowledge of the organisational processes and structures required to ensure that patients can access and benefit from care planning.

“Having someone there to facilitate the changes allowed clinicians to think about the processes that needed to change in their individual practices”

Claire Scott, Berkshire West CCGs

Tackling health inequalities

Roundtable attendees reported that some clinicians believe that some of their patients do not want to be involved in decisions about their healthcare and/or will not be able to understand things like test results. This misunderstands the care planning process and the philosophy that underpins the House of Care.

The House of Care embraces all people with type 2 diabetes, including those with significant mental illnesses, those from disadvantaged backgrounds and those who are unwilling or unable to engage with health services. Responsive commissioning should be in place to ensure everyone has access to the services and opportunities that they need to manage their condition effectively. This might take the form of patient education, community interventions such as attendance at a walking group, or more formal mental health care and support.

Furthermore, healthcare professionals should be supported by NHS England, CCGs and professional bodies to deliver personalised care planning. Depending on the individual patient, professionals may need to play a greater or lesser role in helping them to make decisions. Organisational processes should be implemented to ensure that vulnerable groups or disadvantaged populations are able to benefit from the same infrastructure as other patients. For people from BME backgrounds, this should include providing test results in multiple languages or establishing education sessions with health advocates. Alternatively, this may mean reaching out to different communities, through engagement in places of worship or at community events, to ensure that people are aware of and understand their diabetes. The success of the House of Care approach in places such as Tower Hamlets or Islington demonstrates that it can reduce, rather than exacerbate, health inequalities.
“Many healthcare professionals are not very comfortable with patients having a role in their own healthcare. That is the bottom line.”

Dr Simon Eaton
Commissioning

One of the biggest challenges facing local areas is to ensure that commissioning is responsive to patient needs. While some CCGs will have experience of commissioning large contracts encompassing multiple services, which can save time and be cost effective, the services that some people with type 2 diabetes require may need to be commissioned on a smaller scale. Effective, personalised care planning requires patient needs to be represented in the services that are available. The Year of Care pilots developed a menu of options which patients can use to pick the services that will best meet their needs.

Ensuring that patients’ needs are understood can be achieved by the use of feedback forms or a facilitator who has contact with both patients and clinicians. This information can then be used to advise commissioners about what services are important to patients.

Commissioning services from third sector organisations was also identified as a concern. Islington CCG has commissioned health navigators from Age UK to help patients identify local community services that they could use to help manage their health. The navigators play an important role in understanding what third sector services are available and use this information to help inform commissioning decisions. However, concern was expressed that local authority cuts to third sector organisations has led to a loss of expertise and knowledge in some areas.

Individual choices & population care

MENU OF OPTIONS: Examples

Support for Self management
- Patient Education
- Weight management
- Health Trainers
- Smoking cessation
- Exercise programmes
- Health Coaching sessions
- Community support: Buddying / walking groups...
- Tele health / tele care
- Arts for Health

Specific problem solving

Personal Health Budget

Coordinating clinical / social input

Population level decision making and service delivery based on actual needs of individuals

© Year of Care
Individual

Addressing the issues that affect patients on a personal level is also an essential aspect of the House of Care. Patients are at the centre of the House and should be at the centre of the NHS. As the roundtable participants and the Year of Care Programme highlighted, people with type 2 diabetes spend the vast majority of time (99 per cent) self-managing their condition and a very minimal amount of time with clinicians. This means that people with type 2 diabetes need the skills, knowledge and confidence to manage their condition effectively and to ensure that the time spent in healthcare settings is used in the most productive way possible. As the project participants noted, the levels of shared decision-making will vary as will the services that individual patients need.

The extent of a patient’s knowledge, confidence and skills is known as patient activation and is most commonly measured by the Patient Activation Measure (PAM). Patients who are highly activated are more likely to manage their condition more effectively than those who are not. A study in 2009 found that higher levels of patient activation in people with diabetes was associated with an increased likelihood to perform feet checks, exercise regularly and receive eye tests. As part of their care planning programme, Islington CCG is now measuring patient activation in all people with a long term condition.

Patient adherence

The NHS currently spends over £800m per year on treatments for people with diabetes, which is on average more than £2m every day. However, up to two thirds of people with type 2 diabetes do not take their oral hypoglycemic medication as prescribed. Poor adherence to medicines is a considerable cost to the NHS. A report from the Department of Health indicates that medicines wastage costs the NHS at least £300m every year and that a significant part of this can be prevented through improved adherence. Improving people’s knowledge and understanding of their diabetes can lead to more informed decision making which can impact on levels of non-adherence to treatments.

Diabetes and mental health

Nearly one in five people with diabetes has clinical depression and healthcare costs for those people with anxiety or depression increase by around 50 per cent. Diabetes UK estimates that 41 per cent of people with diabetes have poor psychological wellbeing, which can limit a person’s ability to self-manage their type 2 diabetes. Dementia is significantly under detected generally, and more so in diabetes, which inevitably leads to poorer self-care. This can have a negative impact on adherence to treatments potentially leading to hyperglycaemia and increased complications.

People with mental health problems stand to benefit significantly from care planning. However commissioners and clinicians need to be aware of the significant rate of mental health comorbidity in people with diabetes and the impact that this has on their ability to self-manage.

“There is no doubt at all that people have less controlled blood sugar levels, less ability to take their treatments, less ability to self-manage and lower life expectancy if they have mental health problems. They are more likely to be socially isolated and social isolation is likely to be a predictor of cancer, smoking, high blood pressure and alcohol use.”

Dr Nick Lewis-Barned, Clinical Fellow for Shared Decision Making and Support for Self-Management, Royal College of Physicians,
Patient education

The provision of education for people with type 2 diabetes should be tailored according to a patient’s level of activation and take into account other issues such as their mental health status. In addition, patients need to be aware of the concept of care planning and understand what it involves. It was agreed that one of the biggest barriers to implementing care planning is the lack of awareness amongst both patients and clinicians that it exists. The participants recommended that NHS England should develop and implement a national communications strategy to raise awareness of care planning throughout the NHS and to help to dispel some of the myths surrounding the process. To support this, local clinicians and commissioners need to introduce communication strategies tailored to their local area to ensure that patients appreciate and understand this approach to routine care. This can be strengthened by support from the third sector. National and local patient groups should work with commissioners to ensure that patients have the knowledge and skills to demand better conversations with clinicians and access to the treatment and support that they need. However, simply providing education alone is not enough. The other aspects of the House of Care must be there to support the person with type 2 diabetes to make the most of the education that they receive.

Conclusion

This report shows that the introduction of care planning can have significant benefits for people with type 2 diabetes, clinicians and commissioners. The insight provided by the experts who attended the roundtable and participated in interviews demonstrates that there are measures that need to be taken at a national, local and individual level to ensure that care planning is understood and embedded in routine care. Evidence indicates that empowering people to manage their diabetes more effectively will have a significant impact on the outcomes that they experience and their quality of life. With the considerable financial and demographic pressures facing the NHS, there is an urgent need to ensure that clinicians and patients become equal partners in building a sustainable healthcare system.
Empowering patients through the House of Care: building a patient-centred future for people with type 2 diabetes
Empowering patients through the House of Care: building a patient centred future for people with type 2 diabetes

Case studies

Islington CCG

Overview

The introduction of care planning for people with diabetes in Islington has its roots in the development of a Self-Management Strategy, by Islington PCT, in 2006. This was supported and further developed by the Co-Creating Health programme, implemented from 2007-2012, and a strategy developed by Islington CCG focussing on patient and public engagement strategy in 2010. Islington have tested their House of Care model by commissioning local GPs to deliver diabetes care through the Year of Care approach.

The Co-Creating Health Programme took a whole systems approach to transforming the patient-clinician interaction into a collaborative partnership. The initiative had three elements: engaged, informed patients that participated in a Self-Management Programme (SMP) to build their self-management skills; clinicians committed to partnership working undertaking an Advanced Development Programme (ADP) to develop their consultation and communication skills; and supportive organisational processes in primary, community and acute settings to support self-management. Co-Creating Health gave clinicians the communications skills they needed to have better conversations with patients, while the Self Management Programme changed patient’s expectations of their healthcare and supported them to understand that they have an important role in managing their condition effectively.

Healthcare professionals in Islington have recognised the importance of targeting care at those in greatest need and at greatest risk of unplanned hospital admission. In practice, this has meant that different patients are categorised based on the level of care and treatment they require. GPs bring these patients to the attention of a multidisciplinary team which holds a teleconference on a weekly basis. The goals and needs of the patient are established prior to this conversation, allowing their views to be fully considered.

For less high risk patients, a Year of Care approach has been taken. Patients receive an initial consultation where the primary purpose is to gather as much information about the patient and their condition as possible. This information is then relayed to the patient via a letter ahead of a second care and support planning consultation. Giving the patient this information - along with the time they need to process it - allows them to proactively work with their health professional in the second consultation to create a care plan. 42 per cent of patients with diabetes in Islington have received a Year of Care care planning consultation and almost all practices have signed up to deliver care planning in the CCG area.

Patients can be referred to a choice of self-management support programmes such as the Xpert Patient Programme if, during the care and support planning consultation, it is recognised that such an intervention will support an increase in the individual’s skills, knowledge and confidence.

Patients can also be referred to health navigators who have been commissioned from Age UK. These navigators can help patients identify local services which might be helpful to them in managing their condition and refer patients to these. Furthermore, navigators attend local events to offer information and advice to people, help them with goal planning when managing their diabetes care, provide limited case management to people who are hard to engage, and have created a directory of non-traditional services that are available to professionals.

From October 2014, Islington will commence collecting a Patient Activation Measure (PAM) score for all patients registered with a long-term condition. The PAM is a validated tool, helping to understand and link patient activation (skills, knowledge and confidence), subsequent behaviour and graded need for support to achieve better outcomes. The use of PAM may help inform commissioning decisions in Islington so that self-management support initiatives are commissioned according to a co-produced implementation plan. The local service navigators will use the tool to better structure support depending on need. The CCG is keen to expand the service to encompass more long term conditions as much of the work which has been done for people with diabetes could be usefully extended to other conditions.
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Berkshire West CCG

Overview

At the beginning of 2012 there was a realisation within the federation of the four CCGs of Berkshire West that there was an opportunity to improve diabetes care in the area. Results in both the National Diabetes Audit and the Diabetes Outcomes Versus Expenditure review suggested that changes could be made to lower expenditure and improve patient outcomes in the area. This motivated the local leadership to prioritise diabetes above everything else. In order to improve outcomes, local healthcare professionals and commissioners identified three main areas of focus: care planning, structured patient education and healthcare professional education.

“We have now implemented care planning for 18 months. At the same time, we moved from a doctor-led model to a nurse-led model. The result has been that metrics are improving. Nurses have taken over diabetes annual review care in my practice now.”

Dr Richard Croft, Diabetes & Respiratory Lead, Berkshire West CCGs

The CCGs selected three people to receive training in care planning to enable the delivery of the Year of Care model of care planning. That was a considerable up-front investment. A local framework was developed which financially incentivised practices to implement care planning. Local practices were paid, via an enhanced service, a small fee for every diabetes patient on their practice list to attend the training. Backfill was also provided to cover locum costs when attending training.

Initially, the Berkshire West ‘House of Care’ had few of the necessary elements in place. The missing aspects of the house needing to be commissioned included, but were not limited to: healthcare professional education; structured education for patients; a new community diabetologist; and improvements to the Diabetes Specialist Nurse service. To raise awareness of the project, local stakeholders were invited to a launch event and buy-in from local leadership teams was secured. This helped to foster an expectation within each of the four CCGs that all of the practices within the area would receive training in care planning and then implement it.

The training started in 2013. The training consists of two sessions spread over six weeks. Those being trained did a full day initially and then a half day follow-up training session six weeks later to report back on what they have done. The first three training courses were booked out within a month and an extra course was laid on to meet demand. Four Healthcare Assistant (HCA) workshops were commissioned to train HCAs in their role in care planning. HCAs have welcomed the extended role and have enjoyed learning more about diabetes and care planning. Clinicians who attend the training can initially be very sceptical. However, for many of them, once they had been through the training and the role-play, the feedback was far more positive.

Commissioning Year of Care Partnerships to provide the training and support allowed professionals to access all of the necessary care planning resources such as a Results Letter template which sits in the local practice IT system. Once the HCA has added all the information from the initial information-gathering consultation, the letter is then sent to the patient and is uploaded on to the practice system.

In addition to the training sessions, the CCGs also employ a facilitator to work across the area, for up to 2 days a week, to ensure that local practices have the help and support that they need to implement care planning. Once people have finished their training, the facilitator goes to the practice and holds a whole-practice meeting, helps them set up templates on their IT systems and talks them through any problems they might have.

Outcomes

• The key components which have made the initiative successful so far include: prioritisation by the CCGs to make sure that local people were involved; putting care planning at the heart of this new approach; ensuring that a facilitator was available to support local practices; creating local trainers; and developing local enhanced services and incentives.

• There are now 54 practices in Berkshire West, and training has been delivered to 53 of them. In addition, two-thirds of the practices are now implementing care planning for patients with diabetes. Most of the final third have plans in place to implement care planning soon.

“I now feel that I am included in the care of my diabetes and can make a contribution to the discussions to improve my results”
It has been good to have time to raise my concerns. Knowing my results beforehand, I was able write these questions down”

To be actively involved in my diabetes care is motivational”

(Feedback from patients at the Tilehurst Surgery)

Cumbria CCG

Overview
A local enhanced service for diabetes was introduced in Cumbria in April 2011, following the implementation of the NICE guidance on structured education for type-2 diabetes in 2009. This occurred at the same time as a wider re-organisation of the diabetes service.

Local healthcare professionals found that increasing patient empowerment and knowledge, through the structured education training, led to increased expectations from patients to be more involved in their own care. A key element of this service redesign was to enable care planning to become the standard approach for diabetes care across the health community.

Care Planning is at the heart of this model and enables healthcare professionals to create an environment which facilitates a partnership approach and greater support for self-management. This is enabled by the gathering and sharing of information in advance of the consultation, as well as supporting health professionals to examine, develop and reflect on their own consultation skills and behaviours. There is good evidence that people engage better with healthcare professionals when they have an active role in their own care, which results in improved outcomes.

In partnership with the “Year of Care” national team, Cumbria Diabetes trained five local clinicians as care planning trainers. A local enhanced service from April 2011 resourced and incentivised practices to engage with care planning. In addition, care planning was actively promoted across local specialist teams. Raising awareness (via local media and diabetes user group), IT support, practice visits and networking was undertaken to support implementation. Data was collected in April 2012 via a survey.

Central to implementing this new approach was to build relationships and to ensure that people were operating under the same expectations and assumptions. Local leaders sought buy-in across the local healthcare system and tried to build a new structure for delivering care planning from the bottom up. To generate momentum for implementing a new structure for care planning, Cumbria Diabetes used local networks of people working together to embed change. Having a strong, pre-existing community of people who were keen to work together helped to ensure this happened.

Furthermore, Cumbria Diabetes worked with the CCGs and primary care development teams to ensure that care planning was entrenched into the local healthcare culture and language. This has been achieved through engagement events which all practices were encouraged to attend. This approach built better relationships between practices, specialist teams, and commissioners. The CCG wants to incorporate the principles of personalised care planning into the entire health system. The intention is that care planning processes become the routine for all people with long term conditions.

One of the key challenges is to implement commissioning that is responsive to patient’s needs (the link between the patient ‘wall’ and the ‘commissioning’ foundation). Ideally, the needs identified in the consultation (especially unmet needs) would be fed into the commissioning of traditional and non-traditional services – with subsequent evaluation of these services and their impact on wellbeing and outcomes.

The following measures were introduced in Cumbria to measure both process and quality of care planning implementation: a measure of attendance at approved training; measurement of preparing the person with a long term condition prior to the consultation (e.g. sharing written information and results); a measure of patient enablement and care quality via a validated survey (living with your long term condition patient survey).

Traditional models of care are not as effective as they might be in supporting people to manage their long term conditions. A care planning approach transforms the traditional medical model into a truly collaborative approach; supporting people to self-manage and take more control of their long term condition(s)”

Dr Robert Westgate, Care Planning Lead at Cumbria CCG
Outcomes:

- There are 83 general practices in Cumbria. By April 2012, 80 per cent of all GP practices had attended the care planning training.
- 75 per cent of all practices reported implementing a change in response to the care planning training and 65 per cent of all practices reported that they had implemented a care planning approach in their routine diabetes care.
- Both practitioners and people with diabetes reported satisfaction with the care planning process. Cumbria Diabetes delivered nine cohorts of care planning training across the county for GPs, practice staff and the specialist diabetes team (one and a half days training per cohort).
- 80 per cent (66 practices) of all GP practices in Cumbria have had at least one practice team member attend the one and a half day care planning training sessions with Cumbria Diabetes.
- 75 per cent (62 practices) of all practices in Cumbria report that patients routinely attend for collection of biometric data (e.g. blood tests, height, weight etc.) prior to their main diabetes appointment.
- 50 per cent (41 practices) of all practices report that test results are posted to people with diabetes in advance of their care planning consultation.

The House of Care model is an ideal metaphor to implement, reflect and learn from the care planning process. If any of the structural parts of the house are incomplete it will fall down! If the house is built properly, it can contain truly collaborative personalised care planning consultations; delivering value for the NHS and supporting people to live well with their long term condition(s)“

Dr Robert Westgate, Care Planning Lead at Cumbria CCG

Key lessons from the case studies:

- It is clear that the care planning approach can be applied more broadly to other long term conditions and social care.
- Some practices struggle with both the philosophy and the practical challenges of implementing care planning. It is essential that these practices are given support and encouragement via skilled facilitation.
- It is important to introduce metrics to measure both the process and the quality of care planning implementation.
- One of the main benefits of the care planning model is that after some initial start-up costs, CCGs are enhancing the skills of the healthcare professionals within their area which helps to reduce costs.
- One of the biggest challenges is the cultural shift for healthcare professionals which requires them to approach their patient consultations differently.
- The role of a facilitator to help the local practices put the necessary systems in place to implement care planning has been very successful in Berkshire West. Having someone who is able to provide guidance and support during the transition to care planning is important.
- Raising awareness within the diabetes population is also key to implementing Care Planning. People need to understand the reasons behind the changes and the part they have to play within this. A partnership approach will feel very strange to many who have been used to a very different model of care.
- Capacity is a big issue for general practices. Introducing the House of Care is a significant commitment and primary care is facing considerable resource and time pressures.
Empowering patients through the House of Care: building a patient centred future for people with type 2 diabetes

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